THE WELFARE OF HANDICAPPED CHILDREN:

A GLASGOW STUDY.

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by

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CONTENTS

CHAPTER I.

HISTORICAL BACKGROUND.

1. Introduction.
2. Development of services for the school child.
3. Development of services for the pre-school child.
4. The rôle of voluntary organisations in the welfare of handicapped children.
5. Educational provision for handicapped children (Glasgow).

INTRODUCTION

This thesis is concerned with the study of some of the many problems that arise from the presence in the home of a severely handicapped child.

It is a far cry from the early days of last century, when such thought as was given to the welfare of children found expression in halting efforts to save them from the worst perils of uncontrolled and prolonged employment in unsuitable trades; when the relief of their destitution too often lay in tacit recognition that it would be necessary to allow them to beg for a living and - since it was an easy step from begging to theft - 'relief' came to be largely synonymous with 'repression', only faintly alleviated by the development of Ragged Schools and Schools of Industry. Some years later, in 1872, the old Parochial School system, which had never been other than patchy in its operation, was replaced by a system of Compulsory Education, a system destined to become the medium for much subsequent ameliorative effort to improve the health of young people, and in the same year the first Infant Life Protection Act sought to preserve individual children from ill-treatment,cruelty and neglect.

At the turn of the century the dawning interest in the welfare/

welfare of mothers and children found first expression in efforts to reduce the high infant mortality of the times, turning next to the problems of school age; the pre-school child tended to be neglected between these two lines of attack, his difficulties emerging all the more clearly as the others began to yield to the attention they received.

Recent years have seen big changes - changing patterns of administrative emphasis and, to a large extent, the replacement of voluntary by official action. The prevailing handicaps of children, too, have changed, often reflecting changes affecting their underlying causes, as in the great reduction in prevalence of rickets, tuberculosis and rheumatic fever. On the other hand, new handicaps and new difficulties are constantly arising, some apparently the very outcome of success of earlier measures to save the children - the aftermath of such conditions as prematurity or tuberculous meningitis which would in other days have proved fatal.

There has been a tendency to move away, wherever possible, from institutionalisation in the long-term treatment of the handicapped child, to leave him to grow up in his own home as a member of the family. But this policy, desirable as it may be and with much to commend it, raises compelling problems of its own, and it is with some of these that we are immediately concerned.

DEVELOPMENT OF SERVICES FOR THE SCHOOL CHILD

Over thirty years of compulsory education elapsed before it was officially recognised that much education was being wasted upon children whose physical condition prevented them from obtaining full benefit from it.

The School Medical Service, re-named the School Health Service in 1945, was established in England in 1907, and in Scotland in 1908. Although considered by some to be simply a consequence of the general humanitarian movement that started in the nineteenth century and by others to be the outcome of concern at the wastage of education, the Service more probably followed publication, in 1903 and 1904 respectively,of the Reports of the Royal Commission on Physical Training (Scotland) and of the Interdepartmental Committee on Physical Deterioration (England). These bodies had been set up by a Government alarmed at the evidence of physical deterioration revealed by the recruiting figures for the Boer War.

The members of the Royal Commission found evidence of much ill-health and physical disability in Scottish children. In a representative sample of children attending Board schools in Edinburgh, 52% had nose and throat disease, 42% defective hearing, 31% defective vision, 18% diseased (mostly tubercular) glands, 4% heart disease, 3% lung disease and 2% had bone and joint disease.

The Scottish report recommended amongst other things the provision of systematic medical inspection in schools,pointing out/

out that only at school age could a complete assessment of the population be obtained, its physical condition revealed and measures of a remedial nature applied with reasonable hope of success. The English report similarly recommended the establishment of a system of school medical inspection as well as the inception of arrangements for the feeding of school children where necessary.

Development of the School Health Service in Scotland.

Following the report of the Royal Commission on Physical Training, localised studies of matters concerning the health of school children were carried out in several areas, including Glasgow, Edinburgh and Dundee. These included surveys of the health and housing conditions of 750 children attending schools in certain areas of Glasgow (Chalmers,1904), the physical state and housing conditions of 72,857 children attending the public schools of the Glasgow School Board (Mackenzie and Foster, Scottish Education Department,1907) and a study of the vision of 3,000 Glasgow school children (Pollock,1905). An investigation into the physical condition of 1,700 Glasgow children, 2 to 10 years of age, admitted to the wards of Belvidere Fever Hospital during 1907 and 1908 (Macgregor,1909) revealed that amongst these children the incidence of recognisable rickets in the boys was 31% and in the girls was 26.7%. Macgregor also found that nearly one-half of the children on the roll of attendance of schools for the physically defective in/

in the City of Glasgow were prevented by rickety deformities from making the journey to an ordinary day school.

The results of these localised studies further demonstrated the necessity for the introduction of a system of school medical inspection and several School Boards were progressive enough to anticipate legislation. In June, 1907, Govan Parish School Board appointed ten part-time medical officers at salaries of £50 per annum; their duties were wide and varied and included 'to examine as soon as possible any child specially reported by the Headmaster as suffering from any ailment,' 'to examine the mental and physical condition of children seeking admission to special schools or classes and to grant necessary certificates,' and 'to exercise supervision over special schools and classes, reporting to the Board twice a year on the mental and physical progress of children attending and indicating means to promote their health'.

Although the medical inspection of physically handicapped children was already permissive in terms of the Education of Defective Children (Scotland) Act,1906, it was the Education (Scotland) Act,1908, which empowered the formulation of a School Medical Service. Under this Act, it became possible for School Boards to provide for the medical examination and supervision of pupils attending schools within their district and to employ medical officers or nurses.

At first the provision of medical treatment was not contemplated, but it soon became evident that without treatment, the usefulness of the service must be greatly restricted and the Education (Scotland) Act,1913, legalised the provision of medical (including surgical) and dental treatment. No power to establish clinics for the treatment of diseases of school children existed in Scotland prior to 1913, though some authorities anticipated legislative approval. The first school clinics in Glasgow were opened in 1912.

Successive Education Acts have re-enacted, repealed or extended the provisions laid down in these initial Acts. The Education (Scotland) Act,1946, consolidated all previous Education Acts and imposed upon Local Education Authorities the duty of providing for the medical inspection, supervision and treatment of all pupils in attendance at schools under their management. The National Health Service (Scotland) Act,1947, relieved Local Education Authorities of much of the financial burden of treatment, but most authorities still provide certain schemes of treatment, such as for dental defects, minor ailments and for aural and orthopaedic defects. Whilst treatment for defects of vision of school children is the responsibility of the National Health Service, in practice many Education Authorities undertake the routine refraction work under the general supervision of ophthalmologists of the Regional Hospital Board.

Provision of Special Educational Treatment for Handicapped Children.

The Education of Defective Children (Scotland) Act,1906, had made it lawful for School Boards, either alone or in conjunction with other Boards, to provide specially for the education, medical inspection, and where required, for the conveyance to and from school of physically and mentally defective children between 5 and 16 years of age. To these powers the Education (Scotland) Act,1908, (which empowered the formulation of a School Medical Service) added that of providing both for the education and for the maintenance of such children in homes or institutions in other parts of the country. This Act gave a great impetus to the establishment of special schools and classes for handicapped children, especially in the cities. In Glasgow, for instance, by 1914, there were sixty-three classes for mentally handicapped children - twenty-one in special schools, the others attached to ordinary schools - and seventy-one classes for physically handicapped children, of which thirty-six were in special schools. There were in addition seven classes for partially deaf children and there were visiting teachers for deaf mutes and the blind.

The Education (Scotland) Act,1946, brought provision for the education of handicapped children well into the broad framework of the educational system.

Section 53 of this Act authorised the Secretary of State to make regulations defining the several categories of pupils requiring/

requiring special educational treatment and to make provision as to the special educational arrangements appropriate for pupils of each category. Under Section 54 of the Act, Local Education Authorities had to ascertain what children in their areas, who had attained the age of 5 years, required special educational treatment or were suffering from such a disability of mind as to be ineducable. If the parents request it, Local Education Authorities must medically examine any child who has attained the age of 2 years.

The Special Educational Treatment (Scotland) Regulations, 1954, which came into operation on the 1st of October,1954, defined the several categories of pupils requiring special educational treatment and the arrangements appropriate for each category.

The categories comprised deaf, partially deaf, blind, partially sighted, mentally handicapped, epileptic, maladjusted, physically handicapped pupils and those suffering from speech defects; the method of selecting cases for special educational treatment i.e. ascertainment, and the extent of the particular handicap to warrant inclusion in such categories were also defined.

Unless otherwise determined by the Secretary of State in the case of any particular pupil, every deaf and every blind pupil, who was not mentally handicapped, was to be educated in a special school for the deaf or a special school for the blind;/

blind; and every other pupil falling within the categories defined to be educated in a special school, or in an ordinary school; or arrangements might be made for his education in a hospital or in his home, as appropriate. The special educational treatment to be provided for every handicapped pupil attending an ordinary school had to be appropriate to his disability.

Types of Special Educational Treatment.

In Scotland there are in effect eight types of special educational treatment which may be made for a handicapped pupil. He may be educated in a residential school, a day special school, a special class in an ordinary school, in an ordinary class in an ordinary school with special arrangements (e.g. favourable seating position, exclusion from certain activities, transport provision, additional tuition), in an ordinary school without such arrangements, in hospital,by home tuition or he may attend an occupational centre.

The type of special educational treatment depends on the individual case and on the facilities provided by, or available to, the Education Authority concerned. One of the striking trends in recent years has been the growing tendency to keep handicapped children in ordinary schools whenever possible. In England the policy of the Minister of Education regarding the special educational treatment of children in ordinary or in special schools was expressed in Circular 276 of the Ministry/

Ministry of Education issued on the 25th June,1954. 'No handicapped pupil should be sent to a special school who can satisfactorily be educated in an ordinary school. Where a special school is necessary, a day special school is preferable if it offers a satisfactory and practicable solution'. A similar policy has been advocated and pursued in Scotland (Circular 300. S.E.D. 1955).

This desire to retain handicapped children in ordinary schools whenever possible is not actuated by financial considerations or by administrative convenience; it is made solely in the interests of the children themselves, since, from an upbringing and environment as near normal as possible many of these children derive help in overcoming their disability.

Provision for the Ineducable but Trainable Child.

One noteworthy difference between the Education (Scotland) Act,1946, and the corresponding Act in England, the Education Act,1944, lay in the arrangements to be made for ineducable children. Under the provisions of the Scottish Act, they were to be classified further as trainable or untrainable.

Children considered ineducable but trainable (i.e. incapable of learning the school arts but capable of following simple directions) were now to remain within the ambit of the educational system and the provision of occupational centres to meet their needs was authorised. Prior to this Act, a few of the children excluded from the special schools as ineducable had received training by voluntary associations such as the after-care committee of the Scottish Association for Mental Health, but there was increasing recognition of the need for more provision suitable for the ineducable but trainable children among those excluded from special schools.

The occupational centres thus relieved the schools for the mentally handicapped from the presence of children unable to progress in the subjects taught, and at the same time afforded parents a respite from the task of meeting the demands of these children who are usually well-content with the activities of the centre.

Provision for the Ineducable and Untrainable Child.

Under Section 56 of the Education (Scotland) Act,1946, children suffering from such a disability of mind as to be incapable of receiving education or training in a special school or at an occupational centre would continue to be excluded from schooling, and the Local Education Authority would notify them to the Health Department of the Local Authority and to the General Board of Control for Scotland 'for the purposes of the Mental Deficiency (Scotland) Acts,1913 and 1940,' i.e. in that they may require to be dealt with under these Acts. It then becomes the statutory duty of the Local Authority to examine any such children, and if it is considered desirable to place a child under guardianship (of a relative or other suitable person) or to admit him to an institution for mental defectives, the legal procedure of certifying the child as a mental defective is necessary in accordance with the provisions of the Mental/

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Mental Deficiency Acts.

Under the National Health Service (Scotland) Act,1947, Local Health Authorities were empowered 'to provide, or secure the provision of, suitable training and occupation' for children of school age notified under the Education (Scotland) Act, 1946, as incapable of receiving education and training in a special school or occupational centre. They are also responsible for the supervision of those children who are reported by the Local Education Authority but are not formally certified as mental defectives, and they are likewise responsible for the supervision of those certified defectives under guardianship or awaiting admission to institutional care.

Although Local Health Authorities were thus empowered to make provision for such cases by establishing occupation (training) centres, only two of the fifty-five Local Health Authorities in Scotland had themselves provided centres by February, 1957, two were setting up centres in conjunction with voluntary organisations, and a few other Local Health Authorities contributed financially to local branches of the voluntary organisations who were making provision of this type.

[Under Section 57 of the Education (Scotland) Act,1946, it is also necessary for Local Education Authorities to notify the Local Authority and the General Board of Control for Scotland of those mentally handicapped children about to leave special school or occupational centre, who are likely to require to be dealt with under the Mental Deficiency Acts after leaving. The/

The Local Health Authority is responsible for the supervision and training of any mental defectives over the age of 16 years, whether or not they are certified under the Mental Deficiency Acts.]

Education of Handicapped Children in Hospital.

Until the early part of the century, little was done for the education of the chronically disabled child. Such children received treatment in hospital for their physical ailments and when discharged were, where possible, admitted to cripple schools. Often, however, they were still in need of further treatment and were unable to derive much benefit from broken education.

In 1908, under private arrangements, steps were taken in the Lord Mayor Treloar Hospital at Alton, Hampshire, to provide the children with education at the same time as treatment. The experiment was successful, and in 1912 this hospital school was recognised by the Board of Education, and other orthopaedic hospitals soon followed this lead. The importance of providing education for tuberculous children other than those suffering from surgical tuberculosis was recognised, and resulted in sanatorium schools being opened for these children by many local authorities. Among the other children remaining in hospital long enough to merit education were the rheumatic children, and from 1920 onwards several long-stay establishments were opened, in some instances by voluntary organisations and in others by Local Education Authorities.

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The position, then, towards the end of the first half of the present century was that the principle of providing teaching for long-stay children was widely accepted but that it was not considered necessary to provide teaching in a hospital unless the number of long-stay children justified the establishment of a hospital school.

This situation was altered when Local Education Authorities were granted powers, under Section 56 of the Education Act, 1944,(England), and under Section 14 of the Education (Scotland) Act,1946, to provide education otherwise than at school for any children unable to attend a suitable school. Educational facilities in hospital were now made available to small groups of children and could be provided even for a single child. For the first time, several types of case were now given the benefits of teaching, e.g. those convalescing from acute illness, and those admitted to short-stay hospitals for treatment or investigation. Thus the number of children receiving education in hospital increased, although at the same time the cases for whom provision had been made in the original hospital schools - the orthopaedic, the tuberculous and the rheumatic - decreased and advances in therapy had reduced the length of time required for their treatment.

The provision of education for children in hospital ensures that a child does not fall unduly behind in school work, and is especially valuable for the younger child by providing intellectual occupation commensurate with his development. For the/

the older handicapped or potentially handicapped child in hospital, education compatible with his mental and physical capacity has increasingly become geared to take into account the restricted range of probable activities and future employment. The further education courses provided by Local Education Authorities, including courses of a vocational character, are now available to handicapped children in hospital.

Extensive hospital schooling provision is now made for Glasgow children. In 1923, under private arrangements, Strathblane Convalescent Home established a 'hospital' school which has now been taken over by the Corporation of Glasgow. Hospital schools were opened at Mearnskirk Hospital in 1932 and at the Victoria Infirmary Annexe, Philipshill, in 1943. Following the Education (Scotland) Act,1946, which allowed Local Education Authorities to make provision for short-term cases, hospital schools were established at Stobhill Hospital and at Lenzie Convalescent Home in 1947, at Drumchapel Convalescent Home in 1952 and at the Royal Hospital for Sick Children in 1956. The number of pupils receiving tuition in these hospital schools on the 30th June,1957, totalled 445. Lessons are taken in classrooms at Strathblane and Philipshill, but in the other hospital schools tuition is usually given at the child's bedside. East Park Home for Infirm Children provides teaching facilities for the children under private arrangements.

Provision for Handicapped School Leavers.

After school leaving age, disabled young persons may require further education and training adapted to their needs, which can be given only in special, often residential, establishments. The blind and the physically handicapped are the principal handicapped groups for which such provision is made. Local Education Authorities have powers also to grant financial assistance to enable disabled young persons to attend suitable approved establishments provided by voluntary organisations.

The Youth Employment Service of the Ministry of Labour and National Service, which in Glasgow and many other areas is administered by the Local Education Authority, is required under Part II of the Employment and Training Act,1948, to make vocational guidance and assistance in finding suitable employment available to all young persons at school leaving age and subsequently to the age of 18 years, if desired. The intention is that close contact with the School Health Service should be maintained in order that no young person may be placed in employment where injury to health or aggravation of an existing disability would result.

The Youth Employment Service has a particular responsibility for handicapped children, both in advising on choice of occupation and in helping to find satisfactory employment. Youth Employment Officers are enjoined to work in close co-operation with the Disablement Resettlement Officers of the Ministry/

Ministry of Labour and National Service, and with the voluntary organisations providing for the welfare of the disabled, particularly those organisations concerned with the mentally handicapped and the epileptic.

For many severely handicapped young persons, registration under the Disabled Persons (Employment) Act,1944, may be recommended; the facilities available under this Act include vocational training, assessment or training courses at Industrial Rehabilitation Units and the provision of aids and sheltered employment. Even where registration as a Disabled Person is not desired, informal contact with the Disablement Resettlement Officer (D.R.O.) is helpful to the young handicapped person, as often he may experience difficulty in finding and maintaining suitable employment.

DEVELOPMENT OF SERVICES FOR THE PRE-SCHOOL CHILD

There were many critics of the findings of the Royal Commission on Physical Training (Scotland) 1903, who pointed out that the pre-school child was as much in need of medical inspection as the school child, and that beginning with the school child was already too late. Nevertheless, the members of the Commission held that the work had to be commenced where the greatest service could be rendered and where the child could most conveniently be examined, especially as at school age the child passed under the direct and partial care of the community as represented by the local and central authorities.

Medical inspection of school children having been established, the findings soon proved the general case for the medical supervision of the pre-school child, by showing that the defects and disease found in school age were largely attributable to neglect in the pre-school years. A survey of the results of school medical inspections (carried out by Dr.L.D. Cruickshank, Medical Officer and Inspector of Physical Education,Scottish Education Department) showed that 42.5% of school entrants suffered from defects and diseases, largely preventable, but already of a chronic nature.

These results were borne out by the annual reports of the Sick Children's Hospitals and their out-patient departments and dispensaries. The annual report for 1915 of the Royal Hospital/

Hospital for Sick Children, Glasgow, showed that of 2,091 children treated, 1,668 were under school age; whilst according to the 1914 annual report of the Royal Edinburgh Hospital for Sick Children, 1,339 of the 2,083 children treated were under 5 years of age. At the out-patient department of this hospital in the same year, 3,092 of the 4,340 new medical cases and 1,812 of the 2,742 new surgical cases treated were under 5 years of age.

Obviously the nature of these cases was serious enough to excite the concern of the parents, but the figures for school children in the annual reports of the Scottish Education Department revealed that a large number of diseases had occurred which never resulted in approach to hospitals, or even to out-patient departments. These minor 'ailments' whilst no doubt not a grave or immediate threat to life, often resulted in handicaps sufficiently serious to impair severely the child's efficiency for the rest of his life.

Preoccupation in the field of maternity and child welfare at the beginning of this century was largely with measures to combat infant mortality. Prior to 1915, existing services were provided mainly by voluntary and philanthropic organisations and consisted of milk depots, infant clinics and voluntary health visitor's associations. These were centred on the newly-born child, with the object of reducing the high death-rate of infants under 1 year - a high death-rate largely due to preventable causes - and had tended to the neglect of provision

for/

for children from 1 to 5 years.

The number of disabled, damaged and deformed children presenting themselves at dispensaries, sick children's hospitals, school clinics, cripple homes and other institutions, testified to this omission and demonstrated the need for medical supervision of children of pre-school age.

The passing of the Notification of Births (Extension) Act,1915, which made the notification of births obligatory throughout Scotland, also empowered Local Authorities to make provision for expectant and nursing mothers and for children under 5 years; for this purpose a Treasury grant, amounting to one-half the approved expenditure, was provided. This new Act thus covered the period of child life not provided for under the Education Acts and the development of comprehensive schemes for child welfare followed.

In Glasgow, it became possible to correlate the activities of many of the existing voluntary organisations with those under statutory administration; existing services were further developed and new services inaugurated. The system of infant consultation centres and of the home visiting of infants was extended to cover all children under 5 years. At the Glasgow Maternity Hospital, an infant consultation centre was established for infants born to women under the care of the indoor and outdoor clinics. Arrangements were made for children attending welfare centres in the city, and found to be in need of hospital treatment, to be admitted to the Royal Hospital for Sick/

Sick Children, and special consultation sessions for infants were initiated at the dispensary in West Graham Street. The provision of day nurseries, of country (convalescent) homes and of a domestic help service were further measures in the effort to improve the health and welfare of the pre-school child.

The development of the Maternity and Child Welfare Services of Local Authorities progressed steadily throughout succeeding years. As the infant mortality rate fell, and as welfare services for the pre-school child were extended,many children, who in other days might have developed disabilities through undernourishment, inadequate social care or lack of medical supervision and treatment, were now able to proceed to school life in sound health. At the same time, handicapped and potentially handicapped children were referred increasingly to hospital and out-patient departments and were receiving treatment at an early age.

Welfare provision for handicapped children of pre-school age had however been confined largely to voluntary organisations and these were concerned mainly with the blind, the deaf and some crippled children. As medical supervision of the pre-school child extended, increasing attention was paid to early discovery and diagnosis of the handicapped and the potentially handicapped child. The Education (Scotland) Act,1946, which required Local Education Authorities to ascertain what children over/

over 5 years of age in their areas required special educational treatment and also to examine, at the parents' request, any child who had reached the age of 2 years, further stimulated early discovery and ascertainment of handicapped children. The provision by Local Education Authorities of special educational treatment facilities for suitable pre-school cases permitted integration of arrangements for medical and educational care.

With the inception of a National Health Service, further opportunities were made available for all parents to obtain medical supervision and guidance for their pre-school children. The National Health Service (Scotland) Act, 1947, imposed a statutory duty on Local Health Authorities to ensure that adequate provision was made for the health and well-being of all children under 5 in their area. Under provisions of the same Act, the services of general practitioner and of hospital specialist - consultant paediatrician or specialist consultant - together with the facilities of hospitals and of Local Authority child welfare services became available to all children of pre-school age, irrespective of financial consideration.

Early discovery of a handicapping or a potentially handicapping condition is the keystone to correct diagnosis, adequate medical care and, where necessary, to special educational treatment for the affected child. In recent years, circulars from the central Departments of Health have brought to the notice of general practitioners, local authority and hospital medical officers, the importance of the early discovery in the very young/

young child of potential handicapping conditions, especially apparent defects of hearing, of vision or of posture.

As a result, the original child welfare services have now to face tasks very different from those for which they were originally designed; nowadays their essential aim is less to save life than to see that the lives which are saved grow through healthy and happy childhood. This implies a constant watch over the pre-school child's progress and development, in order to detect at the earliest possible moment any signs of physical and mental disability; but early detection of physical and mental disability is not yet as nearly complete as it might be.

THE RÔLE OF VOLUNTARY ORGANISATIONS IN THE WELFARE OF HANDICAPPED CHILDREN

Organised voluntary effort for the care of the unfortunate, whether sick, disabled or in poverty is a traditional feature of the British social scene. In the scale of its efforts and in the standards which have been set, it may well be that voluntary service in Great Britain is unique.

Some of the agencies which are active to-day have a long history; on the other hand, fresh groups and associations with humanitarian objects of helping the unfortunate spring up every year and sometimes take root. Without doubt, the noblest example of all was the system of voluntary hospitals which has now been absorbed in the National Health Service. But many other voluntary organisations of widespread reputation spring readily to the mind. In this field of effort there is a wide diversity of pattern and scale of organisation.

Among the older of the institutions catering for the needs of the sick child in Scotland were the Sick Children's Hospitals. The Royal Edinburgh Hospital for Sick Children was opened about 1858, its counterpart in Aberdeen in 1876, and Dundee Royal Infirmary, which later included a children's ward, at the close of the eighteenth century. Glasgow Royal Hospital for Sick Children, which was opened in 1882 and moved into new buildings with fully 200 beds in 1914, had an associated dispensary and a country branch at Drumchapel.

These hospitals for sick children have long held an honoured place in the medical resources of the country and have always occupied/

occupied a pivotal position in activities designed to promote child health. The demand for hospital care has exceeded supply and as child welfare schemes developed, the number of children referred to hospital for treatment, indoor and outdoor, steadily increased. With the passage of years, it came to be realised that the child welfare activities of the Local Authorities and the hospitals for the treatment of sick children were essentially complementary to each other.

In addition to the convalescent homes operating in association with, or available to the hospitals for sick children, other homes grew up for crippled and invalid children. Notable amongst these was the East Park Home for Infirm Children, founded in 1874, which with 130 cots was always full, while the Glasgow Poor Children's Fresh Air Fortnight and Crippled Children's League maintained a large number of institutions and agencies in the West of Scotland. At Bridge of Weir, the Quarrier Homes for Orphan Children were opened in 1878 and in 1903 the foundation stone of the Colony for Epileptics was laid. This Colony opened in 1906 with six epileptic boys; facilities for education were provided and a school commenced in 1914. Since then, epileptic children from all Local Authorities in Scotland have been admitted for residential care, training and education.

Prior to 1946, voluntary organisations in Scotland were largely concerned with the provision of facilities for cripple children; the blind, deaf and dumb and in a few areas mentally defective/

defective children were to some extent covered by specific voluntary organisations.

Although no comprehensive orthopaedic scheme was in existence, voluntary schemes on a regional basis e.g. at the Princess Margaret Rose Hospital near Edinburgh,Local Authority schemes at Mearnskirk, Hairmyres and Stonehouse Hospitals,and individual provision for surgical orthopaedic treatment and care by other hospitals and by voluntary institutions covered considerable areas of the country. In 1942, the Scottish Orthopaedic Council was formed which acted as a co-ordinating body for all regions, providing a network of services throughout the country and to which the voluntary Cripple Aid Societies in the large cities were affiliated. This Council ceased to function when,under the National Assistance Act,1948, Local Authorities became responsible for welfare services for the disabled.

The steady reduction in the numbers of severely physically handicapped children, allied to the increasing statutory provision for handicapped pupils authorised by the Education(Scotland) Act,1946, allowed many existing voluntary organisations to divert their attention to the adult disabled.

The National Assistance Act,1948, empowered Local Authorities to make arrangements for promoting the welfare of persons who were blind, deaf or dumb, or otherwise permanently and substantially handicapped. Several Local Authorities commenced to develop their own services for the handicapped on the basis of those provided by the voluntary organisations. Under the National/

National Assistance Act, all voluntary organisations were required to register with the Local Authority and in many cases voluntary organisations were then, and still are, used as agents of the Local Authority who are empowered to make contributions to their funds.

Many of these organisations are concerned mainly with the older handicapped person,but among the voluntary associations closely concerned with the welfare of handicapped children are those for the blind, the deaf, the epileptics, the spastics and the severely mentally handicapped. For the blind and the deaf respectively, organisations are established in the various regions of Scotland and in some areas they cater for individual religious denominations.

The Scottish Epilepsy Association, formed in 1954, provides for the welfare of children and adults suffering from epilepsy; this Association has formed three local branches and its activities include the establishment of social clubs, holiday camps and a sheltered workshop.

The Scottish Council for the Care of Spastics co-ordinates ten local Associations of Parents and Friends of Spastic Children formed since 1952 in various areas of Scotland and three residential schools and a nursery unit for spastic children have been established.

For the welfare of the mentally handicapped, two Associations exist. The Scottish Association of Parents of Handicapped Children, formed in 1954, has promoted the formation of eleven/

eleven local branches; a short-stay residential home has been opened together with several crêches and occupation centres for the daily care of mentally defective children. The Scottish Association for Mental Welfare affiliates twenty-five Local Voluntary Associations for Mental Health. Two junior occupation centres (for school-age defectives), six senior centres (for older defectives), and two clubs for special school leavers have already been provided by the Local Associations. Regular hospital visitation of mentally defective children is carried out on a wide scale, and in addition domiciliary visiting of mental defectives is undertaken for the Local Authority by eight of these Local Voluntary Associations.

Legislation can never embrace or cater for every circumstance arising from every type of disability, and the valuable help of the voluntary organisations who pioneered and who continue to experiment in the field of welfare services for the disabled will always be necessary to supplement the efforts of Local Authorities and to deal with those who fall outside the scope of State assistance.

EDUCATIONAL PROVISION FOR HANDICAPPED CHILDREN (GLASGOW).

The Annual Report of the School Health Service of Glasgow for the year ended 31st July,1957, shows that educational provision was made as follows in schools for handicapped children under the management of the Corporation of Glasgow:-

1. Mentally handicapped - 19 Day Schools and 10 Occupational Centres.
2. Physically handicapped,delicate and convalescent - 10 Day Schools (one having a separate unit for spastic children), 8 Residential Schools, 7 Hospital Schools and a scheme of Home Tuition.

[Nine Day Schools have separate departments for both physically handicapped and mentally handicapped children and are known as Mixed Special Schools. These nine schools are thus included in the Day School provision in 1, and again in 2, above.]

3. Defective vision - 1 Day/Residential School for blind children and 1 Day School for the partially sighted.
4. Defective hearing - 1 Nursery/Infant Day School, 1 Day School and 1 Day/Residential School for the partially deaf and 2 Day/Residential Schools for the deaf. Peripatetic teachers for speech-reading instruction and auditory training from the Central Speech Reading Unit. Advisory clinics at the Nursery/Infant Day School and at one of the Day/ Residential Schools for the deaf.
5. Mentally handicapped and deaf - 1 Class in a Day School for mentally handicapped children.

6. Maladjusted - 4 main and 7 subsidiary clinics for child guidance purposes; 1 Residential School outwith the city for maladjusted children.

At the 30th June,1957, when the number of children on the rolls of all schools administered by the Corporation was 178,155, the number receiving special educational treatment was 4,325, comprising physically handicapped children, 548; children with hearing defects, 321; children with defects of vision, 92; mentally handicapped (educable) children, 2,902; mentally handicapped (ineducable but trainable) children, 462.

(At 30th June,1937, 3,580 physically handicapped children were on the roll of special schools as compared with 548 twenty years later.)

In addition,Glasgow children in need of specialised care and attention were acommodated and educated at fifteen other centres, not under the management of the Corporation. These centres included:-

Biggart Memorial Home, Prestwick - 40 physically handicapped children requiring nursing care.

East Park Homes for Infirm Children, Glasgow and Largs - 44 physically handicapped children requiring long-term nursing care.

The Colony for Epileptics,Bridge of Weir - 11 Protestant children suffering from severe epilepsy.

The Royal Blind School,Edinburgh - 37 Protestant blind children.

Lennox Castle Institution,Lennoxtown - 43 mentally handicapped boys aged 12 to 16 years.

St.Charles' Institution,Carstairs - 62 Roman Catholic mentally handicapped children.

Waverley Park Institution,Kirkintilloch - 20 Protestant mentally handicapped girls.

CHAPTER II

MATERIAL AND METHODS.

AIMS OF THE STUDY

The survey on which this thesis is based was undertaken to ascertain

(1) the circumstances under which severely handicapped children are living in their own homes in the City of Glasgow,

(2) the kind of strains which their presence there imposes on parents and families,

(3) how the problems and needs of these children and their families are being met by existing medical, social and educational services,

and (4) how far it is practicable to lighten the burden of the domiciliary care of the handicapped child.

SOURCES OF MATERIAL

No complete comprehensive record exists of the total numbers of severely handicapped children in the community. Local Education Authorities are aware of most handicapped children of school age, but while it is probable that most severely handicapped children of pre-school age are known to the statutory or voluntary agencies, there is reason to believe that the records of these agencies are seriously incomplete.

In 1956, the number of handicapped children receiving special educational treatment in schools maintained by the Corporation of Glasgow totalled 4,568.

To permit systematic and prolonged study it was decided to select 200 handicapped children for detailed examination; their ages would range from 1 to 13 years so as to provide a balanced picture of the special problems of differing age groups. The cases selected would not represent a mathematical cross-section of the total mass of handicap in the city; rather would they portray a few broad groups, important in themselves and sufficiently wide in scope to indicate the type of problems which commonly arise in any attempt to help severely disabled young people.

The Medical Officer of Health and the Director of Education made available lists of those handicapped children in the City of Glasgow who were known to the School Health Service, the Maternity and Child Welfare Service and the Education Department. These lists embraced children receiving special educational treatment of all kinds, children at home excluded from occupational centres or awaiting admission to special schools or mental deficiency institutions, and any handicapped children of pre-school age as were known to the Health or Education Departments. These basic lists were supplemented by cases, unknown to the statutory authorities, which were brought to notice by hospitals or by voluntary associations interested in the welfare of handicapped persons.

SELECTION OF CASES

From the lists drawn up in this way, the 200 cases were selected for study - 150 under the age of 8 years and 50 between the/

the ages of 8 and 13 years: the emphasis was on the young child, but the older group was included to ascertain how far the problems which they now presented appeared to have roots in earlier years.

Within the 200, six broad groups of children were taken for study - blind and partially sighted; deaf; epileptic; those handicapped by orthopaedic or other physical handicaps; mentally handicapped; and those with multiple handicaps. Twelve cases receiving home tuition were among those chosen.

In selection, the bias was towards the inclusion of the more severely handicapped children at the expense of those with milder disabilities, since the problems to which they gave rise were likely to be more compelling. For this reason, the mentally handicapped children, apart from those of pre-school age, were drawn mainly from among those in attendance at occupational centres, in institutional care, or at home ineducable and untrainable. Cases were especially sought where the mental handicap was associated with another disability, while in many of the cases of deafness selected, another handicap co-existed.

The number in each broad group of handicap selected for detailed study was - Blind and Partially Sighted - 10; Young Deaf (uncomplicated) - 15, Deaf with an additional Handicap - 15; Epileptic - 10; Other Physical Handicap - 30; Mentally Handicapped - 60; Multiple Handicapped - 60.

In practice, it was not found possible to adhere rigidly to these quotas, for in many cases visited the nature of the handicap actually present, or that aspect of it causing disturbance to the child or family, was such that no simple classification was possible, either in terms of the categories of handicapped pupils defined by the School Health Service and Handicapped Pupils Regulations or by other appropriate medical classification. This difficulty was frequently found where the handicap was described as spastic or epileptic, or where a degree of mental retardation complicated a physical disability.

Despite difficulties of classification it was not thought desirable to discard these heavily handicapped cases, especially since the initial home visit revealed that they created severe problems for the family. Many of these cases had to be reclassified as multiple handicapped cases in which physical and mental disability co-existed.

THE SETTING OF THE SURVEY

The cases selected for study were drawn from all areas of the City of Glasgow, varying from those living in old slum tenements to those in the new housing estates on the outskirts of the city as well as from the better residential areas, and it was hoped to include families from all social strata very much in the proportions in which these were represented in the general population of the city.

THE APPROACH TO THE FAMILIES

All these families were visited in their own homes on several occasions. A preliminary visit was made without any formal/

formal notice to the parents; this unexpected visit enabled domestic conditions and housecraft standards to be assessed without affording the parent, as on subsequent visits, the opportunity to make special preparations for the visitor. At this initial visit, the project was discussed and explained, many basic facts obtained and an appointment made for a subsequent visit.

The home of each child was visited on at least four occasions, usually over a period of from four to six weeks. The hour of visiting varied but usually the home of the pre-school child was visited in the early part of the day and that of the school age child in the late afternoon, in order to see the cases in their home setting. Follow-up visits were also made in the evenings so that all members of the family, particularly the father and adult siblings, might be seen. These evening visits afforded an opportunity to collate information and to appraise the impressions gained at earlier visits. Such was the interest taken by parents that many fathers and other relatives made special arrangements at their work in order to be present at visits made during the day.

At all visits the parents were encouraged to talk things over and to clarify any relevant matters with each other or with other relatives, before the date of the next visit. In large families memories of events in infancy are sometimes vague but apart from a few instances, chiefly among those with children/

children in the older age group, there was surprisingly little disparity between the statements submitted from the various sources. We were satisfied that at the completion of visiting a reliable and reasonably complete picture had been built up of each family and its problems.

CONTACT AND DISCUSSION WITH THE SOCIAL AGENCIES

An effort was made to establish contact with the diverse social agencies that had been involved in the care of the child, particularly where the cases presented special difficulties. Essential details were corroborated, and other information obtained from parents was cross-checked with these sources before home visiting of each case was completed. Discussion of individual cases took place and was often supplemented by discussion of the needs and problems of the particular handicapped group as a whole. In addition, many other persons or places concerned with the welfare of handicapped children were visited; this involved visits to statutory and voluntary establishments providing educational and other facilities for the various categories of handicap, specialist clinics, hospitals and other institutions. Contact was also established with the appropriate voluntary social services and organisations for handicapped children in the city; it was found that the office-bearers or leading members of these different organisations were not infrequently themselves the parents of handicapped children included in the survey.

RECORDING OF DATA

A detailed questionnaire form of case-report was used for each case included in the survey: a specimen copy is attached to the back cover . This form was designed to permit the recording during visits of both factual information and of non-factual items involving opinions and emotions; space was also provided for the investigator to insert his impressions during and after each visit. Any details could thus easily be checked on subsequent visits to the home or on contact with other agencies. On completion of all necessary visiting and investigation, an overall analysis of each case was made.

ANALYSIS AND PRESENTATION OF MATERIAL

Inevitably a formidable mass of data was acquired, sufficient in volume and variety to raise problems of classification and presentation.

It was realised that no simple method of classification or compilation of the information - some factual, some opinionative and some frankly impressionistic - could possibly show the cumulative effect of the various needs and problems emerging in any one case or in any one handicapped group. The most promising method seemed to be in considering each handicapped group separately. This would permit detailed analysis of particular cases, especially in relation to their home setting, educational problems and placement, and would also demonstrate any/

any special needs presented by their group. The inclusion of some illustrative case-histories would give further insight into the cumulative problems of, not only the individual cases, but also that particular category of handicap.

CLASSIFICATION OF CASES

On final analysis the 200 cases surveyed were placed in these broad groups:-

Blind and Partially Sighted	10
Deaf (including 12 cases with an additional handicap)	24*
Physically Handicapped (including 5 cases with dual handicap)	41*
Mentally Handicapped (without other serious superadded handicap)	61
Mentally Handicapped with another Handicap	64*

* The Multiple Handicapped Cases studied are included in these groups.

For clarity of presentation and more specific analysis of the findings, some of these broad groups have been subdivided. The following table shows the number of cases studied in each group and in sections of the group, together with the age-distribution of the cases.

