Physical Disability in 1986 and Beyond

A REPORT OF THE ROYAL COLLEGE OF PHYSICIANS

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INTRODUCTION

The past twenty years have seen major changes in the pattern of diseases in the Western World. Acute poliomyelitis has disappeared, tuberculosis is uncommon, peptic ulcers rarely require surgery, bacterial infections can usually be controlled, and the outlook for acute leukaemia and Hodgkin's disease is much improved.

By contrast, many disabling diseases such as rheumatoid arthritis, stroke, multiple sclerosis, Parkinson's disease and motor neurone disease, remain incurable. Some of these patients endure much suffering and require substantial help from the various support services. Dissatisfaction with Disability Services in England and Wales has been expressed both by disabled people and by health workers. The present Report is written against this background.

The Royal College of Physicians' Rehabilitation Committee was established in 1979. It was renamed the Disability Committee in 1983, thus emphasising that the problem concerns not only those patients who are likely to improve (e.g. after head injury or stroke) but also those whose condition may deteriorate (e.g. rheumatoid arthritis and multiple sclerosis). The Committee felt that it should produce a document setting out its views as to the way in which Disability Services in England and Wales might be developed.

In approaching its task, the Committee felt that it could not review all aspects of the problem, and that it would be appropriate to concentrate on the medical aspects of physical disability (defined in Appendix 1). The Report considers mainly (but not exclusively) those aspects of disability that are a responsibility of the NHS as opposed to, for instance, Social Services. It concentrates on disability resulting from disorders which are encountered by physicians and does not deal in detail with disability resulting from, for example, surgical, orthopaedic, or psychiatric disorders. The Report analyses particularly the future role of doctors in the establishment and operation of Medical Disability Services. The Committee recognises that there is much overlap with other professional groups, especially remedial, nursing, and social work, as well as with other statutory services including Social Services, Housing, Education and Employment. We also recognise the important contribution of voluntary societies and of disabled people themselves.

We consider that the medical profession has an essential leadership role in the development of Medical Disability Services. This role includes the catalysis of local initiatives and the setting up of services for particular groups of disabled people. We consider it important that the medical profession is seen to have a major commitment to the subject of medical disability.

Although the Report concentrates on the physical aspects of disability, the Committee is keenly aware of the enormous psychological stresses that are often experienced by disabled people and their families. The ideas put forward in this Report concern certain parts of a large and complex subject. They are not meant to be exclusive, and should be considered within the total context of professional endeavour in this field. It is hoped that the Report will form the basis for constructive discussion and will assist Regional and District Health Authorities to review, organise and evaluate Medical Disability Services.

The Report is divided into four sections. The first, entitled 'Background', deals with the evidence that there are serious shortcomings in the organisation of Disability Services and also discusses epidemiology and terminology. The second, entitled 'Future Evolution of Disability Services' outlines our recommendations for Regional and District Services and discusses medical manpower and administration. The third section deals with 15 specific areas of disability (e.g. Continence Services, Pressure Sores and Wheelchairs), which require particular attention by District and Regional Health Authorities. The last section includes a summary of the Report's main recommendations and lists some basic audit standards.

Acknowledgements

We are very grateful for the help of the following:-
Dr. I. S. Bailey
Dr. P. J. Begley
Dr. M. A. Chamberlain
Mr. H. B. Devlin
Dr. P. M. Enderby
Mr. R. C. L. Feneley
Dr. J. A. A. Hunter
Dr. R. C. King
Mr. M. C. Martin, OBE.
Professor A. E. Read
Dr. G. P. Rubin
Dr. J. T. Scales
Mr. R. J. Sellick
Miss J. Silver
Dr. D. T. Wade
Dr. P. C. Walker
Dr. I. A. Williams
and to Mrs. F. Bickerton, who typed many drafts of the Report.

BACKGROUND

What is Wrong?

For many years there has been professional and public concern about the care given to disabled people. The response to the recommendations of a number of official and other reports[1–6] has been inadequate and unsustained[7,8]. A survey carried out throughout Great Britain in 1971 showed that many disabled people who could be helped by advice, equipment, adaptations and services were not getting such help[9]. The Chronically Sick and Disabled Persons Act, 1970, placed an obligation on Local Authorities to inform themselves of the number of disabled people and their needs, and to take steps to meet these needs. Following the activities of the International Year of Disabled People (1981) there has been increased understanding of the needs and feelings of disabled people, who share the same desires, aspirations and rights as other citizens.

In addition to the national survey mentioned above[9], there have been many community-based surveys[10] and in-depth studies and personal accounts published of the experiences of disabled people[11,12]. These have included accounts of people disabled by rheumatoid arthritis[13], multiple sclerosis[14–16], paraplegia[17,18], strokes[19–21], Parkinsonism[22], spina bifida[23,24], motor neurone disease[25–27], amputations[28,29], cancer[30–32], myocardial infarction[33,34], ileostomy and colostomy[35,36] and incontinence[37].

Certain themes recur throughout the reports and personal accounts. There are major problems concerning housing, employment, and the various financial allowances. There is unevenness of provision between different Regions and Districts. This was highlighted by Lady Hamilton in her 1984 Harding Award Address. She pointed out that there are, for instance, major Regional differences in medical staffing in rheumatology and neurology. The best staffed Region has six times as many rheumatologists per head of population as the worst staffed Region. These reports record a widespread lack of co-ordination between services which results in fragmented help and advice, omissions or duplications of services, delays in obtaining help, and discontinuity of help, as the disabled person is referred from one service to another. Patients with chronic disorders attending for 'follow-up' complain that they are seen by inexperienced junior doctors who are not familiar with the particular problems experienced by the patient. A frequent complaint is the inadequate information given to the disabled person about the nature and expected course of the underlying condition; about the treatment and the plan of management of the ensuing disabilities, and about the opportunities, services and help that are available. Given sufficient information, a disabled person can choose certain courses of action and thus retain autonomy. Many disabled people are concerned about the additional work and restrictions imposed on the spouses, relatives and friends looking after them at home. The carers often give up their jobs, children's contacts and activities become restricted, social and leisure activities are reduced, extra costs are incurred, and disturbance at night leads to physical and mental fatigue.

The picture is not entirely black, and there have been important initiatives. These include the activities of voluntary organisations of all sizes, ranging from the large national charities to small local groups who together offer a considerable range of facilities. Various community-based resources, including the Home Help, Direct Meals, and Community Nursing Services, make it easier for severely disabled people to live in their own homes. The Local Authorities finance adaptations to existing dwellings, and specialised housing has been developed in some areas. Several agencies provide residential care for severely disabled younger people. Disabled Living Centres have been established in some areas of the country—where expert advice is available regarding personal clothing and equipment for disabled people. Some Districts operate a Continence and/or a Stoma Care Service. These various services are provided by a variety of agencies, including Health, Local Authority, the private sector, and voluntary services. The result is a patchy distribution of services, with some areas being very badly served.

It is clear that Health Authorities can make major contributions to improving the quality of life for disabled people. The aim is to enable people with disability to have access to the various medical services they need, so that there is the minimum disruption of their lives and preferred activities. This will involve reviewing local services, identifying and remedying deficiencies, establishing collaboration with resources outside the Health Service, and educating disabled people in safeguarding their health and avoiding the medical complications of their condition.

The Size of the Problem

Estimates of the numbers of people with disability in the population will vary according to the criteria used in defining disability and its severity, and the intensity of case-finding. Broadly speaking, in England and Wales, approximately 10 per cent of the population are physically disabled (excluding sensory and mental disorders); 20–30 per cent of these (i.e. 2–3 per cent of the total population) will be severely or very severely disabled. The Health District with a population of 250,000 is therefore likely to contain about 25,000 disabled people, of whom approximately 6,250 will be severely or very severely disabled. About 10 per cent of all disabled persons are aged under 45 years; 30 per cent are between that age and 64 years, and 60 per cent are 65 years or older. Overall, more women are disabled than men, but at ages up to 65, the prevalence rates of disability are slightly higher in males than in females.

Table 1 gives estimated numbers of people with various disabilities. Table 2 deals with selected diseases and types of impairment (for definitions, see Appendix 1). In an average Health District there will be about 1,810 people with a wheelchair, about 11,000 persons with regular

Table 1. Estimated numbers of disabled people and of those who are severely or very severely disabled or handicapped in various categories in a District with a population of 250,000 people reflecting the national age distribution.

Category		Estimated number in category		Per cent severely or very severely disabled or handicapped	Estimated number severely or very severely disabled or handicapped in District
		Per 10,000 population e.g. typical group practice	Per 250,000 population e.g. typical Health District		
All physically 'disabled' people					
National Sample Survey	[9]	670 adults	16,750 adults	20	3,350 adults
Local Authority Surveys	[10]	557	13,925	30	4,180
Lambeth Survey	[38]	1,150 adults	28,750	—	4,170
Impaired Hearing					
Min. 35 dB HL, at 0.5, 1, 2 & 4 kHz in better ear	[39]	1,000 adults	25,000 adults	10 (66–95dB HL)	2,500 adults
Impaired Vision					
Less than 6/18 with Snellen with glasses	[40]	52 adults	1,300 adults	32 (6/60 or less)	408 adults
Regular Urinary Incontinence (Persons aged 15 yrs or more)	[41]	440	11,000	—	—
Use of Wheelchairs (See page 68)		72	1,810	—	—

Table 2. Estimated number of persons with major physical disabling conditions and of those who are severely or very severely disabled or handicapped thereby in a district with a population of 250,000 people reflecting the national age distribution.

