FIG. 6—Sir David Ferrier at a picnic near his cottage at Porthgwarra, Cornwall.

Hughes Bennett⁴⁴ was on the staff of the Hospital for Epilepsy and Paralysis, Regent's Park, where the operation was performed. He was one of the earliest contributors to *Brain*. He suffered from "a most painful nervous disorder" which enforced early retirement and died at the age of 55 in 1901. I have failed to discover a photograph of this early neurologist.

Holmes,⁴⁵ who knew both Hughlings Jackson and Ferrier, said that when this operation was completed "Hughlings Jackson, in his characteristic slow drawl, said to Ferrier, who stood beside him, "awful, awful." "Awful," said Ferrier, "the operation was performed perfectly." "Yes," replied Jackson, "but he opened a Scotsman's head and failed to put a joke in it."

It was generally acknowledged in 1884 that the success of this event was largely due to the work of Ferrier. Like many a British neurologist, he lived a long time, dying in 1928 at the age of 86. He had been knighted in 1911. Everyone who knew him commented on his extraordinary energy, amiable manner, and enthusiasm.⁴⁶ Kinnier Wilson⁴⁷ wrote that "on the day of Hughlings Jackson's funeral in 1911 I walked away with him from the cemetery and after many minutes of silence, occupied with his own thoughts of his teacher and friend, he suddenly turned and said, "well, when I cease to take an interest in things it will be time for me to go." Sir Charles Ballance⁸ said "as Hughlings Jackson is the Socrates of Neurology, so Ferrier may be described as the John Hunter of Neurology." Sherrington in 1906, dedicated his classic *The Integrative Action of the Nervous System* to "David Ferrier, in token of recognition of his many services to the experimental physiology of the central nervous system."

The concluding part of this paper will appear in next week's issue.

Contemporary Themes

Exeter Project for Handicapped Children

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British Medical Journal, 1974, 4, 706-709

Summary

A project in Exeter has tried to increase the contribution of the paediatric department of a district general hospital to the long-term care, support, and treatment of handicapped children and their families. They include an infant care unit, day units for handicapped children, and holiday projects, and are based on close links with the educational and social services. The availability of such a family support unit may diminish the strain on the families of handicapped children and help them to maintain normal family and social relationships.

Introduction

Among the many considerations that determine whether a severely mentally or physically handicapped child remains at home or is committed to permanent hospital care the extent of the supporting services for home care is among the most impor-

tant. Support includes the essential contributions required from medical, social, educational, and voluntary services. This report describes a project in Exeter which has over the last seven years attempted to increase the contribution of the hospital paediatric service to the long-term care of handicapped children living at home with their families. It has been designed to fill previously unmet needs and has been closely co-ordinated with existing medical, social, educational, and voluntary services. While the paediatric contribution to investigation, diagnosis, and comprehensive assessment of chronic handicap has also been greatly increased over the last decade the Exeter project is concerned with continuing care, support, and treatment on a long-term basis. This project makes no arbitrary distinction between physically, mentally, or socially handicapped children, and in many children all three elements are present in varying proportions.

A paediatric service based on the catchment area of a district general hospital has through its neonatal service a prime opportunity to identify potentially mentally, physically, or socially handicapped children at a very early stage. In addition many infants born elsewhere are referred to the paediatric department in the early months of their lives for investigation of possible handicap. The potential paediatric contribution is both preventive and therapeutic because such children and their families need not only help during the period of diagnosis and comprehensive assessment but also long-term support.

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Resources

In 1967 Honeylands Hospital, a 30-bed children's tuberculosis sanatorium in Exeter, previously managed by the chest service, became obsolete. It was transferred to the paediatric department and has been developed as a family support unit for handicapped children. It is situated within the city of Exeter on a main bus route and has spacious grounds, and it is about one and a half miles (2.4 km) from the main district general hospital. As a part of the development the Devon and Exeter Spastics Society has built its day centre and special school adjacent to the hospital, to which it is joined by a covered way. Many of the services provided are shared between them.

Objectives

Various unmet needs were identified and the unit has attempted to supply each of them.

INFANT CARE UNIT

A few infants after initial treatment in the special care baby unit of the district general hospital need a further short period of expert care before they are sent home. These include premature infants whose homes are unsatisfactory, usually on account of maternal inexperience or poor housing conditions; infants awaiting adoption about whom there is initial doubt regarding their physical status; and infants requiring special treatments, such as highly specialized diets, or daily treatment for severe malformations. Such infants may stay at Honeylands for two to four weeks, during which time appropriate social service support is provided and the mother or foster mother becomes accustomed to handling the infant, first by visiting the unit and then by a few days' stay at the hospital with the baby. Subsequently, the mother and baby may return to the unit for short periods of treatment when this is necessary. The average number of infants needing treatment is about six at any one time.