HANDICAP	No.of cases in each group			Totals	
	up to 5 yrs.	5 to 8 yrs.	8 to 13 yrs.		
BLIND	4	3	-	7	10
PARTIALLY SIGHTED	-	3	-	3	
DEAF					
- with hearing parents	2	4	-	6	24
- with deaf parents	5	1	-	6	
- with additional handicap	4	1	7	12	
PHYSICALLY HANDICAPPED					
- orthopaedic	5	14	5	24	41
- non-orthopaedic	3	6	3	12	
- multiple	-	4	1	5	
MENTALLY HANDICAPPED (without other serious superadded handicap)	22	22	17		61
MENTALLY HANDICAPPED with another HANDICAP	19	27	18		64
- M.H./H.of 'SPASTIC' nature	10	19	8	37	
- M.H./H.of 'EPILEPTIC' nature	2	5	9	16	
- M.H./other P.H.	7	3	1	11	

HOME TUITION GROUP 5 to 8 yrs.- 7;8 to 13 yrs.-5; Total 12.

Explanatory Notes.

1. Cases Mentally Handicapped. The handicap in all these cases was mental retardation, of varying degrees of severity; in some cases there were complicating factors but these were not regarded as sufficiently compelling/

compelling to justify the inclusion in the group 'Mentally Handicapped with another Handicap.'

2. Mentally Handicapped with another Handicap.

   (a) Mentally Handicapped with a Handicap of 'Spastic' nature. These cases were mentally retarded with a physical handicap involving varying degrees of spasticity. Some had been regarded by parents and various welfare agencies as spastic children; some as mentally handicapped children.

   (b) Mentally Handicapped with a Handicap of 'epileptic' nature. Most of these cases had been visited as reported cases of severe epilepsy but varying degrees of mental retardation were found to be co-existent.

3. Home Tuition Group. This group comprised twelve cases drawn from the Physically Handicapped Group. Consideration is confined to problems directly concerned with Home Tuition; the specific needs and problems of these twelve cases are considered in the sections appropriate to their handicaps.

SOCIAL CLASS DISTRIBUTION

The Social Class distribution of the heads of the families in the survey according to the Registrar General's Classification was:-

SOCIAL CLASS	AGE GROUP			TOTAL
	Up to 5 yrs.	5 - 8 yrs.	8 - 13 yrs.	
I Professional	1	4	1	6
II Intermediate	2	7	3	12
III Skilled	34	35	26	95
IV Semi-skilled	17	19	10	46
V Unskilled	10	20	11	41
TOTAL	64	85	51	200

AGE-GROUP AND SEX DISTRIBUTION

The distribution of the 200 cases, according to age and sex, was:-

Age Group	SEX		TOTAL
	MALE	FEMALE	
0 - 5	33	31	64
5 - 8	48	37	85
8 - 13	34	17	51
	115	85	200

For purposes of analysis, the age of the child has been taken as his age at the time of the first home visit.

CHAPTER III.

SOME GENERAL CONSIDERATIONS ARISING FROM THE STUDY.

Housing and Environmental Circumstances.

Co-ordination of Existing Services.

  Need for a Central or Focal Agency.

  The Importance of Early Ascertainment,Periodic Assessment and Home Supervision.

Counselling of Parents.

The Rôle of the Almoner.

Transport Facilities.

Consideration of Palliative Measures.

  Facilities for Residential and Daily Care.

  Availability of Remedial and other Equipment.

  Home Attendant Service.

  Provision for Holidays.

In this chapter some of the general considerations which emerged from the study are discussed,together with some suggestions to promote the well-being of handicapped children and to mitigate the burden of their care at home. Information about the separate groups of children studied and the more specific problems associated with particular handicaps, together with illustrative case histories and some observations on the children receiving home tuition, are presented in subsequent chapters.

HOUSING AND ENVIRONMENTAL CIRCUMSTANCES

One of the chief impressions created by this study is of the/

the often grossly unsatisfactory environment in which many severely handicapped children are being reared. Indeed some are so severely handicapped as to require the institutional care, which in the West of Scotland, is simply not available for them. Even under good housing circumstances, it would be difficult to look after some of these children adequately, and quite impossible under those which commonly prevail. As an example, in no instance in the group of blind and partially sighted children was suitable housing, or even ground floor accommodation,present.

Glasgow is still predominantly a city of tenements, and in the upper storey of a high tenement building, the difficulties of coping with a severely handicapped child are often greatly magnified, as many of the illustrative case histories show. So great was the complicating effect of bad environmental conditions in which many of the children lived, that it was well-nigh impossible to study the problems inherent in the defect itself, for these were often obscured by superimposed difficulties and side-effects resulting from the circumstances in which the family lived.

To some extent the new housing areas on the perimeter of the city escaped these criticisms, but they often presented difficulties of their own, such as arose from the rehousing of the family remote from the relatives and friends of other days, who/

who had done so much to share the care of the child and from the fact that in some of the new areas, the erection of houses long preceded the provision of shops and clinics. Distance from hospital or specialist clinic added severely to the difficulties of these cases and sometimes actually hindered adequate medical supervision and treatment.

The families of some of the handicapped children included in this study have been recommended for rehousing in bygone days but without success. Glasgow's special housing difficulties must,however,be recognised. According to the latest Census, 1951, almost half the population (48%) lived in houses of one or two rooms, as compared with only 2% in Birmingham - another city with one million inhabitants. Since the census year 33,036 houses have been built in Glasgow but in the City Assessor's annual return for 1957, of occupied and unoccupied houses, 42.3% of the houses were still of one or two rooms. Proposed developments in rehousing will involve both a large overspill of the present population and the building of multi-storey flats in the redevelopment areas of the city and it is estimated that on completion of this programme, 98% of the population of Glasgow will then be occupying tenement-type houses. It is scarcely surprising that the present great number of priority recommendations received from various sources for the rehousing of handicapped persons of all ages to obtain ground floor accommodation, garden or to reduce hazards, cannot all be met. Nevertheless some defined method of co-operation between the hospital and the Health/

Health and City Factor's Departments of the Local Authority appears necessary in appropriate cases and would be of mutual advantage. This co-operation is necessary not only in initial considerations for rehousing, but also, when rehousing is due or granted, to ensure placement suited to the child's disability.

CO-ORDINATION OF EXISTING SERVICES.

In a large city, many agencies, statutory and voluntary, touch the welfare of the handicapped or potentially handicapped child in such diverse matters as housing, diagnosis, ascertainment, treatment, education, maintenance, and preparation for employment. These agencies exist to help the child; they do good work, but such is their multiplicity, their difference in outlook and approach that it is often difficult to harness available resources so as to achieve maximum effect. This difficulty of co-ordination and integration of available resources is no new thing. MacKenzie (1917) emphasised this very difficulty more than forty years ago when he wrote, 'in our study of these problems one thing is manifest, the want of co-ordination of the social energies.' It is extremely doubtful if integration of services is any more effective now than it was then. Certainly it still leaves much to be desired. Co-ordination is not merely a matter of administrative tidiness; its absence affects in a vital way the whole life and welfare of the child. It is important to ensure that the greatest possible benefit is derived from the available services, just as it is important to secure the most economic use of specialist resources/

resources through the avoidance of duplication in investigation and assessment on the one hand, and a determination to see that effective supervision and after-care are provided on the other. Lack of effective co-ordination can prejudice not only the welfare of the child, but the well-being of the mother and the other members of the family, for conflicting views and lines of action inevitably spell much distress and anxiety, not to mention needless expense in a setting already often severely strained.

Co-ordination of advice, assessment, treatment and supervision of the case as a whole should have been possible, but even in the cases of uncomplicated disability such as blindness, deafness, or other single physical handicap, such integration of resources was so often lacking under existing arrangements. Where the disability was complex, as in cases of mental handicap and the various types of multiple handicap, the need for co-ordination of care and after-care measures was even greater. Not only physical strain, but more particularly emotional stress, were frequently encountered where several agencies working separately were concerned with the care of the individual child, and appeared to be offering conflicting opinions which were seized upon by the harassed parent.

Need for a Central or Focal Agency.

It is not, nor will it be, easy to secure the co-ordination so vitally necessary, which, to be effective, must clearly take a form acceptable to all the interests concerned. One fundamental weakness of the existing position is that there is no recognised/

recognised central or focal agency where necessary action can be initiated and co-ordinated and requisite after-care arranged and supervised, a centre to which the harassed parents can look for authoritative help and advice in the difficulties that beset them. The need for a clearing-house of this kind is widely recognised; parents, family doctors, members of hospital and Local Authority staffs, social workers and others have all drawn attention to it. The availability of acceptable machinery of this kind would be of great assistance to field workers and would help them to dispel many of the fears and anxieties of the parents. The part such an agency would play in co-ordinating the statutory and voluntary services in Glasgow, and in making the fullest possible effective use of the many excellent facilities available, would be equally important.

The basic functions of any central agency would be to receive information about the circumstances and needs of handicapped or potentially handicapped children, and to take any necessary action to help the children or their parents; it would, for instance, assess the need for special educational treatment, for periodic review, and for home supervision, as well as acting as a source of reference and a focal point for parents and for all those concerned with the welfare of the handicapped child.

Such a clearing house must obviously be staffed by knowledgeable people who are acceptable to the various agencies concerned and who have sufficient background to enable them to help/

help parents to resolve their complex problems.

This kind of beneficent authority might function either centrally (as in Denmark, where the Royal Danish Invalidity Insurance Court is concerned with the welfare of 'invalids' of all ages, the heads of hospitals and schools, as well as doctors, being under obligation to report to the Court 'invalids' and potential invalids coming to their notice)(Danish Invalidity Court 1946) or locally, as seems to be contemplated in Britain where the National Health Service Acts impose responsibility for 'care and after-care' fairly and squarely on the Local Health Authorities.

In Scotland, effective after-care in this field is in its infancy; few Local Authorities are yet staffed to deal with this clamant problem. In most areas there appears still to be no established system which ensures with certainty that all handicapped children, especially those of pre-school age and those hospitalised for long periods are brought to the notice of the Local Authority.

In many authorities in England, where, with only two exceptions (Birmingham and Nottingham), the Medical Officer of Health is also the Principal School Medical Officer, close co-operation between the Maternity and Child Welfare and the School Health Services is facilitated through the employment of common medical and health visiting staffs. Further co-ordination is often obtained through the consultant paediatrician, ophthalmic and aural/

aural surgeons to the local hospitals group serving as consultants to the Local Authority and in some areas (Cardiff, Oldham, etc.), the paediatrician is a co-opted member of the Maternity and Child Welfare committee of the Local Health Authority.

One important outcome of such measures is the ever-increasing emphasis being placed on the early 'ascertainment' of the handicapped child. Potentially handicapped or handicapped children found in the course of home visiting, or referred from any source, are assessed by an experienced medical officer or officers of the Local Authority with appropriate reference to and consultation with the Consultant and Specialist Services. By such a system, up-to-date records are maintained by the Health Department, and most, if not all handicapped and potentially handicapped children are already known and under regular supervision before school age is reached. In some of these areas, the health visitor is the recognised social worker for the family, and has established effective contact, not only with the appropriate services of the Local Authority and with other social workers but also with the hospitals concerned through their social services departments. An increasing and officially encouraged contact between health visitor and family doctor has facilitated the development and maintenance of the closest co-operation between hospital, general practitioner and Local Authority services.

The Medical Officer of Health who is also Principal School Medical/

Medical Officer and is endowed with an organisation such as described is fortunately equipped to help handicapped children, having responsibility for them from birth to school leaving age; in the case of the mentally handicapped, this responsibility and supervision continues further as the Health Committee is statutorily responsible for the care of these children on leaving school and throughout adult life. If the Medical Officer of Health is also responsible for the general oversight of the Welfare Services of the Local Authority, as often happens, he is in a very favourable position to exercise overall care of the welfare of the handicapped.

In England, the Care and After-care Service has been extensively developed by several large authorities, and by establishing close relations between this Service and all the other Social Services - statutory and voluntary - this section of the Health Department has become the focal point for advice and assistance regarding the many problems which arise in association with ill-health and disability.

In Scotland, Care and After-care Services are not yet sufficiently developed to permit the immediate inauguration of a scheme along these lines. In Glasgow, the size of the city, the large number of handicapped children, and the multiplicity of hospitals and other agencies involved, further complicate planning and development of a comprehensive scheme acceptable to all concerned. This notwithstanding, practical steps might be taken/

taken towards amelioration of the present unsatisfactory situation by a greater measure of co-ordination. It is not suggested that a separate (additional) organisation to function as a central agency should be established, but that efforts should be made to integrate the basic functions of such an agency within the framework of existing services. Whilst special local difficulties have to be recognised, and the overall commitments of Local Authority departments, including of course their statutory duties, have to be considered, it would appear that duplication of some services and the incomplete use of others could be avoided by joint planning and joint assessment of resources and requirements. As a result of this first step, more effective co-operation would be established between the agencies operating within the ambit of the Local Authority and those outside; and this enhanced co-operation must necessarily help the handicapped child and his parents.

The Importance of Early Ascertainment, Periodic Assessment and Home Supervision.

One function of a central focal point of the kind described would be to stimulate early discovery and accurate diagnosis, so that appropriate treatment and care could be instituted as early as possible.

The experience of this study emphasises the need for these measures, which are, indeed, fundamental. Mere ascertainment is not enough; it must be allied to a definite, planned scheme of action expressly designed to help the child to make the best use/

use of such talents as he has, under circumstances which will give him the best chance of using them; and, where domiciliary care is considered to be practicable and desirable, the planning must be sufficiently broad in scope to take cognisance of the complex social and environmental factors which so often govern success. To be effective, supervision of this kind must be continuing, for circumstances change, both clinically and socially, and new problems keep arising.

There is an increasing awareness amongst those concerned with the welfare of handicapped children, of the importance of early diagnosis and specialised treatment, both medical and educational. Nevertheless, it is difficult to avoid the impression that, as things are, there is still too much tendency for the official approach to consider handicapped children as falling into one or other of two sharply differentiated phases, pre-school and school, and even then to think too much in terms of educability, without taking account of all the other complex factors involved. Education is of vital importance to many handicapped children, the more so since future economic stability often depends on ability to hold a type of job which may demand a certain educational standard; but the approach to education must be surely based, if it is to succeed, and early ascertainment together with a continuous and integrated system of assessment and care should help in that direction. Ascertainment should not be considered as just a process of labelling the child, or of assigning him to a particular type of school, but/

but also as an opportunity to study fully all aspects of the child's handicap and to consider all the ways of dealing with them.

For the pre-school child and the older child unplaced at home, regular periodic assessment is especially desirable in view of possible changes of medical, psychological, or social circumstances affecting the child or the family. This review would also allow a more reliable long-term estimate, not only of the potentialities of the child, but also of any special educational treatment or placement in the light of all relevant circumstances. It would also permit the immediate rectification of such unsatisfactory features as had arisen. The value to the parents of this periodic assessment with its opportunity for expert discussion of their problems, immediate or long-term, can scarcely be overestimated. The existence of a regular system of review would have helped to lighten the heavy burden in many of the cases studied, and in some, would have forestalled approach to inappropriate agencies.

The need for home supervision is allied to that for periodic assessment by specialist medical staff, and is of equal importance. The health visiting service of the Local Authorities undoubtedly does much good work in these cases, as do visitors under statutory and voluntary agencies, but in many, the special nature and demands of the disability make more specialised visitation and advice necessary. Home supervision by specially trained visitors would afford the opportunity, not only for the counselling of parents, which will be discussed separately in full/

full detail, but also for meeting other demands encountered repeatedly amongst the families visited. These include accurate assessment of the social and environmental circumstances, domiciliary supervision and encouragement of indoctrination of prescribed therapy, ensuring that hospital and other specialist follow-up appointments will be maintained, helping to establish co-ordination, through the appropriate recognised channel, of all agencies dealing with the case, as well as providing a source for the parents to contact in emergency or difficulty. In a large city, several such visitors would be required, and provision on an area basis, or to deal with individual groups of handicap, might be considered. It would be a fundamental principle of a service of this kind that any specially trained Health Visitors of the Local Authority must work in close conjunction with their area colleagues, hospital authorities, general practitioners and the other specialised visitors of statutory and voluntary agencies.

COUNSELLING OF PARENTS

The subject of counselling of parents arises repeatedly throughout the study, and reflects the conviction that this is one of the main needs requiring further consideration when measures to promote the welfare of the handicapped child and his family are contemplated. To cater for this need adequately is exceedingly complex; the number of agencies which may be involved with any particular type of disability, the attitude of either or both parents towards the handicapped child and in consequence to the other children, the attitude of these children themselves/

themselves to the handicapped child, and the multiplicity of inter-related factors pertaining to each individual child and to each individual type of handicap have all to be taken into account.

The hospital consultant, the family doctor, and the medical officers of local authority and hospital may all be involved in various aspects of counselling, as also may the hospital almoner and statutory social workers, personnel of ancillary specialist services, such as the physiotherapist or speech therapist, the staff of school or occupational centre, and members of voluntary organisations. The attitudes of parents of handicapped children may vary from that of the sensible parent, to that of one harassed or beset with fears, rational and irrational, or that of the emotional type of mother, completely unwilling to accept the diagnosis, especially where any question of mental deficiency arises, particularly if that condition is complicated by a physical disability.

Measures to promote the welfare of the handicapped child cannot be carried out effectively in isolation from his family; the parents' anxiety or uncertainty, their confused feelings about the child, the management or treatment of his disability, his own problems and difficulties, are often closely interrelated - the welfare of the one requires the counselling of the other! The predominant needs of the family are for explanation of diagnosis and prognosis, for help in accepting and adjusting to the fact of the disability, and for practical advice on the child's management at home. This explanation and/

and advice to the parents in terms which they can understand, as well as an indication of how much the handicapped child is capable of doing, can often prevent much unhappiness by ensuring that handicapped children are neither constantly overprotected on the one hand, nor ignored on the other, through parental inability to understand the child's handicap and his full potentiality.

Whilst sound advice may be given by the respective agencies concerned, there is a constant danger that the family will be confused by the many items of advice given, since a coherent plan for any individual child is unlikely to be evolved if the advisers work largely independent of each other. This danger was fully recognised by all the agencies concerned, - medical, educational and social.

No detailed discussion is attempted here of the difficulties or apparent shortcomings of the various workers involved. The limit to the value of their advice, through factors of time, of surroundings such as a busy out-patient clinic, of restricted field of work (almoner), of the lack of intimate knowledge of family circumstances or of the full extent of the disability and the state of the parents at the time of interview - emotional, harassed, distraught - would all have to be considered. The rôle each worker might, or should, play is also not discussed in detail, especially since individual circumstances will vary with each particular disability. The basic need for successful counselling is for continuity of oversight between hospital or school/

school and the home; between hospital or school, where the emphasis is on diagnosis and treatment of the child, either through special forms of therapy or in special environments, and the home where the emphasis is on the handling of the child in relation to the family, the environmental circumstances and the capabilities of the parents.

Periodic assessment and home supervision of handicapped children have already been discussed, but their rôle in the field of counselling - where they touch such basic needs as explanation of diagnosis and prognosis, help in adjusting to the fact of the disability and practical advice on the child's management at home - merits consideration.

Home supervision by a specialised visitor would enable advice and guidance to be given in matters ranging from coping with specific and environmental problems, (avoiding hazards, countering prejudices or misguided but well-meaning advice, reiterating and explaining in terms the parents can understand and according to their abilities instructions given by the specialist agencies, the handling of the child and other siblings) to making parents aware of both the immediate and the long-term services available. All these matters are common in some degree to every category of handicap. In many cases,however, the particular nature of the disability will require the link-up between home and external agency to be of an even more specialised kind, and supplementation may prove to be desirable. The family having a blind child awaiting residential school placement would benefit from visitation by a nursery teacher for the blind;/

blind; the family with a deaf child, from a visitor with intimate knowledge of the correct methods of communication to be practised, including the proper use of the hearing aid. The family of the physically handicapped or spastic child would benefit, not only from a visitor able to advise on the provision, adaptation and use of equipment and appliances, but also from domiciliary visits by the therapist, who would supervise the handling of the child, and who would also ensure that training and other measures taken by those responsible for the child's therapy and education were being correctly applied, and were not being counteracted in the home. The home management of the diabetic child, or of the epileptic child in relation to both his therapy and his handling during seizures,would be improved by specialised visiting.

The particular nature of some problems demands that advice should be given only by the paediatrician or other appropriate medical consultant. Advice regarding the likelihood of further children being affected, the capabilities of the young cardiac case, and the outlook for any handicapped child are among many subjects in this category.

Where the handicapped child is attending school,the head teacher should be sufficiently well-informed to be able to impart to the teaching staff necessary information regarding the child's handicap,his special needs,and his capabilities,particularly where multiple handicap exists. Prior to leaving school vocational guidance, not only for the cardiac case or the intellectually/

intellectually retarded child, but for all handicapped groups, would be helpful and might, in addition, lessen the frequent changes of occupation and insufficiency of outside interests, which so often lead to other psychological and social ill-effects.

During the course of the survey, it was observed that where the father took an active interest adjustment of the family to the handicapped child appeared to be better. Throughout the whole field of counselling, whether this takes place in the home or elsewhere, explanatory interviews concerning the disability, the handling of the child, or the services available, should,on some occasions at least, include both parents together and questions should always be encouraged. The experience of those parents who attended open meetings of voluntary associations or group discussions held at the epileptic colony revealed the beneficial influence of contact between parents facing similar problems. Fears, doubts and anxieties fell into perspective and were often resolved in the informal and friendly atmosphere of a gathering united by the common bond of affliction.

THE RÔLE OF THE ALMONER

In other chapters, attention is drawn repeatedly to the infrequent use made of the hospital almoning services and to the transport difficulties encountered by parents. This gives rise to the impression that fuller use, and even development, of the almoning services might have been made, so that many pressing transport, social, environmental and even financial, difficulties might have been elicited and possibly countered at the outset; at/

at that stage the case might often usefully have been referred to the Local Authority for supervision, care and, perhaps specialised ascertainment. The assistance of the almoning service could also have been invoked to arrange integration of therapy facilities, to avoid unnecessary overlap with other agencies, and to operate as a source of contact for parents and Local Authority services.

Few parents (less than 20%) had been referred to, or had themselves contacted the almoning services, even fewer had any prolonged contact - matters such as housing difficulties,nursery admission of the child, or emergencies were typical reasons for sporadic approach. It is appreciated that in the hospitals concerned, almoning staffs varied in strength and in view of their many commitments in the field of social welfare alone, the existing staffs could not meet all demands if every case attending hospital was referred to them. Haphazard referral of individual cases, however, leaves too much to chance; it might be possible in some hospitals for all cases to be referred on initial attendance, or for the existence of the service to be made known to all parents. Handicapped or potentially handicapped children and their parents frequently require the kind of help a good almoner can give and should be regarded as a group with a high degree of priority.

TRANSPORT FACILITIES

Attendance at hospital or clinic inevitably involves some disruption of normal daily routine, whether of occupation,housework or school attendance, and this degree of disruption can be considerable,/

considerable, even in the best regulated households, and even where the patient is mobile and able to attend unescorted. It was therefore not surprising to find that considerable difficulty was experienced by parents in attending hospital, local authority clinic or other specialist agency, and that this was the reason most frequently given for defaulting follow-up appointments. Measures to reduce the incidence of lapsed attendances appear to merit greater consideration than has previously been given to this question.

Particular types of difficulty are associated with certain cases, as with the mentally handicapped child - incontinent, of uncontrolled behaviour, or of unsightly appearance; with the immobile child who must be carried - especially with the weight and relative helplessness of the older hydrocephalic or of the crippled child with or without his calipers; with the child subject to frequent seizures, or as in the orthopaedic or spastic groups having to attend hospital or clinic frequently.

Special difficulties of this kind were often superimposed on the 'trackled' background that so often besets the parent of a handicapped child - difficulties arising from the care of other young children in the home, from the distance involved in attending for treatment, from the inconvenience of ordinary transport services, from ill-health of some other member of the family. Continuity of attendance was often a major undertaking under the weight of these cumulative factors, and in many cases became an impossible, or at best, a precarious event. Suitable measures/

measures to ensure the reduction of the high rate of lapsed attendance, and honouring of the follow-up appointments would be in the best interests of the child and the family, and would be of considerable help to the hospital and other specialist services concerned.

It is recognised that for initial attendance at hospital, unless in emergency, special transport provision would not always be possible or even necessary, although when initially referring severely handicapped cases to hospital, general practitioners should not overlook the question of conveyance; where further attendance for examination or treatment is required, the transport needs of each case should, as a routine, be assessed on its merits. Where repeated attendance for therapy or assessment has to be made, the question of transport provision should always be fully considered. Similar consideration is desirable in appropriate cases, where attendance at Local Authority specialist clinic for ascertainment or periodic assessment is necessary and examination of the child at home is not practicable, as well as when regular attendance at Local Authority specialist clinic for therapy is required.

In some of the cases seen in the course of this study arrangements were made to secure suitable transport for necessary visits to a treatment centre; the contrasting pictures of the position before and after transport had been provided, illustrated the tremendous benefit it had proved to those parents who had previously honoured their appointments regardless of/

of the difficulties and personal expense involved.

Conveying the handicapped child quickly and conveniently to hospital or clinic is, however, not always the complete solution, as repeated attendances for therapy still involve a strain on parents and some disorganization of the household, especially where there are other young children. It is important to consider whether the benefit gained for the child might be outweighed by the strain placed on the mother, and in some cases, educational loss also has to be balanced against the uncertain value of prolonged physiotherapy. To this end careful periodic review of cases receiving prolonged physiotherapy is strongly advocated, in conjunction with the provision, where feasible, of physiotherapy and other therapeutic facilities at nursery or special schools, for suitable cases.

Special transport arrangements would have enabled some of the children receiving home tuition to take part in special outings and events arranged for handicapped children who were at school, or to attend events enjoyed by their mobile companions such as sports meetings or football matches.

The question of special transport arrangements to permit or to facilitate holidays for handicapped children and their families is discussed as part of the larger question of provision for holidays.

CONSIDERATION OF PALLIATIVE MEASURES

Study of the case-histories suggests that, even under existing circumstances, more might have been done to help some of these children and their parents, had the existing facilities been/

been fully used, and their fuller utilisation must clearly be one of the primary functions of the clearing house advocated. But some difficulties are more obstinate of resolution and call for the adoption of palliative measures to lighten the load of adverse circumstances. This field offers scope for the deployment of the resources of statutory and voluntary agencies alike, preferably working in unison.

Unsatisfactory environmental conditions affecting all the groups studied and shortage of accommodation for those cases of mental handicap where no answer other than institutional placement could hope to be satisfactory or feasible well illustrate the magnitude of the problem by causing serious maladjustment of the family or dislocation of other aspects of family life; and several adverse circumstances frequently co-existed.

Facilities for Residential and Daily Care.

Some alleviation might be afforded by the provision of adequate facilities for short-term residential care - for emergencies, periodic relief of the parents, family holidays, - or of crêche for daily care, and, for the less severely mentally handicapped, the provision of special day nursery facilities. The need for provision on these lines applies not only in those cases where institutional care, considered essential and urgently desired, was unhappily not available, but also in cases where the parents wished to retain the handicapped child in the family group, irrespective of the severity of his handicap and of his effect on the family. Even where environmental conditions are reasonably satisfactory, such provision would lighten the burden borne/

borne by the parents and other members of the family, and would help to meet the social and emotional needs of the child. Where conditions in the home leave something to be desired, the full physical, emotional and perhaps even intellectual development of the child would be stimulated and encouraged, and adverse influence or lack of training in the home might be counteracted by short periods of residential care or by admission for daily care. Admission to special accommodation could also be extended to the older defective who is excluded from the occupational centre because of bad toilet habits, and who will not improve unless admitted somewhere where training might be effected. The considerable relief obtained by a small number of parents from the very limited, but most valuable, service of crêche facilities organised and staffed by a voluntary association, indicates the need for a much more extensive service, available to all parents of severely mentally handicapped children and remaining open all the year round.

Modification of crêche or nursery facilities for mentally handicapped children is desirable to meet the special requirements of those cases where that handicap is associated with a physical disability. Suggested modifications are discussed in subsequent chapters as also is the value of admitting certain physically handicapped children to nurseries, equipped to provide simple therapeutic measures, and where assessment of the child's progress may be made, and full development of his personality stimulated. Similarly, the advantage to the less severely mentally/

mentally or physically handicapped child, of ordinary day nursery or nursery school placement, especially where environmental or social circumstances are unsatisfactory, should not be overlooked. Among the less severely handicapped who have left special school or occupational centre, inadequacy of recreational or training facilities often causes anxiety to parents, and provision of this kind might go far to meet the major social problems of early manhood which other experience (Ferguson and Kerr, 1958) has shown to be so formidable among these young people.

Availability of Remedial and other Equipment.

In other chapters, attention is directed to the need that commonly emerged for information about the provision, adaptation and use of suitable appliances or equipment which might help the child and his parents to cope with difficulties arising from the disability. The establishment of a depot from which such articlesmight be loaned or exchanged (or at which they might even be repaired) would be of great value, especially if its availability was made widely known to those concerned with the care and treatment of handicapped children, and if specialised advice was provided at the depot regarding the proper use of the articles supplied. There is not yet sufficient general appreciation of the help to be obtained from official services in this field of appliances.

Home Attendant Service. Often, particularly in cases of multiple handicap the introduction of a Home Attendant Service would be valuable, even if it provided help for only a few hours each week, so enabling the mother to undertake shopping and other/

other activities now performed only with considerable difficulty. On a more extensive scale, such a service would permit the handicapped child and other siblings to be taken out more frequently, especially when physical considerations, or domestic and other commitments prohibit regular outings. It should be possible to provide help of this sort under a Local Authority's Home Help Service. Parallel with the need for a 'taking-out' service runs the need, apparent throughout the survey, for a 'sitting-in' service, to enable the parents to have an occasional evening outing; although it may well be difficult to obtain the services of suitable sitters-in, who would be confidently accepted by parents and child, and who would be conversant with the handicapped child's special requirements. The limited service at present provided on an informal basis by one of the voluntary associations for handicapped children might be developed through collaboration with other benevolent organisations.

Provision for Holidays.

The presence of a handicapped child in the home often means severe restriction or absence of holidays. In some of the cases studied, holidays would have been practicable only if it had been possible to secure temporary placement of the child in residential accommodation able to deal with his handicap; but hospital or institutional facilities were lacking and private arrangements could not be afforded. In some instances, where holidays might have been possible, difficulties of transport and lack of accommodation suited to the child's needs, together with financial/

financial limitations or sensitiveness regarding the appearance of the child, deterred the parents. Several parents went to great lengths to arrange a holiday, which can have been of but little benefit to themselves or other members of the family. There is urgent need for more special holiday home facilities, the provision of which would open up the possibility of a holiday for the child himself, for mother and child, or for the family - with or without the child. Financial considerations or transport difficulties should not be allowed to prevent the utilisation of these facilities.

The twentieth century has seen great changes in the approach to the welfare of all children. At first, pre-occupation was almost entirely with the heavy incidence of deaths in the first year of life. As infant mortality fell, it became possible to focus attention more closely on the problems of disabled children and to devote more effort to their care. Much has been accomplished but much remains to be done, not only on humanitarian grounds, but in the national interest.

Some of the measures advocated in this chapter as likely to promote the welfare of the handicapped child, or to ease the strain on his parents, involve new services or the development of existing ones. It is hoped that the following chapters, in which the individual groups of handicapped children are discussed, will provide ample proof that the need exists for these measures.

CHAPTER IV.

BLIND AND PARTIALLY SIGHTED CHILDREN.

BLIND AND PARTIALLY SIGHTED CHILDREN

This group comprised ten children, of whom seven were blind and three were partially sighted.

(A). BLIND CHILDREN

Four of the seven blind children were under 5 years of age and three were between 5 and 8 years old. The social classes of their families were Class III - 3; Class IV - 2; and Class V - 2.

The four children in the younger age-group - all boys - were at home and those in the older age-group - two girls and one boy - were at residential schools for blind children. No family had any other handicapped children.

Two of the four younger children were only children, one was the first-born of two, and one the third of four children. One of the three older children was the first-born of two, one the third of three, and one the fifth of seven children.

DIAGNOSIS, ASCERTAINMENT AND SUPERVISION

In five cases the disability was due to retrolental fibroplasia and in one case to bilateral congenital cataract; all these children were premature babies, all were born in hospital, and oxygen had been necessary for varying periods during the first two months of life. In the remaining case, a/

a girl aged 6¾ years, the blindness was due to congenital syphilis and the mother, who was confined at home, had not attended for ante-natal care or blood examination.

Although hospital follow-up after discharge from maternity units either had not been established or had lapsed in several of the cases, the children had subsequently been referred to hospital for ophthalmic investigation and the visual defect was confirmed by the age of 9 months in all cases except that of the boy with bilateral cataract. This boy, although under supervision by the family doctor, was not referred to an ophthalmic hospital for specialist opinion until 2 years of age.

Attendance for supervision of the visual defect had been regularly maintained in six of the seven cases; the children were periodically assessed by consultant ophthalmologists at hospital or Local Authority specialist clinics, and in the case of the older children, also by the visiting specialists to the residential schools. In the remaining case the mother's failure to attend hospital regularly was partly due to her heavy domestic commitments and a degree of parental indifference.

Although arrangements for regular ophthalmic supervision were satisfactory, there appeared to be little effective coordination between hospital and Local Authority concerning reference of the child for ascertainment, over-all assessment/

assessment and future supervision and placement. In two cases where parents had raised the question of education, they were advised to wait until the child was 5 years old. Only one family had made use of the hospital almoning service; this was for support for their application for rehousing. In only three cases did the family doctor take an active interest in the progress of the handicapped child.

Although the area health visitor or a blind welfare officer visited the homes periodically, the parents of the younger children seemed to be unaware that the Education Department of the Local Authority must arrange special educational treatment for blind children, and they appeared to need advice on the training of the child and his home management.

By the age of 3 years, five of the seven children were already registered as blind; the two youngest children had not yet been examined at the Regional Clinic with a view to registration as blind persons. Two of the three older children had been admitted at 4 years of age, the other at 2 years of age to residential schools for blind children.

HOUSING AND ENVIRONMENTAL CIRCUMSTANCES

Three families lived in good properties, one having recently been allocated a new Local Authority house, and four lived in slum properties; only two houses had an inside toilet and only one had a bath.

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In all cases, in view of the nature of the child's disability, the housing circumstances were unsuitable. All these families lived on upper floors of tenement buildings; one lived one stair up, three lived two stairs up and three families, whose children were in the younger age-group, lived three stairs up.

The families of the younger children had been on the waiting-list for rehousing for periods ranging from four to ten years and in no case had these parents submitted specialist recommendation to the City Factor's Department in support of their application for rehousing.

One of the three families of the older children had taken no active steps towards rehousing as they believed that the building in which they lived had been condemned and that they would automatically be rehoused. This family had occupied single-roomed houses in the building for sixteen years, formerly three stairs up and later two stairs up; the oldest of the three siblings, a boy aged 16 years, lived with relatives. Another family had been nine years on the waiting-list for rehousing and had not submitted any medical recommendation in support of their application. Their landlord, who was anxious to sell the property, was unwilling to consider the possibility of a private exchange with the tenant of a Local Authority house which had a garden, indoor toilet and bath. The third family, who had been on the waiting-list for eleven years, were rehoused in the past year from a room and kitchen house in a slum/

slum tenement property to a modern flat which was, however, two stairs up. Rehousing had enabled those members of the family who had previously been obliged to live with relatives and neighbours to be reunited, but this move to an upper floor was unsuitable for the handicapped child who had, in addition to his visual disability, associated mental and physical handicaps. The previous home conditions of this family were brought to the attention of the City Factor's Department by the almoner of the hospital which the child attended, and co-operation between the Health and City Factor's Departments of the Local Authority at the time of rehousing might have resulted in the provision of accommodation more suitable for the disabled child.

The children were particularly affected by the difficulties due to their unsatisfactory housing circumstances. The toilet was usually situated on the landing half a flight of stairs down from the home and the child was nervous of the steps. Two of the children, trained at school to use the toilet, had some difficulty in becoming accustomed to a 'pot' during the school holidays. These two children had a bed of their own at school and resented sharing a bed with other siblings at home. Stairs were both a danger and a difficulty in all cases; the older children were confused by the unfamiliar, sometimes winding stairs with worn treads and no handrails. The mothers of the younger children experienced considerable difficulty in negotiating the stairs with a perambulator and their other young children in addition to the handicapped child. The facilities for play, both outside and inside the home, were unsatisfactory.

Due to the confined space, there was an element of danger for six of the children, whose play-space indoors amounted to a few square yards in the centre of the room.

Outside facilities were equally poor; outdoor recreation was severely curtailed by the lack of garden or suitable play-space, the presence of stairs and the busy traffic roads at the close mouth. With the exception of one child, the eldest in the group, who was allowed out to play with her elder sister in the busy street or on the pot-holed waste ground opposite to the tenement, the children went out only with their parents or other suitable adult escort. The youngest child, a boy aged 20 months, had recently commenced walking but the mother's domestic commitments, including the care of a 3-months-old infant, rendered even occasional outings from the house, three stairs up, practically impossible. The child was pale and debilitated and occupied himself by pushing a large perambulator to and fro against a wall of the room in which four adults and four children lived, and in which the family of two adults and four children slept. The presence of a large, though friendly, Alsatian dog and of several bulky sacks of silver paper collected by neighbours "to buy him a guide dog when he is sixteen" added to the chaos and restricted the free floor space to approximately six feet by four.

Hazards.

Potential hazards assumed greater significance than in most other groups in view of the child's handicap and the unsatisfactory housing circumstances. Fire was an especial hazard/

hazard in four homes and gas in two; only five families had fireguards and two of these were inefficient. In four cases the homes were overcrowded with furniture; trailing flexes, scattered household articles and easily accessible sinks under open windows were observed in several instances during home visiting. The restricted space available for living and play purposes increased all risks.

All parents of the younger children would have welcomed either day-nursery or nursery class admission so that the child might have companionship and recreational facilities,especially in view of the unsatisfactory housing and environmental conditions. Suitable placement of this kind, or on the lines of such special nurseries for blind children as the Sunshine Homes in England, might also afford an opportunity for over-all assessment of the child and would fill the period pending the child's placement in residential schooling, which for one denomination was in Edinburgh. By encouraging self-reliance at an earlier age, admission to a nursery or nursery class might have countered the over-protection found among most of these children, due in large part perhaps to the fact that owing to lack of space the mother was always practically 'on top' of the child all day long.

Regular home visiting by a nursery teacher or a home teacher for blind children, until placement in residential schools was effected, would also have been welcomed by the parents. This/

This would have provided a source of practical advice on management and would have prepared the child for the change to the wider environment of school from the restricted environment of home.