Disabling condition		Estimated prevalence of disease/condition (Various sources)		Estimated number of severely or very severely disabled or handicapped in District Based on Harris Survey[9]*
		Per 10,000 population	Per 250,000 population	
Osteoarthritis	[42]	2,900	72,500	860 all forms and unspecified arthritis
	[43]	1,280	32,000	
Rheumatoid arthritis	[42]	250	6,250	
	[43]	100	2,500	
Ischaemic heart disease		c.700	17,500	60
Other heart disease		—	—	110
Respiratory conditions (excluding cancer of lung)		c.800	20,000	115
Stroke (survivors)	[44]	55	1,375	340
Parkinsonism	[44]	20	500	55
Multiple Sclerosis	[44]	8	200	80
Motor Neurone Disease	[44]	1	15	—
Muscular dystrophy	[44]	1	15	—
Epilepsy	[44]	50	1,250	not known
Paraplegia		—	—	35
Colostomies	[45]	16	400	—
Injuries		About 2,500 people per 'District' are treated as in-patients in hospital each year.		40 (head injuries excluded)
Head Injuries	[46]	About 675 people per 'District' are treated as in-patients in hospital each year.		*
Amputations	[46]	About 30 people per 'District' are referred annually for the first time to a Limb Centre.		—
Major congenital malformations		Incidence is about 2 per cent of all live births.		

*The Harris Survey deals mainly with physical disability.

urinary incontinence, and 25,000 adults with significant deafness. The principal causes of severe physical disability are neurological disease and arthritis. In the average Health District there will be 500 people with Parkinsonism, of whom 55 will be severely or very severely disabled. There will be at least 200 patients with multiple sclerosis and there could be up to 6,000 with rheumatoid arthritis.

The epidemiology of physical disability is discussed at greater length in Appendix 2 which deals with the important differences between impairment, disability, and handicap.

The Principles of Medical Involvement

Historically, rehabilitation of the physically disabled developed from the speciality of Physical Medicine and Rehabilitation. This arose largely from the residential Service Rehabilitation Units in World War II.

Specialists in physical medicine were concerned with management of chronic disability and with the diagnosis and management of the rheumatic diseases. In time, the specialty merged with that of rheumatology and became known as rheumatology and rehabilitation. With the expansion of rheumatology in recent years, to become a sub-specialty of medicine in its own right, its proponents no longer feel that their work should necessarily be concerned with the management and rehabilitation of non-rheumatological disorders. This applies particularly to disability resulting from neurological disease in which many rheumatologists have not been trained. However, many Districts welcome a consultant who can not only care for patients with rheumatic disorders in the widest sense (including backache, soft tissue rheumatism, degenerative joint disease, and inflammatory arthritis), but also provide a more general rehabilitation service for chronically disabled people.

England and Wales are almost alone amongst western countries in having no medical specialty of physical medicine, or its equivalent. Only a handful of consultants have a full-time commitment to rehabilitation. In addition, there are a small number of consultants who have dual accreditation—usually in rheumatology and rehabilitation. Some Health Districts do not have any designated sessions in rehabilitation. It seems probable that one of the principal reasons for the poor state of Medical Disability Services in England and Wales is the fact that there are very few doctors with any formal professional commitment to the subject. Few have the experience, time, or responsibility for formulating, presenting, and arguing the case for resources. Planned investment in the area has been small at both Regional and District levels.

In the UK there is a well-developed geriatric service which not only provides for the frequently complicated medical needs of the elderly, but is also concerned with their social problems. In many ways it is a Medical Disability Service for older people. A similar service exists for children in many parts of the country. However, no such service exists for the large number of disabled people aged between 16 and 65 years, who have, to some extent, become a 'deprived population' with few specific facilities (e.g. Day Centres) and a paucity of consultants with specific expertise in the management of their disability problems.

The Working Party on Rehabilitation Medicine of the Royal College of Physicians[47] was firmly of the opinion that 'Rehabilitation is an integral part of total patient care, and is therefore the concern of all clinicians' and considered that clinicians, whatever their specialty, should extend their role and assume at least limited responsibility for the medical aspects of the rehabilitation of all patients under their care. However, virtually all clinicians are fully committed and time has to be found for them to develop this aspect of medicine. Certainly there does not seem to be much evidence of major advances in this particular direction since the Working Party Report of 1978, and the implications of the recommendations have not, as yet, been explored.

This country, through the NHS, is therefore engaged in an important, if unplanned, experiment—'Is it possible to set up an effective care service for the physically disabled without a substantial specialty of rehabilitation, or its equivalent?' The view of the medical profession at the moment appears to be that we should try to do this, and the remainder of the Report is written on this assumption.

Terminology (See Appendix 1)

The term 'Rehabilitation' has been used extensively in the past. Unfortunately, the term lacks any agreed definition (although a large number have been attempted) and is widely misunderstood. For example, some people consider that the term should be confined to the management of sequelae of a 'once and for all' insult such as head injury, or stroke. Others consider that it should include progressive disorders such as multiple sclerosis and rheumatoid arthritis. Historically, rehabilitation has been linked with rheumatology. This link has now, to a large extent, been severed. The term "Physical Medicine" is applied in place of Rehabilitation in some countries. The term Physiatry is used in North America and the term Rehabilitation Medicine in Australia.

The terminology used in this Report reflects the present situation:

1. Services for disabled people are referred to as Disability Services.
2. Existing consultant posts in rehabilitation or rehabilitation medicine are referred to as posts in rehabilitation.
3. The term 'Disability Medicine' is used in this document to cover the application of medical and of general health care services for physically disabled people. The term is also used in reference to new consultant sessions that are devoted specifically to the management of disability and the co-ordination of Health Care Services for physically disabled people.

Consultants

The Royal College of Physicians has published reports on the 'Management of Disabling Chest Diseases'[48] and on the 'Management of Coronary Heart Disease'[49]. A Working Party is currently considering the subject of neurological disability. Rheumatological disability is also the subject of a Working Party Report, to be published shortly. By publishing these documents, the College hopes shortly to be in a position to advise on manpower and training requirements for each of these specialties—with particular reference to the management of disability.

Whatever the details of the final proposal—a substantial increase in the number of consultant sessions devoted to disability and its management is likely to be recommended. This may well involve an increase in the number of doctors in certain specialties—e.g. neurology, with some sessions devoted to disability medicine. Some physical disability falls primarily within the province of surgeons rather than physicians. For example, orthopaedic surgeons are involved with many aspects of disability.

General Practice

The 1978 College Report on Rehabilitation Medicine[47] recognised the important role of the general practitioner in the recognition and management of disability. It commented as follows:

'The great majority of patients, whether suffering from chronic or temporary physical disability, are living in the community. The general practitioner, therefore, has a lynch-pin function of identifying the need for Disability Services. The general practitioner is likely to be most effective in helping the disabled patients in his practice if he is working as a member of a Primary Health Care Team. The Team needs to have access to, and collaboration with, remedial therapists working in the community'.

Community Medicine

Community physicians are concerned with the promotion of health, the prevention of disease and disability, the assessment of the community's health needs and with the provision of services to that community and to special groups within it. They are especially involved with epidemiology, Health Service planning, and in the joint planning of services with Local Authorities and voluntary organisations in respect of child health, young disabled people, and frail elderly people. They provide the medical advice to the Social Services, Education, Housing and other departments of the Local Authorities, and have a collaborative link with the General Practitioner Services. Community physicians have an important contribution to make in developing integrated planning of services, and a concern that the needs of disabled people are brought to the attention of the Health Authorities and, as far as possible, are met.

Occupational Medicine

Occupational physicians have a major responsibility to prevent disability resulting from accidents or occupational disease. Within the individual workplace, they can advise on the employment of disabled people. The Manpower Services Commission is responsible for employment policy in England and Wales, which includes providing services to facilitate the employment of disabled people. One of the resources available is the Employment Medical Advisory Service, which employs trained occupational physicians to help assess people's suitability for employment or training, as well as providing medical advice for the Employment Rehabilitation Centres, and the Disablement Resettlement Officers, who are responsible for assessment and placement services.

FUTURE EVOLUTION OF DISABILITY SERVICES

The Need for the Setting Up of Standards of Care and Audit

Before the quality of services for the management of disability can be judged, standards of care have to be established. This Report lists some of the services which need to be provided. Many of these services will be provided by each District Health Authority, some by one District on behalf of other Districts, and some by other agencies. In whichever way these services are provided, they should be readily available to all disabled people who require them. Subsequent sections of this Report describe essential components of the services listed and suggest simple minimum standards of care. These suggestions can form the standards against which the provision and performance of the services can be reviewed. Such reviews should be carried out periodically in every District and by each Regional Health Authority. It is particularly important to listen to the views of disabled people, and of their spouses or others caring for them at home, about the provision and use of services. As the services required are so diverse and are provided by so many authorities, it is too easy for gaps and unnecessary overlaps to occur. Any review of the services should seek reports from the various voluntary organisations representing particular groups of disabled people.

Basic Criteria for a Disability Service

The remainder of this report outlines our suggestions as to how Disability Services in England and Wales should be planned in the future. In making our recommendations, we have been mindful of the following factors:

1. The urgent need to establish an effective Medical Disability Service.
2. The importance of taking into account the views of disabled people and their families.
3. Proposals must be cost-efficient, using existing facilities where possible.
4. The Service should be based upon the principle that the management of disability is an integral part of total patient care and is the responsibility of all clinicians.
5. Certain consultants should have designated responsibility and commitments for services such as Continence, Stoma Care, the District Head Injury Recovery Service, and Pressure Sores.
6. There should be a system of internal and external checks and audit. These should help the service to

develop in the light of experience and of changing needs. Plans should be flexible enough to allow for local conditions, whilst at the same time ensuring that a basic minimum pattern of provision for physically disabled people is achieved.