DAY CARE OF HANDICAPPED INFANTS

Parents of children with major malformations or severe handicaps which are recognizable in the first months of life have initial feelings of isolation and need much support while they become accustomed to the care of their child. Many mothers need constant encouragement and repeated opportunities to discuss their problems. Day care of their children in a paediatric unit two or three days a week during this initial period is extremely valuable. Discussion groups, coffee mornings, and practical instruction in day-to-day management, including treatment such as physiotherapy, are regular features of the routine. For children with the most severe disabilities a sharing of care between Honeylands and the home is worked out on an individual basis. In this way the stress and strain on what, in contemporary society, is often a nuclear family or a single-parent home is greatly reduced. The parents are enabled to resume normal social activities rather than suffer the isolation commonly encountered by many parents who first find themselves totally responsible for the care of a severely handicapped child. The unit to a large extent takes on the role of the extended family. The parents know that if they want to go out for an evening or away for a weekend they can, without formality, arrange for the child to stay in the unit for the appropriate period. At any one time about 20 handicapped infants under the age of one year receive this service. The average daily attendance is about six.

PRENURSERY-SCHOOL CARE

Exeter is fortunate in that for many deaf, partially sighted, and physically and mentally handicapped children nursery education

is available from two or three years of age onwards. Before this age peripatetic teaching is available for deaf children and therapeutic services for other handicapped children are provided at hospitals and clinics. Even so the constant care which many young children need is a considerable strain on their parents. Honeylands has attempted to fill a previously unmet need in providing supporting care for children between one and two years of age. The particular medical nursing, physiotherapy, and speech therapy needs of each child are determined and emphasis is placed upon parental participation and instruction in treatment. Parents are also encouraged to join in the play activities, thereby gaining insight into ways to provide stimulating activities for their children at home. Practical help in the handling of handicapped children at meal times, over bowel and bladder control, and the carrying out of special treatments learned at Honeylands enhances the standard of home care. The advice of the occupational therapy service has been invaluable in helping both staff and parents over the management problems of individual children. The personal relationships which are created between the staff and children by regular day care ensure that when brief periods of informal residential care are arranged the potential adverse effects of separation from the parents are greatly minimized. The social worker on long-term secondment to the paediatric department has a major role in parent counselling and in the co-ordination of the work at Honeylands with the community social services. Discussion groups for parents and staff are a regular part of the weekly programme. A medical officer with special interests in children attending special schools is a member of the medical staff of the hospital so that the handicapped child's subsequent transfer to the appropriate nursery school is facilitated.

Day attendance of children of pre-nursery-school age and their parents is not restricted to those with severe physical and mental handicaps but includes children whose retardation is predominantly caused by social disadvantage. About 30 handicapped children between 1 and 2 years of age are in contact with Honeylands at any one time. The daily attendance is between five and ten a day, and most children attend for about two days each week.

CHILDREN OF SCHOOL AGE

In Exeter special day-school education is available for handicapped children who need it. Honeylands's main role, therefore, is to complement the educational service by short periods of residential care according to the needs of individual families and by day care during school holidays. These facilities are fully used and are clearly much appreciated by the parents who know that they can call upon them with the minimum of formality at any time. There are often children's parties, to which many children who no longer attend Honeylands regularly are invited. There is no formal age limit but the residential facilities (for which no sex separation arrangements are available) are not designed to accommodate children over the age of puberty. About 90 children of 2-11 years of age use Honeylands. The attendance for day care is about 20 in holiday time but less in term time. The number resident is usually between 15 and 20.

Honeylands also provides a small day hospital school for delicate children of primary school age. This school is used particularly for children with physical disorders such as severe congenital heart disease, rheumatoid arthritis, and cystic fibrosis. There are seldom more than 10 children in this class.

HOLIDAY PROJECTS

Arising from the voluntary support at Honeylands a series of summer holiday projects for handicapped children between 4 and 11 years of age have been organized in the Exeter area. Each of these are undertaken at improvised day holiday centres (such as a primary school closed for the summer holidays) to

which the handicapped children are transported and returned home each day. They are organized entirely by the voluntary effort of local churches, Red Cross, and other local groups. Each project has trained nurses and teachers as members of its staff who give up part of their holidays to take part. Many students, including student teachers and sixth formers also participate. Handicapped children attend these centres daily for one or more weeks during their school summer holidays when their usual schools are closed. The holiday projects activities include swimming and visits to the seaside, game parks, and moors, pony riding, and many other activities. They are greatly enjoyed by both the children and the volunteers, many of whose own children participate.