EFFECT OF THE CHILD ON FAMILY LIFE

The attitude of the parents to the child's handicap and their understanding of his difficulties were on the whole satisfactory. They had all experienced many difficulties and anxieties before the establishment of the diagnosis, but most now accepted their child's disability as permanent and understood his special needs. It was felt that two of the four families in the younger age-group now had a clear grasp of the implications of the handicap; in the older age-group, where the parents were helped by regular contact with the school, two of the three families seemed to understand the child's special needs and were already aware of the extensive welfare and educational services for blind persons.

With the exception of the older boy, all the children, especially the two girls at residential schools, were the centre of attraction in the home. This older boy, the fifth child in a family of seven, had associated physical and mental handicaps in addition to his visual defect. Although recently rehoused and reunited as a family, the members were still inclined to go their own ways and regarded the child as a nuisance when he was at home. His additional disabilities contributed to this attitude and to his difficult behaviour and poor progress at school;/

school; he appeared insecure and was difficult and aggressive with the other siblings. The heavy family commitments of the mother, who was looking after her aged parents - one bedridden and the other suffering from senile dementia - who lived at the opposite end of the city, and the child's additional handicaps were largely responsible for the poor family atmosphere when he was at home.

It was observed, with this one exception, that the blind children, even those attending residential schools, were acepted by the other siblings more as 'one of the family' than was the case with the deaf children, and there was less tendency amongst other siblings to exclude them from play. Other than young relatives, there was no contact with local children as friends. This was partly due to their handicap especially as gathering to watch television, which had fostered friendships in other groups, was naturally not an attraction for these children.

Besides the one instance where disunity was marked,there was evidence of behaviour disorders amongst other siblings in only two cases. In one a minor degree of jealousy existed between two young children over their mother, and in the other the handicapped child, who was idolized by her elderly stepfather, noticeably over-shadowed her older sister, who appeared shy and withdrawn in consequence.

In five of the seven cases the child's adjustment to the visual handicap appeared good. Adjustment had so far proved difficult/

difficult for the youngest child in the group because of his age and a degree of parental apathy; in the remaining case the boy was unsettled and emotionally insecure due to his multiple disabilities and the adverse family atmosphere. The excellent facilities at their residential school had assisted the adjustment of the other two older children.

Parents in this group, more than in any other, lavished presents on the handicapped child, often spending more than they could readily afford; the profusion of soft and rattle toys was often ignored by the children,who seemed to prefer to play at banging doors and splashing water.

In the only instance where the care of the young handicapped child interfered with that of the other children, domestic commitments were already heavy. In the older age-group the position was eased by residential schooling and no interference occurred. With the exception of one mother,the health of parents was good. It was noticeable how little adjustment of family life was necessary; possibly this was partly because parents were not required to attend hospitals, clinics and other agencies at frequent intervals and routine visits could be covered with little difficulty in most cases.

HOLIDAYS AND OUTINGS

Although outings for the children were severely restricted, in no instance were outings for the parents together restricted solely by the special needs of the handicapped child. A regular 'sitting-in' service would have been welcomed by the two families where the handicapped child was an only child.

On the whole, relatives were very willing to help in this respect and were also able to cover emergencies.

Of the seven families, only one managed an annual family holiday. Five were unable to take regular holidays for financial reasons, although no special adaptation would have been necessary because of the handicapped child. In the remaining family the child was usually taken on holiday by an aunt because of the poor health of his mother.

FAMILY LIMITATION

No family had sought to avoid having further children through fear of having another handicapped child, and in no instance did parents feel that they would be unable to cope with a new baby in addition to caring for the handicapped child. In one case, due to ill-health caused by chronic nephritis, the mother had been sterilised after her only pregnancy. One mother welcomed a recent baby as both she and her husband wanted the handicapped child to have someone of his own in case anything unforeseen happened to them, although during her pregnancy the mother had been increasingly apprehensive lest the second child might also be premature and perhaps blind. In another family, where the handicapped child was an only child, the mother felt that she would now be able to cope with another child. In both these cases a second child would help to fill the void in the home when the handicapped child entered residential schooling.

(B)/

(B). PARTIALLY SIGHTED CHILDREN

Three children, two girls and one boy, were certified as partially sighted children. The social classes of their families were Class III - 1; and Class V - 2.

All three children were 6 years old and attended the day special school for partially sighted children in the City. This school occupied the top floor of a three-storied primary school building which was erected in 1903; all toilet accommodation was on the ground floor and the pupils climbed sixty-five steps to reach their classes.

One child was the elder of two girls and the other girl the youngest of three children. The boy was the second of five children and had a younger sister aged 5 years who had favourable seating in her class at school because of her severe myopia.

DIAGNOSIS, ASCERTAINMENT AND SUPERVISION

One of the girls, a premature infant weighing two pounds at birth, had been retained in a maternity unit for almost three months; the elderly mother was admitted to hospital, with severe jaundice, and remained there for the last four months of pregnancy. The other girl had bilateral congenital cataract; her mother had contracted German measles during the early months of pregnancy. The boy had been referred by a child welfare clinic doctor for specialist opinion, and his visual defect was confirmed by 9 months of age. His parents were vague about his early medical history, and had been unable even to remember the cause of the disability.

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In all three cases the children had been referred for specialist opinion before the age of 1 year. They had remained under ophthalmic specialist supervision and their visual acuity was assessed regularly until they were admitted to the day school for partially sighted children, where they were regularly examined by the Consultant Ophthalmologist to the Local Education Authority. Although clinical supervision of the visual disability had been regular, no reference had been made to the Local Authority for pre-school ascertainment or home supervision in two cases. One girl, on the advice of the local clergyman, had been taken to the nearby primary school when 5 years old, and from there she was soon referred by the Head Teacher for ascertainment as a handicapped pupil, following which, admission to the special school was effected. Although the other girl had been under specialist supervision since 3 months of age, she was not ascertained until after she was 5 years old. Both these mothers stated that in pre-school years they had been anxious about the prospects for schooling, but that they had not broached the subject nor had the matter been raised by the hospital or other agencies dealing with their children.

The remaining case, the boy, had been ascertained in pre-school years as a handicapped pupil and was subsequently admitted, at the age of 5 years, to a residential school for partially sighted children. The family lived in a rural district in England in poor social circumstances and his associated debility/

debility and poor physique were additional reasons for residential placement. On the family's removal to Glasgow, he had recently been admitted to the day special school for partially sighted children.

Spectacles had first been prescribed for the boy at 15 months of age and for one of the girls when she was 4 years old; both children were reported to be constantly breaking them and there was no spare pair available in either case. The girl with bilateral cataract had some vision in the left eye but none in the right eye; she had been admitted to hospital several times for needling operations. This child was unable to see without her spectacles, and had first been provided with them when 18 months old. She had a spare pair, was encouraged to take great care of her spectacles and breakages rarely occurred.

Replacement of spectacles for these children appeared to have been more difficult in pre-school years and this was not always due to parental apathy. A specialised visitor would have been able to advise how repairs could be obtained without delay and free of charge, and at the same time home supervision would have encouraged the children to wear their spectacles constantly.

Co-operation between home and special school was good in only one case; the mother visited the school at monthly intervals to discuss the ophthalmic and educational progress of her daughter; in the remaining two cases contact with the school staff was poor. In no case was the prognosis of the visual defect/

defect such that transfer to an ordinary school would be likely in later years. Both girls were making steady progress at school but the scholastic attainments of the boy were unsatisfactory.

HOUSING AND ENVIRONMENTAL CIRCUMSTANCES

The housing and environmental circumstances of two families were very poor. Their room and kitchen homes, one and two stairs up respectively, in slum tenement properties were reached by dark steep winding stairs with worn treads and no handrail. There were no hot water or bathing facilities and the unlit outside toilet on the landing was shared by three or four families.

One family, who had not submitted any medical evidence in support of their application, had been on the waiting-list for rehousing for ten years - having lived four years in their present home following a period of two years in a similar house on a lower floor which they left mainly because of dampness; prior to this, the parents lived in lodgings for fifteen years. The other family also had submitted no medical certificates to support their claim for rehousing and had been three years on the waiting-list. An adult male relative - a post-encephalitic mental defective - lived in the same house. The father of the handicapped child was on permanent night shift work primarily to ease the sleeping arrangements, and when he was at home at week-ends the defective shared the only bedroom with the handicapped child and her younger brother. Owing to his hours of work/

work the father seldom saw his children, and the necessity to keep them quiet during the day restricted what little opportunity for play there was in the home, particularly during school vacations. In the remaining case the parents had returned from England to live with the father's mother. They and their five children shared the four-apartment Local Authority flatted house, which was one stair up, with the father's mother, brother and sister. The handicapped boy shared a bed with three other children, and the youngest child slept in an outgrown cot in the same room. The parents slept on a bed-settee in the living room but as relations between the relatives had deteriorated, they now used the children's bedroom for their living room. The child's mother was eight months pregnant but had not attended for ante-natal care and was in a poor state of health. The handicapped child's enuresis had recently recurred and the parents made no attempt to carry out the practical measures recommended by the child guidance clinic, where he made spasmodic attendances. Family atmosphere was poor and the standard of housecraft low; aggravated by the father's chronic unemployment, the domestic situation was now reflected in the unsatisfactory handling of the children.

Hazards.

In addition to those arising out of the housing and environmental conditions, hazards due to overcrowded rooms and danger from fire were observed in all three cases, and from gas in one. Only one family had a fireguard and this appeared to be insecure. The/

The children had few opportunities for outdoor recreation when not at school and in their homes there was little space for play. Traffic was a danger in all cases. The boy was afraid to go out by himself and had poor traffic sense. One of the girls was stated by her mother to have little traffic sense and casual traffic using the side street which served as the playground for local children was a continual danger. Owing to the absence of any back court and the position of the tenement at the junction of two busy traffic roads, the other girl was allowed out only if escorted by an adult.

There was severe restriction of outings during school vacations and at week-ends and in all three families,owing to the mother's domestic commitments,an outing to the nearest public playground was an infrequent event. As in many other families with handicapped children, often the child's only outing of the day, when not at school, was to accompany the mother on a hurried visit to the shops. A home attendant service to enable these older children to be taken out for walks or play would have been welcomed by the mothers. The parents of the two girls would have welcomed day nursery or nursery class admission for them when younger, especially in view of the gross environmental difficulties and their domestic commitments. Pre-school training facilities or advice regarding management of the child would have been especially welcomed.

EFFECT OF THE CHILD ON FAMILY LIFE

In all three families, the handicapped child was treated as 'just one of the family' and in no case did the parents fuss over the child as was noticed with the blind children. No mother accepted the child's handicap as permanent, all three hoping that the visual defect would be cured or greatly reduced, but in only two cases did the parents appear to understand the implications of their child's handicap.

Relations with the other siblings were good and there was no evidence of maladjusted behaviour, nor did there appear to have been any undue interference with the care of other siblings solely because of any special needs of the handicapped child.

HOLIDAYS

Two of the three families had never had a family holiday; financial stringency was the reason given, and no special arrangements would have been necessary because of the handicapped child. In both families holiday provision appeared desirable for all the children. The remaining family managed an annual holiday.

FAMILY LIMITATION

No family had sought to avoid having further children because of the handicapped child or through fear that another child might be handicapped.

CHAPTER V.

DEAF CHILDREN.

1. Deaf children with hearing parents.
2. Deaf children with deaf parents.
3. Deaf children with an additional handicap.

DEAF CHILDREN WITH HEARING PARENTS

This group comprised six children; the social classes of their families were Class III - 2; Class IV - 1; Class V - 3. In two of the families there was a deaf child in addition to the case selected for study.

The age range, ages and present placement of the children in this group were:

Up to 5 years. Two cases. One, a girl aged 3 years, was attending an infant school for deaf children; the other child, a girl aged 2 years, was attending the advisory clinic attached to this school where her older sister, aged 5 years, was a day pupil. Both the cases studied had always been considered by their families to be deaf.

5 to 8 years. Four cases. One, a girl aged 6 years, was a day pupil at an infant school for deaf children which her younger sister, aged 4 years, also attended; the cause of their deafness was not known. The second case - a boy aged 6 years - had developed deafness following streptomycin therapy for tuberculous meningitis contracted when he was eighteen months of age. He also attended an infant school for deaf children as a day pupil. The third case - a boy aged 7 years - had also developed deafness following streptomycin therapy for tuberculous peritonitis contracted at 2 years of age. He had attended an infant school for deaf children but was now at a school for partially deaf children.

The/

The remaining case - a girl aged 7 years - attended a residential school for deaf children, coming home for one weekend each month. No known cause for her deafness had been established.

DIAGNOSIS, ASCERTAINMENT AND SUPERVISION

Diagnosis.

In all the four cases where deafness had not been acquired at a later stage of infancy, failure on the part of the parents or relatives of the handicapped child to notice apparent deafness appeared to have been aggravated by delay in reference for specialist investigation when suspicion had finally been aroused. In view of the increasing emphasis being placed on the early detection by general practitioners and Local Health Authority personnel of possible deafness in young children, an attempt was made in each of the four cases to establish the cause of the delay.

In one of these cases the deafness had not been suspected by the family until the child was almost 2 years old and, refusing to accept the family doctor's opinion that the child was 'merely slow', they sought other advice. Reference to hospital followed and the parents' suspicions were confirmed when the child was 2½ years of age.

In another case the noise of tin plates accidentally dropped was noticed by the parent to produce no response from the child, aged 2 years. This incident, coupled with the recollection/

recollection of a fall hitherto considered insignificant, aroused the parents' suspicions that the child was not hearing. The family doctor advised observation for a year but the mother attended hospital through another source; after a course of speech therapy which was discontinued because the child did not appear to hear, three other hospitals were attended in turn before diagnosis of the deafness was established when the child was 3 years of age.

The mother of the third case suspected deafness and sought advice when the child was 9 months old, and had been told that she was 'miming' her older sister who, following referral to hospital at 15 months of age, had been confirmed to be deaf a year later. Advice was sought of the Head Teacher of the infant school for deaf children, which the older child by then attended, and following investigation the diagnosis of deafness in this younger child was confirmed.

In the last of these four cases the mother had consulted the family doctor when the child was six months old and her fears had been discounted; she later insisted on reference for specialist opinion and the presence of deafness was confirmed when the child was twelve months old.

Difficulties of, and delay in, diagnosis although not so marked had also been encountered by parents in this group whose children had acquired deafness. These cases demonstrate the importance of the early diagnosis of deafness not only to prevent or reduce worry to parents, but also in order that deaf/

deaf or potentially deaf children may have early training in the interpretation of sounds and in the use to the best advantage of what hearing ability they may have.

Ascertainment and Supervision.

All these children were now either in attendance at, or due for admission to, educational establishments for deaf children in the city, and were under the supervision of Consultant Aural Surgeons at hospital or at Local Education Authority specialist clinic.

Co-ordination of the educational and medical provision for several of these cases appeared unsatisfactory. Some divergence of views in the matter of certain methods of auditory training confused the parents and appeared to undermine the importance and value of other helpful and agreed measures which they had been instructed to apply. It was felt that, in the cases surveyed, the tendency existed to overlook the relationship of the clinical condition to the social circumstances of the family and to the capabilities of the parents to co-operate in the correct training and handling of the child.

If, following confirmation of diagnosis, reference of cases was made to a central agency, integrated arrangements for overall assessment of such children could be undertaken and social conditions and the capabilities of the parents could be determined. These circumstances should all be taken into/

into account in deciding whether either special school placement on a daily, weekly or entirely residential basis or some other arrangement would be to the best advantage of the deaf child.

In all cases in this group it was observed that the children behaved much better under the routine and discipline of school than at home. Regular home visitation by a specialised visitor appeared desirable to promote handling and training of the children at home on lines similar to those employed at school or hospital and, at the same time, to ensure that follow-up appointments were kept by parents and to give any necessary explanation of the implications of the handicap. In marked contrast to the deaf parents of deaf children, no parent in this group had much knowledge of the extent of the services available to the older deaf person, especially in the field of employment and welfare.

The difficulty of communication between the parents or the other siblings and the child was a serious problem often resulting in poor behaviour by the handicapped child. Parents and child were exasperated with this difficulty and temper tantrums through frustration were reported in all children seen in this group. To assist in overcoming this difficulty, more instruction to the parents in the handling of the child and/in the correct method of communication would have been welcome, but such instruction to be fully effective would require regular supervision/

supervision and guidance in the home.

The parents even of the older children of this group failed to co-operate effectively with school or hospital in the use at home of the child's hearing aid, and many well-worn reasons were given for the lack of success, and in some cases none-use, of this appliance. Since to employ the hearing aid successfully in the home depends on understanding, patience and help from the parents, specialist advice on its use, whether given at hospital or at school, should be supplemented by supervision in the home.

Although admission for special educational treatment was effected at an early age for several of these children, and for some was preceded by attendance at advisory clinics at school or at hospital, several of these children might have been considered in earlier years for admission to a day nursery on a priority basis. In three families the handicapped child was the only child in the home in pre-school years.

In this small group of children with hearing parents the diagnosis of deafness in the second or younger child was in each instance somewhat delayed; a system of routine early testing of the hearing ability of young children in families where there is already a deaf child might be worthy of consideration.

HOUSING AND ENVIRONMENTAL CIRCUMSTANCES

The family of one of the two children in the younger age group was satisfactorily housed; however the mother was anxious for/

for an exchange to a house in a different district, as a railway line at the bottom of the garden was a hazard to the safety of the deaf child who was able to squeeze through the damaged fence. As a result the child was usually not allowed out to play without escort. This mother was under chest clinic supervision for pulmonary tuberculosis and was also wearing a plaster jacket for a recently acquired slipped intervertebral disc. The other family had a deaf child in addition to the case studied and, although on the waiting list for rehousing for ten years, the mother was unwilling to accept rehousing owing to the dissolute habits of her husband, who took little interest in the home or the children. The lack of amenities in their room and kitchen property, two stairs up, was aggravated by the presence in the home of an aged infirm relative.

Of the families of the four children in the older age group, two had very poor housing conditions. One family, consisting of the parents and five children, had occupied a single room for fourteen years and although on the housing list for eleven years had never submitted a medical certificate to the City Factor's Department in support of their claim. Admission of the child to a residential school for deaf children had slightly eased their accommodation problem.

The other family unsatisfactorily housed, and on the housing list for five years, had lived in a single room, three stairs up, before moving to a room and kitchen property on the same/

same floor three years ago. This move, made to gain an extra room, had not been satisfactory as there was continual friction between this family and their downstairs neighbours because of the noise made by the two deaf children and their younger sister. The steadily worsening position contributed largely to the mental ill-health of the mother and was now being reflected in the children through her poor handling. The two remaining families were satisfactorily housed.

Hazards.

In this group gas and fire were appreciable dangers to one family which had no fireguard; three of the other families had inadequate fireguards. Traffic was a danger in all cases. The homes of four of the children were situated on busy arterial roads; the older children especially had developed a good traffic sense for crossing busy roads, but casual traffic, filtering into the quieter side-streets used for playing, was always a danger to these deaf children and was a source of worry to their parents. The remaining two families lived in modern housing estates where danger from traffic was reduced as the children could make use of garden and otherproper playing space facilities.

FAMILY LIMITATION

In two families the parents had tried to avoid having further children, partly through fear of having another handicapped child and partly for financial reasons. In three families,/

families, the parents had not tried to avoid further children and in the sixth family the mother, who had been sterilised on account of a cardiac condition, would have welcomed further children as company for the handicapped child, who was an only child.

No family had sought specialist advice regarding the possibility of having other handicapped children.

HOLIDAYS

Five of these families had had no holiday for several years, some not since marriage. The handicapped child was in no case the reason, the prohibiting factor being financial difficulty. The remaining family always managed an annual holiday.

DEAF CHILDREN WITH DEAF PARENTS

This group comprised six children, one of whom was 6 years old and the remainder were under 5 years of age; the social classes of their families were Class III - 5; Class IV - 1.

In all these families both parents were deaf, but in all except one instance the parents had hearing brothers and sisters; in this case, all the father's relatives were deaf, but the mother had hearing relatives.

Three of the families visited had one deaf child. Two of these children, aged 4 and 6 years respectively, were at an infant day school for deaf children; the third child, aged 2 years, attended the advisory clinic of this school. Each of the three other families visited had two deaf children; in one of these families the 3-year-old child was at the same infant school, whilst her younger sister aged 22 months, who had had a recent operation for the removal of her left eye, attended the advisory clinic. In the second family, the children, aged 3 and 5 years respectively, were at a residential school for deaf children, coming home for one week-end each month. In the third family, the child aged 3 years attended an infant day school for deaf children and her elder sister, aged 14 years, was a pupil at the school for partially deaf children in the city.

DIAGNOSIS, ASCERTAINMENT AND SUPERVISION

Diagnosis.

In all six families the possibility that the child might be deaf had been discussed by the parents or other relatives with the family or child welfare doctor before the children were 1 year old. Apart from initial slowness to recognise probable deafness, further reference for specialist investigation or opinion appeared unduly delayed in five of the six cases. Complete oversight of the handicap could not have been the reason, as both parents were themselves deaf and the possibility of the child being similarly handicapped had presumably been present in their minds, and in the minds of others who saw the children.

In view of this, an attempt was made to ascertain as accurately as possible the reasons for the delay in diagnosis and in reference for further investigation, and the following circumstances appeared to have contributed to the delay:

(a) Absence of advice to the parents. None of these deaf parents had received advice, either when contemplating marriage or when married, that the presence or absence of hearing in any children they might have must not be taken for granted until each child had had appropriate specialist investigation, which should be obtained as early as possible.

(b) Absence of an automatic system of routine auditory examination of all children born to deaf parents. (It has already/

already been remarked that a similar arrangement is desirable for all younger children in families with hearing parents who already have a deaf child.) In one of the families in this group, where the parents and two children were deaf, the third and youngest child, aged 15 months, had never been tested and although not speaking was 'presumed' to be hearing normally.

(c) Mistaken convincement of the parents. The deaf mother, in one instance, had noticed her week-old child turning his head when a baby cried in the adjacent cot in a maternity unit; in consequence she had assured herself and her husband of the child's ability to hear. Specialist opinion was not sought for this case until the child was almost 1 year old. Some of the parents had interpreted movements of the lips, or noises made by the children, as speech. Indeed, initial attempts to speak appeared to have been made by some children and later abandoned; this failure was variously attributed to immunisation, teething or ear abscess, but was probably due to the children being unable to develop any existing hearing capacity.

False reassurance had been given by friends and relatives - especially by grandmothers of the children. One grandmother firmly asserted that the deaf child heard whenever she spoke; her speaking tone during the visit had been/

been sufficient almost to make the room vibrate, a habit probably acquired from always having shouted at her deaf daughter.

In four of the six families, parents or other relatives stated that the child had been tested in early infancy by the family doctor or at a child welfare clinic, and that possible deafness had been discounted when the child appeared to give a positive response to testing. In one instance, a relative thought it probable that the child had caught sight of the object being rattled.

Undoubtedly there had been, in this group, a tendency amongst the parents to be frightened of having their own suspicions of the child's probable deafness confirmed.

(d) Difficulty in communication. Due to the deafness of the parents, difficulty in communication hindered explanations and possible advice, or limited the opportunities of taking part in open discussion or other conversation which might have led to earlier recognition of the child's deafness.

(e) Apparent dullness of the child. Recognition of deafness had been delayed in one instance through the handicapped child being considered innately dull and unresponsive. His poor home background had been an aggravating feature and was now reflected in parental inability to carry out proper/

proper auditory and social training.

(f) Failure to attend specialist clinic or hospital. In one case, apathy of the parents was responsible for failure to attend; in another case, the sensitiveness of the deaf mother over the difficulty of communicating with doctor or nurse at the busy clinics, together with domestic commitments, were given as her reasons for discontinuing attendance.

(g) Lack of knowledge of existing services. In some cases, parents and others concerned with the child appeared to have assumed that as the parents were deaf the child would probably be deaf also and that, moreover,neither a reliable estimate of hearing ability nor measures for training were practicable until the child was about 2 years of age.

These observations emphasise the importance of the early reference of new-born children of deaf parents for appropriate specialist investigation. Early detection of deafness,by the up-to-date methods now available for analysing the disability, could then result in early auditory training with much better prospects of success than when diagnosis and treatment measures are delayed.

Ascertainment and Supervision.

At the time of visiting, all these children had been ascertained as handicapped pupils and were either admitted or/

or awaiting admission to educational establishments for deaf children in the city. All were now under regular supervision by Consultant Aural Surgeons at hospital or at Local Education Authority specialist clinic.

Contact between home and special school was satisfactory and was enhanced by the services of the specialised visitor of the Glasgow Mission to the Adult Deaf and Dumb. This lady, already well-known to all deaf parents in this group, was of singular value in acting as interpreter at hospital, advisory clinics and other agencies and, with her assistance, deaf parents were spared much of the embarrassment, worry and misunderstanding frequently attendant upon interviews with hearing persons.

Notwithstanding the efforts of hospital, school and social worker, methods of communication advocated at advisory clinic or school either were not attempted or were not applied in the home. In view of the age of the children and the handicap of their parents, a certain degree of confusion over communication between them and their deaf child was only to be expected, but this difficulty was a major problem in all these families. The different means of communication used confused the children,the parents using finger spelling and gesticulation, whilst other agencies made use of lip-reading and hearing aids. This confusion was increased in some families where a speaking relative, often a grandmother, lived in the home or visited daily

and/

and was unwilling or was too old to alter incorrect methods of communication. In none of the households could full effective use be made of hearing aids supplied to the children and used by them at school; in this matter, the assistance which the specialised visitor for deaf persons was able to give was limited by the disability of the parents.

Several of the parents would have welcomed admission of the child to an ordinary day nursery until the time for entrance to an infant school for deaf children. Priority admission to such a nursery should be a routine provision for young deaf children, even though they may be attending the advisory clinic of hospital or school. In two of the families visited, a younger speaking sibling was in a completely silent household; a similar priority to obtain day nursery and nursery school admission should be afforded speaking children from silent homes, so that normal speech development would be encouraged and maintained.

HOUSING AND ENVIRONMENTAL CIRCUMSTANCES

Four of the six families lived in good or reasonably sound houses; one of these occupied a modern house with a garden. The other three families, who had been on the waiting list for rehousing for periods of from seven to nine years, found the proximity to busy traffic roads and the absence of garden and indoor amenities to be major disadvantages; no medical certificates had been submitted to support their applications for rehousing.

The remaining two families lived in slum properties. One of these families occupied a single-end room, at the end of an artificially lighted passage, and reached by a narrow spiral stair. The open back court was full of potholes and led directly on to an arterial road. The young handicapped child lived and played in this single room, where the cooking range and fire were unprotected; the confined space was crowded with furniture and utensils, and the flexes from improvised electrical fittings trailed over the floor. Despite repeated persuasion by the advisory clinic and by the specialised visitor for deaf persons, the parents would not agree to admission to ordinary day nursery or to the infant school for deaf children for this child from the silent and hazardous home. Although in this matter the attitude of the mother was apathetic and that of the father stubborn, both parents were obviously over-attached to their only child.

The other family were not on the waiting list for re-housing and, after living fifteen years in a single-end room, had moved three years previously to a room and kitchen dwelling in a property now due to be condemned. The adverse environmental conditions contributed to a 'problem family setting'. Both parents were elderly and of limited intelligence, and the chronic unemployment of the father was in marked contrast to the excellent working record found in the rest of this group. Dreadful housecraft standards were associated with the bad environmental/

environmental conditions, despite the efforts of the only hearing member of the family, a daughter aged 18 years, who, in addition to her employment, made some attempt to cope with the domestic chaos. The parents were over-dependent on this girl, who had borne the main burden of the care of the two deaf children until their admission to residential schooling. Both these children were markedly jealous of each other and other behaviour disorders were evident. The effects of training and proper handling at school were countered by the asocial and primitive living conditions at home, and by the parents and older sibling using other methods of communication than those practised at school where the children were observed to be much more settled and happy.

Apart from this one exception, home atmosphere and the care of the children were remarkedly good in all cases.

Hazards.

Fireguards in three homes were satisfactory, and in two homes inefficient; in addition to the other hazards in the home already described, there was no fireguard of any kind.

Traffic was a considerable hazard to all the children, as their homes were on or near busy traffic roads.

Facilities for Play and Outings.

The children in this group were usually not allowed out unless with a responsible escort. Side streets were unsuitable for playing because of casual traffic, and outdoor play for/

for the older children was possible only at school. For this reason, there was little contact with nearby hearing children and in consequence they lacked friends for indoor play. In the only family where there was any real contact with local children, the deaf child had a younger speaking brother.

FAMILY LIMITATION

No family had avoided having further children through fear of having another handicapped child. One family had avoided further children because of poor housing conditions, whilst in another case the parents would have welcomed another child, even if similarly afflicted, as company for their deaf child.

HOLIDAYS

In no instance were holidays restricted or adapted on account of the child's disability.

A relative social isolation of the families in this group arose out of their handicap. Their interests and acquaintances were to a considerable extent amongst those similarly afflicted, and the parents had first met each other in the limited setting of schools or after-care organisations for the deaf. More than in any other handicapped group surveyed, it appeared that the father was the active member of the partnership and this was taken into account when appointments were made for visits to the home with an interpreter. It seemed probable/

probable that the emancipation of the female sex has been less rapid in such families through this isolation from the rest of the community.

Most of the parents appeared to accept their child's handicap as permanent, but had nevertheless welcomed early admission for special educational treatment and hoped for benefit from methods of auditory training which had not been available for themselves. Undue apprehension regarding the future welfare and employment of their children was not encountered; through their shared handicap these deaf parents felt that they could foresee and guard against many of the difficulties likely to be encountered by their children in later life.

DEAF CHILDREN WITH AN ADDITIONAL HANDICAP

This group comprised twelve children; the social classes of their families were Class III - 7; Class IV - 2; Class V - 3.

The intention had been to study young children who had a physical handicap in addition to their handicap of deafness. Despite scrutiny of all the lists supplied and enquiry at the appropriate infant schools and other agencies, the requisite number of such cases could not be obtained; most of those considered to have this type of multiple handicap were older children, and some of these have been included.

Several young children who had been visited as uncomplicated cases of deafness were found however to have associated handicaps, and it was considered that the disabilities present in these cases and the special problems they raised did not warrant their inclusion in the group of uncomplicated deaf cases with hearing parents; they have now been included in this group of deaf children having an additional handicap.

Analysis of this group was extremely difficult owing to the diversity of handicaps, the varied placement of the children and the number of agencies involved.

The broad classification of the twelve cases studied was:-

Up to 5 years:-

4 cases.

Deafness + Physical Handicap - orthopaedic - 1.
Deafness + Probable Mental Handicap - 3.

5 to 8 years:-

1 case.

Deafness + Mental Handicap - 1.

8 to 13 years:-

7 cases.

Deafness + Epilepsy - 1.
Deafness + Physical Handicap - orthopaedic - 1.
Deafness + Mental Handicap - 1.
Deafness + Mental + Physical Handicaps - 2.
Partial Deafness + Physical Handicap - non-orthopaedic - 2.

All these children were receiving special educational treatment; two were in a class for mentally handicapped deaf children at a special school, three attended special schools for physically and mentally handicapped children and the remaining seven children attended educational establishments for deaf children in the City of Glasgow.

For convenience and for clarity of presentation the cases have been considered in their respective age-groups.

Children up to 5 years.

Only one of the four cases in the youngest age group had a physical handicap in addition to his deafness - a residual spasticity of the left leg, now much improved, for which regular assessment/

assessment and therapy was maintained; this physical disability followed an attack of cerebrospinal meningitis at the age of 5 months. Despite careful enquiry, there was no record of deafness having been noticed before admission to hospital, nor of deafness having developed as a result of this illness whilst the child was in hospital. Deafness was first suspected by the parents a few months after the child's discharge from hospital; following a period of observation their suspicions were eventually confirmed when the child, by then 2½ years old, was referred by a child welfare clinic for an aural specialist's opinion. Early admission to a nursery class in a residential school for deaf children was then effected. Since admission, no routine had been established as the parents had allowed the child to alternate between residential monthly or weekly, and daily attendance. Poor parental handling of the child's deafness, and behaviour disorders associated with his over-protection undermined the effects of the medical and educational supervision and training which had been arranged. The child had a hearing aid and had some degree of speech, but in the home little effective use was made of either.

The remaining three cases in this age group appeared to have a degree of associated mental retardation. In all three cases, reference for specialist investigation of the deafness or suspected deafness had not occurred until the children were 2 years old, although suspicion of the existence of the handicap had been aroused much earlier. Grossly unsatisfactory environmental/

environmental circumstances and poor family atmosphere had largely been the cause of the tardy reference for specialist opinion, and were later responsible for the unsatisfactory training and handling of the children. In consequence, accurate assessment of the relative degrees of deafness and innate dullness had so far been impossible; none of these children had any degree of intelligible speech and the hearing aids supplied were not used in the home. A 'problem family setting' existed in two homes and had caused much concern to the agencies tackling the numerous side-effects; in the third household, the commitments caused by an even younger physically handicapped child aggravated the poor parental handling and general apathy of the family towards the deaf child, whom the parents and older siblings considered as 'really mentally defective.'

The three children were admitted as day pupils to the nursery class in infant schools for deaf children, and one was subsequently transferred to a similar class on a residential basis. This admission for special educational treatment, although not removing the basic unsatisfactory features, was, however, counteracting some of the effects and would in due course facilitate accurate estimate of the extent of the auditory handicap.

Children from 5 to 8 years.

The only child in this age range, a boy now aged 6 years, had a replacement transfusion at birth. When referred for specialist opinion, on account of retardation of the milestones of/

of walking and talking or for extreme behaviour disorders, he was considered to be severely mentally handicapped. When 5 years old, admission to a special school for mentally handicapped children had been arranged, but shortly before this was effected the boy was referred to hospital for tonsillectomy; the consultant aural surgeon concerned considered that the child might be deaf and that appropriate training should have been commenced at a much earlier age. Admission as a day pupil to an infant school for deaf children had recently been arranged, and at the time of home visting, although a prolonged assessment of progress was not then possible, it appeared likely that in addition to the severe deafness, a marked degree of mental retardation also existed.

The emotional nature of the child's mother, earlier upset by the seemingly conflicting opinions expressed by the specialist agencies consulted, and recently by the question of deafness, had contributed to the poor handling and marked unsatisfactory behaviour of her child. At school, speech therapy and a hearing aid had been provided, but response to both measures so far appeared very doubtful; any improvement in behaviour was largely due to the efforts of the teaching staff.

<u>Children from 8 to 13 years</u>.

Among these older cases, a diffuse pattern of associated handicap and of educational placement existed.

One child - a girl aged 12 years, handicapped by deafness and/

and epilepsy - had an uneventful history until she contracted tuberculous meningitis when 2½ years old; streptomycin therapy had been necessary and during a further spell of eighteen months in hospital due to a relapse, deafness was confirmed. Epileptiform seizures of a major type had also developed following the meningitis and several specialists had since confirmed the existence of both handicaps. Regular medication for the epilepsy had been maintained and no seizures had occurred during the past two years. Delay had occurred in commencing appropriate auditory training whilst in hospital, and although a hearing aid was now used both at school and in the home with benefit to the child, her speech remained practically unintelligible. Change of family residence resulted in her admission to a day school for deaf children in Glasgow. Subsequently the parents had been unable to secure admission to a residential school in England for deaf children of Jewish Faith; in their opinion this was due to unnecessary disclosure of the epilepsy when the transfer was being negotiated. This matter had aggravated the inherent emotional nature of the mother and contributed to the parents' failure to co-operate with the school in the training of the child, who was noticeably over-protected on account of the epilepsy and the deafness. The child's difficulties were increased by inevitable comparison of her attainments with those of the other sibling, her brother, who was shortly entering Glasgow University.

In addition to their deafness, two children had physical handicaps/

handicaps of an orthopaedic nature. One boy, almost 13 years old, who attended a residential school for deaf children as a day pupil, had an additional handicap of a mild spastic nature. Deafness had been suspected by the mother when the boy was 8 months old, but the father and grandmother would not countenance her suspicions; instead they attributed the slow progress in sitting up, walking and talking, and the apparent lack of response to sounds to the orthopaedic condition, which was already under regular supervision at hospital. Diagnosis of the deafness was established at school entry age and the child had since attended schools for deaf children; a hearing aid was worn regularly but speech and educational attainments were poor. Previous difficulties associated with the physical handicap, largely due to the family living in the upper storey of a tenement building in a congested industrial district, had lessened as the boy grew older. He was, however, becoming increasingly withdrawn and over-protected as, isolated from his school companions and with no playmates in the neighbourhood, he was entirely dependent on his parents and an adult sister for companionship at home.

The other child - a boy aged 9 years - was, in addition to his deafness, physically handicapped due to tuberculosis of the spine and right knee joint. The tuberculous infection, which caused meningitis at 3 years of age, had been contracted from his mother; the only other three children of this family had all died in infancy from tuberculous conditions. Following

his/

his initial illness, relapses and sequelae had necessitated long spells of hospitalisation, and treatment with streptomycin had caused his present deafness. His orthopaedic disability necessitated the fitting of an extended caliper to his right leg, and on discharge from hospital he was admitted to a school for physically handicapped children, where he was given a favourable seating position in a large class. His educational attainments were unsatisfactory despite the seating position, some ability to lip read and the use of a hearing aid; these were supplemented by tuition for half-an-hour weekly from a peripatetic teacher for partially deaf and deaf children. He had recently been assessed for admission to a school for partially deaf children and this placement, on a trial basis, was shortly being effected; more intensive and integrated measures for his speech and hearing disabilities and facilities for vocational training would be available on the school premises.

Unfortunately, the nervous temperament of the mother had been agitated by the contradictory views expressed by those handling the child, concerning the suitability of the auditory training measures he was receiving and the suggested alternative placement; needless distress and annoyance had been caused to the parents and teaching and medical staff. The family had recently been rehoused from a single room property, three stairs up, to a modern ground floor council house. In view of the mother's ill-health and the father's disability due to a war injury, this move resolved many erstwhile major difficulties, including/

including that of lifting and carrying the heavy child with his plaster cast or caliper.

Two children had been admitted to a special class for mentally handicapped deaf children. One, a boy aged 9½ years, had not commenced talking until 3½ years old; after two years in a primary infant school, medical assessment resulted in his present placement. His educational attainments were poor; his speech was intelligible, but no hearing aid had yet been obtained for him as the parent constantly defaulted repeated appointments for audiometric examination.