7. Regional and District plans should include a timetable for the development of adequate services, with provision for review if targets are not achieved.

8. A simple permanent administrative structure should be set up at both District and Regional level.

Regional Units

We recommend that each Region should have at least one Unit which would be concerned with certain specific aspects of disability.

Functions

1. The assessment of severely physically disabled people. Some severely disabled patients have multiple problems which require considerable expertise and knowledge relating to a wide variety of techniques and equipment. For instance, a patient with Duchenne muscular dystrophy may have as many as 15 different problems, including difficulty with breathing, difficulty with sitting comfortably because of a severe scoliosis, pain (associated with skeletal deformity), severe immobility, difficulty with sleeping (partly due to discomfort) and a wide range of impaired self-care activities. Such a patient may require a specially built wheelchair, specialised seating, a moulded back support, a special bed, and a hoist. In addition, the relatives and carers will need to be trained in the best ways of handling the patient. The majority of hospital physiotherapy and occupational therapy departments are not equipped to undertake this type of assessment.

A unit catering for patients with severe and multiple physical disabilities and handicap is Mary Marlborough Lodge, Oxford, established in 1960. The activities of the Unit have recently been reviewed and evaluated (see Appendix 3). This evaluation shows that the Oxford Region itself generates a substantial number of patients and that there is a substantial demand for the type of services offered from far beyond Oxfordshire. It appears clear from this evaluation and from the experience of members of the Committee, that facilities of this type should be widely available throughout the country.

We therefore recommend that each Region should establish a Unit whose functions would include:

a) The assessment of the severely physically disabled person—many of whom have multiple handicaps.

b) The provision of appliances, aids and equipment (including Possum) not readily available from other centres and some of which may need to be modified or adapted in the Unit workshops.

c) The training of the disabled person so that he achieves his maximum potential.

2. The Regional Unit should provide facilities for orthotics (e.g. splints), prosthetics (e.g. artificial limbs), and difficult wheelchair problems. Some of these functions are currently provided by the Artificial Limb and Appliance Centres (ALAC's), and it would seem sensible to incorporate these into the Regional Units. This concept was introduced by the ALAC Review[50]. The Unit might well incorporate a Regional Communication Aids Centre (see page 179).

3. The Unit could include a Disabled Living Centre (see page 173) where a wide variety of equipment should be available for inspection and trial by physically disabled people, their relatives, and professional workers.

4. It might be possible for the Unit to encompass the management of certain specific disorders—for example, a Regional Spinal Injuries facility and/or a Stroke Unit. It would provide an important service for its own Health District.

5. The Unit would act as a focus for teaching and training of professional staff.

6. A major function of the Unit would involve research. The development and evaluation of the various types of equipment for disabled people could, and should, take place in the Unit. The Centres might well become a focus for the design and modification of wheelchairs and other equipment.

Siting and Staffing

These Regional Units should be sited in a major centre and would ideally be linked with a university and a medical school. The Unit should have facilities for inpatients and also engineering workshops. There would be a staff of trained therapists. It is essential to avoid isolation and in our view the Unit should usually be situated in the grounds of a District General Hospital (DGH) to give ready access to a wide variety of medical specialist skills, and allow for medical 'on call' cover, and ensure that a close relationship develops with the staff of the DGH. Rotation of staff in training, both medical and non-medical, should be arranged. Hostel accommodation for relatives and for less disabled patients living at a distance from the Centre, should be available.

We recommend that there should be, at the Regional Unit, the equivalent of at least two full-time consultants in disability medicine. The possibility of appointing consultants with dual accreditation who are still practising in another specialty, e.g. rheumatology, neurology, geriatrics or orthopaedics, should be considered.

We consider that these Regional Units are absolutely essential for the establishment of proper Disability Services in England and Wales. The precise way in which they are established will clearly depend upon local circumstances, including existing facilities.

District Services

What are the main requirements for Medical Disability Services within a Health District? We have compiled a list, which, although not entirely comprehensive, should form the basis for review and audit. In making our suggestions we are well aware that there is overlap with many other organisations, both statutory and non-statutory. These include Social Services, Education, and the Local Authority.

It is clearly important that the relevant staff, including the district nurses, in each Health District should be adequately trained in the management of disability. The domiciliary occupational therapists and physiotherapists are trained to assess the disabled person in his own home. This service is particularly important.

Generic Services

The Committee has outlined brief criteria for the establishment of services in 15 particular areas which are discussed in Section III of the Report. We suggest that all Health Districts should give consideration to these areas but in some instances it may be appropriate for certain facilities to be shared with adjacent Health Districts.

Aids and Equipment Centres.
Housing, Housing Modifications and Re-Housing.
The Physically Disabled School Leaver.
Support Services for Younger Severely Handicapped People.
Driving for the Disabled.
Sexual Counselling.
Head Injury Services.
Visual Impairment.
Hearing Impairment.
Communication Aids.
Wheelchairs.
Prosthetics and Orthotics.
Urinary Incontinence.
Stoma Care Service.
Pressure Sore Service.

Information about Services for Disabled People within the Health District

Each Health District should maintain an up-to-date data base of facilities locally available for disabled people. This could be accessed using a Ceefax-type system if television screens were provided in health centres and elsewhere. This data base should be used to produce a booklet, to be updated annually, of facilities that are available for disabled people locally. These lists should include facilities provided not only by the Health Service, but also by Social Services, voluntary bodies, and other organisations. This information is needed by disabled people themselves, and also by doctors and other Health Service professionals, teachers, social workers, and others. The lists should include the names and addresses and telephone numbers of local charities and organisations for the disabled, and advice on how to obtain information about matters such as wheelchair provision, sexual counselling and leisure facilities for disabled people.

A list of some of the national organisations and charities concerned with facilities for disabled people is included in Appendix 7 of this Report. More detailed information can be found in the *Directory for the Disabled* (1985) and the *Disability Rights Handbook*.

Medical Staff

Consultants with Designated Sessions in Disability Medicine

The precise organisation of Disability Services within the Health District will also depend upon local circumstances. A few Health Districts already have a consultant whose main commitment is to Disability Medicine. However, the majority do not do so. We make our recommendations on the assumption that it is generally agreed that individual specialists should supervise the management of their own disabled patients. It is realised, however, that this does not always happen at present. In our view, there should be a number of designated disability sessions in each Health District. We suggest that, in addition to the care of his own patients, the consultant would undertake some, or all, of the following:-

1. Giving advice to consultant colleagues about disability problems relating to patients under their care.
2. Looking after in-patient facilities for physically disabled people, especially the Young Disabled Unit where one exists, but also planned short-stay, crisis admission, holiday relief and terminal care beds.
3. Catalysing the District Health Authority in the provision of Disability Services. This may involve membership of the District Disability Committee.
4. Being involved in running a number of services including, for example, continence, splint making, wheelchair and stroke disability. In addition, there should be a commitment to the local Disabled Living Centre.

We regard it as essential that there should be clear-cut areas of responsibility.

5. Operating a Head Injury Recovery Service. At present, patients with head injury tend to get admitted under a number of different consultants in various specialities. We suggest that one consultant in each Health District should be responsible for implementing the District policy on the management of head injury (see page 177).
6. The consultant(s) would have responsibility for the training of undergraduates, doctors, nursing and paramedical staff.
7. As mentioned below, there are important requirements for research.

We suggest that there should, initially, be 10–11 disability sessions per week (the equivalent of one full-time post) in a Health District and these might be held by two or more consultants. These consultants, together with the community physician mentioned below, would be responsible for the medical input concerned with General Disability Services, and would, in addition, be responsible for ensuring that Disability Services in their own particular discipline were developed.

We have suggested some general guidelines. We wish to avoid rigid rules, but we consider that the principle of a substantial number of designated disability sessions held in each Health District is absolutely essential. These sessions could be held by consultants from a wide number of disciplines, including general medicine, rheumatology, geriatric medicine, neurology, and orthopaedic surgery.

Community Physician

There should be a community physician with designated responsibility for the development of District Disability Services. The precise nature and distribution of the community physician's responsibilities would depend upon the medical staffing structure within the Health District. The responsibilities might include:-

1. Membership of the District and Regional Medical Disability Advisory Committees.
2. The collection of epidemiological data relating, for example, to patients suffering with pressure sores, incontinence, head injury, and severe physical dependency.
3. Maintaining a list of severely disabled people within the Health District who are living at home but are 'at risk'.
4. Monitoring the inappropriate use of beds within the Health District. For example, it may be important to identify patients who are occupying hospital beds for 'social' reasons, or because a long-stay bed cannot be found.
5. Ensuring that there is an effective District policy for housing and housing alterations for disabled people. The person concerned might be responsible for drawing up a list of priority cases. This work would involve close liaison with other statutory bodies, notably Housing and Social Services.
6. Ensuring that the plan for disabled school leavers is drawn up and implemented (see page 174).
7. Ensuring that a five year plan for Disability Services is drawn up by the Health District and updated regularly.
8. Compiling annual reports on Disability Services for the managers and for the District and Regional Disability Committees, with particular emphasis on cost and effectiveness.
9. Being responsible for running the data base relating to services for disabled people and for compiling a booklet on these services, which would be updated annually.