These holidays are also appreciated by the families of the handicapped child for several reasons. Firstly, they find that many of the relationships formed between their children and the volunteers are not restricted to the period of the project but that the relationship continues and develops throughout the rest of the year. Secondly, the holiday project provides a break during the long summer holiday during which the parents can undertake activities with their non-handicapped children which might be impracticable if the handicapped child was at home. In all seven such projects took place in the Exeter area during the summer of 1974, involving about 200 handicapped children and about 800 volunteers.

Administration

Honeylands is a part of the Health Service and is a section of the paediatric department of the Royal Devon and Exeter Hospital. The medical staff consists of the consultant paediatricians, a medical officer from the school health service, the senior registrar and registrar in paediatrics, and the senior paediatric house officers, who are in turn assigned to Honeylands as part of their general paediatric training. The nursing staff work under the direction of the paediatric nursing officer and include sisters, state registered nurses, state enrolled nurses, and nursery nurses. Most of the nursing staff, including some nursery nurses, have been on the staff for several years so they are able to develop long-term relationships with the children and their parents.

Nursing uniforms are not worn and slacks have been found to be practical. The atmosphere is informal and not institutional. Nursing staff previously used to a more conventional pattern of children's nursing have adapted rapidly to this different philosophy, and there has been no difficulty in filling the allocated staff establishment. Newer recruits to the nursing team enjoy the work and express a wish to continue in the unit. There is a qualified school teacher and a play-group leader supported by volunteers. The medical ancillary staff, which includes physiotherapists, speech therapists, and occupational therapists, none of whom wear uniforms, are shared with the Devon and Exeter Spastics Society. The social worker on long-term secondment to the paediatric department is an integral member of the team. There are also close relationships with the professional staffs of the special schools and the educational psychologists. Voluntary support is freely available and university students and sixth formers form an important element of the voluntary staff. Expeditions into the town for shopping or other visits are a regular activity.

OTHER FACILITIES

Voluntary effort has done much to promote a stimulating environment at Honeylands. Volunteers often bring their own children to participate in the play activities. An adventure playground for handicapped children has been constructed and currently an indoor swimming and hydrotherapy pool is planned as a joint enterprise between the League of Friends of the hospital and the Devon and Exeter Spastics Society. Honeylands has become closely integrated with the precinct of Exeter in which it is situated. Youth clubs, boy scouts, and girl guides from the neighbourhood all participate in its daily activities. Honeylands possesses its own beach hut at the seaside, and a sunshine coach has been donated by the Variety Club of Great Britain for transport.

Results

It must be emphasized that most children who attend Honeylands have severe physical or mental handicaps. In a few children their retarded development is due predominantly to social disadvantage which has accentuated defects which in other circumstances might have caused only a minor disability. The types of handicaps found among the Honeylands children are indicated in the table, which shows the handicaps of the 139 children receiving care over a one-year period. Many children had multiple handicaps so that for simplicity only the predominant handicap affecting each individual child is shown. All the children listed under "predominantly mental handicap (severe)" were mentally handicapped to the degree that required special education, most being severely subnormal. Many were mongols and others were hyperkinetic, microcephalic, or showed no physical stigmata apart from severe mental subnormality. Severely mentally subnormal children with significant physical handicaps included children with cerebral palsy, spina bifida, multiple malformations, mongolism with severe congenital heart disease, and children with special sensory defects. Mentally normal children or those with a minor degree of mental handicap but with severe physical handicap again included children with cerebral palsy and spina bifida and a small group of children with conditions such as symptomatic cystic fibrosis, severe asthma, atresia of the bile ducts who had survived into mid-childhood and severe congenital heart disease. This latter group attended the special primary school class for delicate children. The group of children listed under "predominantly socially disadvantaged" were children who were found to be significantly retarded in their intellectual or physical development in the first five years of life but who were expected to attend normal schools in due course. A large proportion of these children also had minor physical handicaps.

EXAMPLES OF CARE PROVIDED

The amount of support given to particular children and their families varies. Some families make only occasional use of the residential facilities while others are regular users. About one-third of the children receiving day care also from time to time make use of the residential facilities, one-third receive day care only, and one-third use only the residential facilities, mainly for

Number of Children receiving Day Care and Intermittent Residential Care at Honeylands August 1973-July 1974 according to Age and Disability