The other boy - aged 11 years - was transferred to this class after four years in a school for physically handicapped children, which placement had been made due to the child having a right-sided hemiparesis following tuberculous meningitis contracted at 5 years of age. Although specialist supervision of the orthopaedic disability had been satisfactory, measures of auditory training for the severe degree of deafness which had followed streptomycin therapy, had been poorly maintained at home and at his former school and a marked degree of educational retardation had developed. Although lip reading was now quite well established, the boy had poor speech and his hearing aid was effectively used only at school.

In neither of these cases could a reliable appraisal be made of how far the deafness and the associated mental retardation were interrelated, or of how much they had contributed individually/

individually or together to the child's behaviour difficulties and poor educational attainments. Parental handling and home training were poor and contact with the special school was only sporadic.

The remaining two children in this age-range - girls aged 10½ and 11 years - were partially deaf and had an additional non-orthopaedic physical handicap, caused by tuberculous illness in pre-school years. In both cases this illness had been suspected to be an infection of the mediastinal glands; streptomycin therapy could be confirmed in only one case. School attendance had been irregular and the partial deafness had not been detected until observed by school teachers when the children were between 6 and 7 years old. Both girls attended special schools for physically and mentally handicapped children and had favourable seating position in class; both had hearing aids and regular audiometric assessment took place. One girl had good speech, the other poor; educational attainments in both cases were poor and little co-operation existed between school authorities and home.

In this group the superimposed handicap tended to add difficulties out of all proportion to the degree of severity of each handicap individually. The needs peculiar to either handicap have not been considered in detail unless applicable to/

to the case concerned; however there was no doubt that ordinary needs arising from the separate handicaps assumed even greater significance where another handicap existed with the deafness.

DIAGNOSIS, ASCERTAINMENT AND SUPERVISION

In this group of deaf children with additional handicaps, it was particularly noticeable that few parents appeared to realise the degree of their child's deafness or the implications of the auditory handicap, nor did they understand the handling of the child or the correct use of the hearing aid.

Delayed reference for specialist investigation and consequent delay in diagnosis had occurred in all cases where deafness was not acquired through illness.

Frequently in the cases where there was an associated physical disability, parents and some of the agencies attended were concerned with obtaining treatment for this more obtrusive but often less severe disability rather than with the hearing defect.

In many cases where mental retardation appeared to exist, secondary effects of deafness, such as lack of response to sound or backwardness with speech, were attributed to slowness or laziness, and behaviour difficulties were often suspected to originate in mental retardation. It had not been possible to make an overall assessment of the case to ascertain the precise degree of deafness and its relation to the apparent retardation of the child, nor had it been possible to ascertain the converse relationship of the precise degree of mental retardation to the apparent/

apparent deafness of the child.

Although pre-occupation with one aspect of the dual handicap undoubtedly hindered overall assessment of the handicapped child, other factors contributed to the delay before complete assessment could take place.

It was necessary for parents to attend different agencies for diagnosis, audiometric examination and for the child to be fitted with a hearing aid; in addition, other agencies were attended for assessment and therapy for the associated physical handicap. This difficulty was more applicable to the older children, since in their pre-school years the methods of diagnosis and training at audiology clinics for young children with hearing loss were not so well established nor developed as at the present time. Through this necessity to attend so many agencies, parents appeared confused by the various items of advice proffered, and integration of opinions from all sources was often difficult. At the same time, parents had tended to default appointments at audiology, audiometric or other specialist clinics and to place undue emphasis on a particular facet of the investigation.

Most of the parents understood little of the meaning of the specialised findings; in consequence they had limited understanding of the disability and its effects, and so failed to meet the needs of the child.

In this group parental apathy towards the child's deafness was noticeable in many cases, owing to the pressure of domestic commitments/

commitments or to lack of knowledge and failure to understand the child's handicap, or simply to lack of interest. This apathy was reflected in the relative absence of contact between home and school; few parents knew much about the child's progress and welfare at school. The services of a specialised home visitor would have been helpful in forming a link between home and school, and would also have helped to co-ordinate the handling of the child in accordance with the measures advocated by hospital, specialist clinics and school. Not only did it appear necessary to encourage contact between parent and teacher, but there seemed also a need to establish more contact between the head teacher and other agencies dealing with the child, in order that the teaching staff would be fully conversant with the requirements of both aspects of the double handicap.

EDUCATION AND AUDITORY TRAINING IN HOSPITAL

Several children had undergone periods of prolonged hospitalisation, some due to the illness from which the deafness had resulted and some, already deaf, for treatment of the additional physical handicap.

Although teaching facilities in isolation hospitals and in general hospitals present special difficulties not encountered in children's hospitals or paediatric units of general hospitals, the provision of education for children in these hospitals merits special consideration, particularly where deafness is already present or develops during hospitalisation.

In one case in this group, the deaf child, whilst an in-patient/

in-patient in a long-stay hospital where there were schooling facilities, developed an infective skin condition. Prolonged isolation deprived her of lessons already limited on account of her deafness.

Where deafness is suspected or diagnosed during hospitalisation, auditory training and instruction in lip reading should be instituted as soon as possible and rigorously pursued so that existing speech and educational attainments may be preserved. Measures should not be delayed until the protracted treatment of the causative illness is complete, or until the child is discharged from hospital.

ADMISSION TO DAY NURSERY OR NURSERY SCHOOL

Several parents would have welcomed their child's admission to day nursery or nursery school in pre-school years. Priority admission seemed especially desirable where gross environmental difficulties existed or where there were no other siblings in the home. Admission to ordinary day nursery would have been equally valuable in aiding the development of the child and in facilitating assessment of those cases where the possibility of mental retardation existed. In other cases, admission would have encouraged naturally acquired speech, discouraged finger pointing and shouting as means of communication, and would have counteracted over-protection by the parents in several instances.

HOUSING AND ENVIRONMENTAL CIRCUMSTANCES

Unsatisfactory housing conditions and associated environmental difficulties were present in seven of the twelve cases, and had existed in others before rehousing was effected. Although/

Although of particular significance to the deaf child with an additional physical handicap, such conditions were also prejudicial to the deaf child with other handicaps by restricting play space in the home, limiting outdoor play or outings, and by presenting hazards.

CHAPTER VI.

PHYSICALLY HANDICAPPED CHILDREN.

1. Orthopaedic group.
2. Non-orthopaedic group.
3. Multiple handicapped group.

PHYSICALLY HANDICAPPED CHILDREN.

ORTHOPAEDIC GROUP.

Twenty-four of the cases studied have been placed in this group; all had physical handicaps of an orthopaedic nature.

The cases are considered in two age-groups - those under the age of 5 years and those over that age. This allows the pre-school children to be considered together and permits the children of school age to be studied in the light of their educational placement at the time of the first home visit.

(A) CHILDREN UNDER FIVE YEARS

Five children, all at home, were in this age group; their ages ranged from 19 months to 4 years 9 months. In none of these cases was there any question of mental retardation. The social classes of their families were Class III - 3; Class IV - 2.

The physical handicaps, all congenital in origin, were:- Bilateral Talipes; Bilateral Dislocation of the Hip; Absence of Right Hand; Supernumary Digits of Both Hands; Spina Bifida.

DIAGNOSIS, ASCERTAINMENT AND SUPERVISION

There had been delay in initial diagnosis and in reference for specialist opinion in only one instance. This child suffered from bilateral congenital dislocation of the hip and had/

had not been referred to hospital until 16 months of age when, on commencing to walk, she fell repeatedly and a definite waddling gait was noticed.

All the children still attended the hospital to which they had been first referred, and for one child additional reference to a child psychiatric unit had been arranged. All parents expressed satisfaction with hospital care.

A hospital almoner had been consulted in only one instance - this in an unsuccessful attempt to obtain nursery admission - although two other families would have benefited from the use of the almoning service. In no instance had special transport facilities been provided for attendance at hospital, nor had they been suggested; two mothers would have appreciated the provision of transport, in view of their heavy domestic commitments and the necessity to attend hospital frequently with an immobile child for assessment or physiotherapy.

No child was under medical supervision at the local child welfare clinics; the area health visitor called at the house occasionally and in two of the five cases, the family doctor followed closely the progress of the handicapped child. Four of the five families would have welcomed pre-school contact with the School Health Service to discuss the management of the child and his suitability for schooling at the appropriate age. Although in some cases the physical handicap was unlikely to preclude admission in due course to ordinary primary school,/

school, reference of the child to the Local Authority for periodic assessment and home supervision would have relieved the parents of anxiety concerning their child's education, particularly in those cases where special educational treatment might be necessary.

ADMISSION TO DAY NURSERY OR NURSERY SCHOOL

In three cases parents had made unsuccessful application for admission of the handicapped child to day nursery or nursery school.

In view of the poor environmental conditions, the admission of one of these - a girl with bilateral congenital dislocation of the hip - or of some of the three other pre-school children in that home, would have lessened the mother's commitments. The hospital almoner had supported this application for nursery admission but the limited nursery accommodation for the area was already filled by cases granted priority for social reasons.

Marked aggressiveness, screaming attacks and other behaviour disorders evidenced considerable maladjustment in another case - the boy with spina bifida - and had resulted in reference to a child psychiatric unit. Following spells of hospitalisation for his orthopaedic condition, his maladjusted behaviour was aggravated by the return to grossly unsatisfactory housing conditions and the mother felt that nursery admission would be beneficial. Rehousing to a modern council house and attendance at a child guidance clinic had resulted in marked improvement in the attitude of the child towards the older siblings and his playmates/

playmates in the new neighbourhood; at this clinic, play therapy for the child was supplemented by guidance to both parents in handling the boy and for their marital disharmony.

Admission to day nursery or nursery school for the third case - a girl with congenital absence of the right hand - would have helped to overcome increasing sensitiveness about her disability and her dislike of an artificial hand, and would have prepared her for the rough and tumble of ordinary school life. This family had been rehoused recently and nursery school facilities were not yet available in the new housing estate. The mother had desired an artificial limb for the child at an early age; although advised by the family doctor that the child was too young,she persisted in her request and the child was finally referred, at 4 years of age, to the limb-fitting centre of the Ministry of Pensions,where an artificial hand was supplied. Although this aid improved the child's appearance, its heavy and cumbersome nature, the difficulty of fastening the attachments, together with the wear and tear on clothing were deterrent to regular and effective use.

HOUSING AND ENVIRONMENTAL CIRCUMSTANCES

Two families had been rehoused, both since the birth of the handicapped child; earlier rehousing would have been of help. Of the remaining three families, rehousing was unnecessary for one, desirable for another owing to poor housing conditions/

conditions and essential for the third family, whose child was the most severely handicapped of the group. This family lived two stairs up in a congested area; steep stairs and lack of indoor and outdoor amenities added to the burden of the parents, who had three other pre-school children. These last two families were on the waiting list for rehousing, but no priority had been granted.

Hazards.

Only two families had efficient fireguards; other potential hazards were those applicable to all pre-school children, especially the danger from traffic.

ATTITUDE OF PARENTS TO THE HANDICAP

All parents hoped that in due course the effects of the handicap might be greatly reduced. The implications of the handicap appeared to be understood in four of the five families; in the remaining case the unmarried mother was of limited mentality. She was working and her child - the youngest and least severely handicapped in this group - who had supernumary digits on both hands, was completely monopolised by the great-grandmother with whom they lived.

FAMILY LIMITATION

Among the four cases applicable, one family had avoided having further children and this only because the father of the handicapped child - a boy with bilateral talipes - considered their two children to be sufficient in view of the poor housing conditions.

EFFECT OF THE CHILD ON FAMILY LIFE

With one exception, there was no undue interference by the handicapped child with the care of any other siblings. Relatively infrequent hospital visits and the tendency to treat the child as 'just another one of the family' permitted most parents to pursue everyday commitments without much inconvenience and easily arranged cover by relatives or neighbours was available for emergencies. In this one exception, the parents, strangers to the city, had no relatives to provide cover; heavy domestic commitments and unsatisfactory housing conditions, together with the commitments of the handicapped child, restricted outings for this child and for all the family. Some form of home attendant service would have been welcomed, and during the mother's previous confinements, residential placement of the handicapped child or of the other children in a short-stay home would have relieved the strain on the family.

There was no interference due to the handicapped child, with outings or holidays in the other families; this was a pleasant and marked contrast to those families who had a mentally or multiple handicapped child of similar age to these children.

(B)/

(B) CHILDREN FROM 5 TO 13 YEARS

Nineteen of the twenty-four cases physically handicapped by orthopaedic disabilities were in this age-group and of these, fourteen were under 8 years of age. The ages of the children ranged from 5 years 1 month to 11 years 4 months. The social classes of their families were Class I - 2; Class II - 1; Class III - 11; Class IV - 5.

The physical handicaps were of a varied character.

Children aged 5 to 8 years:- 14.

Tuberculosis - of left hip-joint, of right knee-joint, of spine and right knee-joint - 3 cases; Spina Bifida with paralysis of lower limbs - 3 cases; Cerebral Palsy - 2 cases; Spastic Hemiplegia following tuberculous meningtis; Hydrocephalus; Congenital absence of right leg and buttock; Bilateral Talipes; Post-traumatic incontinence; Fragilitas Ossium.

Children aged 8 to 13 years:- 5.

Tuberculosis of spine - 2 cases; Spinal Tumour; Perthe's Disease of left hip-joint; Fragilitas Ossium.

Six of the children were at home, receiving home tuition; six children attended mixed special schools; three children attended a spastic unit in a special school and four children attended ordinary schools.

The cases are discussed according to the handicapped child's educational placement at the time of the first home visit. This permits/

permits some grouping of the needs and problems of cases of a similar nature, whilst still allowing consideration of specific aspects of any individual case or of any particular disability.

Consideration of the needs and problems of the six children receiving home tuition is restricted to those arising out of the disability; needs and problems directly connected with their education are considered in a chapter devoted to the Home Tuition Group.

The cases attending mixed special schools afforded an opportunity to examine some of the problems accompanying prolonged hospitalisation.

CHILDREN AT HOME RECEIVING HOME TUITION

Six children, all unfit for school, were receiving home tuition; these were three cases of spina bifida with paralysis of lower limbs - a girl aged 5½ years, a girl aged 6½ years and a boy aged 6¾ years; two cases of fragilitas ossium - boys aged 6 years and 11 years; and one case of spinal tumour, a boy aged 8½ years.

Diagnosis, Ascertainment and Supervision.

Five of these children had been under regular hospital supervision since birth, three at the hospital initially attended. When the amputation of a limb had been considered, alternative specialist opinion was sought for the fourth child - a girl with spina bifida - and she had since remained under supervision of this specialist at another hospital; the fifth case -

the/

the boy with spina bifida - had been referred on separate occasions to specialists at different hospitals in the city. In addition to the regular supervision of the two cases with fragilitas ossium, arrangements for emergency admission had been established by the hospital; one of these boys had sustained twenty-six fractures by the age of 2½ years, although the incidence had lessened in later years.

The sixth child of this section - the case of spinal tumour - was admitted, at 18 months of age, to hospital with meningitis suspected to be tuberculous, but this diagnosis was never conclusively established; recovery had been considered complete and admission to primary school took place at 5 years of age. Vague symptoms when the boy was 7 years old were at first thought, in the absence of obvious presenting signs, to be the child's excuse to miss school. Hospital reference finally took place, and after repeated investigation and surveillance, to determine the condition and to exclude a tuberculous cause, recent admission for surgical exploration revealed a dermoid tumour of the spinal canal which has since been excised. At the time of visiting - in the pre-operative period - the child was at home receiving tuition; since the operation, the specialist concerned has recommended return to ordinary school life in due course.

None of the three cases of spina bifida had attended school; they were assessed regularly by the School Health Service, and before home visiting was completed they had been reassessed and recommended/

recommended for admission, on a trial basis, to special schools for physically handicapped children. There was no alternative to home tuition for the two cases of fragilitas ossium.

Although hospital attendance and supervision had been regular in the five cases applicable, no reference was made to the Local Authority until school entry age was reached, despite the severity of the handicaps. Many of the parents' fears and difficulties might have been discussed and resolved if earlier reference, periodic assessment and home supervision had taken place.

The provision of special transport facilities to attend hospital and specialist clinics would have been welcomed by the parents for these children; in two cases, the father conveyed the child to hospital and clinic in his car, but to do so it was necessary to adapt working hours, and much time was lost. In another family, where there was a second handicapped child, hospital attendance with the case studied - the boy with spinal tumour - had imposed considerable strain on the parent, owing to her domestic commitments and the distance involved; subsequent provision of ambulance transport proved an immense relief. In one case of fragilitas ossium, a taxi was used, and on one journey to hospital the child had sustained a fractured leg.

Arrangements for therapy for the immobile cases at Local Authority specialist clinics adjacent to their homes would, in two instances, have saved the mothers considerable time and much inconvenience when honouring the frequent appointments for therapy at hospital clinics distant from their homes. In no case

had/

had domiciliary therapy been considered; visits by the physiotherapist would also have made available specialised advice on appliances for the relatively immobile children, and on the adaptation of furniture in the home.

Housing and Environmental Circumstances.

In all these cases, housing circumstances were satisfactory; two families owned their semi-detached houses and the other four families had been rehoused in recent years, one following medical recommendation. Facilities such as toilet, bath, indoor play space and a suitable garden were particularly valuable in view of the severity of the handicaps and were a marked contrast to the unsatisfactory conditions surrounding equally severely handicapped cases in other groups.

The physical effort involved in lifting the heavy child imposed considerable strain on the parents in several cases, especially as careful handling was imperative; bathing the children was particularly difficult.

None of these children had a suitable wheel-chair. As they outgrew their perambulators, difficulty was experienced in carrying the growing child and the distance and frequency of outings were restricted accordingly. Three of the children were still unable to walk. An unsuitable push-chair and an old perambulator were used to take out the two cases of fragilitas ossium; locomotion in the home was effected by scrambling along on the buttocks, although the father of one child had made a pair of crutches which the child used with great dexterity. The third child, although able to make limited slow progress/

progress in the house with calipers and crutches was, for outdoor recreation, confined to drives in her father's car when business commitments permitted; this restriction of outings in contrast to the physical freedom of the other siblings caused increasing distress to the child.

Hazards.

Neither gas nor fire were hazards in these homes, and danger from traffic was inapplicable. The likelihood of accidents occurring through the immobility, the unsteadiness or the fragility of the children decreased as they became older.

Effect of the Child on Family Life.

Although in all cases, the handicapped child was the centre of attraction in the family and in three cases was over-protected by the parents, no appreciable maladjustment of the child or of other siblings, was apparent. This was largely due to the good family atmosphere and satisfactory housing circumstances. In no case were outings for parents and other siblings severely restricted, as relatives or friends were able to give adequate cover. None of the families had avoided having further children.

Holidays.

For two families, satisfactory financial circumstances and a car facilitated holidays adapted to suit the handicapped child, but in two other families the fathers were obliged to take their annual holidays during the "Fair Fortnight" and the child's handicap was a deterrent to holidays away from home. Financial commitments entailed by rehousing had prevented holidays/

holidays in recent years for the remaining two families.

CHILDREN ATTENDING MIXED SPECIAL SCHOOLS

Six children were placed on the physically handicapped side of mixed special schools for both physically and mentally handicapped children. Five of these had disabilities due to tuberculosis. These were, 2 cases of tuberculosis of the spine - boys aged 8½ and 9¾ years; a girl aged 7¼ years with tuberculosis of the left hip-joint; a girl aged 7 years with tuberculosis of the right knee-joint; and a girl aged 6¼ years with tuberculosis of the spine and right knee-joint. One boy aged 6 years with post-traumatic incontinence was the sixth case studied.

Diagnosis, Ascertainment and Supervision.

The six-year-old boy was involved in a road accident when 4½ years of age and had sustained a fractured skull and a fractured pelvis with rupture of the bladder; following hospitalisation, urinary incontinence was now the main residual handicap. In this case, where the position was aggravated by a protracted action for compensation, special school admission had been too recent to assess how far associated behaviour disorders in the child were attributable to hospitalisation aggravated by poor parental handling on return home, or whether they arose from other causes. Parents and child bitterly resented his placement in a special school, when his playmates attended the infant school in the street in which he lived. Although all circumstances had been assessed, the mother was of the opinion that slight adjustment of routine would have enabled the child

to/

to attend the local school, and felt that her views had not been given full consideration. The impending admission to this school of the child's younger brother would aggravate the position still further. There was no contact between home and special school. The chronic ill-health of the father, the anaemic state and nervous condition of the mother, the poor handling of the children, together with adverse social circumstances were additional difficulties in this family. The continual provision of trousers on account of the incontinence of the handicapped child was a financial hardship. Specialised advice for problems arising through the parents' illnesses and the child's handicap, some holiday provision, and possibly financial help for clothes would have been welcomed by the parents.

The other five children attending special schools had developed an orthopaedic disability due to tuberculosis, contracted in early pre-school life, which in all cases had resulted in long spells of hospitalisation. On hospital discharge or on reaching 5 years of age, assessment by the School Health Service had resulted in subsequent admission to their present schools.

Although the difficulty of early diagnosis of cases of surgical tuberculosis must be recognised, there had, in three cases, been delay in suspecting the condition and in reference for specialist opinion before final diagnosis was established. In/

In two of these, the presence in the house of a relative suffering from tuberculosis might have aroused earlier suspicion; in the third case the mother, dissatisfied with the family doctor's opinion, utilised an appointment, made for the examination of a younger sibling at the child welfare clinic, to have the handicapped child examined with a view to specialist opinion being obtained. Reference to hospital was followed by admission for investigation and the diagnosis was confirmed.

Four of the five children, following confirmation of the diagnosis, had been transferred to a long-stay hospital for orthopaedic cases, where a consultant surgeon on the staff of the hospital was also the Consultant Orthopaedic Surgeon to the Local Education Authority. This had resulted in the establishment of co-ordinated arrangements for the care of these children in hospital or at home, and in subsequent supervision either at the hospital or at one of the Local Authority specialist clinics adjacent to their homes. The remaining child had been transferred to an annexe for long-stay cases, after diagnosis had been confirmed by the orthopaedic surgeon at the parent hospital to which he had been initially referred; on discharge he remained under the care of this hospital as an out-patient.

Hospital school facilities at both the long-stay hospitals had ensured a degree of continuity in the education of all these children. Breaks had been caused by subsequent hospital re-admissions although where possible, if not for urgent reasons, these were planned for the vacations.

The regular pattern of medical and educational care, similar for all five cases, had resolved many problems previously of major concern to the parents.

Problems Associated with Schooling.

Although anxiety regarding continuity of education had been largely dispelled and the children were now all attending special schools, dissatisfaction with the placement was shared by children and parents in four of the five cases where the child was handicapped by tuberculous disabilities; the children felt stigmatised and resented separation from playmates,whilst the parents feared that the limited educational facilities might be a handicap to their child's prospects in later life. Regular contact with school was maintained by only two families.

Several parents felt that the presence of stairs in ordinary schools was the reason for debarring the child from attendance and thought this to be inconsistent, since the children had to manage several flights at home; in addition, two of the four specialist clinics of the Local Authority attended by physically handicapped children had the orthopaedic section on an upper floor.

These apparent anomalies emphasised the need to consider each case on its merits; discussion between educational and medical personnel - especially the orthopaedic specialist - would ensure that all those concerned with the child are aware of existing facilities or possible modifications at ordinary schools, which might permit an alternative to special school placement./

placement. Where a child has been admitted to a special school, regular review of the necessity to continue this placement is equally desirable.

Inevitably, due to the nature of the illness, schooling for these children had suffered some interruption. Several parents felt that some lessons for the child in hospital during the long summer vacation might help to make good this loss of education, although they recognised that teachers' holidays and hospital commitments would have to be considered.

Several of these children had also spent much time in hospital in pre-school years. In view of the protracted treatment necessary and the likelihood of interrupted education when older, the possibility of schooling in hospital for these cases by a kindergarten or nursery teacher might be considered. Occupational therapy compatible with the child's age is also especially desirable for the older pre-school child; suitable toys, adapted equipment or a routine for normal daily occupations could be used to promote habit training and intellectual activity. No organised activities for pre-school children were yet in existence at hospital schools visited.

In these cases, every effort was made to reduce the time lag before these children returned to special schools after discharge from hospitals - a feature by no means common to all cases in the survey where prolonged hospitalisation had occurred.

Visiting the children in hospital was allowed once a week, and special transport to the long-stay hospitals was provided. Parents/

Parents or adult siblings had thus visited regularly at no great financial inconvenience. Several parents felt that readjustment to family life would have been easier for the handicapped child if some relaxation of the rules allowed younger siblings to visit the child occasionally in hospital.

Housing and Environmental Circumstances.

Although the domestic circumstances surrounding the boy with incontinence left much to be desired, housing in this case was satisfactory.

In the five families where the handicapped child had a physical disability due to tuberculosis, the unsatisfactory housing circumstances had given, or still gave rise, to many difficulties, and the flights of stone stairs were always a potential danger to children wearing calipers or plasters.

Priority rehousing from a ground floor room and kitchen house had been granted to one family following specialist recommendation in respect of the handicapped child; the house offered, and only too gratefully accepted, was two stairs up, and this was a source of great difficulty to the child before full mobility was established.

Another family, also recently rehoused on specialist recommendation after eleven years on the waiting list had,because of the number of other siblings, finally to accept a house three stairs up, despite protest and approaches from official sources and other, unofficial, agencies on their behalf for ground-floor accommodation. Here, too, the child experienced difficulty/

difficulty with the stairs.

The third family, rehoused to a house two stairs up from a slum clearance property before the child was born, was now anxious for an exchange; the change of house was desired partly because of the handicapped child's difficulty with stairs and partly because of poor relations with a neighbour who complained of the noise made by the child's caliper, which, in consequence, was not worn indoors.

The fourth family had been eight years on the waiting list for rehousing and recommendations for priority rehousing had been unsuccessful. The parents and four children occupied a room and kitchen house, three stairs up, in a slum tenement; in addition to the lack of amenities in the house, the stairs were a difficulty to the child, who wore a caliper.

The remaining family, fourteen years on the waiting list, occupied a ground floor room and kitchen house in a proposed clearance area. This family consisted of two parents and nine children - three males and six females; four of the children were over 20 years of age, and the eldest daughter was obliged to sleep in a neighbour's house. Although these living quarters had been assessed on several occasions by the Local Authority, and the family had been told repeatedly that they would be rehoused, no house large enough was available. The periodic hospitalisation of the handicapped child helped to relieve the drastic overcrowding.

The return to such unsatisfactory circumstances following periods of hospitalisation, especially after being the centre of/

of attraction when visited in hospital or on returning home, had, in several cases, resulted in marked difficulty in subsequent readjustment, and especially in settling down with the other siblings. The transfer from the sheltered atmosphere of hospital to the restricted indoor and outdoor facilities of home, combined with their own physical limitations, had caused appreciable frustration and temperamental difficulties in at least three of the cases. Only one of the five children had his own bed.

Footwear and Clothing Difficulties.

Expenditure on footwear caused concern to all parents; the child's awkward gait, especially where one leg was longer than the other, or the effect of the caliper on the leather necessitated frequent replacements, and children wearing calipers did not qualify for surgical boots. Footwear was built-up free of charge by the hospital splintmaker, but often a special journey or postage was necessary to obtain this service, and in several cases the expenditure involved exceeded the cost of alteration by the local shoe maker.

Most of these children had only one pair of boots. Parents claimed that, regardless of quality, boots were worn out within two months; the rate of wear was especially noticeable in comparison with the boots of other siblings. One parent claimed to have bought four or five pairs of boots in addition to the two pairs provided yearly by the Local Education Authority.

The recognised practice of 'handing down' footwear and clothing/

clothing was impracticable in all five cases; where a spinal brace was worn, there was excessive wear on clothing. In the sixth case studied, the only clothing problem was that of maintaining a continual supply of trousers for the incontinent boy.

Holidays and Outings.

Cover in emergencies and for outings had been adequate; in three families, the grandparent, in the other three, adult siblings had been available when required.

Only one family had regular holidays, the other five families would have been able to arrange a holiday with their handicapped child if financial circumstances had permitted.

CHILDREN ATTENDING THE SPASTIC UNIT IN A SPECIAL SCHOOL

Three children attended the unit for spastic children recently established in a day school for physically handicapped children.

These were a boy, 5½ years old, and a girl, 7¼ years old, with cerebral palsy; and a boy aged 7½ years, with a left-sided spastic hemiplegia following tuberculous meningitis.

Diagnosis, Ascertainment and Supervision.

Pre-school care and treatment for these children had been entirely in relation to a physical handicap; no question of any appreciable degree of associated mental retardation had arisen. The three children were assessed when school entrance was due, ascertained as physically handicapped children, and after screening they were admitted to the separate unit for spastic children in the special school.

The/

The two younger children had been seriously ill in the neonatal period; one, a premature child, was given a replacement transfusion at birth. In neither case was regular hospital supervision established until they were referred, when almost one year old, for delay in sitting up and standing; from that time until admission to the spastic unit, they had attended hospital regularly for assessment and therapy.

The oldest child, the boy aged 7½ years, had contracted tuberculous meningitis at 3 years of age, and after discharge from hospital a relapse resulted in further hospitalisation for two years; on discharge he had a residual left-sided hemiplegia. Following one year at home, during which he received home tuition and was under regular orthopaedic supervision, he was admitted to this spastic unit when 6½ years old. Since completion of visiting, further relapses necessitated readmission to hospital, and the boy has since died.

In all cases, the numerous anxieties and difficulties in relation to treatment and care in pre-school years tended to be forgotten now that the children were admitted to school and arrangements for medical supervision, education and therapy were integrated, so that most of their needs could be met at one source.

Contact between home and school was good in all cases and was supplemented by the mothers' attendance at the school once weekly to discuss the progress and handling of the handicapped children.

Housing/

Housing and Environmental Circumstances.

Although in the main the difficulties relating to medical care had been resolved, unsatisfactory housing circumstances had given rise.to many other problems, which, although the children were now mobile, so far had been solved in only one case. This family had been rehoused in the past year from a room and kitchen house, one stair up in a condemned property at the top of a steep hill, to a ground floor house; no priority had been granted on medical grounds.

The remaining two families occupied tenement houses in slum areas on main traffic roads, and had no indoor sanitation or hot water. One of these had exchanged houses with the child's grandparents, from a single room one stair up to a room and kitchen property two stairs up, in order to gain an extra room; the move had been unsatisfactory as the immobile child, weighted by the plaster casts on her legs, had to be carried up and down an additional flight of stairs. This family had been five years on the waiting list for rehousing, and had submitted no medical support for their application. The other family lived three stairs up, and their attempts to maintain a decent standard of life were frustrated by their environment and their neighbours. Specialist recommendation supporting their application for rehousing had been submitted to the City Factor's Department, and their application was refused on the grounds that there was no overcrowding; the parents still felt that there had been no consideration of the medical circumstances. This case emphasised the importance of submitting to the Health Department/

Department any medical recommendations to support an application for rehousing and of subsequent adequate co-operation between this department and the City Factor's Department.

In all three cases, the housing circumstances had added to the problems of handling and training the child in the home, and had restricted outings for the child and any young siblings, due to the difficulty of managing an immobile child, perambulator and other young children up and down flights of stairs. The absence of inside toilet and of hot water had made habit training especially difficult.

Hazards.

The cramped living quarters and restricted indoor play space increased the difficulty of establishing posture and locomotion and added to the risk of accidents. Although all families had fireguards, only two of these were efficient.

One family was now rehoused and previous hazards no longer existed, but gas had now become an especial danger in this home. The tap of the gas boiler, although in a relatively inaccessible position, fascinated the 5-year-old child as he crawled around the floor. On one occasion, when the mother had a temporary anosmia due to a cold, the opportune arrival of a neighbour averted a gassing accident.

Traffic did not represent a hazard to these children as they were always escorted on outings.

Effect of the Child on Family Life.

Parents appeared to understand their child's difficulties and hoped that in time the handicap would be greatly reduced; they/

they were most appreciative of the attention their children had always received.

Family atmosphere was remarkably good despite the fact that outings either with or without the child were severely restricted. In two families the father had adapted his working hours, now to allow the mother opportunities for errands, and in previous years to allow her to attend hospital and specialist clinics with the child. A grandmother living in the same close was willing to 'sit in' for outings and emergencies in one family, but in the other two cases a regular 'sitting-in' arrangement would have been welcomed. One of the children, an only child, would have benefited from the company of a playmate in the house; although the other two children were the centre of attraction in their families, parents and relatives had endeavoured to maintain a sensible balance towards the other siblings and there were no signs of maladjustment. Despite the cramped living quarters, one of these families had bought a piano for the handicapped child and was paying for music lessons to assist her fine finger movements.

Family Limitation.

Further children had been avoided in two families; in one, the parents had decided to have no more children until the handicapped child, the only child, was walking freely. The poor housing conditions, together with the care of the handicapped child, were reasons for limiting the family in the other instance.

Holidays./

Holidays.

Holidays away from home had been restricted in all cases due to the difficulty of meeting the special requirements of the handicapped child, particularly those of transport and suitable accommodation. Special holiday facilities, with the provision of transport, would have been greatly welcomed by the parents so that the child and the family might have a holiday together.

CHILDREN ATTENDING ORDINARY SCHOOLS

Four children attended ordinary primary schools; these were a boy aged 5 years 1 month with congenital absence of right leg and buttock; a girl aged 5 years 2 months with static hydrocephalus; a boy aged 6½ years with bilateral talipes; and a boy aged 11 years 4 months with Perthe's disease of the left hip-joint.

A twin boy, aged 5 years 1 month, with congenital absence of right leg and buttock, had attended hospital regularly until fitted with an artificial limb at sixteen months; by 2 years of age he was able to walk unaided. His achievements were little affected, and apart from occasional frustration at being last in running games and resentment if mocked, he appeared well adjusted to his handicap. The boy and his parents were anxious for a promised foot-attachment to be fitted, in order to improve the unsightly appearance of the artificial limb before he entered school.

When school entrance was due, the school medical and welfare officers and the head teacher had expressed diverse views on/

on his fitness for entry and on the possibility of arrangements to overcome playground, toilet and transport difficulties - in emergencies especially, the time taken to remove the limb for toilet purposes was a difficulty, and adequate space and lighting were essential. The differing opinions had caused anxiety to the parents, and the position was aggravated since the child's home was just outside the area served by a near-by school, which was already overcrowded. His twin brother had been an ideal companion, and the mother was primarily concerned to avoid separating the handicapped child from his company and help during the first years at school; in inclement weather she would have been willing even to take the child to school in an adapted push-chair. The anxiety suffered by the parents and the last minute confusion at school entry age could have been avoided if earlier reference of the case had been made to the Local Authority, and subsequent co-ordinated assessment had taken place.

The 5-year-old girl with hydrocephalus, an only child, had remained under hospital supervision from birth until 3½ years of age; by then, enlargment of the child's head had ceased and the parent considered further supervision unnecessary. The child's inability to support her enlarged head had retarded sitting and walking, and the mother's difficulty in carrying the heavy child had restricted outings, as the family lived on the top floor of a tenement building on a main traffic street; the unsuitable environment now limited outdoor play. The child had/

had recently been admitted to the near-by primary school and although she appeared settled, her educational possibilities could not yet be estimated. Although the difficulties and worries of earlier years were now resolved, pre-school supervision and assessment would have been both helpful and welcome.

The 6-year-old boy with bilateral talipes had been first referred to hospital when one week old; since then he had attended three hospitals and had undergone several spells of hospitalisation. He had worn splints, plasters, calipers and special boots and had been given remedial exercises; a residual facial paralysis, caused by a recent ear infection, had also required specialised therapy. Following an initial sheltered spell of two months at a local infant school, plaster casts and calipers again had to be worn, and on this account the boy attended a special school for nine months; when plaster casts were no longer necessary, he was reassessed and admitted to a primary school. Although progressing satisfactorily without undue limitation of his physical activities, impending re-admission to hospital for further treatment would necessitate another break in schooling and probable subsequent alternative placement.

Despite this chequered career, the child appeared well-adjusted to his handicap, and by regarding his calipers as spurs - 'like the cowboys on television' - had even aroused a degree of envy in his more mobile playmates. The family had been rehoused in the last two years from a slum tenement in condemned/

condemned property; the previous unsatisfactory housing conditions had aggravated the heavy domestic commitments of the mother and had increased the difficulty of attending hospital several times weekly for therapy. The facial paralysis following the ear infection had occurred after the family had moved to the new district and the boy was now attending two hospitals for therapy.

Both parents were increasingly apprehensive that lack of schooling in hospital, and the frequent changes of school might hinder the child's prospects in later life, especially since his disability might necessitate restricted or even sedentary employment. Earlier reference to the Local Authority and subsequent home supervision and periodic assessment might have permitted a specific long-term plan for orthopaedic supervision and treatment, and for the child's education. Many of the parents' difficulties during the child's pre-school years could have been resolved by reference to the almoning services, the provision of transport for hospital attendance and by arrangements for therapy at the nearby Local Authority specialist clinic.

The remaining case, the 11-year-old boy, had an apparently uneventful history until 8 years of age, when his physical condition and a deterioration in his school work and activities had caused concern to the parents and head teacher. After some delay he was referred for specialist opinion. Following immediate admission to hospital for investigation, Perthe's disease/

disease of the left hip-joint was confirmed and the boy spent eighteen months in the paediatric hospital and its annexe for long-stay cases. The demand for beds due to an outbreak of dysentery in the parent hospital accelerated his discharge; the mother was willing to undertake domiciliary nursing care, and outpatient surveillance took place at six-weekly intervals with the aid of ambulance transport. The boy's home was situated two stairs up, in a tenement building, and had few amenities. There was no periodic assessment of the social circumstances, or domiciliary supervision of the orthopaedic care to ensure that the régime for graduated weight-bearing was followed. Home tuition was eventually provided for the boy. A second-hand invalid chair was purchased and adapted for outings. Since completion of visiting, the child has returned to his former school, after an absence of two-and-a-half years. In this case, early reference for specialist opinion and subsequent co-ordination between hospital and Local Authority services in respect of domiciliary supervision and care were desirable. These measures might have saved the parents much anxiety; they are now concerned that the break in schooling will hinder the chance of eventual suitable employment necessary to maintain the favourable prognosis given at hospital.

PHYSICALLY HANDICAPPED CHILDREN

NON-ORTHOPAEDIC GROUP.

Twelve cases were placed in this group; all had non-orthopaedic physical disabilities. The social classes of the families were Class I - 1; Class II - 2; Class III - 5; Class IV - 2; and Class V - 2.

The ages of the children ranged from 1 year 8 months to 11 years 8 months. The age-group distribution and the disabilities were:-*

Birth to 5 years: - 3 cases.

Congenital Heart Disease - 2. Generalised Ichthyosis.

5 to 8 years: - 6 cases.

Diabetes. Congenital Dystrophy of the Skin. -(a)
Congenital Heart Disease - 3. -(b)
Congenital Abnormalities of Genito-urinary system. -(c)

8 to 13 years: - 3 cases.