We see the community physician as having a most important function in collecting and analysing data, identifying trends, and acting as a co-ordinator for certain important clinical groups. We envisage that the community physician and consultant(s) in medical disability would work closely together.

General Practitioners

General practitioners have a most important role. The list of 10,000 people cared for by a group of four or five principals will include up to 1,000 who are physically disabled; 200 of these will be severely or very severely disabled. To function effectively as the primary medical adviser to disabled people, the general practitioner undertakes the following:-

1. Defines his patients' problems in physical, psychological and social terms. Problem-orientated records can be helpful.
2. Helps the patient in the management of everyday maladies to which the disabled population are at least as prone as the rest of society; the management will often be modified by the disability.
3. Together with the district nurse and health visitor, members of the Primary Health Care Team, he provides information about a wide range of locally available public and voluntary sources of assistance, advice and support.
4. Helps the disabled person to live with his disability and his family to support him in doing so.
5. Refers to the social workers, remedial therapists and other agencies, including voluntary societies working in the community. He will therefore need to be aware of the provisions of such services from the National Health Service, Local Authority, and the voluntary services in his District.
6. Refers to appropriate consultants, including those with particular expertise in disability. He would also make appropriate use of the specific District Disability Services (e.g. Continence, Stoma Care, etc.)

Research and Development

Disability involves problems that cause much stress and unhappiness. The costs, both to individuals and to the State, are very considerable. Many treatment and management regimes have never been scientifically evaluated and the task of drawing up criteria for 'model' Disability Services is seriously hampered by lack of epidemiological and operational data. There is clearly a need for a substantial investment in research.

Recent Developments

Developments during the last few years have included the following:

1. Scientific journals now contain a small but increasing number of refereed papers relating to disability.
2. The Society for Research in Rehabilitation (SRR) was started six years ago. The Society is multi-professional, drawn from a wide variety of disciplines, including medicine (less than 50 per cent of the Membership are doctors), the remedial professions, nursing, social work, psychology, physiology, and engineering. The object of SRR is to provide a forum for the presentation of scientific papers relating to causes, prevention, effects and management of disability.
3. Demonstration Centres.

Twenty-seven Demonstration Centres have been established in England and Wales (see Appendix 6) and these have provided a valuable focus for training and the development of services.

4. Academic Departments.

There are now two Academic Departments of Rehabilitation in the UK (Edinburgh and Southampton).

Future Research

There is an urgent need for the drawing up of validated audit criteria on which model services could eventually be based. The establishment of agreed criteria will require considerable experimentation. The research areas to be covered are very large, and the following list gives some examples:-

1. Epidemiology. There is a need for epidemiological data relating to disability in a number of areas—e.g. head injury and multiple sclerosis. We need to know the numbers of people and the costs involved. Community physicians are well placed to initiate and participate in this type of research.
2. The development of reliable measures of outcome

which can be used for clinical audit and research purposes.
3. Research into the natural history and physiology of recovery.
4. Social implications of disability.
5. Evaluation of equipment, e.g. splints, wheelchairs, etc.
6. Evaluation of rehabilitation techniques, e.g. assessment of the effectiveness of various types of therapy (new and old).
7. Evaluation of different ways of providing care, e.g. home versus hospital for stroke patients. There is also a need to examine the different ways of improving collaboration between professional staff and between members of different disciplines.

Implications of Research Needs

More academic units are needed to undertake research into various aspects of disability. Such units would probably need to be attached to major hospitals where there is a steady flow of patients. The proposed Regional Disability Units (see page 166) should have an important function in this regard. Not only would they undertake research projects, but they would also be concerned with the training of staff in research methodology. The importance of enthusiastic medical leadership in this field seems clear.

The Arthritis and Rheumatism Council Research Unit in Manchester has provided valuable data on the epidemiology of rheumatic diseases. We consider that more of these units may be needed and commend particularly the possibility of establishing research units concerned with the epidemiology and management of neurological disability.

Organisation and Administration

We think it unlikely that Disability Services at Regional and District level will be properly established until a clear-cut administrative structure is set up. This would involve committees at both Regional and District levels. These committees would, amongst other functions, be concerned with providing an internal audit system for Disability Services. In making our recommendations, we have been mindful of four particular points:-
1. The need to avoid unnecessary bureaucracy. The number of committees should be kept to a minimum and the membership should be kept as low as is reasonable.
2. The lack of published experience. It is known that various District advisory bodies already exist. These operate under a number of different names, including the District Disability Committee, the Principal User Committee, and the Health Care Planning Team for Disability. To our knowledge, there have been no published accounts of the workings of these bodies.
3. The fact that a large number of professional bodies, and individuals, are concerned with providing services. Within the NHS there are doctors (working in the hospital and in general practice), nurses and therapists. Many groups are not part of the NHS, including Social Services, the Employment Resettlement Service, some occupational therapists, the Artificial Limb and Appliance Centres, the Department of Housing, and the Department of Education. All these bodies will need, at some point, to be involved with various aspects of District Disability Services.
4. The wish of disabled people themselves to be involved with discussions relating to the operation of Disability Services. It will not be easy to satisfy all these requirements. Any administrative plans will necessarily be experimental and subject to modification in the light of experience.

Each Region and District will need to develop its own structure. As far as the committee membership is concerned, a number of theoretical options exist:-
1. A membership consisting of doctors only.
2. A multi-professional membership—composed of NHS employees only (e.g. doctors, therapists, and nurses).
3. The membership could be both multi-professional and multi-organisational—including representatives of some or all of the various bodies itemised above—e.g. Social Services, Housing, etc.

Our suggestion is that Regional Committees should be multi-professional, but confined to NHS employees. District Committees would probably be multi-professional and multi-organisational. The lack of co-terminous administrative boundaries for, for example, the NHS and Social Services, is likely to be a significant problem and a matter which will need to be discussed locally.

Regional Disability Medicine Subcommittee

It is suggested that each Regional Health Authority should have a Regional Disability Medicine Subcommittee. The Subcommittee would have the following functions:-
1. Being responsible for reviewing supra-District facilities, including the Regional Disability Unit(s).
2. Producing, and updating annually, short and long-term plans for Regional and supra-District Disability Services. Realistic targets for the establishment of Regional Disability facilities should be set and the Committee would be responsible for monitoring these.
3. Reviewing Disability Services in constituent Health Districts. The Regional Disability Committee would receive annual reports from each District Disability Committee. The Committee would also expect to receive copies of the short and long-term plans for each Health District.
4. The Regional Disability Committee would produce its own annual report for the Regional Manager; this would review the current situation in constituent Health Districts, and at Regional level.

It is suggested that the membership of this Committee might be multi-professional. There would be at least one representative from each Health District within the Region. The person concerned would be a member of the relevant District Disability Committee, and might be its Chairman. At least one of the full-time consultants in disability medicine based on the Regional Unit, would be a member.

District Advisory Machinery

The District Health Authority will require well thought-out advice and recommendations on a wide variety of issues. We suggest that each DHA should have a small Advisory Disability Committee which would certainly be multi-disciplinary, and would probably be multi-organisational. It would thus include not only doctors, but also a social worker and a representative of the nursing and remedial professions. The Committee would need to represent both hospital and community interests.

The District Advisory Disability Committee would draw up an annual report for the District Manager, and this would be available for the Regional Disability Committee and for the Regional Manager. It would also draw up short and long-term plans for the development of Disability Services within the Health District.

It is important that medical staff locally should develop a mechanism for the discussion and formulation of its views. This might be done by a small subcommittee of the medical staff, which would report to the main Medical Staff Committee. The committee would include consultants with designated sessions in Disability Medicine and also the community physician with responsibility for the development of Disability Services. This committee would be concerned primarily with the medical aspects of disability (e.g organisation of stroke care within the DGH). At least one member of the Medical Disability Subcommittee would also be a member of the District Advisory Disability Committee.

The suggested administrative structure is necessarily experimental. We would strongly encourage Health Districts to publish their experience with various types of committee structure. A national survey of the matter might be worthwhile. Hopefully, within a short time, the basis for a nationally applicable administrative structure will have been established.

Medical Staffing

This section deals with the medical staffing implications of the recommendations in this Report.

Consultant Staff

Consultants in Disability Medicine working mainly at the Regional Centre

We have recommended the setting up of Regional Disability Units and that each Unit should be staffed by the equivalent of two full-time consultants, whose principal commitment would be to Disability Medicine. If all the consultants were to be full-time, then 30–35 full-time appointments would probably need to be made. However, if a substantial proportion of the appointees continue practising in another field (e.g. geriatric medicine or neurology) then the number required would be greater—in order to make up the equivalent of two full-time posts. There is clearly scope for considerable flexibility. It should be noted that there are at present only a handful of posts with a major disability/rehabilitation component, and it is clear that in some cases it will be necessary to create new posts.

Consultants with dual responsibility and accreditation

We recommend that there should be about 10 disability sessions held in each Health District. We envisage that in the majority of Health Districts, the sessions would be divided amongst 2–3 consultants in different specialties. It is possible that some Health Districts will be able to identify 'spare' sessions where consultants feel that they can take on additional responsibilities. However, there will need to be a significant increase in the number of consultant posts, many of which will involve dual accreditation (e.g. neurology and disability medicine).