Age (Years)	Severely Mentally Handicapped		Severely Physically Handicapped with Normal or Near Normal Intelligence	Socially Disadvantaged with Minor Physical or Mental Handicap	Total
	Mental Handicap Only	Mental Handicap + Physical Handicap			
<1	0	4	8	8	20
1-4	20	26	15	20	81
5-11	12	16	8	2	38
Total	32	46	31	30	139

short periods of parent relief. Examples include a severely mentally handicapped child with bulbar palsy who has to be tube fed and who lives at Honeylands from Mondays to Fridays but is at home with her parents at weekends. An unmarried mother with a 4-year-old mongol boy with severe congenital heart disease has a full-time job, so her child attends a day special school and normally returns home to her at night though when her working hours make this impracticable he comes to Honeylands for the night. He attends Honeylands daily when his special school is closed for holidays. After a 6-week old infant had been placed for adoption she developed acute heart failure due to what was considered to be a cardiomyopathy. On recovery she came to Honeylands and after a long period of illness recovered sufficiently to be transferred to a foster home. The foster mother, who was a member of the domestic staff at Honeylands, had already come to know her well. She continued for the next two years to bring the child with her daily to Honeylands. The child's medical condition greatly improved and she now attends a normal school. Legal adoption has taken place and the family relationships are excellent.

During the last seven years only two children under the age of 11 from the Exeter area have, so far as I am aware, been committed to permanent care in a mental subnormality hospital. For all the remainder the parents or foster parents have, with the support provided, continued to bring up their handicapped child as a member of their own family. My general impression is that over the last seven years the stress, bitterness, and frustration encountered in families with children with severe handicaps has been considerably diminished. There are many reasons for this, including notable improvements in the local educational and social service facilities available, but the direct contribution towards the improvement by Honeylands has been substantial.

Discussion

The difficulties encountered in mental subnormality hospitals have received much publicity in recent years. On the other hand Freeston¹ and Walker *et al.*² have provided eloquent descriptions of the difficulties that may be encountered by families who continue to accept responsibility for their handicapped child's care at home. A children's hospital or the paediatric department of a district general hospital has a major opportunity to support the families who elect to continue to care for their child. The reorganization of the Health Service and the formation of child health care planning teams can help to ensure that the paediatric contribution is appropriate and does not duplicate existing services. The paediatric contribution must be integrated with the educational, social, and voluntary services already available as well as with the more acute work of its own department.

There is a danger that the wish felt by professional advisers and the parents to keep a handicapped child at home can lead to intolerable pressures on the family or to a disadvantageous situation for the child. As children reach secondary school age or adulthood new difficulties and the declining strength of the parents may add to the problems so that the amount of responsibility that the home can satisfactorily undertake may diminish. For younger children home care supported by the type of service described here can be satisfactory for all but a very few families. It is the type of support given immediately the handicap is identified and in the immediate years that follow that enable the parents to adjust well to the situation and maintain their normal social relationships. Subsequently, constant interest and flexible

support must be maintained. Parents and children must never be allowed to feel that the hospital has lost interest in them. Honeylands accepts a responsibility for children of the usual paediatric age range. A major concern is to attempt to ensure continuity of appropriate care and support once the child has outgrown this age group. The need for such provision is a most relevant subject for discussion by child health care planning teams.

The mixing at Honeylands of groups of children suffering from mental subnormality, physical handicaps with normal intelligence, and children retarded as a result of social disadvantage has not created the problems that might have been envisaged. The children are divided into appropriate groupings for particular activities such as education and organized play and treatment such as physiotherapy. At other times there is a positive approach to communal activities, including meals, outdoor recreation, entertainments, and other social activities. Many of the voluntary helpers and some of the professional staff bring their own unhandicapped children to Honeylands for the day, particularly during the school holidays. The intention is to create the atmosphere of an extended family in which there is recognition of the fact that each member has his own particular talents and his own particular difficulties.

Only two of the 139 children cared for over the past year received no home care. In both cases the parents visited their children and were encouraged to undertake a degree of home care.

It is apparent from the table that most children were under 5 years of age. It is considered that the support given to the family during this period helps them to adjust to their situation. After the age of 5 special day education is available for all children in the Exeter area who need it. The day holiday projects are very popular among these older children and their families and have reduced the number of children who need residential care during school holidays.

All paediatric departments of district general hospitals have a teaching responsibility towards their junior medical and nursing staff. In many departments the teaching emphasis has tended to be upon acute illness, sometimes with less attention to the need for long-term support for handicapped children. The lack of appropriate hospital accommodation may add to the difficulties; in particular there are many problems in attempting effectively to meet the varying needs of acutely ill and chronically handicapped children in a single ward. The availability of accommodation such as that at Honeylands provides an opportunity to extend the range of service and to bring the work of the paediatric department into direct involvement with domiciliary care as a part of a unified service. This is helpful for medical and nursing training as well as beneficial to the patients and their families.

I thank Dr. Joyce Rubissow and Dr. Leonard Haas and all the staff of Honeylands Hospital for their help, particularly Miss Timms, paediatric nursing officer, Miss Petersen, nursing sister in charge of Honeylands, Miss D. Gascoigne, nursing sister, and Mrs. Wordsworth, social worker.

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