Latent Tuberculosis. -(b)
Haemophilia (Christmas Disease). Bronchiectasis. -(c)

The educational placement of these cases at time of visiting was:-

Birth to 5 years.

At home - 3.

5 to 8 years.

At primary schools - 2. -(a)
At special schools - 3. -(b)
At home, receiving home tuition - 1. -(c)

8 to 13 years.

At special school - 1. -(b)
At home, receiving home tuition - 2. -(c)

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* The small letters in brackets give the relationship between disability and educational placement of the individual cases.

In view of the wide age-range and the varied nature of the disabilities, the cases are not considered in relation to their educational placement at the time of visiting. Those handicaps of a similar nature have, however, been considered together. The needs and problems directly connected with the education of those children receiving Home Tuition are considered in a chapter devoted to the Home Tuition Group.

CASES OF CONGENITAL HEART DISEASE

Five cases of congenital heart disease were studied; two children of pre-school age - a girl aged 20 months and a boy aged 3 years - were at home, whilst three between the ages of 5 and 8 years were placed on the physically handicapped side of mixed special schools. In all cases there was visible evidence of cyanosis or some limitation of physical effort.

Diagnosis, Ascertainment and Supervision.

The ages of these children when the cardiac condition was diagnosed varied from 3 weeks to 18 months.

In one case, the lesion had been discovered by a child welfare clinic doctor when the infant was 3 weeks old and the family doctor was duly informed. The mother remained unaware of the disability until three months later, when reference to the lesion was made by the family.doctor who was under the impression that she was aware of the condition. The exact nature of the lesion was confirmed on subsequent reference to hospital.

In three other cases, the condition was discovered during an illness - pneumonia at 4 months, whooping cough at 6 months and/

and bronchitis at 10 months of age respectively; the hospital medical officer had drawn attention to the condition in two of these cases.

In the fifth case, the child was referred for specialist opinion on several occasions, and diagnosis of the exact nature of the lesion was finally established when, at 18 months of age, he was admitted to hospital for investigation.

All cases had attended hospital regularly for periodic supervision and had all been admitted for assessment of the condition with a view to possible surgical treatment, which was proposed or was still under consideration for four of the children. In the remaining case the frequent occurrence of chest illness had influenced the decision that surgical measures were impracticable.

The two pre-school children and one of the older children continued to attend the hospital to which they had initially been referred; whilst the Consultant Cardiologist to the Local Education Authority continued the supervision of the remaining two older children at regular intervals. The three older children had been assessed at school entry age and in accordance with specialist recommendation they were admitted to special schools.

<u>Housing and Environmental Circumstances</u>.

Three of these families lived two stairs up and one three stairs up. Only one family had ground floor accommodation; chiefly in the interest of the child, this family had moved two years/

years previously from a single apartment three stairs up, to an unsatisfactory room and kitchen house on the ground floor of the same slum tenement. Two of the three families living two stairs up had purchased flats in good residential areas before the birth of the handicapped child; the third family were soon to be rehoused from their condemned tenement. The family living three stairs up had moved from a ground floor house mainly because of rat infestation; the effect on the handicapped child and the two other young siblings had not been considered before this unsatisfactory move took place. Even if more suitable accommodation were available, this family would be unable, for financial reasons, to consider another move.

Attitude of Parents to the Handicap.

The mothers of the two pre-school children appeared apprehensive and over-protective; this seemed largely due to failure to understand the child's capacity in relation to the severity and extent of the cardiac disability. Newspaper articles, a television programme and frequent examinations at hospital for assessment or for clinical demonstration had helped to sustain in them a feeling of apprehension. In neither case did the father accompany the mother on visits to hospital for periodic assessment of the child. It was felt that a better understanding of the child's special needs and of his limitations would result if both parents attended the hospital together, even/

even occasionally. Domiciliary supervision would have provided further advice and guidance to ensure proper handling of the child in both these cases.

With one exception, the pre-school difficulties in handling and managing the three older children had now been largely resolved and no undue apprehension or over-protection was observed. In the one exception, marked maladjustment of the older sister was aggravated by the over-protective attitude of the mother towards the handicapped child, who made full use of his disability to obtain his own way.

CASES OF SKIN DISEASE

Two cases had severe skin disorders, a girl aged 3 years and a girl aged 7 years who had recently returned to primary school after receiving home tuition for one year.

In one of these cases - the pre-school child - generalised ichthyosis had been diagnosed at 4 months of age, and since then numerous specialised measures to cure or alleviate the condition had been unavailing. Preventing her from interfering with medicaments applied to the skin had always been a major problem with this child, and the discomfort of clothes and of perspiration had caused her much distress. She had also been unwilling to attempt crawling or kneeling and her physical development was now being further retarded by her difficulty in climbing steps and with fine finger movements.

Obvious behaviour disorders were now aggravated by growing sensitiveness about her disability. A vicious circle had developed;/

developed; the appearance of the child attracted public attention in the new housing estate where she lived and through her to the unmarried status of the mother, who was living on sufferance in the home of her widowed father. The young mother's unsatisfactory social circumstances were reflected in her over-anxious state of mind and in her mismanagement of the child, and her anxiety was increased by the inefficacy of treatment for the child's skin condition.

Regular visits to the home by a specialised visitor might have done much to encourage and advise this harassed and well-meaning parent. The mother was anxious for the child to be admitted to day nursery or nursery school, but these facilities were not yet available on the new housing estate; such admission would have assisted the development of the child by providing companionship and contact with other young children, and by counteracting the misguided parental handling. At the same time, admission would have helped to relieve the unsatisfactory domestic circumstances.

The other case - a girl aged 7 years - had been severely handicapped by congenital dystrophy of the skin (a Weber-Cockayne type of epidermolysis bullosa). By the time of the final home visit, the position in this case had undergone a radical change.

Her skin condition had been present from birth, and until recent months had proved unresponsive to therapy; several dermatologists had been consulted and a variety of medicaments had been/

been prescribed. The entire family life was disrupted by the child's fretfulness and the difficulty of preventing her from tearing the lesions, and of restricting the medicaments to the areas intended. Lesions on her feet had retarded walking, and on outings she had been carried or taken in an adapted push-chair until she was almost 6½ years old. This family lived in a room and kitchen house two stairs up and the absence of hot water or bathing facilities was an especial difficulty.

Recent admission of the child to hospital for further investigation and for intensive therapy had resulted in a steady improvement in the skin condition. An earlier spell of hospitilisation would have been welcomed by the parents, and might have been beneficial in view of the unsatisfactory home circumstances, and the consequent difficulty in treating the young child as an outpatient.

This child had received schooling while in hospital, and on discharge,home tuition was provided until her improved condition allowed admission to the primary school near her home. At the time of the last visit, the child was rapidly adjusting herself, at school and at home, to her new-found freedom.

Only one case of <u>diabetes</u> was studied, a boy aged 5½ years. The diagnosis had been established at the age of 22 months,when his polyuria and copious thirst had quickly aroused his mother's suspicion as her own mother had diabetes. Hospital admission for investigation and stabilisation of the condition was followed/

followed by regular out-patient supervision. Several emergency admissions of the child to hospital, some unnecessary, some precautionary, followed initial difficulties with dietary and insulin measures. These difficulties were due largely to uncertainty and over-anxiety on the part of the parents, and the mother was under a severe nervous strain until a satisfactory régime was established. An early visit to the home from the hospital dietitian or a specialised visitor, followed by periodic domiciliary supervision, would have helped to ensure that the instructions given at the hospital were carried out correctly.

Since the early setbacks, the subsequent history had been uneventful and attendance at a nearby infants' school had caused no upset to the boy's diabetic routine. Attendance at hospital, however, had raised problems; apart from loss of schooling and special arrangements to cover other family commitments, the time of attendance usually interfered with the child's main meal. Any delay before the child was seen at hospital meant that the mother would be unable to wait to see the dietitian.

It was interesting to note that the outlay for 'extras' in the child's diet was well over £1 per week, but as most of the other siblings were now working, this caused no financial hardship. The boy, the youngest of the large family, was the centre of attraction and was over-protected by the mother. The parents had gained much useful information from the journal issued/

issued by the British Diabetic Association but there was no contact with the Glasgow branch of that organisation.

One of the cases - a boy aged 11 years 8 months - had <u>Christmas Disease</u> and was reported to be the first case of this condition recorded in Scotland and the eleventh in Great Britain. Diagnosis of his haemophiliac condition had been established at 15 months of age; medical and dental care and supervision had been regular and emergencies arising from falls, knocks and other injuries were covered as necessary by a system of automatic admission to one particular medical ward of a children's hospital. The boy was also under regular orthopaedic supervision for a disability resulting from a haemorrhage into the right knee-joint; a caliper was worn for this disability but caused little restriction of his activities.

After exclusion from special school, this boy had been receiving home tuition; since the recent death of his invalid mother, he was alone in the home for long periods during the day while his father and older sister were at work. Lack of company in the home heightened the existing needs, which were concerned largely with his education and arose from the repeated interruption of his schooling and the limited amount of tuition he received under the present arrangements; these needs are considered in the chapter devoted to the Home Tuition Group.

One case of congenital abnormalities of the genito-urinary system/

system was studied in this group. A boy aged $6\frac{1}{2}$ years had been recognised 'officially' as a girl until the age of 5 years. The incomplete development of the genital organs had inevitably caused considerable confusion, and diverse agencies had been consulted by the parents; in addition, several periods of hospitalisation had been necessary for plastic repair of congenital abnormalities of the urinary system.

The child had spent the greater part of his pre-school years in hospital; during one spell of hospitalisation, the mother had travelled eighty miles every day for a year to visit him, and thereafter made four journeys weekly until his discharge from hospital. Complete disruption of normal family life had ensued and the care and management of the older sibling had suffered. The mother's now embittered outlook and harassed state of mind increased the difficulties of the handicapped child and of the family in adapting themselves to the consequences of his change of sex and name.

Following a recent plastic operation, to employ the abdominal muscles as a urinary sphincter, the boy required constant attention for his toilet needs, and this imposed an additional burden on the mother. Fortunately for this family, the housing conditions were satisfactory and hot water, bath and other facilities were adequate.

At the time of visiting, the boy was receiving home tuition, but his educational attainments were extremely poor; even this slow/

slow progress would be interrupted by imminent further prolonged hospitalisation for the treatment of his congenital abnormalities.

A boy aged 10 years had bronchiectasis; this condition had been confirmed at 5 years of age. There was a long history of repeated chest ailments and many specialist agencies had been attended for associated features of the disease. The unsatisfactory housing conditions had, in the past, contributed to the frequent attacks of chest illness and to the poor parental handling of the boy. Despite rehousing of the family there had been no improvement in his management, and the boy was now grossly over-protected by both mother and grandmother. He had been considered unfit for attendance at a special school and was now at home receiving home tuition. Due to the parents' lack of co-operation, medical supervision of his disability was poorly maintained, and the position concerning medical care and education of the child was unsatisfactory and was steadily deteriorating.

Another 10-year-old child studied, also a boy, had contracted pulmonary tuberculosis when 3 years of age and several spells of prolonged hospitalisation had been necessary before the condition was considered inert. Since discharge from hospital, the boy remained under regular supervision at a chest clinic. His/

His family occupied a room and kitchen house three stairs up, in a slum tenement, and at the time of visiting rehousing was imminent owing to the dangerous state of the property. These adverse housing conditions and the poor housecraft standards, however, had already begun to undermine the value of the after-care measures for his disability, and the benefit of the special school placement which followed his discharge from hospital.

FAMILY LIMITATION

In the families applicable in this group, there had been no question of avoiding further children on account of the handicapped child, or through fear that another child might be handicapped.

HOLIDAYS

Holidays were restricted in only two families because of the handicapped child; in the other families where holidays were impossible, financial considerations were given as the reason.

In this group follow-up attendance at hospital had been satisfactory in most cases, but little use had been made of almoning services; only two families had sought assistance, both in an emergency. Several families would have benefited from the provision of transport for hospital attendance. Domiciliary visits/

visits by a specialised visitor would have been welcomed by most parents for advice and help for emotional and physical difficulties which arose as a result of the handicap.

At the time of visiting, no child was immobilised although the physical handicaps were severe in nature. In this group there was, on the whole, less disruption of family life than in many of the other groups studied. Most difficulties in connection with diagnosis and medical supervision or concerning assessment of the disability and subsequent educational placement of the child appeared to have been solved satisfactorily and without undue delay.

PHYSICALLY HANDICAPPED CHILDREN

MULTIPLE HANDICAPPED GROUP.

Only five of the cases studied fell into the group of children having more than one physical handicap. The social classes of their families were Class II - 1; Class III - 1; Class IV - 3.

Four of these children were in the age-group 5 to 8 years, and one in the age-group 8 to 13 years.

Two children attended mixed special schools and their disabilities were:- Bronchiectasis and Epilepsy; Cleft Palate and Urinary Incontinence. Three children were at home receiving home tuition and their disabilities were:- Spina Bifida with paralysis of lower limbs and incontinence - 2 cases; Multiple Disabilities, including partial cleft palate, congenital heart disease and paralysis of lower limbs.

The cases are considered in the light of their educational placement at the time of the first home visit.

CHILDREN ATTENDING MIXED SPECIAL SCHOOLS

Two children - a boy aged 7 years, with bronchiectasis and epilepsy, and a girl also aged 7 years, with cleft palate and urinary incontinence - were placed on the physically handicapped side of mixed special schools.

These children had attended numerous specialist agencies since birth and repeated spells of hospitalisation had occurred, either for childhood ailments or for features associated with their/

their disabilities.

In the case of the boy handicapped by bronchiectasis and epilepsy, specialist opinion had discounted the possibility of a connection between the two conditions. Hospital supervision of the chest condition had been allowed to lapse; treatment for the epilepsy consisted of phenobarbitone tablets administered haphazardly by the parent. No specialist assessment had been made of the efficacy of this medication in stabilising the condition since initial prescription two years previously, and epileptiform seizures continued to occur at irregular intervals. Repeated exacerbations of the chest condition occurred and were partly due to the dreadful housing circumstances.

This boy was admitted to primary school at 5 years of age, but following medical assessment, he was soon transferred to a special school. He was absent frequently because of respiratory illness and due to the parents' apathy, co-operation between home and school was poor.

The second child, the seven-year-old girl, had encountered feeding difficulties in the early months of infancy before operative measures for the cleft palate were practicable. Subsequent operative treatment had not been completed through lapsed attendance at the hospitals where follow-up appointments for assessment had been arranged; this was due to the various changes of residence arising from the father's Service commitments. The child had urinary incontinence in addition; at an early age, the question of spina bifida occulta had arisen but attendance/

attendance for follow-up investigation had lapsed.

Shortly after admission to primary school, she too had been assessed and transferred to a special school. A severe speech defect was now present, and without the further necessary surgical treatment, speech therapy given at the special school was having little effect. Frustration at her defective speech not being easily understood, as well as sensitiveness about her incontinence had been aggravated by poor parental handling and by the derision of her schoolmates, and were reflected in her poor educational attainments and her troublesome behaviour in the home.

In both these families the parents hoped that their child's disabilities would be reduced through time, but neither family had a clear grasp of the implications of the handicaps and had treated the handicapped child as 'just another one of the family'. The parents had tended to ignore any special needs and would be unlikely to take the initiative in any positive action for the future welfare of the child. The other siblings reflected the attitude of the parents.

Housing and Environmental Circumstances.

Rehousing appeared urgently necessary in both cases. The boy, his parents and eight other children lived in a room and kitchen house two stairs up, in a slum tenement. This family had been fourteen years on the waiting list for rehousing; no priority had been granted, despite medical recommendations that the living conditions were contributing to the frequent respiratory upsets of the child. Rehousing was now imminent following/

following recent condemnation of the building. At the time of visiting, despite the risk from seizures, an ineffective fireguard was noted.

The girl's family occupied a room and kitchen three stairs up, in a slum tenement; three of the five children were under five years of age. The lack of essential facilities increased the mother's difficulty in coping with the incontinence and the troublesome behaviour of the handicapped child.

Holidays and Outings.

Domestic commitments restricted outings for the parents and younger children in these two families, although the handicapped child was mobile and attending school. Family holidays away from home were also hindered by domestic commitments and by financial circumstances.

CHILDREN AT HOME RECEIVING HOME TUITION

Three children - a boy aged 6 years and a girl aged 7 years, both with spina bifida causing paralysis of lower limbs and urinary incontinence, and a girl aged 11 years with multiple disabilities including partial cleft palate, congenital **heart** disease and paralysis of lower limbs - were all at home and receiving home tuition.

All were under regular supervision for their disabilities; one of the cases of spina bifida had attended the same hospital since birth. The other two children were now under the supervision of the Consultant Orthopaedic Surgeon to the Local Education Authority. One had been referred, from the hospital initially/

initially attended, for admission to a long-stay hospital where she came under the care of this consultant. The other child - the girl with multiple disabilities - underwent operative treatment when two weeks old; hospital follow-up eventually lapsed when the family doctor considered further attendance to be unnecessary in view of the unfavourable prognosis given, but following assessment at school entry age this child also came under the care of the Consultant Orthopaedic Surgeon to the Local Education Authority; in this case, additional surgical treatment had been impossible in view of her associated cardiac disability.

Both cases of spina bifida had been provided with calipers and crutches; one child was now able to cover short distances unescorted, but in the other case the child's thin legs, even with the aid of calipers, would not bear her own weight.

A routine had been established for timing the expression of urine in relation to fluid intake. Both children had now learned to express their urine for themselves, but there still remained the difficulty of locomotion to the toilet and of the removal of the cumbersome abdominal fittings attached to the calipers.

All three children had been assessed at 5 years of age and had subsequently received home tuition. In the case of the older girl, no other provision than home tuition was possible. The walking and toilet difficulties of the two younger children had precluded admission to adjacent special schools/

schools so far, although placement in school was so earnestly desired that the mothers were even willing to call at the school daily at intervals in order to attend to the child's toilet.

None of these children was mentally retarded, although the gross speech disorder and the emotional nature of the older girl made accurate assessment of her intellectual capacity extremely difficult.

Housing and Environmental Circumstances.

Housing conditions in two of the three cases were satisfactory; the families had been rehoused, one by private arrangement in the first year of the child's life and the other on medical grounds when the child was 3 years old. In both instances rehousing had provided the hot water, bath and toilet facilities essential to the child's care; one family had removed to the present prefabricated house from a room and kitchen property two stairs up, in a slum tenement where there had been the additional difficulty of negotiating flights of stairs with the immobile child.

Although rehousing appeared essential in the remaining case, this family had not sought priority in rehousing on account of the unfavourable prognosis given for the child. The severely handicapped girl was now 11 years old, and her father - who had previously helped with lifting and carrying her - had recently had an attack of coronary thrombosis. This dwelling also lacked hot water and toilet, but being on the ground floor of the tenement and in a cul-de-sac, the child could at least be placed at the/

the close-mouth in her push chair when the weather was suitable.

Effect of the Child on Family Life.

One child was an only child, another the only child now in the home and the other was the youngest of four, of whom three were at school; in consequence these mothers were able to devote considerable time to the disabled child.

The attitude of the parents with no other siblings in the home was over-protective and the routine of the household, and of their own lives,was entirely adapted to meet the needs of the child; the parents of the other child showed a sensible attitude in coping with his special needs, and although he was obviously the centre of attraction, his relationship with the other siblings was good. All parents understood the implications of the child's handicap and accepted it as permanent.

The parents of the two children with spina bifida expressed anxiety regarding the welfare and employment services for handicapped persons in later life, especially if they themselves were by then no longer living to look after their child. In earlier years when housing circumstances had been unsatisfactory, they would have welcomed the child's admission to a nursery for physically handicapped children, which in one case would also have provided companionship for the child.

Family Limitation.

Two families had limited their family size because of the commitments in caring for the handicapped child,who was in one case an only child.

Holidays/

Holidays and Outings.

Outings for these immobile children were restricted to short distances; the provision of a folding type of wheel-chair would have facilitated expeditions at greater distances from home. Despite the age of the children, two families still used an adapted push-chair and one, an adapted perambulator; a wheel-chair had been supplied for one child, but owing to its bulk, this chair had been of only limited use and was discarded.

The major holiday problem for these families was not one of finance but of transport. Apart from this difficulty, little adaptation of family holidays was necessary in two cases; suitable boarding-house arrangements were made in one case and the other family stayed with relatives at the coast. In the remaining family, holidays for the severely handicapped child and her parents were impracticable due to transport and accommodation problems.

CHAPTER VII.

MENTALLY HANDICAPPED CHILDREN.

MENTALLY HANDICAPPED CHILDREN

Sixty-one of the children studied have been placed in this group. The chief handicap in all these cases was mental retardation; in some there were complicating factors, but these were not regarded as sufficiently compelling to justify the child's inclusion in the multiple handicapped group.

The severity of the disability varied widely from the high-grade Mongolian child, who tended to become the pet of the family and the centre of attraction, to the very severely handicapped with little appreciation of anything, often completely incontinent, and inevitably a sore trial to his parents.

The social classes of the families were: Class I - 1; Class II - 5; Class III - 24; Class IV - 12 and Class V - 19.

Twenty-two of the sixty-one children were under 5 years of age and thirty-nine in the age-group from 5 to 13 years.

These children are considered in two age-groups - those under the age of 5 and those over that age.

(A) CHILDREN UNDER 5 YEARS

Five of this younger group were very severely retarded; of the remaining seventeen, seven were Mongols. One child suffered from a congenital metabolic disorder, phenyl ketonuria; he had an older brother (recently admitted to institutional care) similarly afflicted and even more severely handicapped.

All of the twenty-two children were living at home. In nine cases residential care appeared to be urgently necessary, but in only two were the parents willing to agree to this course, even/

even if institutional accommodation had been available.

DIAGNOSIS, ASCERTAINMENT AND SUPERVISION

Nineteen of the children had been referred to hospital, twelve of them without appreciable delay at an early age. Three were not referred, either by their own doctor or any other agency, for specialist advice and information. Doubtless in these cases, especially where mental retardation was the sole disability, this omission did not affect the child's condition or prospects, though it appeared that in some cases earlier referral might have reduced the anxiety of the parents. Three of the children were attending one particular hospital where a regular follow-up system was in operation, with the same specialist seeing the child at each visit; in these cases the parents fully understood the implications of their child's handicap and were appreciative of the opportunity of discussing their problems with the hospital staff. A few families would not accept the diagnosis and passed from specialist to specialist until finally they resorted to spiritualism or kindred agencies in quest of hope.

Only three of the twenty-two children were seen regularly by their family doctor; in one case in which minor seizures were a prominent feature of the severely retarded state, the child had not been seen by the doctor for over a year, although she was under medicinal treatment throughout. Of the nineteen cases which had been referred to hospital, subsequent follow-up was regarded as adequate in thirteen; in the remaining six, inadequacy/

inadequacy appeared to be due to lack of hospital follow-up in three, and to home circumstances in the remaining three - domestic commitments, apathy and a further pregnancy.

In five cases, the family had been directly referred by the hospital to the Local Authority for supervision, usually with some specific object in view, such as institutional care.

The desirability of a system of notification of handicapped or potentially handicapped children to the Local Authority in order that further supervision and integrated care may be made available is considered elsewhere as a general question arising out of the findings of this survey; but it may be emphasised that in this group of mentally retarded children, the need for some system of this kind was particularly clamant. In families where continuing supervision was adequate, the general experience was that adjustment to the child's handicap appeared considerably better.

In some of the twenty-two cases under consideration, the Child Welfare Service of the Local Health Authority, especially the welfare clinics and Health Visiting Service, provided a degree of supervision; but with their numerous commitments, the health visitors were not always able to devote the time and attention which such cases often required. In six families the parents stated that they had had no supervision from the Child Welfare Service and in some of the others supervision had been sketchy. Among the reasons which had most frequently contributed to the non-attendance at welfare clinics were domestic commitments,/

commitments, transport difficulties (often aggravated by tenement stairs), the child already under hospital or family doctor care and other supervision felt to be unnecessary, and a reluctance of the mother to see her handicapped child among normal children of the same age. It was noted that eleven of these children had been immunised against diphtheria, while eleven had not been so protected; immunisation had been withheld on medical advice in two cases.

Often special arrangements had to be made by families in this group so that hospital appointments could be honoured, and in several cases transport difficulties had prevented desirable attendance at hospital, especially with the older immobile or incontinent child. There was a general lack of knowledge among parents about the possibility of obtaining transport, though in practice little difficulty had been experienced when the appropriate approach was made.

Despite the fact that nineteen of the children had attended hospital, most of them at regular intervals, little use had been made of the almoning services; in only four of the cases had parents seen the almoner and only three of these were in regular contact with her; ten other families might have been helped by approach to the almoning service.

It may well be difficult for the hospital almoning service to preserve real contact with these cases; this only serves to emphasise the need for regular sessions at Local Authority clinics for handicapped or potentially handicapped children, supplemented/

supplemented by intimate home visitation by a specialised and knowledgeable visitor. There was great scope for the activities of such a visitor among the cases in this group.

HOUSING AND ENVIRONMENTAL CIRCUMSTANCES

Housing conditions played a large part in the lives of these families. One family, in which there were two mentally handicapped children, had been rehoused in the previous year, from a room and kitchen house three stairs up in a slum tenement, and now felt that life was again worth living. No priority for rehousing had been granted this family, despite medical recommendations.

Rehousing appeared desirable for thirteen families - in eight of these essential - but six were not on the Local Authority's housing list at all and seven had already been on the list for periods ranging from two to fourteen years with little prospect of success. Four of this group lived three stairs up and three lived two stairs up; in only one instance among the five families rehoused had the previous accommodation been at ground floor level.

Lack of space in which to erect a play-pen increased the hazards from fire, gas and furniture. The absence of indoor sanitation, hot water and drying space was a serious problem, especially where the child was incontinent. Outings were severely restricted by unsatisfactory environmental circumstances and under the prevailing cramped housing conditions, common hazards assumed a special significance. Eighteen of the/

the twenty-two families had fireguards but in nine cases these appeared to be inefficient.

EFFECT OF THE CHILD ON FAMILY LIFE

In nine cases ill-health of the mother seemed to be attributable directly to worry about the child and his behaviour; in two of these cases, the husband was more concerned about his wife's ill-health than the child's disability. The relief afforded by short-term care or a crêche type of nursery in some of these cases would have been invaluable. A crêche, conducted by a voluntary association subsidised by the Local Authority, was used by one family but existing demands on its accommodation limited the attendance of this child to one day a week. Services of this kind were not nearly sufficiently available. In the milder type of case, priority admission to a day nursery might have been considered, irrespective of financial criteria, especially where gross environmental difficulties were present.

The presence of the handicapped child in the family caused varying degrees of disturbance, not only to the parents, but to the other members of the family. Nine families, without relatives or friendly neighbours on whom they could call, would have welcomed an arrangement where someone would 'sit-in' with the child, either to permit shopping, or for outings with the other pre-school children in the home. In one family, all the shopping was done by a boy of 15; in three others the father had taken shift-work solely to help with the child, while in at least three other families, shopping was done by the mother,who dashed/

dashed out while the child was asleep and hoped that all would be well until her return.

Attitude of Parents to the Handicap.

In eight of these cases the parents accepted the child's handicap as permanent but still hoped that with the passage of time it would be greatly reduced; it was felt that these parents fully understood the implications of the handicap. In ten of the remaining fourteen cases, the parents obviously did not fully appreciate the circumstances or the outlook for the child. The desire to discuss doubts and fears was emphasised, during the course of home visiting, by the eagerness shown by the parents for further enlightenment. Constant and repeated explanations are necessary to resolve the anxieties of the parents and to give them a measure of confidence. In most families the father tried to help as much as possible with the care of the child and in only two families was it felt that he rejected his handicapped child.

Family Limitation.

Seven of the families had tried to avoid having further children, two from the fear of having another handicapped child, five because the mother did not feel physically fit to have,or cope with, a new baby as well as the handicapped child. The subject of family limitation had rarely been discussed with the family doctor or with hospital staffs and the parents had made their decision on the subject without specialist advice.

HOLIDAYS

In the cases where gross environmental difficulties were most obvious, holidays were rarely taken. Financial considerations were mainly responsible for the absence of holidays in six cases, while in six others financial stringency was an important contributory factor. Five families had adapted their holidays to suit the handicapped child; in other five,financial considerations apart, a holiday would have been impossible unless short-term care could have been arranged for the child while the family went away. In one family the feeling that 'it would be no holiday anyway' discouraged the family from trying to arrange a holiday which would have entailed financial sacrifice and which they thought would not be worth while in the end. There was no doubt that many families badly required a break away from the child, with the child having a separate change away from the family.

PROVISION OF SHORT-TERM RESIDENTIAL CARE

Short-term residential care would have been welcomed by six of the seven families who were unwilling to consider permanent residential care for the child, and it was felt that had this been available, it might have helped to overcome their objection to institutional care. These families were not prepared to consider such a placement, even in an emergency, though in one of these cases the parents subsequently changed their minds and were anxious to have institutional care arranged only to find that it was not available. Among the reasons given by parents/

parents for their objections were, 'feeling of guilt'; 'what the neighbours or relatives would think'; 'it would be like putting her away'; 'she would have to be certified and never get out again'. In some cases the mother would have been willing to allow the child to go away, but the father, not realising the strain to which his wife was subjected, would not agree.

There was undoubtedly need for short-term care, especially in this younger-age group, on the lines of a general hospital or residential home, which would be readily available not only for emergencies, but for periodic relief of the parents and for holidays.

At present residential care, on a long or short-term basis, is extremely difficult to secure even where it is urgently necessary with the result that the whole family gradually and unconsciously adapts its mode of living to the handicapped child.

(B) CHILDREN FROM 5 TO 13 YEARS

Thirty-nine of the sixty-one mentally handicapped children were in this age-group and of these, nineteen were regarded as very severely retarded while twenty were less severely handicapped.

At the time of the first home visit, three of these children were in institutional care; thirteen were at home unplaced; seventeen were attending occupational centres and six were pupils on the mentally handicapped side of mixed special schools.

Several of these families contained other mentally handicapped children in addition to the one included in this study. Three/

Three siblings, for instance, were attending special schools; two were attending occupational centres; one sibling - a moral defective - was in institutional care and two were awaiting admission to special schools.

Of the thirteen children at home unplaced, eleven had been notified to the Local Health Authority and their names placed on the waiting-list for institutional care. One of the remaining two cases, at home unplaced, was a severely handicapped girl aged 7 years, an only child, for whom no other arrangement was desired by the parents; the other child, a boy aged 6 years, was, on reassessment, recommended for admission to an occupational centre, but after a short trial period he had to be excluded because of unclean personal habits.

At the time of visiting, ten of the eleven cases on the waiting-list for institutional care appeared to be in urgent need of this; although his name still remained on the waiting-list, the remaining case, a boy aged 5½ years, had been reassessed on reaching school entry age and recommended for admission to an occupational centre. In view of the severe disruption caused in the home by the handicapped child, the parents in eight of these ten urgent cases, were anxious for institutional care; the remaining two families were no longer willing to consider such care, although their child's name had not been removed from the waiting-list.

DIAGNOSIS, ASCERTAINMENT AND SUPERVISION

Twenty-six of the thirty-nine cases in this group had been referred to hospital before attaining the age of 5 years for some matter associated with their disability. Of the cases referred, three were not required to attend after the initial visit, nine had remained under regular hospital supervision, whilst subsequent hospital care had been irregularly maintained or had lapsed completely in the remaining fourteen cases. It was impossible, on account of the numerous agencies involved, to assess accurately how many of the children would have benefited by reference for specialist opinion or investigation at an earlier stage, especially in view of the neonatal history in some cases, or where the mental handicap had resulted from infectious disease or other illness in early infancy.

As with the children under five, few cases had prolonged supervision from the almoning department and there were many instances where the availability of transport provision would have helped to facilitate necessary supervision. Health visiting is not carried out as a routine measure for children over 5 years of age and the absence of transport sometimes accounted for lack of contact with Local Authority services. The extent of contact of parents and children with the Child Welfare services of the Local Health Authority in the child's pre-school years could not be accurately assessed.

One abiding impression left from the study of the earlier history of the children was the lack of overall assessment at an/

an early stage in these cases, an assessment made in the light of all relevant circumstances and designed to map out a plan of action best suited to all the needs of the case; this lack emphasised the need for the services of a specialised visitor experienced in this kind of work, who would have the time and knowledge to help the parents and children with the many problems that arise.

Mode of Reference; Subsequent Ascertainment and Placement.

The presence of mental retardation appeared to have been confirmed to the parents at these ages:-

Age in Years.

	Less than 1	1-	2-	3-	4-	5-	6 - 7	Total
Severe	5	5	3	3	3	0	0	19
Less severe	1	3	2	0	5	7	2	20
	6	8	5	3	8	7	2	39

In the great majority of cases, no action had been taken in regard to the child's future until he was approaching the age of 5 years.

Parents had contacted the Education Department or the Local Health Authority in nine cases, usually just before the age of school entry and in nine instances parents had brought the child's condition to the notice of School Welfare Officers visiting homes to check lists of children due to enter school. In eighteen cases the Head Teacher of the local primary school had raised the matter, after the handicapped child had attended for a period ranging from mere initial interview to the time of routine/

routine examination by the School Medical Officer. Two children who had been under the supervision of Local Health Authorities in England, and had been in attendance at occupation centres there, were admitted to occupational centres in Glasgow when their families changed residence. The condition of another child was brought to notice by a children's hospital which had schooling facilities.

All the children were subsequently assessed by the School Health Service. At the time of the first home visit, of the nine children referred by parents to the Education Department or Local Health Authority just at or before school entry, two were under institutional care; four, at home and unplaced,were on waiting-lists for admission to institutions; one was attending an occupational centre, and of two others at home, one had been excluded from such a centre and the other remained at home as no educational placement was practicable.

Of the nine children brought to the notice of School Welfare Officers and assessed by the School Health Service, six had been referred to the Local Health Authority and all of these were on waiting-lists for institutions; two children were at occupational centres, and one who had been excluded from an occupational centre was at home and on the waiting-list for admission to an institution.

Of the eighteen children who had been referred by Head Teachers of primary schools, six were attending special schools for mentally handicapped children, and twelve were attending occupational/

occupational centres - six of these having previously been tried out in special schools for varying periods and from there transferred to occupational centres. The child referred by the children's hospital was attending an occupational centre, and of the two children from England, one was still attending an occupational centre, while the other had to be admitted to an institution for mental defective children after exclusion from the occupational centre.

Contact of Parent with Special School or Occupational Centre.

The parents of the great majority of the children had little real contact with the teachers in special schools or with the staffs of occupational centres which their children were attending. Yet, in many cases, the parents evinced a real interest in the educational progress of their children and were concerned about such questions as what they were being taught, why they did not learn to read or write, why they did not mix with others as most children did; some parents asked why their child did not have the facilities, such as speech therapy or physiotherapy, that he had formerly had when attending a special school. In some cases the Head Teacher of the special school or Superintendent of the occupational centre had established a degree of contact with the parents by herself visiting the home, or by repeated messages to the parent. This kind of contact appeared to have only a limited degree of value and some form of regular home supervision appeared necessary,so that/

that the methods used in handling and training the child in the special school or occupational centre would be followed in the home. More effective links should be developed, and probably this can be best done through the agency of Health Visitors, especially in Glasgow, where occupational centres are within the educational system and the Mental Health Officers of the Local Health Authority are, on that account, not in such close contact as is the case in England.

HOUSING AND ENVIRONMENTAL CIRCUMSTANCES

Seven of the families studied had been rehoused in the course of the previous five years after varying periods on the waiting-list for rehousing. One of these families had received priority in rehousing due to the presence in the home of an aged relative with active tuberculosis; a mentally defective sister of the handicapped child's mother also lived with the family.

Of the other thirty-two families, rehousing did not appear necessary in eleven cases, but in twenty-one cases rehousing was desirable and in fourteen of these the need for rehousing was urgent. The periods on the waiting-list varied from two to seventeen years; three families had been offered rehousing but, owing to the high rent or the distance from the house offered to the father's work, they had not accepted. Two families in urgent need of rehousing had not submitted any application; one family had, for seven years, expected that the property in which they lived would be demolished and that rehousing/

rehousing would result; in the other family, the parents had no wish to be rehoused as the older children were living elsewhere and the handicapped child, who was the sole child of the second marriage, was the only child now in the home.

One family had been five years on the waiting-list for rehousing, having moved, because of the mother's inability to mount the stairs with the handicapped child, from a house three stairs up where they had lived for ten years to a single room ground-floor property; shortly after this move, their previous house had been condemned and the tenants rehoused. The robust 10-year-old mentally handicapped boy, who was in addition incontinent and severely maladjusted, his parents and his 12-year-old sister shared this single room house where there was neither toilet nor hot water.

One severely handicapped child, in urgent need of institutional care, and his unmarried mother lived on sufferance with four adult relatives. She and her child slept in the kitchen, the unsatisfactory state of affairs being periodically relieved when the child was admitted to hospital due to respiratory illnesses.

When a home visit was made to one family, the father, on night work, was unable to go to bed until after the family doctor had called in the late afternoon to see a sick child, as his bed-settee could not be put down owing to lack of space. In this house, a single room, there lived three adults,three children and an older unmarried daughter who was pregnant; the family/

family lived three stairs up and the mother, who suffered from severe bronchitis, was almost house-bound on account of the stairs. The gramophone records of the older members of the family were kept in the gas cooker as there was nowhere else to put them.

Several other families for whom rehousing was considered essential had severely defective children and were living in houses, three stairs up, in tenement buildings.

Hazards.

Hazards such as fire, gas, easy access to open windows and trailing flexes were all present. Nineteen of the families had fireguards, but eleven of these were inefficient, while twenty families had no fireguard.

EFFECT OF THE CHILD ON FAMILY LIFE

In this older age-group there was greater evidence of difficulty within the family arising from the presence of the handicapped child and from his behaviour. In nearly every case where the child was at home, unplaced, there was a degree of ill-health of the mother arising from nervous tension and the constant need to supervise the child, both by day and by night. The night supervision tended to fall to the mother almost exclusively, as the father had to have what sleep was possible in order to carry on at his work. One mother had had a nervous breakdown two years previously and although advised by her doctor to have as much rest as possible found that this was well-nigh impossible; her husband worked away from home and had tried unsuccessfully/

unsuccessfully to find suitable employment locally. Another mother who had suffered from pulmonary tuberculosis some years previously went to bed when she developed a cold in case her health broke down again, and her husband then had to stay off work to look after the handicapped child, who was at home. It was not surprising that he frequently lost his job, partly because of this and partly because of irregular time-keeping through broken sleep.

Many of the children damaged clothes and sheets by tearing and biting them, so that frequent repairs and renewals were necessary; expenditure on footwear was heavy and clothes could not be 'handed down' to young children. Since several of the mothers would have been out at work if the child had been normal, this extra wear and tear represented an additional hardship to them under circumstances where financial conditions were often already severely strained.