Training of existing consultants in disability skills

Some existing consultants should be asked to take on designated disability sessions. It is hoped that where appropriate, the RHA will allow the doctors concerned to have a substantial period of study leave (perhaps 3–6 months spread over two years) in order to allow him/her to acquire the requisite skills. Full use should be made of the Demonstration Centres (see Appendix 6) and specialist units. The precise content of the training programme required will depend upon the experience of the consultant and the particular needs of the Health District.

Academic Posts

We have already discussed (page 168) the importance of research into a wide range of problems involving disability. We recommend that there should be an increase in the number of academic appointments which concentrate on Disability Medicine.

Senior Registrars

Full-time Posts

It is, at the moment, unclear as to how many senior registrar posts will be required in order to achieve the target of 30–35 full-time consultants in Disability Medicine/Rehabilitation. The number needed will become clear once Regions have drawn up their plans. In the short term, it will be necessary to train a number of doctors at senior registrar level, so that eventually these consultant posts can be filled. We envisage that some existing senior registrars in, say, neurology or geriatrics, may wish to move 'sideways' into Disability Medicine. Some of the doctors may wish to consider continuing practising in their primary specialty, whilst allocating the major part of their time to Disability Medicine. Once the posts are filled, then the number of replacements required annually will be small. The posts can be suitable for part-timers who have domestic responsibilities, but who are of high calibre and are otherwise suitably qualified. It is worth repeating that the short-term aim is to have in post, within five years, 30–35 consultants working mainly in Regional Centres whose principal (although not necessarily exclusive) commitment will be to Disability Medicine. The wide range of responsibilities listed on page 166 indicates that considerable flexibility in training and ultimate responsibility is both inevitable and desirable.

We wish to emphasise the importance that we place on the consultant posts in Disability Medicine. There will be considerable clinical and organisational responsibility, and in addition the Regional Units will have an important research function (see page 168). It is essential that high quality candidates be recruited.

Dual Training and Accreditation

A substantial number of posts involving dual training and accreditation should be set up—particularly in neurology, but also in general medicine, geriatrics and rheumatology. The relevant SAC's should be asked to draw up training standards as a matter of urgency. In some instances, there may be proleptic consultant appointments—the appointee being seconded to appropriate centres for training in Disability Medicine.

Clinical Assistants and Hospital General Practitioner Sessions

Continuity of care is an essential principle in the management of all chronic disorders. We strongly support the proposition that patients with serious disabling diseases should be dealt with by doctors who are trained and who know the patient concerned. Unsupervised follow-up by a succession of different junior doctors is not good clinical practice and is generally unacceptable. Clinical assistants and hospital general practitioners working in out-patient departments could provide very useful help in the running of Disability Services. This suggestion should be tried and evaluated.

Education of Medical Students and Postgraduates

Any discussion of education and training starts with the assumption that the management of disability is the responsibility of all clinical doctors. If this premise is accepted, then it follows that the subject should be taught routinely. We consider that in the education of undergraduates and postgraduates the management of disease and its consequences should receive similar emphasis as diagnosis and treatment. Some practical ways in which this might be implemented include the following:-

1. Disability should be routinely included when a 'case' is discussed—whether it be on a routine ward round, a clinical meeting, or a grand round.
2. Examinations should routinely contain questions relating to disability.
3. Disability management should be included in vocational training schemes for general practitioners.
4. Disability and its implications and management should be discussed in medical textbooks.

Training schedules should include visits to the Regional Disability Centre, a Hospice, a Spinal Injuries Centre, an ALAC, and one or more Demonstration Centres. The possibility of attaching undergraduates to a family, in which there is a disabled person, for the whole or part of their clinical course, should be considered. Training should reflect the emphasis being put on the management of disabled people in the community rather than in institutions.

Timetable

We are keenly aware of the poor state of Disability Services in many parts of England and Wales, and that the recommendations of previous reports (e.g. the Reid Report on epilepsy[51] and the Tunbridge Report (1972)[4] have been largely ignored. We think it important that action on Disability Services be taken in the very near future, and for this reason we are suggesting a timetable and a mechanism for ensuring that the Medical Disability Service is actually set up. In making our suggestions, we have tried to be realistic and it is fully appreciated that the recommendations cannot be implemented immediately.

Suggested Timetable

1. *July 1986*—publication of this Report.
2. *End of 1986*—the Report should have been read and digested by relevant organisations and authorities.
3. *1986–1987*—We would hope that during these years Regional and District Medical Advisory Disability machinery should have been established. By the end of this time there will be in existence a five-year plan for Regional and District Disability Services and the siting for Regional Disability Units should have been identified. The number of senior registrar training posts required for future service needs will have been agreed, and the number of new training posts approved by the relevant specialist advisory committees of the JCHMT.
4. *1988*—In all Health Districts, sessions in Disability Medicine will have been designated, with the responsibilities for the services outlined in this Report. A sufficient number of senior registrar training posts approved in Disability (Rehabilitation) Medicine (many of which are likely to involve dual approval with another specialty) will have been established to train the number of senior registrars required to fill those consultant posts which are to contain designated Disability Medicine sessions.
5. *Early 1990's*—Sessions in Disability Medicine should by now have been established and filled in all Health Districts, covering responsibility for the services outlined in this Report.

A major review of Disability Services in England and Wales should be taken in the early 1990's to ascertain whether the targets itemised above have been met. If there has been no substantial improvement in Medical Disability Services by the early 1990's, and if no improvement appears likely within the foreseeable future, then the option of establishing a much larger specialty of Disability Medicine such as exists in other countries, should be considered. However, this would almost certainly be much more expensive than the plan suggested here. It would probably involve the appointment of at least one full-time consultant in disability medicine/rehabilitation in each Health District.

Audit Function

We have attempted in this Report to draw up some professional standards for Medical Disability Services. We have suggested some audit criteria in certain specific areas (e.g. management of incontinence). It is obviously important to ensure that the relevant services are actually established, and the question arises as to how this is to be achieved.

Much of the responsibility for the provision of services will fall on Regional and District Managers. However, they will undoubtedly be under pressure from many other directions, and in times of financial stringency may find it difficult to implement the suggestions outlined in this Report. We think it likely that some form of external 'Watchdog' mechanism will be required to stimulate Managers and Health Authorities to make sure that Disability Services are actually established. It may be these checks should be made by some independent organisation which is not funded by the NHS. A number of possible organisations exist, including the local Community Health Councils, the Health Advisory Service, and The Consumer Association (which has published the *Drug and Therapeutics Bulletin* for many years).

It is envisaged that the independent organisation concerned would have access to annual disability reports produced by District and Regional Health Authorities. In addition, they should be in a position to undertake their own checks—e.g. how many Health Districts within the Region have a trained and designated senior nurse to run the Continence Service?

The precise way in which the performance of Disability Services is monitored will require further discussion. We hope that the monitoring function can be undertaken by existing organisations. We certainly think it highly desirable that a regular review should be undertaken, and published. We hope that the basic audit standards that have been suggested in this Report will prove useful as a basis for the review.

It may be asked why such a special system of review and audit is required for Disability. We would answer this question by pointing out that no high quality medical service has ever been established without a substantial core of doctors committed to the topic (e.g. geriatrics, renal failure, spinal injury, mental handicap, etc.). As indicated earlier in the Report—we are attempting to set up an effective Medical Disability Service with very few doctors committed whole-time to the subject. For this reason, and because of the long history of inaction, we think that the system of audit and checks that we have suggested is justified.

Costs and Resources

We recognise that additional expenditure will be involved in many Regions and Districts if the basic standards of provision of services and help for people with severe disabilities, set out in this Report, are to be achieved. The cost of providing good basic services must, however, be set against the enormous hidden costs of not providing them. In many Districts, these concealed costs are being borne by disabled people themselves or their carers, in terms of misery, deprivation, loss of access to facilities enjoyed by the rest of the population, and loss of choice and autonomy. There are, in addition, direct costs that fall on their families if they feel obliged to provide facilities which should be made available to them through an adequate Disability Service.

We have not carried out a survey to ascertain the level of present provision. There is no doubt that some Districts have good services and some District and Regional units are pioneers and leaders in the provision of certain facilities. However, there is evidence, set out at the beginning of this Report, that there is scope for considerable improvement. Without detailed knowledge of services currently being provided, it is not possible to identify what resources are required to implement our recommendations. For example, the recommendation that each Region should have at least one Regional Centre concerned with the assessment of very severely disabled people, the development of equipment and other forms of help, and research and training, may require little action from two or three Regions, some expansion of an existing Centre or Unit for some Regions, and major developments in others. Similarly, at District level, the recommendations concerning consultant sessions in Disability Medicine, or involvement in a Continence Clinic, may require no more than revising the contract of a consultant who is already carrying out the function. In some instances, however, additional consultant sessions will be required. Again, the method of funding will have to be discussed locally. For example—if there is to be a Disabled Living Centre in each Region—'joint' funding money may be available. Similarly, where equipment is not available through the NHS, private companies might loan samples of such equipment for trial. Voluntary bodies may be able to raise money for such equipment.

We are well aware that many disabled people require, and benefit from, 'acute' services and from many technological advances—e.g. joint replacement and kidney transplants. It is clear, therefore, that although there may be some need to transfer resources from the acute to the chronic sector, this process needs to be done with considerable circumspection. A balance has to be sought, and this will be helped, the Committee believes, if the present trend for all specialties to be involved in the management of disability arising from diseases within their purview, is further developed, and is backed up by explicit District and Regional policies.

Additional expenditure will undoubtedly be required, particularly for the establishment of Regional Centres. Three areas are currently given priority for funding by the NHS—mental illness, mental handicap, and the care of the elderly. We suggest that physical disability should be a fourth such area.

Our views on costs may be summarised as follows:-

1. There is clear evidence of major defects in the provision of medical services for patients with physical disability (see page 162).

2. We note the extraordinarily low level of current investment in medical disability—considering the extent and size of the problem. We have noted previously that virtually all other developed countries have substantial specialties of physical medicine or rehabilitation medicine incorporating considerable numbers of specialists whose main professional responsibility is the management of Medical Disability.

3. Physical disability is expensive, however it is managed. It is obviously important to ensure that money is spent effectively (e.g. money spent on the prevention and early treatment of pressure sores may avoid lengthy and expensive stays in hospital).

4. The Committee recommends that physical disability should be recognised by the DHSS as an area for top priority funding.

GENERIC SERVICES

The term Generic Services is used in respect of those services which are likely to be used by a variety of disabled patients, but are not necessarily the responsibility of a particular specialty. We have identified fifteen specific areas. It is recommended that Health Districts should have a policy on each of these topics. We have outlined some brief guidelines, and we hope that these will be helpful to Health Authorities as they draw up and check their plans for these particular areas. The policy guidelines have been written on the following principles:

1. There should be agreed professional standards of care and provision.
2. A system of audit should be established. The audit criteria should be unambiguous and be based on (1).
3. Clear-cut areas of responsibility should be defined (e.g. there should be a named consultant in charge of the District Continence Service).
4. Each Health District should keep records of certain specific problems (e.g. the number of significant pressure sores occurring in the District during the year).
5. As far as possible, the costs of each generic service should be identified and the details published in the Annual Report of the Health District.

The object of this section is emphatically not to produce a mini-textbook of Disability Medicine. The purpose is to demonstrate that it should be possible to set, and achieve, realistic standards of care in a number of important areas.

Disabled Living Centres (DLCs)

(Previously called Aids and Equipment Centres)

The provision of aids and appliances is one of the most important activities associated with a District Disability Service. Aids need to be appropriate both in their function in the timing of supply. This requires assessment facilities and an adequate supply procedure. Although most, if not all, occupational therapy departments, both in the NHS and in Local Authority Services, do provide assessment facilities, supply is often very limited and this may make the assessment irrelevant. There is obviously no point in recommending an aid if it is not likely to be provided reasonably quickly. Many Local Authorities only provide aids associated with a limited range of activities such as toileting, and there are often large gaps in what is available. Even when an activity is covered—the range of products offered may well be limited.

About a dozen DLC's have been opened in this country. Some Regions (e.g. the South West) do not have a single Centre. The Centres are usually large rooms (the size of one or two standard hospital wards) in which a wide range of equipment is on permanent display. To the best of our knowledge, no formal evaluation has been published but experience indicates that they are much used by both patients and staff. Examples of the kind of equipment displayed include various types of bed, chairs, walking aids, and non-statutory electric wheelchairs. Some Centres include some of the less sophisticated Possum equipment and British Telecom usually have a permanent display.

Ideally, all significantly disabled people should live within easy reach of a Disabled Living Centre. Initially there should be at least one Centre in each Region. Later, satellite Centres should be established in each reasonably sized town. We strongly recommend that adjacent Health Districts should combine their efforts so that there is a reasonable scatter of Disabled Living Centres throughout the country. Rural areas might need to be covered by a mobile unit.

The Disabled Living Centres would have two principal functions:-

1. To provide a permanent standing exhibition of a comprehensive range of aids and equipment with a supporting information service.
2. To act as an educational centre for staff, volunteers and patients.

Requirements for Disabled Living Centres

1. To carry as large and representative as possible a selection of aids and equipment.
2. To ensure that skilled professional advice (e.g. from nurses, occupational therapists, and physiotherapists) is available to disabled persons, their relatives and professionals visiting the Centre.
3. To provide adequate space for assessment, with privacy, of the client with the equipment.
4. To provide information on a wide variety of problems arising out of disability.
5. To act as a teaching centre for all classes of people dealing with disability, including such groups as architects and school teachers.
6. To gather information about the usage of aids and equipment and feed back information to manufacturers and other interested parties, including other Disabled Living Centres.

Conditions which need to be met when setting up Disabled Living Centres

1. They must be properly funded with contributions from both NHS and Local Authority Services, even where charitable funding is, or was, responsible for the establishment of the Centre. This activity is well suited for joint funding.
2. Whoever is appointed to be in charge of the Centre would need to have a wide experience of disability and its management. It might be appropriate to appoint a therapist with good managerial skills. Health Authorities might like to consider the possibility of having a doctor with designated sessions in the Centre.
3. The therapist appointments should be part of the local NHS or local Authority manpower establishments to ensure a proper career structure for the therapist.
4. The Centre could be situated in the grounds of a hospital, but this need not necessarily be the case and some successful Centres have been established elsewhere. An advantage of a hospital site is that staff can be easily rotated through the Centre. The Centre needs to be housed in adequate premises with good access and ample car parking space. There must be sufficient floor space to allow the display of aids and equipment, and for assessment.
5. A library and information service, including appropriate audio-visual teaching aids must be available. Ultimately, Centres need to be linked together and to be able to provide information for a computerised data base on aids, equipment and other aspects of disability.
6. Where it is appropriate that the aid or appliance is provided from public funds, these should be rapidly supplied and each Health District must establish with the appropriate Local Authority or Authorities joint aid stores which contain stocks of essential items such as commodes, which can be delivered to the client within 24 hours of being ordered.

Referral to the Centre should be encouraged from any source, including self referral by disabled people.

Housing, Housing modifications and Re-housing

The provision of residential accommodation is not primarily an NHS responsibility. However, it is clearly essential that, when a disabled patient (e.g. after an amputation or following a stroke) is fit for discharge from hospital—appropriate accommodation should be available. Our experience is that a substantial proportion of hospital beds are currently being occupied inappropriately by patients who are waiting either for re-housing or for housing modifications. As in other areas, the problem involves the need to provide a humane and caring service that is also related to economics. It seems likely that a more effective and efficient service could be provided at little extra cost.[52]

During the last few years there have been important developments in the housing field, including the setting up of a considerable amount of warden-supervised accommodation. However, important problems remain, and these are exacerbated by the complexity of the administrative system. Many different organisations are involved, including the Housing Department, Social Services and the NHS. In many instances, the administrative boundaries do not coincide. Other problems include the small stock of appropriate housing for the disabled, the fact that new houses are still being constructed without a downstairs toilet, and long and inappropriate delays in effecting housing modifications, such as the installation of stair-rails and the widening of doors for wheelchairs.

We think it important that each Health District should ensure that proper liaison exists between the hospital-based services (including the occupational therapy department), Social Services, the Housing Department, and the Voluntary Housing Associations. Some mechanism must be established which would allow housing modifications to proceed without prolonged committee wrangling.

Recommendations

The problems are complex and clearly cannot all be solved by the NHS. However, the NHS can, and should, make an important contribution.

We suggest the following:-

1. The Health Authority, Social Services and the Housing Authority should be represented on a joint committee (for example, we propose the District Disability Committee—see page 170), which would be concerned with all aspects of housing modifications for the disabled. Others could be co-opted as appropriate, including representatives of voluntary bodies and of disabled people themselves.
2. There should be a community physician with specific responsibility for housing matters (see page 168). He/she would have specific responsibility for allocating medical priorities for housing (this would be done after consultation with the appropriate clinician) and for other housing matters. He/she would probably be a member of the local Committee (see above) concerned with housing modifications for the disabled, and would be responsible for keeping records of the numbers of people with outstanding housing needs.

The Physically Disabled School Leaver

The problem of the disabled school leaver has been recognised for many years, but little action has been taken. The following quotation, taken from a *Lancet* annotation[53], commented:

> Handicapped people need sequential care. Yet doctors based in hospitals tend to see their illnesses as episodic; instead of taking a personal grip on follow-up, they often leave the patients to organise return visits. In general, the pre-school leaver and school-aged person gets adequate continued care, but not so the school leaver and the young adult. When these people pass from the care of the Paediatric Hospital and Paediatric Community Health Service, often there is no organisation waiting to take

over. Handicapped school leavers and young adults need follow-up services comparable to those that they had before they left school.

A recent important study was undertaken by a Working Party set up by the Regional Medical Committee of the S.E. Thames Regional Health Authority[54] which set out to investigate the medical needs of the physically disabled school leaver. It found very little published information on the subject. It surveyed all the Regional Health Authorities in England, Scotland and Wales, and found that the majority of Regional Health Authorities made no specific provision for, nor were investigating, this group of patients. It also found in its catchment area that:-

1. There were inadequate routine medical examinations for the disabled child, leading to lack of understanding of his future needs.
2. There was lack of liaison between the School Medical Services and those services which would be responsible for the care of the disabled child when he or she left school; this included the District General Hospital and the Primary Care Team. There was no adequate arrangement ensuring that the disabled child was referred to the appropriate discipline for ongoing adult medical care. The parents commented that there was lack of communication between them and the medical and caring services concerning the facilities that were available, such as appliances, wheelchairs, and finance.
3. Orthotic appliances and wheelchairs were frequently unsatisfactory.

Recommendations

Our recommendations are based partly on the findings of the S.E. Thames Working Party which suggested that a pilot study should be set up to assess the practical implications of its recommendations, and this we support.