Assistance of Neighbours and other Siblings.

Neighbours played little part in the lives of these children; in only three cases did neighbours take an active interest in them. On the whole, neighbours were not over-anxious to help in those cases where help was most needed. Often, where a child was severely handicapped, older members of the family were not anxious, sometimes not even willing, to help and were apt to throw the full responsibility for his care on the mother - in contrast to the under-5 group, who were more frequently accepted as a family responsibility. In some of the families, the older/

older members felt that a degree of stigma attached to them because of the existence of the handicapped child.

Attitude of Parents to the Handicap.

It was felt that in ten of the families there was understanding and acceptance of the handicap; as one father summed it up 'if it's not there, you can't put it there'. In the other twenty-nine families the parents appeared not to realise fully the implications of the child's handicap; one mother, whose child (over 8 years old) could not feed himself and was incontinent, still wondered why he could not be educated.

FAMILY LIMITATION

In nineteen of the thirty-nine families efforts had been made to avoid having further children, in ten instances because the parents felt that the family was large enough already, and in nine instances because of the presence of the handicapped child - because of fear that another child might be handicapped, or simply from inability to cope with a new baby in addition to the handicapped child already present in the family.

HOLIDAYS

Holiday arrangements were completely disrupted in nearly all the families where a child was at home unplaced; although seven of these thirteen families adapted their holidays by staying with relatives, the impression was gained that little benefit resulted from the holiday. Financial considerations were mainly responsible for the absence of holidays in those families where the child was less severely handicapped.

PROVISION OF SHORT-TERM RESIDENTIAL CARE

Short-term residential care would have been welcomed by many families, so that the rest of the family could have a holiday without the child. Provision of this kind would also have been of great value in giving the mothers of unplaced children a much needed break, and would have been of especial value in tiding over domestic emergencies. One mother, who had tried at intervals during a subsequent pregnancy to arrange short-term care for her severely handicapped child, managed to get the child removed to an institution for mental defectives on the evening of the day on which her child was born, by which time she was almost on the point of collapse. Another mother admitted to hospital following a miscarriage, had to leave hospital after only one day because relatives who were looking after the handicapped child - and who had previously insisted that he was quite normal - said they simply could not cope with him and 'he would just have to go into an institution.'

Admission for short-term care should be on as informal a basis as possible. Where alternative forms of residential placement are impracticable admission for short-term care to institutions for mental defectives should be possible without the need for statutory certification of the child under the Mental Deficiency Acts; because of this requirement parents of several less severely handicapped children had been deterred from considering this form of temporary relief, even where it was urgently required due to adverse domestic or social circumstances.

ADMISSION FOR DAILY CARE

Some form of daily crêche or special occupational centre for those unplaced at home, where the child might also be habit-trained would have been welcomed by all these families. Admission in the child's early years, to a nursery for handicapped children, or a crêche, would have been of benefit for nearly all cases in this age-group; thirty-one out of thirty-nine families would have welcomed such a service.

HOME SUPERVISION

It was in the group of children unplaced and at home that the greatest need for supervision and regular guidance was apparent. The use of a specialised visitor for this work would have been of benefit in all families, in giving practical advice to parents, in regular assessment of the condition and progress of the child, and in helping to smooth out the difficulties of the parents and other members of the family. There was a very noticeable lack of regular assessment and supervision. To some extent, assessment of this kind was doubtless inhibited by the practical difficulties of obtaining institutional care, even where it was urgently necessary, or of dealing with the bad housing and other poor environmental conditions present;however, discussion of these difficulties and consideration of alternative alleviating measures would have been appreciated. The impression left with the parents was that they and their children were forgotten and that no one was really interested in them. Regular home supervision would help these parents to bear their burden/

burden better, would allow constant review of the necessity for institutional care, and it could not do the Local Authority any harm to be reminded repeatedly of the conditions in which many of these children live.

CHAPTER VIII.

MENTALLY HANDICAPPED CHILDREN WITH ANOTHER HANDICAP.

1. Mentally handicapped with a handicap of 'SPASTIC' nature.
2. Mentally handicapped with a handicap of 'EPILEPTIC' nature.
3. Mentally handicapped with an additional PHYSICAL handicap.

CHILDREN MENTALLY HANDICAPPED WITH A HANDICAP OF 'SPASTIC' NATURE

This group was composed of children who were mentally handicapped and were in addition physically handicapped by varying degrees of spasticity. Some had been regarded by parents and various welfare agencies as spastic children and some as mentally handicapped children. Although many had been reported as cases of cerebral palsy and were initially visited as such, it became clear that they could not be regarded as true cases of cerebral palsy.

In the younger children a very complicated pattern of disability was found and in most cases overall assessment of the child by team ascertainment had not yet been possible; even where overall assessment had been attempted, it had been impossible where mental and physical involvement co-existed to ascertain which was the major disability. In some, despite the obvious associated degree of mental retardation, the physical disability for which the children were under supervision and treatment was always uppermost in the minds of parents since meeting its needs gave rise to immediate problems.

Classification of the older children was also complicated, but because of their age it was possible in most cases to estimate the degree of associated mental retardation more accurately.

The needs and problems of parents and children have therefore been studied in the light of the dual handicap common to all cases placed in this group.

The/

The degree of disability ranged from a severe physical and mental handicap to a major physical or mental handicap with a mild degree of mental or physical involvement. Cases where there was no question of any appreciable degree of mental retardation associated with the physical handicap of spastic nature have been regarded as physically handicapped children and are considered elsewhere.

Thirty-seven cases were placed in this group, and are now considered in two age-groups - those under the age of 5 years and those over that age.

(A) CHILDREN UNDER 5 YEARS

The ten children studied in this age-group were at home; their ages ranged from 1½ to 4½ years. All were severely mentally and physically handicapped and all except one were incontinent and unable to walk or to feed themselves. The social classes of their families were:- Class II - 1; Class III - 4; Class IV - 3; Class V - 2.

DIAGNOSIS, ASCERTAINMENT AND SUPERVISION

In two cases, the disability had followed the occurrence of pneumococcal meningitis at 5 months and tuberculous meningitis at 6 months of age respectively; the previous histories of both children were otherwise uneventful.

Seven of the other eight children were born in maternity hospitals, two by Caesarean section due to antenatal or possible obstetrical difficulties, and five had suffered birth injury, two of these being also severely asphyxiated; three of the mothers had a history of antenatal complications. In the remaining/

remaining case the mother had been discharged, after four weeks in hospital on account of an antenatal haemorrhage, and labour commenced one week later, when she was only six months pregnant. In seven of these eight cases, parental suspicion of possible abnormality was aroused before the child was 6 months of age, some parents being aware of the possibility since the birth of the child; and in one case suspicion was aroused when the child was not sitting up at 15 months of age. Including those where follow-up since birth had been continuous, reference to paediatric hospitals had taken place in seven cases by nine months and in the eighth by sixteen months, and had also been arranged in the two cases where the disability had been acquired following illness. In all cases, following hospital reference, some mental and/or physical involvement was confirmed without undue delay.

Four of the ten cases were still being supervised at the hospital originally attended. Of the remaining six cases, hospital follow-up was considered unnecessary for two when mental deficiency was confirmed at the initial visit; the parents of the other four children discontinued attendance possibly because of apathy, or resentment at the suggestion of mental retardation, or they felt that apparently little was being done for the child's physical condition and in view of their commitments, attendance was pointless. One of these six children was lying at home and no further action had been taken by the parents who were both trained nurses, and one child was awaiting reference to the Consultant Orthopaedic Surgeon to the

Local/

Local Education Authority. The other four had subsequently been referred by child welfare clinic doctors to this consultant; these referrals were partly due to the parents' obsession with the physical aspect of the disability and partly to the growing emphasis on diagnosis and treatment of spastic cases. The diagnosis of mental retardation was confirmed and cerebral palsy was excluded in two cases; the other two cases were now regularly attending Local Authority specialist clinics for therapy and were seen at regular intervals by this same orthopaedic specialist. One of these, a boy aged 3 years, would have benefited from admission to a nursery unit for spastic children so that regular assessment and integration of treatment might take place, especially in view of his mother's commitments with an older handicapped child. Although nursery admission would have been a relief to the mother of the other child, a boy aged 3½ years, the quadriplegia associated with his apparently severe mentally retarded state would have rendered such placement impracticable; this family lived three stairs up in a tenement and the difficulty of handling the child had become acute since the recent death of his father.

Reference to the almoning service had been made in only two instances, both on account of housing difficulties. Reference to the almoner with subsequent close co-operation between hospital and Local Authority is desirable for this type of case, and would permit the determination of immediate transport, domestic and environmental difficulties, thus facilitating the subsequent/

subsequent assessment and supervision of the case.

Transport for hospital attendance had been neither initially suggested nor subsequently offered for nine of the ten cases; one case was taken to hospital for treatment in a neighbour's car. Only one child was able to walk and all the others had to be carried by an adult. No undue difficulty was experienced in obtaining transport when parents were eventually advised how the appropriate approach should be made.

Transport difficulty was also experienced by parents of the children attending Local Authority specialist clinics for therapy or supervision; this difficulty was more acute among the parents of school age children and is therefore discussed fully in that section.

General Practitioner and Child Welfare Clinic Supervision.

No child attended local child welfare clinics but area health visitors saw eight of the children periodically; only one child received routine visits from the family doctor; in all other cases the general practitioner attended when specifically requested. Convulsions were a prominent associated feature of the severe handicap in one of the cases; the parent administered the prescribed drugs haphazardly, and the only occasion on which assessment of the efficacy of medication took place was when the child was seen by the orthopaedic specialist at periodic intervals.

HOUSING AND ENVIRONMENTAL CIRCUMSTANCES

Rehousing was considered essential for seven families, desirable for one and unnecessary for two. Where rehousing was considered essential, the families lived in tenements in slum areas, occupying either a single room with the gas cooker in the small lobby,or a room and kitchen house, and in only one instance a two room and kitchen house; only three of the families lived on the ground floor.

Six of these seven families had been on the waiting-list for rehousing for periods of from three and a half to twelve years; medical recommendations had been submitted in support of two applications, but without effect. The remaining family of two adults and four children occupied a room and kitchen house at the rear of premises used for hair processing and adjacent to a catgut factory; this home was reached by narrow winding stairs and the small entrance lobby was blocked by both gas stove and perambulator. The family had been refused permission by the landlord to seek a private exchange, and an approach by the hospital almoner to the Local Authority to obtain rehousing for the family had been unavailing.

None of these homes had adequate living space, indoor toilet or bath and few had the running hot water so necessary in view of the incontinence of these children; both indoors and outside, the lack of drying facilities for clothes was a further problem. Stairs added to the mother's difficulties in several cases; a perambulator placed at the close mouth could not/

not be supervised as the mother went about her household tasks and was liable to be overturned. Many of the mothers feared that their handicapped children would choke with sweets given to them by other children. An empty perambulator left at the foot of the stairs was liable to be stolen, damaged or fouled by cats.

The family for whom rehousing, although not essential,was desirable had removed from England and the parents and their handicapped child shared the home with the mother's mother and stepfather. Relations between the two families had deteriorated. Indoor amenities were adequate but three flights of stairs made it impossible to give the helpless and heavy handicapped child regular outings.

In one of the two cases where housing was satisfactory,the burden on the mother, who also had an older mentally handicapped child, was increased by the improving mobility of the younger child for whom the adjacent traffic road was now a danger to guard against constantly. There were no housing or environmental difficulties for the other family and their handicapped child was the only one in this age-group to have her own room.

Seven of the children slept in cots, one on a couch in the kitchen and two shared beds with their parents; since in most cases the parents slept in the kitchen, regular sleeping habits for the children were impossible.

Hazards.

As all but one of the children were unable to walk, many of the hazards which would undoubtedly have arisen out of the poor/

poor housing conditions were not applicable to these cases. Four families had fireguards, two of which were inefficient, and for the one mobile child traffic had now become an additional hazard. Lack of facilities and particularly lack of space, were likely to hinder any possible development in crawling or walking.

USE OF EQUIPMENT AND APPLIANCES

In all cases except that of the child who was now able to walk, the handicapped child, irrespective of his age, was taken out in a perambulator or had to be carried by an adult; neither a push-chair nor a wheel-chair was used in any instance. One child who had outgrown his adapted perambulator required a suitable wheel-chair and although the mother regularly attended hospital with the child, she was unaware that this appliance might be provided through the National Health Service on specialist recommendation. Several parents realised that a perambulator was now unsuitable but felt that when the handicapped child was taken out, the hood shielded the child from curious interest.

None of the families had equipment suitable for the handicapped child. Eight of the children lay for most of the day in cots or on the floor of the living room and in no case was a play-pen used. The parents of one child had paid £4: 10: 0 for a high chair, which had been unsuitably adapted and still failed to support the child in a comfortable sitting position. Only one of the ten children would have been unable to sit up in/

in a suitably adapted chair which could have been used at meal-times; as it was, in all cases the child was fed whilst sitting on the mother's lap.

EFFECT OF THE CHILD ON FAMILY LIFE

Owing to the unsatisfactory housing conditions and inadequate living accommodation, parents and siblings were frequently disturbed by the more severely mentally handicapped child, to the detriment of schooling, work, family atmosphere and health.

With only one exception, the health of the mothers appeared adversely affected by the strain of the full-time care of the handicapped child, by the physical effort of lifting and by the lack of outings and relaxation, and they appeared in need of some respite from their demanding domestic commitments. One of these mothers suffered considerable ill-health and was unable to avail herself of recommended hospital treatment. In the one exception, financial circumstances were satisfactory, domestic help was adequate, housing conditions were good and the mother maintained good health.

Attitude of Parents to the Handicap.

No family accepted the child's handicap as permanent; all parents hoped that their child's condition might at least be considerably improved. In most cases there appeared to be no complete and realistic understanding of the disability and its implications; most parents thought entirely in terms of the physical disability and regarded any slight improvement with undue/

undue optimism.

Attitude of Siblings.

Little jealousy of the handicapped child existed amongst other siblings, although in two families older children appeared resentful of the attention paid to the handicapped child and of the fact that their outings and freedom were restricted by his helplessness.

FAMILY LIMITATION

In only one case had parents avoided having further children through fear of having another handicapped child; in this family an older handicapped child had died. One family with one other sibling had avoided having further children because of their unsatisfactory circumstances and one family would have welcomed a second child for company and encouragement for the handicapped child.

HOLIDAYS AND OUTINGS

Two families spent their holidays with relatives and one mother took her handicapped child for short spells to his aunt who had a modern house with a garden in a new housing scheme in Glasgow. Financial stringency and the difficulties of caring for the child away from home had prevented the other seven families from taking holidays. For these families, only the provision of short-term care would enable them to take a holiday without the child, and a family holiday with the child would only be practicable if some special holiday home facilities were available irrespective of financial means.

In/

In all except the one family who had adequate domestic help, essential outings were severely restricted and even shopping was a considerable undertaking unless there was someone to look after the handicapped child in the mother's absence. Two of the fathers had taken shift work to help the mother with daily shopping or with the care of the child; in other cases the mothers relied on older siblings and on neighbours, or could shop only on Saturday mornings when the husband or adult siblings were at home. A service by which a reliable person would 'sit in' with the child would have permitted the mother to go out at suitable times for shopping and to have more frequent outings with her other pre-school children.

PROVISION OF SHORT-TERM RESIDENTIAL CARE

Residential care would have been desirable for seven of these cases, and in four it was felt that domiciliary care might soon be impossible under existing circumstances and residential care would then be the only satisfactory solution. Only one case was already on the waiting-list for institutional care and the parents in four cases were unwilling to agree to this course when it had been recommended by the hospital consultant. In the remaining two cases, although placement had not been recommended, the mothers would have welcomed residential care in hospital or long-stay home, but would not have considered institutional placement for the children even if accommodation had been available. Most of these parents, however, would have welcomed short-term care for emergencies or for periodic relief.

ADMISSION FOR DAILY CARE

Admission of the handicapped child to a nursery or crêche would have been welcomed by all families including the one case where the child was adequately catered for at home. One mother, recently widowed, was anxious for the child to be admitted to a nursery so that she could obtain employment. In all cases admission to nurseries, especially if equipped to provide simple therapeutic measures, would have provided a relief from the continual care and would have in some cases reduced the commitments of hospital and clinic attendance for physiotherapy.

General practitioners, midwives and health visitors should be alive to the importance of early reference for paediatric specialist opinion of cases where the obstetric history or the occurrence of neonatal illness, following hospital or domiciliary confinements, gives rise to the possibility of physical abnormality. Where the question of cerebral palsy arises, treatment might then be initiated at the age when the best results are achieved i.e. in early infancy. Earlier reference for specialist opinion would have prevented much of the anxiety experienced by parents before eventual action by the family or clinic doctor had resulted in specialist opinion and treatment.

Subsequent co-ordinated action following, wherever possible, team ascertainment by the various specialist agencies concerned would give an integrated approach to the case. Domiciliary supervision,/

supervision, by specialised visitors, of the handling and training of the child appears equally necessary and would also allow regular assessment to be made of the child's needs and the parents' difficulties.

The needs and problems arising from the associated mental handicap have not been considered in detail here, since they are similar to those considered for mentally handicapped children. They were, however, much more obstinate of resolution because of the unwillingness or inability of the parents to recognise or accept the mental involvement and their insistence on treatment for the physical aspect of the handicap.

(B) CHILDREN FROM 5 TO 13 YEARS

Twenty-seven children were in this age group. The social classes of their families were Class I - 2; Class II - 1; Class III - 16; Class IV - 5 and Class V - 3. Twenty-three of the children were severely handicapped and four were less severely so; in two cases the physical disability was of a severe athetoid nature.

At the time of visiting, three of the children were in institutional care and five were at home unplaced. Four children attended a spastic unit in a special school, nine were at mixed special schools and six attended occupational centres.

The cases have been grouped according to their placement, since in this way the common needs and problems encountered by/

by cases with a like degree of mental and physical disability can be considered together, and the way in which the interaction of the problems affects the utilisation of the existing services may be seen, whilst still allowing particular needs of individual cases to be examined. The over-all picture of diagnosis, ascertainment and supervision, and the effect on family life are discussed at the outset to give the background of the cases before considering them in the light of their present placement.

DIAGNOSIS, ASCERTAINMENT AND SUPERVISION

In six cases the disability had resulted from acquired illness or accident - tuberculous meningitis at 18 months and 3 years respectively, cerebrospinal meningitis at 4 months, polio-encephalitis at 1 year, cerebral haemorrhage at 18 months, and a depressed fracture of the skull due to a road accident in the case of a boy aged 6 years. In the other twenty-one cases, antenatal complications, rhesus factor incompatibility, birth injury, prematurity, congenital abnormality,or multiple pregnancy had been either contributory or main factors.

The pattern of follow-up from birth by the maternity hospital, or of reference to hospital for specialist opinion by family doctor or child welfare clinic, and of subsequent follow-up, was exceedingly complex and could not be checked completely in every case owing to the number of agencies involved.

Of/

Of the six cases where the disability had followed an acquired illness, hospital or Local Authority specialist clinic follow-up had remained regular in four. Of the other twenty-one cases, only one parent had continued regularly at the hospital originally attended and had not sought other opinion, although in one case an alternative reference had been suggested and arranged by the hospital. Parents gave various reasons for ceasing to attend; some had resented the opinion expressed, some were dissatisfied at the absence, or with the apparent inefficacy, of treatment; while some parents reported having been told that their child was mentally handicapped and that nothing could be done for him. Several parents had discontinued attendance at the hospital originally visited when they sought and obtained a further source of possible advice or treatment. Some children had been referred to hospital for presenting features of the handicap, such as the apparent inability to see or on the occurrence of seizures, and the parents had ceased further attendance when these presenting features had been considered.

Difficulty in the over-all assessment of the condition, especially if the young child was seen at hospital only once or very occasionally, was aggravated in many instances by the parents' pre-occupation with the physical handicap and their refusal to accept mental retardation, no matter how severe, as the essential cause of the disability. The extensive propaganda/

propaganda campaign which has aroused public interest in the spastic child and the formation in Glasgow of a local branch of the Association of Parents and Friends of Spastic Children led many of the parents to become members of this Association, and from then onwards they have considered their children as 'spastics'.

The Consultant Orthopaedic Specialist to the Local Education Authority, who in addition was keenly interested in the work of this voluntary organisation, had seen eighteen of the twenty-seven cases in this group before they had reached school entry age. Reference had been made either by hospital, child welfare clinic or family doctor, or on the advice of social workers, friends of the families or through the Association. In many of these eighteen cases, the mere fact that this specialist had examined the children had been sufficient for the parents to consider them to be 'spastic' even although the diagnosis and prognosis already given had been endorsed. In some cases, although severely retarded both mentally and physically, continued supervision had been considered desirable in order to watch the progress of these severely handicapped children and to advise the parents on management and handling, and in some cases therapy had been considered of possible benefit or at least worthy of a trial. This attendance for assessment or therapy had also fostered the parents' conviction that their children were 'spastics'.

More than in any other handicapped group studied,numerous and/

and diverse agencies, both professional and lay, had been attended for treatment and advice. The majority of these parents were determined to leave no stone unturned in the hope that something might be done to help their child. Improvement, due to increasing age, in the limited capabilities of some of the children had helped to cloud the true picture, especially where the original prognosis given to the parents had appeared so unfavourable. Even where the diagnosis of mental retardation was in no doubt and ancillary measures were not feasible, other opinions were sought in addition to those from the specialist clinic and the hospital first attended. Numerous agencies had been consulted by both written and personal approach; one parent had attended six hospitals in addition to various clinics. In five other cases, three of whom were now placed at special school or occupational centre, physiotherapy was being obtained from such sources as a hospital physiotherapist in her spare time, a physiotherapist attached to a junior football club, osteopaths, and a bone-setter in the parents' home town forty miles away. Four parents were themselves giving the child exercises, two on the strength of observation and reputed experience as hospital orderlies or plaster-room attendants, and two using limited knowledge acquired from books or from attending lectures. In another case where the mother's emotional reaction to cessation would have been adverse, her severely handicapped child had continued to receive physiotherapy on a limited scale at the clinic/

clinic for longer than was considered to be practicable, and the father was now seriously considering training as a physiotherapist in order to give his child treatment. None of these cases was among those where home exercises had been advised by the physiotherapist or orthopaedic consultant.

The question of physiotherapy loomed large in this group and many of the problems arose through the difficulty of transporting the child to clinic or hospital for examination or therapy. As in the younger age group, little use had been made of the almoning service; timely reference might have solved the ever-present problem of conveying the child, and indeed many other problems. From the time when these children commenced physiotherapy in pre-school years, attendance at hospital and clinic with the child had been, and still was, a major problem for many parents with other family commitments. Where periodic attendance for assessment was required, in most instances the parents made suitable domestic arrangements to enable them to keep their appointments but where attendance for therapy was required two or three times weekly, considerable difficulty arose, and to the transport problems already present for the mentally handicapped child was added the difficulty of conveying an immobile child - especially an older immobile child. It seemed that transport difficulties had contributed considerably to lapsed attendance at hospital or clinic. Where the parent should have brought the child for periodic assessment and for ancillary treatment, failure to attend regularly not only jeopardised the immediate treatment but, equally important, meant/

meant that further specialist examination also lapsed.

It was felt that in several cases co-ordinated arrangements of therapy facilities by hospital and Local Authority specialist clinics might have secured regular attendance. One mother had discontinued attendance at hospital for physiotherapy and further orthopaedic assessment, and the child's caliper was discarded on becoming too small; a Local Authority specialist clinic with adequate facilities was only half a mile from the home and therapy at this clinic would have permitted the mother to attend with ease as well as to meet her domestic commitments. By contrast,however, two mothers had pushed their children in adapted perambulators more than four miles through the busy city streets, in all weathers, to fulfil their hospital appointments, yet Local Authority clinics could have been attended without undue inconvenience.

Difficulty was also encountered by many parents attending Local Authority clinics, even where ambulance transport was arranged. The times of departure from both home and clinic depended on the other calls on the ambulance service; when several cases were to be collected, all arrived at the clinic together and all had to wait until every child had had treatment before the return journey was made. 'All morning there for half an hour's treatment' was too often heard to be disregarded and it was felt that an attendant on the ambulance journeys and at the clinic might have covered the situation, especially as the mother was required mainly for undressing and dressing the child and/

and was not usually in the room during the treatment. The mothers could have attended once weekly to discuss treatment and handling with the therapist. Four mothers attending specialist clinics had dispensed with the services of the ambulance and although they lived appreciable distances from the clinics, usually pushed the children there and back in adapted perambulators.

Discussion with the agencies treating the children, and with the mothers, confirmed the opinion that there was considerable room for improvement in the present arrangements for transporting these handicapped children to and from clinics or hospitals. It is realised that the demands on the ambulance service are already heavy and in view of this, the possibility of providing an alternative method of transport, especially to Local Authority specialist clinics, might be worthy of consideration.

Discontinuance of therapy at the majority of the Local Authority specialist clinics during two of the summer months was a source of anxiety to parents of those children attending regularly, especially as the mothers had been impressed with the necessity for regular therapy and had been attending with great difficulty two or three times a week. Even though alternative arrangements were available at a central clinic for some of the cases, the distance involved and the difficulties with transport resulted in only sporadic attendance. The parents would have welcomed a less intensive but continuous service at the local clinics and some such arrangement might cover the summer break more adequately, although it is recognised that the/

the major obstacle is the difficulty of staffing these clinics during the holidays. The remedial gymnasts who were mainly concerned with the physiotherapy for spastic cases were on holiday for the whole school vacation period and the depleted physiotherapy staff had to meet the demands of all orthopaedic cases.

Whilst home supervision by a specialised visitor is important, and for the same reasons as in the younger age group, a system of regular domiciliary visits by the therapist treating the child is also desirable for these cases. There was need for advice concerning the handling of the child and the adaptation and proper use of furniture and other equipment. Where the children attended special schools, particularly the recently developed spastic unit in one school where special appliances and furniture were used to meet the child's disability, there was a great contrast at home where often the child sat on an ordinary chair or couch. Some of the parents in this group had, without prior advice and sometimes at considerable expense, bought special chairs or appliances which were unsuitable, when a less expensive but more suitable adaptation to existing furniture could have been advised. In several instances suitable chairs, play-pens and other equipment, often bought at financial sacrifice, had been outgrown; in other instances, these appliances were desirable but could not be afforded. Four parents raised the question of exchange or second-hand sale of equipment. This might be arranged through the establishment of some form of central depot where appliances could/

could be loaned, exchanged, bought or sold, and which family doctor, health visitor and all agencies concerned would be aware of. A very limited private service of this kind,run for their members by one of the voluntary organisations, was known to only two of the families in this group.

Even in those homes with a bath, some parents experienced difficulty in washing the severely handicapped child; although the child enjoyed bathing, this undertaking was often impossible unless both parents were present owing to the difficulty of handling and lifting the immobile child.

EFFECT OF THE CHILD ON FAMILY LIFE

The impact of the handicapped child on the life of the family was in most cases relative to the degree of severity of the disability. Nevertheless the child's helplessness, the constant care required and the physical strain of lifting were difficulties which had been encountered by all parents at some period in the domiciliary care of these children. The health of one or both parents, the care and normal life of other siblings, outings, holidays and hobbies had all been affected adversely by the presence of the handicapped child in the home. However, many problems and difficulties which had been acute in previous years had become less pressing in those families whose children were now in attendance at special schools or occupational centres.

Only twelve of the twenty-seven mothers were in good health; eleven mothers suffered ill-health from conditions due to the mental or physical strain of coping with the handicapped child, two suffered from tuberculosis, one of whom was still having pneumo-peritoneal refill therapy, whilst two suffered from other systemic illnesses. Four fathers complained of varying degrees of mental ill-health, and recovery from a recent attack of coronary thrombosis in one and a peptic ulcer condition in another was hindered by the demands of the handicapped child. In two families sedatives had been prescribed by the family doctor for several years for both parents. In the three families where the child had been admitted to institutional care, the health of the mothers had afterwards improved considerably; two of these mothers had so adapted their lives to the child that when institutional care was effected they had taken employment to fill the void.

Two fathers had taken permanent night-shift work to assist their wives with shopping and hospital appointments, whilst one father periodically took spells of work away from home to obtain relief from the unsatisfactory domestic circumstances and the child's disruptive effect on family life. In two families the father had lost the chance of promotion at work - one changing his employment in an effort to obtain a house suitable for the child and one refusing promotion to an area where facilities for the child's treatment were less readily available.

The general atmosphere of the home was outstandingly good in five, reasonably satisfactory in fifteen and poor in seven cases. In twelve of the twenty-seven families the commitments due to the handicapped child appeared to interfere excessively with/

with the care of other members of the family. Several parents remarked that it was impossible to entertain friends in the home because of their own state of physical exhaustion and the handicapped child's behaviour and the constant interruptions.

It was felt that the parents accepted the diagnosis and prognosis of both aspects of the disability in only five of the twenty-seven families; most parents still thought entirely or almost entirely in terms of the physical factor and not in terms of the associated factor of mental retardation, regardless of the present placement of the child. Twenty-two families still hoped that the handicap would be cured or greatly reduced, but of these only eleven appeared to understand the child's difficulties. In several instances the child's apparent helplessness led to over-protection which hindered possible development of self-assurance and independence. The mother of one child, concerned with the care of a new-born infant, had left the handicapped child, who had previously been considered unable to feed himself, to manage this task as best he could; he was now able to feed himself unassisted, yet the mother's intention was again to assist him with feeding as soon as the younger sibling could look after herself. Even among the less severely handicapped, over-protection in the home, possibly a legacy from the continual care needed in earlier years, was not uncommon and contrasted with the more independent attitude encouraged in the child at the special school or occupational centre.

The/

The reactions of siblings to the handicapped child varied greatly, depending on the position of the handicapped child in the family, the amount of disruption his care involved, the social circumstances and the placement of the child. In three families jealousy of the handicapped child was evident and in four families the siblings were resentful or ashamed of his presence; where siblings had other children of suitable ages for playmates little resentment was observed.

The attitude of neighbours and their children was mainly one of sympathy; in thirteen cases neighbours were positively understanding and helpful and in eleven cases they or their children took an active part in the life of the handicapped child, varying from cover in emergencies to playing with the immobile child in his perambulator or wheel-chair.

HOLIDAYS AND OUTINGS

In those families where the handicapped children were older, family holidays were more often impracticable because of financial reasons than because of the handicapped child. In the whole group, thirteen families had no holidays - in four cases primarily because of the handicapped child, in six cases financial considerations were a contributory factor and in three cases financial stringency was given as the main reason. Three families made modified arrangements to suit the needs of the handicapped child, whilst eleven families did not consider the handicapped child interfered with the holidays which they took occasionally if financial circumstances permitted. In

one/

one family the question of a holiday was now complicated by the older children who no longer wanted to stay always with the same relatives, and this was causing a considerable amount of resentment. Financial assistance, short-stay home facilities, or special holiday home arrangements would have been necessary to ensure regular family holidays for many in this group.

In eleven families the care of the handicapped child seriously interfered with outings, but in the remaining sixteen no undue interference was experienced; these families were mainly those of the children at the special schools or occupational centres, or where cover by relatives or neighbours was usually available. Nine of those families whose outings were restricted also had difficulty in meeting ordinary shopping requirements and in some cases the father took night shift work or adapted his hours of work.

FAMILY LIMITATION

In the twenty-three families applicable, fear of having another handicapped child had in only one case been given as the reason for avoiding further children; in ten other cases inability to cope with an additional child was the reason for seeking to avoid having further children, and for the same reason two of the three families whose handicapped child was an adopted child had not carried out their early intention to adopt other children.

CHILDREN IN INSTITUTIONAL CARE

Three children, at the time of visiting aged between 7 and

8/

8 years, had been admitted to institutional care when between 5 and 6 years old.

One girl had attended hospital since early infancy for supervision and treatment for the presenting features of spastic diplegia and major epileptiform seizures. Hospital attendance, although somewhat irregular, had continued until at 5 years of age she was brought to the notice of a school welfare officer; subsequent ascertainment and reference to the Local Health Authority resulted in institutional care being arranged and her present state indicated no alternative to continual care. In this family the parents and the four pre-school siblings occupied a single-room house, three stairs up, in a slum tenement without even a back-court, and on a busy traffic road. Although, following various recommendations, their housing circumstances had frequently been assessed by the Health Department no priority had been granted; but at the time of visiting the building had been condemned and the chimney of the room had been removed, and it was felt that rehousing would soon be effected.

The second child ceased attendance at hospital at an early age, and the family doctor had placed him on the waiting-list for institutional care at 2 years of age. No home supervision appeared to have taken place to review the necessity for institutional care, although the father reported to the Local Health Authority every three or four months. At school entry age the child was ascertained as ineducable and again referred to the Local Health Authority, and placement in an institution for/

for mental defectives followed. Aided by physiotherapy, the child had commenced to walk since admission and was now at the occupation centre of the institution. Following this the father's earlier embittered attitude changed, and the change was reflected in the expense and work undertaken to help the Parents' Association connected with the institution. This family had suffered great distress, as the child - the only grandson and the sole hope of carrying on the family name - would have inherited the family croft in the Highlands. The difficulty of caring for the child at home had been intensified by the unsatisfactory housing circumstances, their two-roomed house being one stair up in a tenement on a main traffic road in the centre of the city.

In the remaining case the child had been ascertained as ineducable at school entry age but the parents had been unwilling to consider institutional placement at that time despite the recommendations of the hospital paediatrician and the Consultant Orthopaedic Surgeon. Following medical recommendation, the family was rehoused from a room and kitchen property, three stairs up in a slum tenement, to a modern house one stair up with a balcony where the child could be placed. The parents had first refused the offer of a ground-floor house where they felt that the child would be too much exposed to view. Shortly after rehousing, admission of the child to institutional care became imperative due to the rapid deterioration of the mother's health as a result of the violent behaviour of the child and his/

his disruptive effect on the household. Since his admission, improvement in the mother's health and the arrival of another child appeared to have completely altered the family atmosphere and the parents' outlook on life.

All these three children had been visited regularly by one or other of their parents, despite the pressure of family commitments and the expense of the journey to the institution.

CHILDREN AT HOME UNPLACED

All five children were severely mentally and physically handicapped, three also having epileptiform seizures.

One of these five, following a private domiciliary consultation, had been seen periodically at the hospital originally attended in infancy; three had ceased to attend the hospital to which they had initially been referred, but were being periodically assessed at a Local Authority specialist clinic, where two were receiving physiotherapy; the remaining child was under regular supervision at another hospital, and was also being assessed and was receiving therapy at a Local Authority Clinic. This child, an 'adopted' child whose adopters were both healed pulmonary cases, had contracted tuberculous meningitis at 18 months from another relative in the house and became severely handicapped; since completion of visiting the child has died. Special circumstances were associated with the 'adoption'; the adoptive parents were tremendously attached to the child and, in view of his helplessness, had completely adapted every facet of their life to his care.

Parents were willing in only one instance to consider institutional care, and that only after several changes of mind; all however would have welcomed relief for holidays or emergencies. A period of short-term care had been arranged recently in one case, where the father was recovering from an attack of coronary thrombosis and hospital admission for medical treatment had become necessary for the mother. All parents would have welcomed a crêche for handicapped children, particularly one where medical supervision and physiotherapy facilities were available.

The care of the rest of the family was noticeably affected by the presence of the handicapped child especially as, despite their ages, four of the five children had to be fed, washed, changed and carried everywhere. Two children required to be constantly secured in cot or chair and one, strapped to a chair all day as her perambulator was too small, had a flexion contraction of the legs, although the mother tried to exercise the limbs for half an hour twice daily.

Despite the weight and immobility of these older children, only two had wheel-chairs; these chairs had been obtained at the instigation of the local voluntary organisation, but the weight of the chairs and the fact that they did not fold for storage on public transport limited their value, and the position of the release brake handle was easily accessible to the occupants and to other children. In the other three cases the parent carried the child, although two families occasionally used adapted perambulators which were obviously much too small.

The possibility of providing a folding type of wheel-chair is worthy of consideration, and all agencies concerned with such cases should be able to inform parents how the appliance might be obtained through official channels.

Housing Circumstances.

Rehousing appeared necessary for two families, one family was satisfactorily housed and one - no longer applicable - unsatisfactorily housed. The remaining family had been rehoused in the last two years, having submitted medical recommendations which had expedited rehousing. Although application for ground-floor accommodation had been approved, a house reached by a flight of thirty-six steps was offered and subsequently declined and a house, one stair up with sixteen steps, was ultimately accepted; when the child is able to walk these steps will be a hazard and are at present a difficulty to the parent since the child must be carried up and down.

One of the two families where rehousing appeared necessary had been on the waiting-list for rehousing but, on moving to ground-floor accommodation, had not pursued the matter. The facilities in this home, enhanced by the father's hobby of carpentry, were excellent but the presence of a flight of steep steps at the close-mouth, the absence of a back garden, and the situation of the house on a main traffic road would prevent the child being placed outside even if a wheel-chair were obtained, particularly as the parents were sensitive about their severely deformed child being exposed to the view of passers-by. The/

The other family unsatisfactorily housed had forfeited their place on the housing list by moving, three years previously, from lodgings to a room and kitchen house, one stair up, on a main traffic road. The absence of toilet, bath or hot water facilities, the stairs and the unsuitable outdoor conditions increased the mother's difficulties in coping with the 7-year-old handicapped girl. In consequence the other sibling, a 4-year-old boy, was confined to the house much more than was desirable and had only the company of the mother and the helpless child, who lay strapped to a chair all day long with no awareness of anything. This family managed only one real outing each year, to relatives at Christmas, making the journey by taxi; the preparation involved and the equipment needed for this short expedition was as great as that for their last annual holiday, five years previously.

CHILDREN ATTENDING THE SPASTIC UNIT IN A SPECIAL SCHOOL

Four children had recently been admitted to a separate unit for spastic cases in a day school for physically handicapped children. All the children were severely physically handicapped - two markedly athetoidal - and it had not been possible to assess with accuracy the degree of associated mental retardation or to estimate how they would respond to special educational treatment. Three of the children were unable to stand, or to sit except in special enclosed chairs, they had to be carried or wheeled and were wearing napkins; the fourth child was becoming increasingly mobile and was now continent. One, an adopted child, was an only child, two were only children until/

until the recent birth of another child and the remaining case was a twin child, the only girl in a family of three children. The mothers had all been able to devote considerable time to the care of the child and had spared no effort to help the child, regardless of time, inconvenience and expense; in all cases the routine of the household had been adapted to the care of the child.

In every case numerous agencies had been consulted by the parents; two of the children had been seen at hospital in early infancy but had ceased to attend after a diagnosis of mental deficiency had been made and endorsed at another hospital, while in another case a visual defect - a marked strabismus - had necessitated continued hospital and clinic attendance for observation of the eye condition and for the provision and replacement of spectacles.

Prior to the interview by the screening panel and admission to this spastic unit for a trial period, pre-school reference to the Consultant Orthopaedic Surgeon to the Local Education Authority had been made in all four cases and, despite the transport problem and the mothers' difficulties in attending clinics, the children had been periodically assessed and had received therapy. In every case the parents' frustration and disappointment over the diagnosis and prognosis given for the child in early infancy had now given way to an over-protective attitude towards the child, and their emotional instability was evident/

evident when the child's previous history, his condition and his capabilities and difficulties were under discussion. Two mothers were members of the appropriate voluntary organisation and were aware of all the facilities available for spastic children both nationally and locally. Since admission to the unit, these four children had maintained regular daily attendance. The relief to the mothers, who now had more freedom to manage their domestic commitments, was secondary to the satisfaction at the child's placement where not only some educational training might be possible, but where facilities for all requisite therapy were also on the premises and where periodic supervision and over-all co-ordinated assessment of the child could be effected.

Although all cases are admitted to this unit for an initial trial period in view of the uncertainty of whether a child will respond favourably to both medical and educational treatment, it appeared that this system of the trial period was not fully understood by these parents and that difficulty and misunderstanding would arise if their child was later found unsuitable. In this connection it appeared important that the approximate duration of the trial period should be decided upon, and whether this was to be for therapy alone or for therapy and special education should be discussed and agreed to by educational, medical and therapy staff. If exclusion subsequently became necessary there would then be no disparity of reasons to cause resentment or dissatisfaction to the parents, who, often too ready to grasp at the slightest straw to help their child,would see/

see another setback in their long battle against misfortune after their hopes had seemed to be realised.

Facilities for children in this school were under constant review and were aided by the tremendous keenness of the head teacher and the staff. Contact between home and school was good, and the parents were encouraged to attend at least once weekly to discuss the progress and handling of their child. Nevertheless it was felt that home supervision by a specialised visitor or occasional domiciliary visits from the therapist, as well as supplementing advice given to the parents on the correct handling and training of the child compatible with his capabilities, would also help to ensure that the measures taken by those responsible for the child's therapy and education were not counteracted in the home, and would be a source of advice on the provision and adaptation of equipment and appliances.

All these families lived in ground-floor houses. Rehousing appeared essential for one family living in a slum property; the remaining three families were satisfactorily housed, one having recently been rehoused following specialist recommendation. In one instance, although the accommodation was satisfactory, the stairs at the close-mouth were a major difficulty but exchange of housing was not desired as the house was convenient to specialist clinics, special school and the father's place of work.

CHILDREN ATTENDING MIXED SPECIAL SCHOOLS

Nine children attended mixed special schools, five in the 5 to 8 years and four in the 8 to 13 years age ranges. The pattern in pre-school years for all these children was similar to that for the younger children already considered.

Four of the five children in the 5 to 8 years age range attended mixed special schools which had facilities for both physically and mentally handicapped children. In line with the usual practice, these children had been admitted at school entry age to the physically handicapped side, but were all now on the mentally handicapped side, although the headmistress felt that impending re-ascertainment of one girl would result in her transfer to an occupational centre. As a result of private approach by the parent, apparently because of an associated visual defect, the fifth child was now a day pupil at the school for blind and deaf children of his denomination.

In all these cases discussion with the teaching staff and observation of the children and their school work indicated that their progress at school was hindered much more by the mental handicap than by the physical disability. In one case the occurrence of seizures was a complicating factor, and in another the multiple handicap, the additional disability of defective vision and the unsatisfactory parental handling made any teaching by the recognised methods at the school, or any accurate assessment of the degree of visual defect extremely difficult.

Two/

Two of these five children were handicapped as a result of acquired illness, one following a cerebral haemorrhage at 18 months, and the other following meningitis at 3 years of age, due to tuberculosis contracted from the mother before diagnosis of her condition had been established. Since hospital discharge, attendance for supervision of the orthopaedic disability had been regular in both cases, one had been immediately and the other subsequently referred to the Consultant Orthopaedic Specialist to the Local Education Authority and both children had continued to receive regular therapy. In the remaining three cases the disability was attributed to birth injury, and hospital attendance had been discontinued after a diagnosis of mental retardation was established; two of these children were later referred to the Consultant Orthopaedic Specialist, and periodic supervision and physiotherapy were arranged but later discontinued in one case owing to the child's unco-operative attitude. Several agencies had been attended for the third child, primarily on account of the visual defect, but treatment for the associated physical disability had also been sought, including the services of an osteopath, which were obtained free until his death; his successor charged a fee of £1 per visit for the twice-weekly treatment, which has nevertheless been maintained, as in the mother's opinion it was of great benefit to the child.

The tendency among parents to concentrate on the physical signs of abnormality, and the importance of complete over-all assessment/

assessment and home supervision for this type of disability were illustrated by two of the cases. Sedative drugs had been prescribed for both children in infancy, but supervision of the medication over the following six years appeared unsatisfactory. In one case phenobarbitone had been prescribed for convulsions attributed to birth injury, and medication had since been administered at irregular intervals and with varying dosage; the child's restlessness or drowsiness was the index for administration at home. A visit to the school revealed that neither the head teacher nor the school nurse was aware that the boy was receiving drug therapy. The absence of the child's father at sea and the influence of the grandmother, who lived in a house in the same close, had contributed to gross maladjustment of the younger sibling and alienation from his family; he even slept in the grandmother's house and, completely spoiled and lavished with favours, he had become increasingly hostile to both his mother and his handicapped brother. This situation appeared to have developed insidiously through the sibling being left in the care of the grandmother whilst his mother attended hospital and clinics with the older child, and the position had gradually drifted out of control. Attempts had been made, but without success, to refer the younger sibling to a child guidance clinic. The mother's efforts to move elsewhere seemed only feebly supported by the father on his occasional visits home, possibly due to filial devotion and gratitude for past help with the handicapped child.

Epileptiform seizures were an additional feature of the handicap/

handicap in the other case, and although hospital and Local Authority specialist clinic attendance had been regular, an interesting error in administering the prescribed medicine was revealed during the course of visiting, when the mother stated that no matter how she tried to disguise the powder by placing it in the child's food, the bitter taste made the child spit it out; this drew attention to the fact that the mother had been removing the contents from the capsule before administering the dose to the child. The mother was by no means of low mentality and strongly affirmed that she was unaware of the correct method of administering the drug and for about a year had done so in the manner described; moreover, on account of the difficulty she had always mixed the powder in food without the child's knowledge, ensuring that she herself was always at home for this purpose. The history of increased severity of the seizures, already noted on a previous visit, and the failure of the medicine to control them would seem now to be explained.

The four children in the 8 to 13 years age range who attended special schools were also now on the mentally handicapped side. In these cases the difficulties and problems of early school years had in the main been overcome, partly through the development of the child's physical powers as he grew older, and partly through the parents' gradual acceptance of the associated mental retardation, aided by repeated assessment and explanations/

explanations by medical and teaching staff, of the child's condition and progress during school life.

One notable exception was recorded, however, where the boy's handicap had been acquired at 6 years of age following a road accident causing a depressed fracture of the skull. Prolonged hospitalisation in an adult ward, where there had been a tendency to indulge the child, had contributed to his maladjustment and his almost uncontrollable behaviour on returning home. The previously unsatisfactory social circumstances - the mother divorced the father before the child was born and was obliged to give up her modern house and to obtain employment - were aggravated by the marked aggressiveness of the boy towards his older sister, who was then sent to the care of an aged grandparent. Child guidance therapy was unsuccessful and residential care was not considered to be necessary, but the position had been eased and the mother's mental and physical state had improved when the boy was sent to relatives. On his return home, although his behaviour was much improved, his scholastic attainments by contrast with his achievements before the accident were poor, although undoubtedly hindered by the appreciable paresis of his right arm and leg. The mother's worries, due to unsatisfactory housing, her financial circumstances and the behaviour of this child, were aggravated by the elder sibling who now regarded, and was encouraged to regard, the grandmother's house as her permanent home. The increasing disunity of the her family greatly distressed the mother, who appeared very attached to her children./

children. Further unnecessary worry, when physiotherapy at a local adult general hospital was discontinued due to pressure of cases, could have been avoided by referring the handicapped child through his school to an adjacent Local Authority specialist clinic; his periodic assessment by the neurosurgeon at the hospital would not, as the mother feared, have been affected if an alternative source had been obtained for physiotherapy.

The housing and environmental circumstances of the families of these nine children attending special schools were no longer so much the cause of difficulty as when the children were younger and less mobile. Only two of these families, however, occupied ground-floor accommodation and in both cases rehousing had taken place in recent years, one following priority recommendation in the child's interest; four families lived in houses one stair up and three lived two stairs up. The stairs still presented some difficulty to four children; only one home had a garden and adjacent traffic roads were a constant hazard to seven children. Rehousing appeared unnecessary for two families, desirable for three and essential for four families who lived in slum properties.

CHILDREN ATTENDING OCCUPATIONAL CENTRES

Two of the six children attending occupational centres were 5 years old and four were between 8 and 13 years of age.

Before the two younger children reached school entry age, there had been a tendency to focus attention on individual presenting/

presenting features of the multiple handicap. One of the children, a girl, had attended hospital initially because of defective vision; emphasis had later been on the physical signs of abnormality and finally on the associated mental disability, for which the prognosis given was poor and the mother ceased to attend hospital. At 5 years of age the child came to the attention of a school welfare officer, and her subsequent assessment by the School Health Service resulted in her present placement. The parents had invoked the assistance of several agencies, including the Association of Parents and Friends of Spastic Children and had also endeavoured to have the child registered as a blind person in the hope of obtaining special educational treatment in Edinburgh or at a school for blind children with additional handicaps in Shropshire,England. The child's poor attendance at the occupational centre, where the mother claimed that she was learning nothing but swear words, reflected the parents' dissatisfaction with the placement. Failure to achieve rehousing, from a room and kitchen house in a slum tenement where the parents and four children were living, had contributed to the mother's present ill-health and to the parents' failure to understand or accept the full extent of the child's disability.

Hospital attendance for supervision had been regularly maintained by the parents of the other 5-year-old child, but their main concern had been to obtain treatment for his associated seizures. The physical disability, which mainly involved the/

the upper limbs, was now much less noticeable than the obvious mental retardation; but as the early prognosis was so unfavourable, the cessation of convulsions and the child's increased mobility had encouraged the elderly mother to be over-optimistic of his possible attainments. Recent rehousing to a modern house, from a slum tenement home three stairs up,and the admission of the boy to the occupational centre had helped to reduce the mother's worries and had lessened his previous disruptive effect on the household, in which he was the youngest and now very much the 'pet' of the large family.

Three of the four older children had been admitted to occupational centres at school entry age; the fourth child had been excluded from a special school after a year's trial, was later reassessed and admitted to an occupational centre where, because of long spells of hospitalisation, he was more or less in only nominal attendance. This boy, aged 8½ years, had a left-sided hemiplegia, congenital absence of the right eye and was subject to frequent seizures. His mother, burdened by domestic commitments and the care of two younger siblings, had, despite the transport difficulties and the time and expense involved, attended hospitals and clinics ranging from plastic surgery and ophthalmic units to orthopaedic, neurological and homeopathic clinics. The numerous agencies attended had resulted in conflicting opinions concerning the prognosis of both the mental and the physical aspects of the child's multiple disabilities.

Reference/

Reference for specialist opinion and investigation had not been unduly delayed in the case of an 11-year-old child - one of twin boys - and hospital attendance for supervision had been regularly maintained. The family was of good social standing and lived in one of the better residential areas of the city, and no problems arose due to housing or financial circumstances. The parents' understanding of the child's difficulties was clouded by inevitable comparison of his progress with that of his twin brother and by a feeling of shame towards his handicap. His poor attainments due to his mental retardation, his difficulty with locomotion, and a severe speech disorder due to a congenital malformation of the nasal passages were the source of continual frustration to the child. Although no other placement than an occupational centre was feasible, the parents remained unwilling to recognise that the child was ineducable. He was still attending an independent child guidance clinic where he received speech and play therapy, and in addition he had private tuition once weekly from a retired school teacher. The mother was an office-bearer in a voluntary organisation for the parents of handicapped children and was conversant with all the services which might be provided; she was on this account somewhat critical of any apparent deficiency or lack of co-ordination in existing local services, particularly where opinions of the statutory and voluntary agencies attended appeared to be at variance concerning her own child or any others similarly handicapped.

A/

A severe visual defect, for which the child was under regular ophthalmic specialist supervision and had been registered as a blind person, complicated the pronounced spastic condition in another case, a 9-year-old boy. His mother's emotional instability and her unwillingness to acknowledge the presence of the associated mental retardation had resulted in approach to numerous agencies in a ceaseless search for some placement other than an occupational centre. When examination for admission to special educational establishments was finally arranged and the result was unfavourable, the mother blamed the method of testing, the time, the place, or the effect on the child of strange surroundings, either individually or together, for the failure. Despite repeated assessment and explanations, the mother was quite unable even to think in terms of her child's state as a whole, or to understand that the disability of defective vision was merely an additional disability to the major one of mental retardation.

The remaining child in this age-range, a girl aged 10 years, was placed at 3 months of age, by the Children's Department of the Local Authority, with prospective adopters approaching 40 years of age,and the adoption order became effective before reference of the child to a paediatric hospital eventually resulted in a diagnosis of mental deficiency. The adoptive parents claimed that they had been advised to return the child, and considerable resentment of the Children's Department followed when this was found to be impossible. They were unable to reconcile/

reconcile themselves to the position and have since alternated between shame of, and sympathy and affection for, the handicapped child; her continual purposeless activity, coupled with her physical limitations, her unsightly appearance and her frustration at the inability to speak properly have added to their distress. She was the only child in the house and lack of contact with other children, except at the occupational centre, was hindering any possible improvement in her emotional and social development. The purchase of a car for outings and of a caravan for holidays, self-enforced isolation from neighbours and friends, obtaining the services of a speech therapist, a masseur, and a bone-setter had all involved the parents in considerable expense, but had done little to improve a deteriorating situation. Contact with and friendly supervision by the Children's Department had in the main been clouded by the original misunderstanding and resentment, and even after a school welfare officer had referred the child to the School Health Service for assessment, specialised advice to the parents and home supervision of the case appeared to be still inadequate in view of the special circumstances. The present attitude of the parents was that their duty would cease when the child became sixteen years of age and they would then request residential placing for her. It seemed however that over the past ten years the child had caused such a tremendous adaptation to the parents' life, that even if she was removed to residential care the future position would not be stable; a feeling of regret/

regret and guilt over 'putting the child away' and a feeling of loneliness when their burden was lifted would probably result in alternation between wanting her back and then, especially in view of their advancing years, wanting her away again. A much more positive line of action might have been taken by the Local Authority at an early stage to mitigate the distressing features surrounding this case.

Four of these six families occupied ground-floor accommodation and two were living in houses one stair up. Rehousing was unnecessary for four families, three of whom had been rehoused in recent years; two, following priority recommendation, removed from houses three stairs up in congested slum tenements where the difficulty of caring for the child in earlier years had been considerable. Rehousing appeared desirable for one family and essential for another. In both these cases traffic was also a constant hazard to the children in view of the absence of a garden or suitable play space, especially for one child whose visual defect added to his danger when negotiating the stairs or when out at play.

Three children have been included in this group who had been adopted either legally or by private arrangement and were later found to be severely handicapped. These cases emphasised that the most careful approach should be made if any question arises of severe handicap in an adopted child, and the utmost tact should be employed when discussing the matter with the adoptive/

adoptive parents. It should be realised that such mothers, especially as they are usually older than the natural mothers of a first baby, lack practical knowledge concerning the normal developmental stages of a young child. Unlike the young mother with her first-born child, these mothers will not have had the opportunities available in antenatal and postnatal visiting and clinic supervision for instruction and for general discussion about the baby with medical and nursing staff and with other mothers.

CHILDREN MENTALLY HANDICAPPED WITH A HANDICAP OF 'EPILEPTIC' NATURE

This group was composed of children who were mentally handicapped and were in addition handicapped by 'epilepsy'.

At the outset the intention had been to study a group of children severely handicapped by epilepsy alone; those cases sufficiently stabilised to attend ordinary schools were therefore not considered, preliminary enquiries having revealed that in these cases the condition now gave rise to few serious problems.

Twenty-five children reported as cases severely handicapped by epilepsy alone were then visited. Although epilepsy was the major handicap affecting placement, the main reason for hospital or specialist attendance, or the disability uppermost in the parents' minds, it was found that most of these children had varying degrees of mental retardation in addition (the youngest child studied was possibly an exception). In nine of these cases the accompanying degree of mental retardation or of spasticity with mental retardation was in fact the major handicap; these cases could not be considered as cases of epilepsy with another disability, since the needs and problems arising were predominantly those relating to the severe mental or the mental and physical disabilities.

The remaining sixteen cases were studied as a group

where/

where epilepsy was the major disability and the needs and problems of the children and their families, either at present or in pre-school years, were directly related to the occurrence of epileptic seizures, which in some cases had also affected the placement of the child.

In some cases of multiple handicap already considered, e.g. deafness and epilepsy, bronchiectasis and epilepsy,the epilepsy was the additional handicap complicating the major disability, and the main problems arising from the epilepsy were similar to those found in this group where epilepsy was the major disability.

In this epileptic group the sixteen cases have been studied according to their placement, so that those children with a like degree of mental retardation can be considered together, thus allowing the problems arising out of the epilepsy to be examined in the light of the associated disability.

Two children were under 5 years of age, five were between 5 and 8 years, and nine were between 8 and 13 years of age. The social classes of their families were Class II - 1; Class III - 8; Class IV - 4; and Class V - 3.

The placement of the children was varied; both pre-school children were at home, and of the older children, two were at home unplaced, two were in an epileptic colony, four were in attendance at mixed special schools and six attended occupational centres.

Among/

Among these children the frequency and severity of seizures varied enormously. According to the statements of the parents, four children were having daily seizures, nine were having several per week to two or three per year, while three children who were still having regular medication had had none for three, three and five years respectively.

DIAGNOSIS, ASCERTAINMENT AND SUPERVISION

PRE-SCHOOL CHILDREN AT HOME

Two children, girls aged 19 months and 4½ years respectively, were visited.

In early infancy the 19-month-old child had undergone operative treatment for suspected intestinal obstruction. At 15 months of age seizures occurred which the family doctor thought to be choreiform in nature, but on reference to hospital, epilepsy was diagnosed. With regular medication, no seizures had occurred for almost four months, but behaviour disorders which had arisen still persisted and were aggravated by poor parental handling. Maladjustment of an older pre-school child in this family had also recently developed. Both children were now under hospital supervision, but they had not yet been referred for psychiatric opinion.

The other pre-school child, the 4½-years-old girl, had defective vision and had regularly attended an eye hospital since she was 3 months old. On the occurrence of a seizure at 18 months of age the child was admitted to hospital and since/

since discharge had remained on phenobarbitone for three years - seizures occurring twice to three times yearly. No re-assessment had been made of the condition, or of the efficacy of medication, as hospital follow-up had not taken place. Behaviour disorders were present and the over-protective and indulgent attitude of the mother towards the handicapped child was reacting adversely on the other two children.

Among the older children the causes of the seizures and the age of onset varied; the disability being attributed by the parents to immunisation, to injuries, or to illnesses at various ages. In some cases the associated degree of mental retardation had been suggested or confirmed - either on the child's attendance at hospital, following hospitalisation, or on assessment at school entry age - and it seemed that such incidents as immunisation, injury or illness had not been regarded as landmarks in the child's history until after the disability had become apparent.

CHILDREN AT HOME UNPLACED

Two children, a boy aged 9 years and a girl aged 8 years, were at home. Both children were severely mentally handicapped, and had been ascertained at 5 years of age by the School Health Service, considered ineducable and untrainable and referred to the Local Health Authority for supervision. Placement in residential care had been recommended for both children. Residential care for the boy had been refused when first/

first offered and although now urgently desired, was impossible to obtain. Although the mother was agreeable, the father of the girl had refused to consider residential placement, partly because of intense devotion to the child and partly because of a feeling that stigma would attach to her certification and removal. Both children had caused complete disruption of any semblance of normal family life; in one family the only other sibling had at one period been temporarily admitted to a residential school for maladjusted children.

The contrast in treatment for the epilepsy in these two cases was striking. In the case of the boy, specialists had been consulted privately, specialised investigations carried out, two periods of short-term care in an epileptic colony arranged and regular medication with the modern anti-convulsant drugs established and supervised at periodic intervals. The girl, on the other hand, had not attended hospital since discharge seven years previously, when 1 year old; since then treatment had consisted of phenobarbitone tablets, prescribed one hundred at a time, the dosage administered depending on the occurrence and severity of the seizures and on the degree of her restlessness.

In both cases the frequency and severity of the seizures had decreased, although at the time of visiting they were still occurring on an average of once per week in the boy despite heavy sedation, and once every two months in the girl despite the irregular medication.

CHILDREN IN THE EPILEPTIC COLONY

Two children, a boy aged 7 years and a girl aged 9 years, were in the Colony for Epileptics at Bridge of Weir. Both had daily schooling and the intelligence quotients were 69 and 82 respectively.

The boy had been admitted to the Colony three years previously due to the frequency and severity of his seizures,his adverse effect on the younger siblings and the unsatisfactory housing circumstances of the family. The myoclonic seizures caused injury to the child and despite treatment thirty to sixty seizures per month were still occurring. Co-operation between parents and Colony was good and recent rehousing of his family enabled the child to spend school vacations at home.

The girl had been admitted two years previously due to the unsatisfactory housing and social circumstances, the severity of her seizures, and her associated behaviour difficulties which still showed in the production of self-inflicted wounds. Despite heavy sedation, she was still having approximately four minor and two major seizures per month.

CHILDREN ATTENDING MIXED SPECIAL SCHOOLS

Four children were now placed on the mentally handicapped side of mixed special schools. Their intelligence quotients when last assessed were 71, 70, 68 and 65.

Two of the children had been admitted after periods of up to one year in primary schools, the associated mental retardation being the reason for transfer in both cases. A boy,

aged/

aged 8 years, with a history of a single seizure three years previously, but in whom restlessness and temperamental behaviour were marked, had been kept on regular therapy and had remained under supervision for epilepsy at the hospital initially attended. Opposing views had been expressed to the parent by hospital and school on both the reason for, and the amount of medication prescribed and its relation to the child's lack of progress at school. The position was aggravated by the parents' reluctance to recognise the existence of an associated degree of mental retardation and by inevitable comparison of his poor attainments with the progress of the only other sibling, his brother who was one year older. The head teacher was of the opinion that when further assessment took place the boy would be admitted to an occupational centre, a move which would almost certainly cause further resentment.

Seizures were attributed to an attack of measles at 2 years of age in the case of the other child, a 9-year-old boy. He was subsequently admitted to hospital for investigation of the attacks and had since remained on regular anti-convulsant therapy and under periodic supervision. In this case, no seizures have occurred for five years.

Two children had been admitted direct to special schools, and this placement was due to a history of epilepsy. One child, a girl aged 11 years, had been referred by the head teacher of the local primary school, when the child was presented for admission and her pre-school history discussed. She had been admitted to hospital in infancy, epilepsy was diagnosed, and on reference/

reference to another hospital two years later the diagnosis was endorsed; hospital follow-up was not maintained on either occasion. School attendance and progress were poor and minor seizures frequently occurred in class. The girl's mother was of the opinion that the frequency and severity of the seizures were increasing and might be related to the possible onset of menstruation. The ill-health of both parents contributed to their poor handling of the child.

The other child, a 10-year-old girl, was admitted to the special school at 7 years of age on discharge from the Colony at Bridge of Weir, where she had spent 1½ years after varying spells of hospitalisation. In her case, specialist investigation and treatment at hospital and in the Colony had eventually resulted in stabilisation of the petit mal seizures and no attacks had occurred for over three years. Regular hospital follow-up and medication were still maintained.

CHILDREN ATTENDING OCCUPATIONAL CENTRES

Six children attended occupational centres. The intelligence quotients in two cases were 65 and 40 but in the remaining four cases, where the seizures were associated with a severe degree of mental retardation, estimation had been impracticable.

Residential care appeared desirable for two and urgently necessary for four of these six cases because of severe disruption of family life - especially in relation to younger siblings - unsatisfactory housing and environmental circumstances or severe ill-health of either or both parents.

One/

One child, previously considered unsuitable for admission to the epileptic colony, has been committed to institutional care since visiting was completed. Three other children were on the waiting-list and similar placing, though urgently necessary, was impossible to effect. One of these children had previous spells of short-term care in an institution and at the colony, and had been temporarily admitted to the occupational centre to relieve the family; another caused severe disruption of family life to the detriment of the care of his younger brother, who in turn was learning his unsatisfactory habits and becoming the target for his aggressive and vicious behaviour; and in the third family the mother was awaiting re-admission to hospital for treatment of her active pulmonary tuberculosis.

In the two cases where residential care was desirable, heavy family commitments and unsatisfactory housing conditions were present; in one of these families both parents were under domiciliary supervision for pulmonary tuberculosis and the father also had a gastric ulcer.

Despite the severity of the associated mental handicap, in pre-school years emphasis had been on the accompanying epileptiform seizures. The ages of the children when the first seizure occurred varied from shortly after birth to two years; the attributable causes reported by the parents included obstetric injury, immunisation and in two instances, virus encephalitis, and in two cases the possible cause was unknown to the parents. All six children had been referred to hospital, although/

although referral for investigation appeared to have been delayed by two and three years in two cases where the family doctor had reassured the mother that the child would grow out of the seizures.

Since initial attendance or admission, hospital follow-up had been regularly maintained in three cases and had lapsed in three. Where hospital follow-up was regularly maintained, the efficacy of medication had been assessed at each visit and the frequency of seizures had decreased. In two of these cases, home medication of the anti-convulsant drugs appeared satisfactory despite the child's severe mental handicap and seizures were reported to be reduced from three or four per day to occasional attacks over the past twelve and eighteen months; in the third case, although attendance at hospital for assessment had been regularly maintained and the seizures reported to be reduced from six or eight per day to two or three per year, home medication appeared erratic.

In the three cases where no follow-up had taken place at the hospital initially attended, the responsibility for further attendance appeared to have been left to the family doctor or the parent; in one a solitary reference had been made to another hospital two years later. Home medication was erratic in two of these three cases; in one the seizures were now less frequent but the administration and dosage of phenobarbitone over the past three years appeared to vary according to the restlessness of the child or the occurrence of a seizure. In the other,/

other, conflicting advice from the family doctor and his partner resulted in the suggested dosage varying from two to eight tablets a day. The tablets were administered haphazardly and it was reported that this child chewed and spat out most of them; the number and severity of the seizures had in consequence been little affected.

The family doctor took an active interest in the third case but although the various anti-convulsant drugs prescribed were apparently administered conscientiously by the parents, there had been little change in the frequency and severity of the seizures. The ill-health of the mother and her increasing inability to cope with the child's seizures, and his aggressive and spiteful behaviour have recently resulted in his admission to institutional care where the seizures are already less frequent.

HOUSING AND ENVIRONMENTAL CIRCUMSTANCES

Re-housing appeared desirable for five and essential for three families; five of these had been on the waiting-list for re-housing for periods ranging from six to eleven years. The housing circumstances of the other eight families were satisfactory; five of these had been re-housed over the last five years, four from grossly unsatisfactory conditions which had increased the difficulties of coping with the handicapped child. Only one family had been granted priority, this on medical recommendation from the epileptic colony; for three families re-housing had meant removal from relatives or neighbours who had assisted/

assisted with shopping and the care of younger children.

In one of the families unsatisfactorily housed the father, a fire-brigade officer, had refused the housing accommodation provided mainly because he felt that his child,who was severely mentally handicapped in addition to the epilepsy, would disturb the sleep of the night duty staff during the day.

During the school vacation, one child - in the epileptic colony - had to face the marked contrast between the colony and her home, which was situated at one of the main crossings in the city. Outdoor recreation unescorted was impossible for her, whilst indoors the absence of playing space, of hot water and bath, and the necessity to share a bed were all resented. Her temperamental outbursts and aggressive disposition completely disrupted the household and had a deleterious effect on the mother's health and on the upbringing and behaviour of the three pre-school siblings.

Hazards.

Traffic was a potential hazard for ten children, but only four were allowed out to play unescorted and two of these were allowed to ride bicycles. Gas was a definite hazard in four homes and fire in three; only nine families had fireguards and four of these, one in the fire-brigade officer's home, were considered inefficient. Owing to the associated mental retardation it was impossible to assess accurately the extent to which, through fear of seizures, parents in this group over-protected the handicapped child from traffic and other hazards.

EFFECT OF THE CHILD ON FAMILY LIFE

With many parents the emphasis was on the dramatic epileptic aspect of the disability and unless severe, the implications of the associated mental retardation were not fully realised. In assessing the parents' understanding and acceptance of their child's handicap, it was impossible to consider the two aspects separately. In five families the parents appeared to accept the handicap as permanent; the remaining eleven hoped that it would eventually be cured or greatly reduced and of these, five parents seemed not to understand the full implications of their child's disability. One mother, on the advice of the gas-man, had paid half a crown weekly for over a year to attend faith-healing sessions; three mothers had sought numerous medical and lay opinions but remained unconvinced of their child's mental retardation. Several mothers made many of their own problems, aggravated existing problems and were incapable of tackling simple ones.

There appeared to be considerable confusion concerning the management of the child. The over-protective attitude of one parent often conflicted with a desire to discipline the child by the other, and it naturally followed that the father was 'played off' against the mother, or the child did as he liked. Four parents had discouraged admonition and chastisement for fear of precipitating a seizure.

Much anxiety was experienced by parents in several instances through their lack of knowledge of how to handle the child/

child in a seizure. Their reactions varied; among the more dramatic of these were, 'father always leaves the room', 'father sits down and weeps', 'mother applies cold compresses to the child's head', 'mother expects the child to die every time a fit occurs'. Positioning the child's head and freeing restrictive clothing were invariably unknown; placing a spoon between the child's teeth was known to some but it was felt that in practice, especially if the spoon was unprotected, this must have done more harm than good.

Although the number studied was small, the case-histories illustrate the considerable amount of maladjusted behaviour and of jealousy towards the handicapped child existing amongst other siblings. Three children were attending child guidance clinics for behaviour disorders attributed to the handicapped sibling having more than his share of attention. In other instances, it was difficult to assess to what extent such disorders were due to poor parental handling; in several of these families the chastisement of the other young children for misdeeds, while the handicapped child escaped punishment, led to a vicious circle and further deterioration resulted.

There was a high proportion of ill-health among parents in this group - more so than in any other group - which,particularl in view of their highly emotional state, often had an adverse influence on the conduct and care of the other young members of the family. Six fathers had poor health, their illnesses ranging from gastric and duodenal ulcers, hypertension, nervous debility/

debility to quiescent pulmonary tuberculosis.

The health of six mothers was poor, two had been under specialist care for nervous breakdowns, one had a cardiac condition and one was partially immobilised by severe phlebitis. Two mothers suffered from pulmonary tuberculosis; one was still under domiciliary supervision and the other, at home after leaving a sanatorium against medical advice, slept on a bed in the living-room with the handicapped child. Although her chest condition had relapsed, this mother was unwilling to re-enter hospital as the remainder of the family ignored the handicapped child, for whom residential care was not available.

FAMILY LIMITATION

Two families had sought to avoid having further children, one through fear that another Caesarean section might be necessary, the other because of the attention required by the handicapped child and the poor housing conditions, and both through fear of having another child who might be handicapped.

HOLIDAYS

Nine of the sixteen families had no regular annual holidays, five due entirely to the handicapped child and four for financial or domestic reasons in addition. Holidays were unaffected for five families and the remaining two made special arrangements. Admission of the handicapped child to the epileptic colony on two occasions had previously enabled one of these two families to take a holiday; in the past year when all efforts to obtain short-term care were unavailing, holiday arrangements had to be cancelled at the last minute.

SPECIAL NEEDS AND PROBLEMS

The study of the cases in this group brought to light some particular points which are applicable also to those cases studied elsewhere who were handicapped by epilepsy in addition to their major disability.

Early reference for specialist opinion and investigation should be made when seizures, especially if repeated or of unknown origin, occur in young children. Much of the empirical or symptomatic treatment often prescribed might then be withheld until all possible aetiological factors have been considered with the aid of modern methods of diagnosis and therapy. Subsequent reference to hospital appears equally desirable where there is a record of convulsions accompanying acute febrile disorders in infancy.

The existence of a previous encephalographic examination was confirmed in ten of these sixteen cases, and in four other cases in the survey where epilepsy or epileptiform seizures were associated with other handicaps. Whilst in many cases the limitations of this form of investigation and the complex aetiology of the seizures must be recognised, specialised investigation, either at the initial examination or during follow-up assessment, should if possible include an electro-encephalographic examination. Where such facilities do not exist at the hospital attended, it might be possible to make arrangements for the reference of appropriate cases elsewhere for this examination.

The possibility of admitting cases where the question of epilepsy arises, to an epilepsy assessment unit or centre might be considered; this would allow electro-encephalographic investigation to be arranged and would also permit other examinations, e.g. neurological, psychological, intelligence testing, which would assist over-all assessment of the case and would permit integration of the different findings in relation to the specific disability. Some provision of this kind would help to prevent piecemeal consideration of the child and his subsequent treatment, and might lessen the possibility, which exists when examinations are carried out at different periods and in separate places, of seemingly conflicting opinions, and of undue emphasis on less relevant presenting features of the disability, especially in cases where there is an associated degree of mental retardation.

For the first step in after-care supervision, use should be made of the almoning services of the hospital; the service was utilised in only two instances in this group, despite the severe social and environmental problems often present. Transport for hospital attendance had been provided in only one case; two families made private arrangements by taxi, which involved them in expense they could ill-afford.

Following assessment of, and action for, immediate needs and problems, reference of the case by hospital almoner to a central agency would have allowed future medical, social and possible educational measures to be co-ordinated. To secure effective/

effective co-ordination close contact between hospital,family doctor and Local Authority is necessary, and this could be maintained through home supervision of the cases by an appropriate field worker.

The nature and amount of medication for the epilepsy had often to be varied in the cases studied, Such variations gave rise to a tendency to confusion among parents as to the number of tablets required and the frequency of administration; in some cases this resulted in the medicine not being administered at all.

The assortment of tablets and capsules of varying sizes and colours and the different numbers of each to be taken also confused many parents, and left the impression that more attention should be given to ensuring that parents fully understand the dosage to be given of the different drugs - irrespective of the size of the tablet or capsule - and the use of half tablets should be avoided.

Some form of card, clearly showing the type and amount of the anti-convulsant drugs prescribed, would have been helpful to many families. Such a card would then be available to the parents for reference and the instructions on it could be explained again if necessary, on follow-up visits to hospital or by field workers in the home.

The method of administering the drugs to the child should be carefully explained and where administration proves difficult, appropriate advice should be given to the parents.

The general management of the child and the handling during seizures/

seizures have already been referred to as a source of confusion and worry to parents. The value of adequate counselling to both parents,at hospital, by the family doctor, and especially in the home, cannot be too strongly emphasised. The parents of children who had been in the epileptic colony testified to the value of the question and answer sessions which took place there and which helped to resolve many of their difficulties and worries.

Anxiety concerning the education of their children was often expressed by the parents. The effect of sedation on the child's attainments at school was in some cases a matter causing uncertainty and confusion to parents and teaching staff. Anxiety about future welfare and employment was of course, in view of the ages of the children, less often encountered; some of the parents of the older children, however, had already begun to worry lest prospective employers would be prejudiced against a person with this type of disability. Despite this, contact with school and occupational centre was poor and only two parents were members of the Glasgow branch of the Scottish Epilepsy Association.

Home supervision by a specialised visitor would seem to be the best means of achieving fully effective after-care. In this group the services of such a visitor would have been of particular value in explaining the instructions given to the parent at hospital, in supervising both the management of the child and the administering of the prescribed therapy, and in advising/

advising on handling during seizures. This field worker could have acted as a link between home, hospital and school, and would have dispelled much of the anxiety concerning future educational prospects or placement or, in the case of the older children, regarding future employment and welfare and would have acquainted the parents with the services - statutory and voluntary - available for epileptic children and their families.

Any needs and problems arising from the associated handicap were similar to those in other groups where mental retardation was present and they are not considered again in this section. An attempt has been made to examine the special problems directly associated with the 'epilepsy', although those problems arising from mental retardation should be borne in mind as in the type of case studied, the combination of the two disabilities magnified the significance of the needs and problems of both.

CHILDREN MENTALLY HANDICAPPED WITH AN ADDITIONAL PHYSICAL HANDICAP

Eleven of the cases studied have been placed in this group of children with multiple handicaps. The social classes of the families were Class III - 5; Class IV - 4; Class V - 2. The ages of the children ranged from 8 months to 8 years 9 months; seven children were under 5 years of age and four were between 5 and 13 years.

The degree of mental retardation was severe in four and less severe in three of the cases under 5 years of age, and all were doubly incontinent due to either physical or mental handicap. In those cases over 5 years of age, the degree of mental retardation was severe in three and less severe in one.

The associated physical handicaps were of a varied nature.

Children under 5 years: - 7.

Cleft Palate with 'suspected' Blindness (8-months-old child); Congenital Heart Disease and Hypercalcaemia;Bilateral Ptosis; Hydrocephalus - 3 cases (two also had paralysis of the lower limbs); Endocrine Disorder (Obesity).

All these children were at home.

Children from 5 to 13 years: - 4.

Achondroplasia
Congenital Heart Disease } - both at home, unplaced.

Multiple Disabilities including cleft palate and deformities of both hands - attending an occupational centre.

Severe Speech Defect and Strabismus - attending a mixed special school.

DIAGNOSIS,/

DIAGNOSIS, ASCERTAINMENT AND SUPERVISION

In this group, the problems and needs related to diagnosis, ascertainment and supervision were often similar to those found for children handicapped either mentally or physically, but the cumulative effect of the dual handicap resulted in the emergence of other problems and needs which were more difficult to resolve, partly through inco-ordination of the agencies involved and partly because of the unsuitability of appropriate measures for the one disability in the light of the other, and in some cases because of the lack of suitable services. Hospital follow-up for the physical disability appeared to be regularly maintained in four cases, irregular or lapsed for various reasons in six and absent in one; this child was seen at birth and on account of the poor prognosis given no further reference was contemplated. Regular follow-up at the hospital initially attended took place in only one instance and in this case proposed surgical treatment for the hydrocephalus had now been considered impracticable, but the mother still attended with the child for supervision.

Some illustrative case-histories reveal the difficulties confronting the specialist agencies concerned with diagnosis, ascertainment and supervision when major physical disabilities of varied nature are complicated by the presence of mental handicap.