1. Every Health District should have a written policy on the subject of the physically disabled school leaver.
2. Each District Health Authority should have a District Handicap Team for children. This team may be based in a Child Development Centre or in an out-patient department. The leadership of this multi-disciplinary team may be a consultant paediatrician with special experience in complex handicap, and/or paediatric neurology, but may be a community paediatrician.
3. Early in the year before leaving school—the physically disabled child should be the subject of a case conference at which there is medical (representing both the paediatric and adult services), educational, employment and Social Services representation. Whenever possible, parents should be encouraged to attend such conferences. The careers adviser and the DRO would also be involved.
4. At the final school medical examination of physically disabled school leavers there should be a full clinical examination and all the various disability problems would be reviewed. Hopefully—this exercise would be the culmination of a programme which began when the various disabilities were first recognised. If necessary, there should be referral to an appropriate consultant or Assessment Centre where the future needs of the disabled school leaver could be further explored.
5. An accurate Register of disabled school leavers in each Health District should be compiled, with a senior medical officer, perhaps the community physician, made responsible for organising and assessing the ongoing care of the individual disabled school leaver. It is suggested that each child should remain on the Register for three years. There should be liaison with the various services, medical, social, educational and employment.
6. The paediatric team at the District Hospital level should develop a transfer procedure that would ensure continuity of care for disabled school leavers who will require ongoing adult medical care.
7. Appliances and wheelchairs should be checked at regular intervals by a designated person.

Support Services for Younger Severely Disabled and Handicapped People

Every district contains an important group of severely disabled people below retirement age. Cerebral palsy is the principal cause of the disabilities that date from birth. Of those that are acquired, the principal causes are rheumatoid arthritis, multiple sclerosis, stroke, and injuries of the brain and spinal cord. A Royal College of Physicians' Report (about to be published) will give details of the epidemiology and discuss many aspects of the support and care which these people require[55].

In both public and voluntary sectors, there has been a tendency, until quite recently, to concentrate on the provision of residential care. It is now recognised that many people with severe disabilities not only live in the community, but prefer to do so, provided that adequate facilities exist. Improved community services have increased disabled people's living options, but much remains to be done[56]. A balance has to be maintained between the desire of many younger people not to be identified with the 'elderly' and needless duplication of facilities caused by the rigid segregation into two age-group categories.

If younger disabled people are to live in their own homes, then certain criteria need to be met:-

1. The house must be suitable. Necessary requirements may include fittings and space for wheelchair living, and for storage of special equipment, wide door-frames, ready accessibility to shops, post offices and bank, and special provisions to ensure safety.
2. The support services must be adequate, and when, as is usual, responsibility falls heavily on one or two carers, these people must not be subjected to unmanageable workloads. Provision of 'respite care' facilities is often crucial, as are day centres, residential homes, and a variety of hospital-based services.
3. Helping a disabled person to find an occupation and/or leisure activity is often highly desirable, and is frequently essential. Day centres and special workshops are a partial solution, but access to activities in which able-bodied people participate may be of even greater importance.
4. Changes in the underlying illness and/or disability may require reassessment of the subject's needs, e.g. a

flare-up of multiple sclerosis may suddenly lead to incontinence and inability to walk. Efficient assessment services must exist in the Health District.
5. Realistic contingency plans should be prepared in the event of crises such as the development of intercurrent illness by disabled people or their principal carers.

Recommendations

1. The Health District should keep an up-to-date list of the severely disabled people among its population (although it is acknowledged that the methodology for keeping such lists is yet to be properly developed). We suggest that this task could be undertaken either by one of the designated consultants in Disability Medicine, or by the designated community physician.
2. Support services for the young physically disabled would be a responsibility of the District Disability Committee. This Committee would be expected to produce an annual report for the District Manager. The report would include matters itemised below (3–6).
3. The stock of houses suitable for disabled people would be reviewed annually. A similar exercise would be conducted for houses under construction or planned.
4. There should exist, somewhere within or near to the Health District, some permanent residential accommodation for the most severely physically disabled patients. The adequacy, or otherwise, of this would be reviewed annually.
5. The residential accommodation could include provision for intermittent planned short-stay, and for coping with occasional crises. Periods of short-stay can often be combined with reassessment of existing problems and active intervention, if appropriate. Some carers are reluctant to allow their dependants to go into residential homes or hospitals, because they fear that the care will be less good than that provided at home. For these reasons, it is essential that the staff involved are present in sufficient numbers. There must be access to the various skills represented in a multi-disciplinary team (particularly including remedial therapists).
6. A Day Centre for younger disabled patients should be available.

Driving for the Disabled

Car driving is an essential constituent of independence for many people. The loss of the ability to drive a car can be one of the most devastating results of illness and injury. Additionally, the ability to drive a car is often the key factor in finding and keeping employment.

It is not always recognised that many patients with very severe disability are still able to drive suitably adapted vehicles. Thus, some tetraplegics and most paraplegics can drive. Some stroke patients can also drive. Problems that virtually preclude driving include severe athetosis, uncontrolled epilepsy, and hemianopia.

There have recently been considerable advances in technology which are enabling an increasing number of disabled people to re-start driving.

The majority of Health Districts do not provide specific assessment and training facilities for re-learning driving skills. However, a variety of options are available and these are listed in Appendix 3.

We recommend that each District Health Authority should review the local facilities for the assessment and re-training of patients for driving. We regard it as essential that each severely disabled patient in whom there is the slightest possibility of re-starting driving should be able to be assessed without undue difficulty.

Sexual Counselling

In these days when the media seem to assume that sexual athleticism is a part of normal personality—it is particularly important that the physically disabled should not be, or feel, at a total disadvantage. Doctors need to recognise that the vast majority of people—however badly disabled, have sexual needs[57].

Sexual dysfunction may occur in disabled people for a considerable number of different reasons. Particular problems are likely to be experienced by patients who have a urinary or supra-pubic catheter, colostomy, mastectomy, or severe facial disfigurement due to burns. The doctor is frequently in a position to offer helpful advice. Examples include:-
1. The treatment of depression, which is very common amongst disabled people, and is an important cause of impotence.
2. A knowledge of the effects of drugs may be helpful—particularly those that have an effect on potency.
3. Genetic counselling may be helpful, as some patients have an unspoken but unwarranted fear that they may pass on their disease (e.g. multiple sclerosis) to a child.
4. Many patients are anxious about the effect of sexual intercourse on their disease—this is particularly liable to occur in patients who have suffered a myocardial infarction or a stroke. Medical 'permission' to have sex can be important.
5. Analgesics, given before intercourse, may help patients with an inflammatory arthropathy. Counselling about positions, appropriately placed cushions and pillows, may be helpful in relieving discomfort.
6. Orthopaedic operations may be helpful in improving mobility (e.g. hip replacement in a patient with severe osteo-arthritis).

Some severely disabled patients are not capable of undertaking full sexual intercourse and may need advice on other ways of achieving sexual gratification.

Recommendations

1. Counselling advice should be available by someone who is knowledgeable both about sexuality and physical disability. Sometimes advice can be given by the general practitioner, or the hospital consultant. In other instances, more detailed help may be required, and this can sometimes be provided by a psychiatrist or psychologist who has developed an expertise in the subject. SPOD (Sex and Personal Relationships of the Disabled) is a voluntary organisation which provides information sheets and is sometimes able to provide counselling.

2. Patients who are being looked after in long-term residential accommodation should be provided with privacy and the opportunity for sexual contact, if this seems appropriate. (This provision is frequently not met in Units for the Younger Physically Disabled.)
3. The management of sexual problems in the physically disabled should be included in both undergraduate and postgraduate educational curricula.

Head Injury Services

In our experience, head injury services are frequently not well organised and there is considerable scope for improvement. This is occurring despite the obvious heavy economic cost, both to the State, and for individuals. These costs are incurred as a result of a number of factors, including the use of a considerable number of hospital beds, heavy use of staff time, and the consequences of unemployment. There is evidence that some patients are inappropriately placed. For instance, eight patients with head injury were found to have been in the acute wards of a London teaching hospital for up to two and a half years. Six of these were said to have potential for rehabilitation, but apparently had nowhere else to go[58].

The majority of Health Districts do not appear to have developed specific facilities for the management of disabled head injured patients. A similar position exists for the immediate post-traumatic period, although this matter is not strictly within the remit of this Report. In some hospitals, a neurosurgical or neurological opinion cannot easily be obtained. Head injured patients are frequently scattered among many different wards, thus making it difficult for the staff to acquire a reasonable level of expertise. Research in these circumstances is usually not possible, and the MRC Working Group[59] suggested that Assessment and Therapeutic Units should be established, where patients from several Districts could attend during the early months after the acute brain damage. There seems to be little evidence that Health Districts have acted on this suggestion, although a successful experiment, involving the admission of head injured patients to one unit, has recently been conducted at the Edinburgh Royal Infirmary[60].

There is some evidence that severe post-traumatic behaviour disorder can be lastingly improved by behavioural modification techniques[61]. The present position relating to head injury Disability Services has been summarised in two recent articles by Gloag[62].

Epidemiology

Field[63] estimated that there are about 7,500 major head injuries annually in England and Wales (34 per Health District of 250,000 people). About eight patients per Health District will be left with a severe permanent disability. The MRC Group on Stroke and Head Injury[59] estimated that 250 persons with head injury per 100,000 population (625 per Health District) are admitted to hospital annually. This figure corresponds reasonably well with the figure of 675 given in Table 2. The prevalence of serious head injury disability is probably about 150 per 100,000 population (375 per Health District).