The parents of the youngest child in this group had already attended several agencies by the time she was 8 months old/

old and now appeared confused by the various opinions which had been expressed. Following discharge from a maternity unit, the child was later referred to hospital by her general practitioner. On lay advice, and to the family doctor's annoyance, the mother attended two further hospitals - dental and ophthalmic - regarding two presenting features of the handicap - the cleft palate and suspected blindness. At the dental hospital the parents were advised that they could not obtain treatment for the cleft palate until the child reached the age of 1 year, although the feeding difficulty was the immediate problem; attendance at the ophthalmic hospital for assessment of the degree of visual acuity had already lapsed. The parents appeared not to connect the child's feeding difficulties or the apparent lack of vision with the possibility of mental retardation, although the child lay helpless in her cot all day long. Since recent admission to an isolation hospital the child had been weaned and the previous feeding difficulties, which had been aggravated by her cleft palate, were now considerably reduced. Despite heavy domestic commitments, the mother was desperately anxious to explore any possibility of obtaining help for the child. Home supervision would have encouraged this mother to maintain attendance at the paediatric hospital to which she had initially been referred and would have discouraged her from making headlong approach to other agencies; at the same time some guidance and advice would have solved many of the difficulties in the home caused/

caused by her over-emotional attitude towards the handicapped child.

In another case, bilateral ptosis was noticed by the parents when the child was 3 months old, but was considered by clinic and family doctors to be due to lazy eyelids. The retardation of the milestones of sitting, walking and of other developmental stages was not suspected to be due to the presence of an associated mental retardation until the child was admitted to hospital at 18 months of age for operative treatment for his physical disability. Although the boy was now 2½ years old and required to be fed and carried, was not talking and was incontinent, the parents still thought his delayed development was due to the now unilateral ptosis and not to mental retardation.

The obesity of a 2½-year-old boy was thought at first to be due to thyroid deficiency, but was later attributed to pituitary dysfunction caused by meningitis. The meningitis developed as a result of pneumonia for which he was admitted to hospital at 2 months of age. This child was born prematurely and had been retained in a maternity hospital until 6 weeks old and on discharge home, tube feeding was still necessary. Following the second period of hospitalisation, which lasted for twelve weeks, he had remained under regular supervision by the family doctor and at the outpatient department of the hospital. Although the question of an associated mental retardation/

retardation as another sequel to his illness had been raised, the mother had continued to consider only the physical aspect of the child's disability, since this was responsible for her greatest immediate difficulty - that of lifting and transporting the oversized and helpless child who now weighed thirty-nine pounds.

The congenital deformities - meningocele and talipes - of a girl now aged 3½ years were noticed at birth. This child was born at home and was referred to hospital when 5 weeks old, by which time progressive enlargement of the skull had also become apparent. Although attendance at hospital for orthopaedic supervision of the limb condition and for assessment of the hydrocephalus involved separate attendances to the same hospital, the mother had kept the appointments regularly until the child was almost 2½ years old. When proposed surgical intervention for the hydrocephalus was no longer considered to be necessary, the mother gave up the struggle to attend because of domestic commitments including the care of three other young children, the difficulty in transporting the handicapped child and because she was confused by apparently conflicting opinions regarding prognosis and treatment. No specialist agency had since been attended and the caliper supplied for the child was now too small and had been discarded. This was one of the four cases in this group where the parents had been given to understand that the child's expectation of life was poor and the early prognosis that the child would be unlikely to survive was/

was partly responsible for the mother's apathy towards seeking further specialised care.

In the other two cases of hydrocephalus, surgical treatment had been considered impracticable; gross enlargement of the head and a spastic paralysis of the lower limbs were present in both cases. Hospital attendance for supervision had been regularly maintained by one family, but the parents of the other child had been unwilling to accept the diagnosis and prognosis given when the child was referred to hospital at 6 months of age. The father of this child was later employed in a hospital, and through the matron he obtained an appointment for the child with another specialist who endorsed the early opinion. Despite this, the parents had joined a voluntary organisation through which they hoped to obtain further specialist advice.

One of the two unplaced children in the older age-group, an 8-year-old boy, had been referred initially to hospital at 9 months of age. When this family was rehoused, the mother had great difficulty in conveying the child to hospital and follow-up supervision of the congenital cardiac lesion and assessment of the degree of mental retardation eventually lapsed. On ascertainment at 5 years of age by the School Health Service, the child was considered to be unfit for special school or occupational centre. Although he was able to move freely around the home, he was still conveyed in an adapted perambulator on any outdoor journey. This child had not been/

been referred again to hospital and due to his exclusion from schooling he had not come under the supervision of the Consultant Cardiologist to the Local Education Authority, nor were the Local Authority dental services available to him. On account of his cardiac condition and his mental retardation, the mother had experienced considerable difficulty when seeking dental treatment for the child from other sources.

The other child unplaced at home - a 7-year-old boy - had a chequered early history; achondroplasia had been confirmed shortly after birth and he underwent several spells of hospitalisation for other illnesses. When the child was almost 4 years old, the mother heard a wireless programme on bone-grafting which she thought relevant to her child's condition, and, although attending hospital and seeing the area health visitor regularly, without consulting either she wrote for an appointment to a London hospital. This was given to her without query and the mother, although six months pregnant, accompanied only by an aged relative who was unable to help her to carry the handicapped child, travelled to London by the special night excursion train at a cost of over £7. Although sympathetically received by the specialist, who expressed surprise that she had been given an appointment and at the distance she had travelled, the mother was told that her journey had been futile and that she had been mistaken in believing that the measures described on the wireless would be of any avail to her child.

This/

This boy had subsequently been excluded from the occupational centre and was now out of control; he disrupted the household, was very aggressive to his younger sister, and was a source of constant danger and expense through his habits of burning articles indoors and throwing missiles in the garden. Although he would be assessed periodically by the School Health Service for re-admission to the occupational centre, this case illustrated the desirability of admitting such children, either for long-term residential training or on a daily basis to a special occupational centre or crêche, where the vicious circle of bad social habits and unsatisfactory parental handling and training preventing admission to the occupational centre might be broken.

The parents of both these unplaced children would not have agreed to institutional care, but they would have welcomed some other form of residential placing to provide short spells of relief and for emergencies.

The child with multiple disabilities - a girl aged 7 years - was admitted to an occupational centre at school entry age. She had been reared by her grandmother, and the mother, now married, had a normal child whose father, although well-disposed to the mother's illegitimate child, would not accept her as a member of his family group. Although the two children, markedly different in appearance and attainments, were good companions, the position will deteriorate in time and will become acute on the death of the idolizing aged grandmother, who was/

was extremely over-protective and attributed all the retarded milestones of development to the child's prematurity and the unfavourable prognosis given at birth. Notwithstanding the deformities of hands and palate, the severe speech disorder, and the child's continual purposeless actions, her grandmother was convinced that removal of the tonsils would make all the difference. No reference to hospital with a view to treatment of the cleft palate or for the speech defect had been considered necessary in pre-school years, and in view of the child's mental retardation treatment was now considered impracticable.

In the case of the child attending a special school, no assessment of the degree of mental retardation had taken place before school entry; emphasis had been on the absence of speech and possible deafness had been excluded. This child, a girl now aged 8 years, had a severe speech defect and was practically unintelligible. Ophthalmic supervision of her visual defect had been established and regularly maintained since her admission to school, and she had recently been admitted to hospital for surgical treatment of the strabismus and also for tonsillectomy. Although now receiving speech therapy, appreciable improvement of the severe speech disorder appeared unlikely due to the associated mental retardation and the child's increasing sensitiveness towards her disabilities.

No case had been referred to the hospital almoning departments, either to ascertain immediate difficulties or to initiate reference for possible future assessment and supervision/

supervision by Local Authority services. Domestic commitments, distance, the unsightly appearance of the child or his immobility, behaviour, and incontinence, appeared to warrant the provision of special transport. In some instances the child's disability was such that a journey to hospital by public transport was an extraordinary accomplishment on the part of the parent, and it was evident that this was a major reason for lapsed attendance. Ten of the eleven families would have benefited by the provision of transport for attendance at hospital; in one of these,however, the mother felt that an ambulance would have drawn unwelcome attention from neighbours to the handicapped child. Transport was later supplied for one case and two families travelled to hospital by taxi.

Provision of special transport facilities would also have been of help to the parents of these severely handicapped children when attending Local Authority clinics for the child to be assessed for future educational placement. In many of these cases a preliminary visit by a health visitor, if the social circumstances or approximate severity of the physical disability were not already known, might have prevented some unnecessary and embarrassing attendances for initial assessment, and arrangements might possibly have been made to enable the most severely handicapped children to be assessed in their own homes.

The consideration of the practicability of assessing the child in his own home applies equally where mental handicap is/

is involved; the child may well be untestable, yet no matter how sympathetic or tactful an examining medical officer may be, if the child is found unfit for a desired placement the mother may still be convinced that his poor attainments are due to his strange surroundings and other difficulties, and that her child would have given a much better account of himself at home.

The cases studied demonstrated the need for full clinical assessment by joint team ascertainment, the need to avoid apparently divergent views among the specialist agencies attended, and the need for early reference of this type of case to the Local Authority for supervision and after-care. Subsequent initial co-ordinated assessment of the case - clinical and social - followed by periodic review, together with home supervision by a specialised visitor appeared especially desirable for the pre-school cases. Provision of this kind would prevent much of the anxiety concerning ascertainment and possible educational placement at school entry age which had invariably been experienced by the parents of the older children.

HOUSING AND ENVIRONMENTAL CIRCUMSTANCES

Rehousing appeared essential for six families, desirable for one, and unnecessary for four families who had been rehoused over the past five years. Two, who had been on the waiting-list for rehousing, supported their applications with medical certificates and following reconsideration by the Health Department, a degree of priority was given.

In one instance where rehousing was considered essential the parents and the grossly hydrocephalic immobile and incontinent child lived in a small room and shared the unlit toilet in the close with fourteen other people; the home was so crowded with furniture that the bed had to be put up every night. A wheel-chair had been supplied but was obviously unsuitable for the child because of the weight of his unsupported head, and as it was not a folding chair it was an added obstacle to negotiate in the over-crowded room. During the course of visiting, this mother had a second child, and although the new-born infant was exposed to such adverse conditions and would cause some adaptation of the continuous care previously given to the handicapped child, the parents hoped that priority in rehousing, previously considered and refused, would now be granted. A new problem had now arisen, as the handicapped child was too large and unwieldy to share the perambulator with the new baby.

In another case where rehousing seemed essential the parents and the 8-months-old handicapped child slept in the kitchen of the grandmother's home, whilst the grandmother slept in the other small and obviously damp room with the remaining four children, one of whom was at a special school and under chest clinic supervision for a primary tuberculous infection. This home, at the rear of a slum tenement situated on a busy traffic road and on a steep hill, was overshadowed by adjacent houses and factories.

Hazards./

Hazards.

Fire and traffic were the main hazards for three of the five mobile children in this group; two of these three families had inefficient fireguards, and one family had none.

One child, who required constant supervision, was himself a hazard to others, throwing stones if allowed in the garden, and causing accidents in the home through his obsession for pushing long sticks in the fire. Chastisement for this was now useless, since his mother sometimes gave him a slow-burning stick to keep him reasonably quiet.

EFFECT OF THE CHILD ON FAMILY LIFE

A tendency among parents to attribute delayed milestones of development to the physical disability rather than to the associated mental retardation has been noted. In the older age-group, assessment at school entry age and subsequent placement had forced the parents to realise that there was an appreciable degree of mental handicap associated with the child's physical disability, and resulted in some change in the parents' attitude towards the handicap. It was felt that the complete picture of the child's disability was completely accepted and realistically understood in only two of the eleven families.

In five families the parents, especially the mothers, appeared over-anxious and over-protective and it was felt that either the unfavourable prognosis or the inability to understand the exact implications of the handicap had fostered this attitude. Four of these children were the centre of attraction amongst their family and friends and until an emergency or an/

an event such as the arrival of a new baby occurred, the parents had not realised how much time and attention they had been devoting to their child.

Family atmosphere was generally good; most siblings accepted the handicapped child and his effects without adverse results. Maladjustment of a sibling was noticed in only two instances - in one, the sibling, only a year older, was markedly jealous of the handicapped child - the boy with bilateral ptosis - and he was unable to understand why he was chastised for his misdeeds whilst his handicapped brother escaped punishment. In the other instance the younger sibling resented the handicapped child, who was the centre of attraction and was rarely chastised.

In one case the handicapped child was somewhat maladjusted, largely because the parents unconsciously compared her attainments with those of the only other sibling - a sister one year older. With her many accomplishments the sister was the centre of attraction, unintentionally aggravating the parents' difficulty in adjusting themselves to the fact of their child's handicap and accepting her unsightly appearance and her limitations. The handicapped child's feeling of isolation and shyness was intensified both in the home and outside with local children, especially as none of her own friends at the special school lived in the neighbourhood.

FAMILY LIMITATION

Three families had sought to avoid having further children because they felt unable to cope with another child as well as the handicapped child, although two also feared the possibility of having another handicapped child.

HOLIDAYS AND OUTINGS

Two families managed regular annual holidays, one with relatives; five would have been able to take regular holidays adapted to the child's needs if financial considerations had permitted. A holiday without the child would have been of considerable benefit to three other mothers who appeared worn out by the strain of continually caring for the child. Short-term residential care for the child would have enabled one of these mothers to join her sailor husband whose short periods of shore leave in a southern port did not allow him to travel home and she was unable to make the journey south with the heavy child. The remaining family took a quiet holiday during an off-peak period as they were sensitive about the appearance of their handicapped child.

For most of these families, any form of day outing with the child was rare, due to the amount of preparation required, the luggage involved and the transport difficulties. One mother however pushed her hydrocephalic child four miles in an adapted baby carriage to utilise the bath and garden facilities at the grandmother's home. Cover by other members of the family, relatives or neighbours varied; no family had regular sitting-in/

sitting-in arrangements although emergencies could usually be met. In four families, the father had adapted his hours of work in order to facilitate shopping arrangements and hospital attendance, and to assist with the care of the child.

CHAPTER IX.

HOME TUITION GROUP.

HOME TUITION GROUP

Twelve of the two hundred cases studied were receiving home tuition. The specific problems associated with their handicaps have been considered and consideration is now given only to matters directly connected with home tuition.

The ages of the cases ranged from 5½ to 12½ years; seven were in the 5 to 8 years and five in the 8 to 13 years age groups. All were physically handicapped - six by orthopaedic, three by non-orthopaedic and three by multiple disabilities - the handicap being of a congenital nature in most cases.

5 to 8 age group:- 5 cases of Spina Bifida with paralysis of lower limbs, one of these having urinary, and one other double, incontinence; Fragilitas Ossium - 1; Congenital Abnormalities of Genito-urinary system - 1.

8 to 13 age group:- Spinal Tumour - 1; Bronchiectasis - 1; Haemophilia (Christmas Disease) - 1; Fragilitas Ossium - 1; Multiple Disabilities (partial cleft palate, congenital heart disease and paralysis of lower limbs) - 1.

Duration, Amount and Time of Home Tuition.

The period since commencement of home tuition ranged from 5 months to 6 years. Nine of the twelve children had never attended school; two - those handicapped by bronchiectasis and haemophilia - had been excluded from special schools, and the remaining child - the spinal tumour case - had been provided with home tuition, following his exclusion from ordinary school, while/

while awaiting hospital admission. Three cases of spina bifida with paralysis of the lower limbs had been assessed regularly by the School Health Service, and before home visiting was completed, they had been reassessed and recommended for admission to special schools for physically handicapped children at the beginning of the next school year. The incontinence of the remaining two cases of spina bifida had always precluded them from admission to special schools.

At the time of visiting, all children were receiving two hours tuition weekly, usually in two spells of one hour. Although all parents were grateful for the provision of the service they felt, with one exception, that the amount of tuition given was insufficient; in this exception, the child - the oldest and most severely handicapped of this group - was an avid reader, which, with the presence of a television set in the home and the company of relatives, influenced the opinion of the parents.

In no case was it anticipated that either the prognosis or the intellectual capacity of the children would preclude them from continued education. Where no alternative to home tuition was possible, the need to consider fully some of the problems which emerged during the course of visiting assumes added significance. It is appreciated that some of the other factors which might influence the amount of home tuition to be given would be the age and aptitude of the child, the degree of intelligence and interest of the parents and the encouragement

and/

and help of the other children in the home. It was felt, however, that the children visited were not receiving sufficient tuition, especially in view of the fact that being physically handicapped, any livelihood must depend largely on an adequate educational background.

In four cases the limitation of tuition was aggravated by the child's previous lengthy spells in hospitals where there had been no teaching facilities, and in consequence educational retardation had resulted; in two other cases, where hospital teaching facilities had been satisfactory, the present limited home tuition was by contrast equally disturbing to the parents.

In each of three cases where the handicapped child was either an only child or the only child in the home during the day, he appeared bored, often frustrated and, perhaps unintentionally, he caused continual interruptions of the mother's domestic routine. These children obviously lacked the regular routine which some form of placed schooling would have given them.

In families where other siblings attended school, the absence of school life put the handicapped child at a disadvantage when each day they discussed school activities in which he was prevented by his physical handicap from taking part, although his mental acuity was such that he was well able to appreciate what he was missing. The limitations imposed by his handicap were thus continually in the minds of all.

All these children were given home tuition in the late afternoon/

afternoon by teachers who had to travel to the child's home after the normal day's teaching, and this arrangement appeared unsatisfactory. Interruptions at that time of the day were more frequent, and interference with the evening meal-time or the preparations, gave rise to a considerable domestic problem.

Most of the parents felt that by late afternoon the handicapped child was tired and less interested; the presence of the other siblings or of playmates, now home from school and free for play either in the home or outside and whose company he had missed all day, was an added distraction.

Discussion with several of the teachers, whilst revealing their keenness to help these children as much as possible, endorsed the views of the parents. If staffing difficulties could be overcome, a similar arrangement would be acceptable for these cases to that reported in operation for some children not included in the survey, who were receiving home tuition at more suitable times and for longer periods, and where occasionally an older child was receiving some form of vocational training, such as typing.

Consideration of Ancillary Facilities.

Some parents deprecated the absence during the long summer vacation of even the limited amount of home tuition provided; voluntary visiting at less frequent intervals by his home teacher to one child, by a school teacher relative to another, and the assistance of parents and older siblings helped some of these children to continue with their lessons during the/

the long break. Most parents thought that their children would enjoy some form of occupational therapy, which would enable them to take part when the handiwork of the other siblings at school was discussed or displayed at home.

Until their child was assessed and found unfit to attend school, most of the parents had been unaware of the home tuition service, and of how to avail themselves of ancillary services such as the provision of free milk; by drawing attention to these services when future school placement was unlikely for any child, specialised agencies or social workers to the home would help to dispel the anxiety of parents.

For pre-school age cases, home visits by a nursery school teacher, even only occasionally, would help to encourage and assist parents in training and teaching the child.

With the exception of one isolated case, the parents of the older children, already concerned by the comparative lack of scholastic progress due to the limited amount of tuition, were becoming increasingly worried by the absence of any vocational training likely to fit their handicapped child for later life. In addition, there was in these families a noticeable lack of knowledge of existing statutory and voluntary services for young adult handicapped persons. To remedy this and to reassure parents, an outline of such services should be given long before the child reaches school-leaving age, and vocational training facilities should also be discussed. Contact between the families of these children and the appropriate statutory and voluntary welfare associations should be encouraged; the information and advice afforded the family of the case applicable, by the Association for Haemophiliacs, were of considerable assistance in overcoming problems which are outwith the field of the specialist agencies concerned.

All these children missed the social events and outings of school in which their playmates took part; one boy, aged 11 years, a keen football fan, had never been able to see his favourite team in action. The provision of arrangements, to enable those children having home tuition to join the children of special schools for outings, educational films, Christmas parties and other functions, would have been welcomed.

Four families expressed concern regarding lack of religious instruction for their children; extension of home tuition to include religious instruction by the appropriate teachers, or by voluntary workers from the respective churches, would have been appreciated.

The value to the children of school broadcasts and certain television programmes had been realised by those families of a higher social standard; but the effectiveness of the programmes was somewhat diminished owing to the difficulty of interesting the child by himself when no immediate discussion or explanation was available. B.B.C. pamphlets for school broadcasts might be provided automatically for children on home tuition.

A school medical officer visited children on home tuition once or twice yearly; owing to the commitments of the School Health/

Health Service in term time, these visits usually took place during the vacations. Discussion between medical officer and teacher concerning the child and his attainments therefore did not take place. Co-ordinated assessment of the child by medical and teaching staff to determine the extent of tuition compatible with his physical disability, or his suitability for alternative placement - so valuable a feature in the hospital schools visited - could not be effected. Regular home visiting by the school health visitor attached to the nearest school for physically handicapped children would help to co-ordinate the medical and educational provision made by the Local Authority for these children.

Consideration of Alternative Educational Placement.

Admission to a residential special school might have been a more satisfactory placement for several of these children owing to either the unsatisfactory housing circumstances, or the gross over-protection of the child, or to the failure of some parents to co-operate in the medical and educational care of the child.

One case, a boy aged 10 years, had developed bronchiectasis and had frequent absences for trivial reasons from both primary and special schools; the question of residential schooling had been raised on several occasions at an early stage in school life, but had not been actively pursued. The parents' unwillingness, on the grounds that the child would fret, might have been overcome if regular overall assessment and home supervision had taken place, and had included discussion with both parents to/

to explain the necessity for such a placement. Residential schooling would have counteracted the gross over-protection of this child by mother and grandmother, and would have arrested the steady deterioration of the child's medical condition and the increasingly marked educational retardation which were resulting from unsatisfactory home co-operation.

In other cases, the family had become over-attached to their handicapped child by reason of previous years of care and trouble, the special difficulties of the handicap, and the insidious adaptation of family life to the child's needs. Although residential special schooling was applicable, the parents had been unwilling to consider this course for their child.

The establishment of a 'sheltered school' with the facilities of a long-stay hospital and special school combined might be an answer for such cases, and attendance could be on a weekly basis. This would allow the child to retain contact with the family at week-ends, would counteract over-protection, would help to overcome the lack of assurance and independence so common to these children, and would also help to supply the companionship and training not available at home. Where residential placing for schooling or vocational training may be the best course for the future welfare of the handicapped child, an introductory spell in a 'sheltered school' might help to overcome parental prejudice against residential schooling. An establishment of this kind could be provided on a regional basis to/

to overcome difficulties in supplying the specialised medical and educational services necessary for these severely handicapped children.

One of the cases in this group - a boy aged 11 years 8 months with Christmas Disease - had, since the recent death of his mother, spent long periods of the day by himself. The boy was intelligent and active, but although reasonably careful in his play pursuits with other children, he had to be excluded from a special school owing to the danger from knocks or blows. Companionship, more education and some form of vocational training were now essential, and might have been met by placement in a 'sheltered school'.

This consideration of alternative types of placement, and the anxiety shown by the parents with regard to the limited amount of home tuition provided, affirm the importance of ensuring that no child whose medical condition might allow him to attend an adjacent special school should be automatically excluded on account of special difficulties, until it is quite certain that he cannot somehow be fitted into school life. Close discussion between all concerned should be undertaken in these cases to explore the possibility of adaptations to meet any special difficulties; where a desired placement is found to be impracticable, parents would then be satisfied that the views of all those concerned with the child had been taken into consideration.

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SURVEY OF HANDICAPPED CHILDREN.
CASE REPORT.

Ser. No. ....

Name of child ....

Address ....   Is family in lodgings here? Y/N

(change, if any) ....   How long has family lived here? ....years.   Sex ....

Date of birth .... Age at time of 1st visit .....   If came here within past 5 years, where from   Religion ....

Nature of handicap ....

Name and address of family doctor ....

....

Since .... If changed recently, reason for change . ...

FAMILY BACKGROUND.

Persons living in home at commencement of investigation

Father of child Y/N Age .... If step-father Y/N

Mother of child Y/N Age .... " step-mother Y/N

If guardians, are parents alive? M Y/N F Y/N

Brothers of child, ages: (if any) ....

Sisters of child, ages: (if any) ....

Step-brothers, ages: (if any) ....

Step-sisters, ages: (if any) ....

Maternal grand-father: grandmother: both: neither. Age ....

Paternal grand-father: grandmother: both: neither. Age ....

Other relatives living in family (specify, indicating length of residence)

....

....

Other persons, not relatives, living with family (lodgers, etc.) specify,

indicating length of residence ....

TOTAL / ....

Supplementary observations by Investigator.

TOTAL NO. OF PERSONS LIVING IN HOUSE ....

If father not living in family, indicate whether
dead: divorced: separated: elsewhere (specify) ....
.... not known.

If mother not living in family, indicate whether
dead: divorced: separated: elsewhere (specify) ....
.... not known.

No. of children under 18 years of age living away from home ....

Where .... Why ....
....

No. of grown-up children unmarried, over 18, away from home ....

" " " " married, away from home, but living near family ....

" " " " " living remote from family ....

No. of children dead ....

For each such, state:	age at death:	cause of death	years older or younger than handicapped child.
	....	....	
	....	....	....
	....	....	....
	....	....	....

<u>The parents.</u>

Marital status at birth of handicapped child F ....
M ....

Age /

Supplementary observations by Investigator.

(Cohabitation ?)

Age of father at birth of handicapped child ....
Father's state of health
good: fair: bad: not known.
Illnesses incapacitating father from work during past 3 years:
specify ....
....
Father's occupation: specify as accurately as possible
....
Registrar General's classification ....
Father going out to work daily Yes/No/N.A.
Father's work necessitates long absences from home Yes/No/N.A.
Father at work in the home Yes/No/N.A.
Father unemployed at 1st visit Yes/No/N.K.
Months unemployed during past 3 years ....
How does father spend his time if unemployed?
....
....
Father's hobbies (specify) ....
....
Age of mother at birth of handicapped child ....
Mother's state of health: good: fair: bad: N.K.
Illnesses of mother during past 3 years (specify) ....
....
....
If mother working out of home, specify job ....
....
No. of hours worked out of home per week ....
Has mother worked out of home at any time during past 3 years.
Y/N/N.A.

Supplementary observations by Investigator.

The /

The Siblings.

Are any of the siblings physically or mentally handicapped Yes/No

If so, specify ....

....

Have any of the siblings been ill during the past year in the sense of needing special care or attention Yes/No

If so, specify ....

....

Educational status of each sibling, based where appropriate on school last attended:

	1	2	3	4	5	6	7
Pre-school, at home							
Primary.							
Secondary, gram.							
" mod.							
Special day school.							
" residential school.							
Residential institution.							
Ineducable, at home.							
Educable, at home.							

Occupation /

Supplementary observations by Investigator.

Occupation of siblings who have left school.

	1	2	3	4	5	6	7
Non-manual							
Manual, skilled.							
" semi-skilled.							
" unskilled.							
Unemployed.							
H.M. Forces.							

Home conditions.

Type of district: residential: good artisan: poor.

The house.

Good: fair: slum: 'new' Local Authority: Pre-fab: Other.

Terrace: detached: semi-detached.

Enclosed garden or yard Y/N

Opens out of court Y/N

Tenement: height of flat occupied: 1: 2: 3: 4: 5+

Distance from nearest public playing space, yards ....

Total No. of rooms, excluding scullery ....

OCCUPANCY RATIO (PEOPLE/ROOMS) ....

Has house its own W.C. or does it share?...............

W.C. inside/outside/on common stair

Has house fixed bath? Y/N

Does handicapped child have own bed? Y/N

If not, how many does he share with 1/2/3.

Does handicapped child have own room? Y/N

If /

Supplementary observations by Investigator.

If not. how many does he share with? 1/2/3/4.

Ages of sharers ....

Condition of Home, as distinct from house.

Clean: reasonably satisfactory: dirty.
Very comfortable: reasonably comfortable: obviously uncomfortable.
Financial conditions: easy: difficult: poverty.
Sources of family income: Earnings of father: mother: children.
From lodgers: Unemp. benefit: Sickness benefit: Family allowance.
Assistance Board: Other (specify) ....

....

....

Does the mother appear to be reasonably sensible in the ordinary things of life? Y/N/N.A.

Does the father appear to be reasonably sensible in the ordinary things of life? Y/N/N.A.

Does the general 'atmosphere' of the home appear to be outstandingly good: reasonably satisfactory: "poorish": obviously bad.

The handicapped child.

Position in family .... of ...., living.
Age at which parents first noticed anything wrong ....
" " " handicap first diagnosed by family doctor ....
" " " " " " " hosp./other clinic ....
Did parent have difficulty in getting condition diagnosed? Y/N
If so, specify ....

....

The nature of the handicap.

(A full description of the handicap present, with an indication of its severity, location (if appropriate), and the extent to which it interferes with normal living and education. The aim should be to present as complete a picture as possible of all the difficulties of the child, including the presence of plural handicaps, whether /

Supplementary observations by Investigator.

whether related or not.)

....

....

....

....

....

....

....

....

....

....

Is there any complicating concomitant difficulty of

Sight Y/N speech Y/N hearing Y/N intelligence Y/N

Can he walk and run like a normal child? Y/N
Can he walk with help? Y/N
Can he walk only with an appliance? Y/N
Could he walk with an appliance (e.g. Bonaped)? Y/N
Has he to be carried everywhere? Y/N
Can he feed himself with help? Y/N without help? Y/N
Has he to be fed completely? Y/N
Can he attend to his own toilet needs? Y/N
Does he wash himself? Y/N
Can he dress himself? Y/N

Use/

Supplementary observations by Investigator.

Use of arms.

	Rt.	Left.	Both.
Not affected			
Affected			
Unable to grasp			
" " hold pencil			
" " use fingers for fine movements.			

Appliance

None ....

If any,nature	Rt.	Left.	Both.
Artificial limb			
Stick			
Crutch			
Caliper			
Special chair			
Wheel chair (outside)			
Walking machine			
Other			

Appliance provided by parent Cost ....
" " through hospital
" " " Local Authority
" " " other source (specify) ....

....

Presence of any of the undernoted conditions.

Convulsions.

More than one a week	Y/N
1 per week - 1 per month	Y/N
Less than 1 per month	Y/N
Previous fits	Y/N

Incontinence. /

Supplementary observations by Investigator.

Incontinence.

Urine and faeces	Y/N
Day and night	D/N/B
Urine only	Y/N
Day and night	Day/Night/Both
Faeces only	Y/N

Behaviour.

Amenable to reason	Y/N
Fit to be left alone in room	Y/N
Personal danger if left	Y/N
Aggressive	Y/N
Liable to injure siblings	Y/N
Unduly noisy	Y/N

Other (specify) ....

....

Age at which child started to speak .... years: not yet.
" " " " " " walk .... years: not yet.
Does child convey an impression of general contentment? Y/N
Has he any interests? Y/N

If so, specify ....

....

Has he any occupation? Y/N

If so, specify ....

....

Is he bored/lonely/miserable/none of these things?
Does he worry about his disability? Y/N
Does he mix with other children outside the home? Y/N
Is he resentful? Y/N

Status of child within the family.

Does he take a fairly normal part in family life? Y/N

Is /

Supplementary observations by Investigator.

Is he the centre of attraction? Y/N
Does he seem neglected: physically: emotionally: both: neither.

Attitude of mother to child.

Apparently normal Y/N
Over-anxious Y/N Over-solicitous Y/N
Solicitous but not obviously anxious Y/N Rather tough Y/N
Overtly rejecting Y/N
Rejecting under cover of solicitude Y/N
Is mother satisfied that child is making reasonable progress in
general health Y/N in learning to behave normally Y/N
in his general schooling Y/N
Is she worried about the future of the child? Y/N

Attitude of mother to handicap.

Accepts it as permanent/Still acts on hope it will be cured or greatly reduced.
Is she actively resentful, blaming hospital, midwife, or other agency concerned? Y/N
Do parents appear to understand the child's difficulties? Y/N

Attitude of siblings to handicapped child.

Do any appear to be actively resentful of child? Y/N
" " " " take some responsibility for him? Y/N
" " " " " great " " " ? Y/N
Are they ashamed of him/cruel to him/jealous/frightened of him/ none of these.
Does the child's presence deter them from bringing friends to the house? Y/N
Does the child's presence prevent them from having holidays? Y/N

Reactions of neighbours and their children.

Are they resentful of presence of handicapped child? Y/N
Are they cruel to him? Y/N Frightened of him? Y/N
Are they understanding and helpful? Y/N
Do they take any active part in his life? Y/N

Effect of handicap on parents.

Does /

Supplementary observations by Investigator.

Does the presence of the handicapped child seem to prejudice relations between husband and wife? Y/N/NK/NA.

Does it interfere with the care of other members of the family? Y/N

" " " " " family shopping? Y/N

" " " " " " outings? Y/N

" " " " " " holidays? Y/N

" " impose any financial hardship? Y/N

If so, specify ....

....

Has the existence of the handicapped child prompted the parents to seek to avoid having other children? Y/N/NK/NA.

Has the presence of the child affected father's prospects of promotion? Y/N. If so, specify ....

....

Has the mother had to go out to work on account of handicap? Y/N

If so, why? ....

....

Has the mother any difficulty with the child? Y/N

If so, indicate the cause of greatest difficulty:

Helplessness: violence: constancy of care: weight-lifting: expense: other (specify) ....

....

Any other family problems arising from the presence of the child:

specify ....

....

Supplementary observations by Investigator.

Advice and Treatment.

When the defect was first diagnosed by the doctor, did parent discuss its /

its implications with him once/repeatedly/No

Has parent discussed the child recently with family doctor? Y/N
" " " " " " " hospital? Y/N
" " " " " " " clinic? Y/N
" " " " " " " Health Visitor? Y/N
" " " " " " " Vol^{y} agency? Y/N

How often has the Health Visitor, or other social worker, seen the child in the course of the past 12 months? Never: once: repeatedly

Is child seen by family doctor from time to time apart from specific requests? Y/N

Was the child referred by family doctor or other agency for advice;
to hospital Y/N Local health authority specialist Y/N

Was the child admitted to hospital for diagnosis and advice? Y/N
" " " examined at hospital O.P. dept. only? Y/N

To how many hospitals has parent taken the child for advice or treatment? 1. 2. 3. 4. 5+

Is the child attending regularly -
Hosp. OPD: special clinic: local health auth.clinic: none of these.

If not, reason for discontinued attendance domestic commitments: financial considerations: transport difficulties: resented opinion expressed: other reason:

specify ....

....

Are parents satisfied in their own minds that everything possible has been done for the child? Y/N

Is their a suitable Parents' Association in the area? Y/N

Are the parents members of it? Y/N
Have they found membership helpful? Y/N

If so, how? ....

....

Which of the following services are available within reasonable distance of the child's home:

Maternity and child welfare clinic Y/N school clinic Y/N
Hospital out-patient department Y/N
Hospital or clinic offering regular and appropriate treatment (e.g. physiotherapy for spastics) Y/N
Day nursery unit able to take the child Y/N
Health visitor who really feels competent to advise/

Supplementary observations by Investigator.

advise on child with this particular handicap Y/N
Special statutory or voluntary home visitor Y/N
Specify Blind Welfare Officer: Mental Welfare Officer: other ....

Voluntary groups willing to help in a specified way Y/N
e.g. voluntary society: transport pool: baby sisters: parents group: W.V.S.: other: specify ....

....

Which of these services, though available and apparently appropriate, have not been used ....

....

Why? ....

....

Is suitable transport readily available (a) public Y/N
(b) specially provided Y/N by statutory agency Y/N
" voluntary " Y/N
Is child statutorily 'ascertained' by L.E.A. Y/N
If so, at age ....
Is child under periodic assessment by L.E.A. Y/N
Is child under care of L.H.A. Y/N
Has parent had instruction in teaching him (re special handicap, e.g. deafness?) Y/N
Has parent had instruction in managing child? Y/N
Has parent had instruction in giving physio-therapy (e.g. cerebral palsy) or similar home treatment? Y/N
If child in long-stay hospital, how many months has he been there .....
How often has parent visited him during that period? ....
Cost per individual per visit ....
Would parent like to visit child more frequently? Y/N

Education.

Child attending ordinary primary school Y/N
" " " " " with special placing in class Y/N
" " " " " special class Y/N
Whether /

Supplementary observations by Investigator.

Whether attending full time/part time.
Whether subject to any restrictions, e.g. P.T. Y/N

Child attending Special School.

Type	Day	Residential
E.S.N.		
P.H.		
Blind.		
Deaf.		
Open air.		
Other		

Child attending Private School Y/N
" " Nursery School of Class Y/N
" " Occupational Centre Y/N
" in long-stay hospital Y/N in hospital school Y/N
receiving regular education Y/N
" receiving home tuition Y/N
If so, frequency per week 1, 2, 3, 4, 5.
Local Educ. Auth. or Private.
If private, cost to parent .... per month.
If child at school, indicate educational assessment ....
....
....

If child of school age, but not attending any of above, state reason.

Excluded by LEA/LHA from ordinary school.
Unable to be placed because of double defect
Awaiting placement in Spec.School (Day/Residential) Period of waiting (months) ....
Awaiting placement in Spec.School but at present too young
" " " " " " " no vacancies.
" " " occupational centre or too young for it.
No special school facilities available.
Parent not agreeable to placing recommended because: /

Supplementary observations by Investigator.

because: doesn't want him to mix with kind of child there: embarrassed about taking him there: thinks can look after him better at home: wants another school: other.

Difficulty in attending because

transport not available: transport too costly: domestic commitments: other difficulties.

Specify ....

Where child excluded from ordinary school by LEA

Is parent able to cope with it at home? Y/N

Is parent willing to accept institutional care:

Complete: for holiday periods: in emergency, for short term care: not at all.

Parent willing to accept institutional care: reasons given

advice of doctor or nurse:
to enable child to be looked after better:
on account of inability to cope with child's behaviour:
too exhausting for mother:
for sake of other siblings:
for sake of marital relationship:
in order to have more children:
to enable parents to go out to work:
to get rid of child:
other: specify ....

....

Supplementary observations by Investigator.

Research Worker's comments on the Case and General Summary,
(including sources of information, notes on any special difficulties encountered in investigation and estimate of needs revealed).

PPs. 5-6. Home conditions.

Add

The house - Owned/Rented.

If not own bed, sharers and their ages 1/2/3 ....

If not own room, sharers and their ages 1/2/3 ....

PPs. 11-13. Advice and Treatment.

P.11.

Add

Who first suspected presence of handicap?....................

When did family doctor first see the child?..................

P.12.

Substitution.

Which of the following services are available and at what distance from the child's home.

P.13.

Add (at end of section)

Which of the above services have been actively offered ....

....

....

....

PPs. 13-15. Education.

P.14.

Add Age at which school attendance began ....

(after) Whether attending full-time/part-time. No. of days per week......

Supplementary observations by Investigator.