Males outnumber females by about two to one. About 50 per cent of those admitted to hospital are under the age of 20 years. Road traffic accidents account for 33–37 per cent of head injured patients admitted to hospital[63].

The data relating to head injury disabilities are, in general, not of high quality and many are out of date. The problem is compounded by the changing patterns of injury resulting from a variety of factors, including seat-belt legislation. Head injury is an excellent example of a topic where up-to-date epidemiological information is required.

The Nature of the Deficits

Closed head injury produces a number of different, and overlapping, deficits. These may be roughly characterised as follows:-
1. Cognitive disorders. Patients may experience problems with learning, language, and memory. In addition, there may be difficulties with concentration and attention. These patients are frequently described as being ‘poorly motivated’.
2. Emotional difficulties. Irritability is common occurring in 63–71 per cent of cases, in a recent study by McKinley *et al.*[64] Mood swings and severe depression also occur.
3. Behavioural disorders. These include irrational, antisocial and disinhibited behaviour. A few patients become violent.
4. A proportion of patients have associated ‘physical defects’ including hemiplegia, speech disorders and epilepsy. Some have multiple fractures.

The profound effect of change in personality and mood on the relatives has become recognised[65]. Families tend to feel lonely, isolated and under stress for many years. In addition—there are obvious financial and economic consequences.

Many of these problems do not readily fall within the province of conventional psychiatry. Nonetheless, psychiatrists can have an important role to play. Neuropsychologists are trained in the assessment and management of many of the problems, but unfortunately very few are available, and most Health Districts do not have the benefit of their services.

Some patients with mild/moderate head injuries appear to recover quickly. However, some have intellectual and behavioural disorders which are not always recognised. These patients are in danger of losing their jobs if they return to work too early. A case can be made out for ensuring that they have at least one routine neuropsychological assessment.

Basic Criteria for Head Injury Services within an Average Health District

1. Every Health District should have a written policy for the management of head injury—both in the acute and the recovery phase. This should be updated regularly.
2. Statistics should be kept and reviewed regularly.

These would include the number of cases, severity, bed occupancy, and some measure of outcome. An estimate of head injury costs to the Health District should be made annually. We suggest that this information should be available in the annual Report of each Health District.

3. There should be a named consultant in each Health District who would be in charge of the Head Injury Recovery Service. He would have allocated sessional time for this work. It might also be appropriate to identify a consultant who would 'run' the acute head injury service. In some instances this job could be undertaken by the same consultant. Consultants from a variety of disciplines could be involved in the Recovery Service—including neurology, neurosurgery, psychiatry, and general medicine.
4. Patients in the acute stage (the first 1–2 weeks) require intensive nursing and are probably best cared for where there are other similar patients (e.g. those who are suffering the effects of an acute stroke).
5. Patients with significant head injury in the recovery phase (3–30 weeks) should be managed on a ward where the staff are fully trained. The Health District would probably not generate sufficient head injured cases to justify a specific ward dedicated to head injury. We suggest that these patients might be 'mixed' with patients who have suffered a stroke and other forms of allied neurological disability (e.g. multiple sclerosis). Patients with other disorders could be included in the rehabilitation ward—depending on the particular circumstances of the hospital.
6. Special facilities will probably be required for severe behavioural and emotional problems. The District Psychiatric Service should be actively involved with this group. Specific provision should exist for the management of noisy and aggressive patients.
7. Follow-up. There should be a system to ensure the effective follow-up of all patients with a significant head injury. A register should be kept of such patients. A clinical psychologist (preferably a neuropsychologist) would be the appropriate person to supervise the long-term care of patients with severe residual cognitive problems.
8. Employment. There should be facilities for the assessment and re-training of head injured patients.
9. Day care. Many patients with severe residual disability impose an enormous strain on their families. Some form of day care facilities for this younger group of patients is required. We do not think that it would be suitable for the younger patients to be managed in a geriatric day hospital.

Staff

We consider it essential that there should be a named consultant in charge of the running and development of the Head Injury Recovery Service. We also recommend that a psychologist should be appointed, and he/she would work closely with the consultant. Other staff will also need to be recruited and trained. This operation would include social workers, remedial therapists, and nursing staff.

Other Comments

Although the scale of the problems posed by head injury can be predicted from published surveys, there is insufficient evidence to identify the features that would constitute a model service. The sporadic placement of isolated patients in wards such as general surgical and general orthopaedic wards is widely regarded as inappropriate and has been a very considerable barrier to the conduct of clinical research in this field. The alternatives of a general rehabilitation ward in the District Hospital, or a District head injury ward, or a Supra-District (or Regional) Head Injury Unit have not yet been evaluated. There is an urgent need for research into the optimum organisation of the in-patient care of head injury rehabilitation and also into the techniques of cognitive and behavioural therapy employed in such units. It is essential that current Head Injury Services are evaluated and that a detailed system of audit is written into the operational policy of all head injury units.

Many patients are helped by Headway, a voluntary organisation concerned with the support of head injury victims and their families. Referral to Headway should be made in all appropriate cases.

Visual Impairment

We fully appreciate that the medical responsibility for problems of vision and hearing rests primarily with clinical departments of ophthalmology and otorhinolaryngology. But, as many patients with impaired limb function also have these problems, we thought it appropriate to include short sections on visual impairment and defective hearing.

Visual impairment is defined as corrected vision of lower than 6/18. The prevalence of visual handicap was found to be 520 per 100,000 population[66]. An average Health District of 250,000 would thus generate about 1,300 visually impaired people. Five per cent occur under the age of 16; 24 per cent in persons of working age, and the remainder in elderly and old people. Major causes are cataract, macular degeneration, diabetic retinopathy, glaucoma and retinal detachment.

Clearly, each Health District will require a detection service for preventable and treatable causes of blindness, such as glaucoma, cataract, and diabetic retinopathy[67]. This would involve the appropriate training of opticians and general practitioners. It is assumed, also, that each District will have ophthalmic services for the treatment of ocular disorders, for example, cataract.

In setting up a District Low Vision Service a close link will need to be maintained with the Social Services Department and with the various voluntary bodies. The suggested basic components include the following:

1. Each Health District should have a written policy.
2. There should be a consultant ophthalmologist with designated responsibility and sessions for the management of visual impairment. This consultant would be expected to act as a catalyst for the setting up and operation of the District Low Vision Service.

3. There would be an optician with designated sessions for the management of visual impairment.
4. A Low Vision Clinic, to which there would be open access, including by self-referral. The Clinic would provide an assessment and follow-up service for patients with visual handicap (both total and partial blindness), as well as other visual problems including hemianopia and diplopia. The Clinic staff would be expected to undertake home assessments and to keep in regular touch with the patients. They would give advice on simple measures to overcome visual problems, including those involving housing, good lighting and the use of contrast. The staff would be knowledgeable about the various types of magnifiers and telescopic lenses. Training in various compensatory techniques, including eccentric fixation for patients with macular degeneration, should be available. A supply of equipment should be available for display and trial by patients.
5. There should be a domiciliary service—so that elderly and immobile patients can receive advice in their own homes.
6. There should be a static display of equipment for the visually handicapped.

Hearing Impairment

Taking an average hearing level of 35 dB or more over the range 500–4000 Hz in the better hearing ear as significant impairment, the prevalence of such impairment is around 10 per cent in the adult population of the UK[39]. This figure rises to 75 per cent in those over 70 years old. Significant sensorineural hearing impairment in the newborn is found in approximately one case per 1000 live births. From these figures it would appear that hearing impairment is one of the most widespread of all physical disabilities having a marked effect on the ability to communicate socially and in the work place.

In most Health Districts, the Hearing Impairment Service will be organised by the local ENT Department. The following are some suggested criteria for the setting up and running of District Services:
1. There should be a written District policy for the management of hearing impairment.
2. There should be a named consultant with designated responsibility for hearing assessment and the provision of services for hearing impairment.
3. A Hearing Assessment Clinic should be held regularly within the Health District. Ease of access is important, bearing in mind that much hearing impairment occurs in elderly people.
4. There should be a fixed site Clinic. This could, if appropriate, be combined with other Disability Services such as those concerned with visual impairment. The Clinic would have several sound-proofed rooms for assessment. There would be a static display of equipment for the hearing impaired ('environmental aids'), for example visual doorbells, television listening devices and telephone amplifiers.
5. Clearly defined links should be established with the Social Services Department which is empowered to provide environmental aids.
6. Specific services should be available for the assessment and management of hearing deficit in small (pre-school) children. This will require an appropriately trained audiological scientist with access to the necessary equipment.
7. The Hearing Assessment Clinic should have facilities for the management of tinnitus.
8. Domiciliary Services. Many deaf people are living in residential homes for the elderly. Others are too disabled to easily attend clinics. There should, therefore, be a domciliary service for the assessment of hearing impairment and the provision of aids.
9. Each Health District should have a hearing therapist who would provide support and after-care for deaf people (for example, running classes and visiting people in their homes). The duties of the hearing therapist would include teaching lip-reading and sign language, and giving advice on environmental aids. The therapist would also be concerned with the education of institutional (old people's homes) and hospital staff in ways of communicating with deaf people.

Communication Aids

In each Health District there are a substantial number of patients who are unable to communicate in the normal way. Examples of communication disorders include: cleft palate, laryngectomy, bulbar involvement in motor neurone disease, and writer's cramp. Deafness is considered elsewhere. Many patients can be helped by electronic, or other devices termed 'communication aids'. Space-age technology has had a major influence in this area, and a large number of devices are available in a rapidly changing field.

A 1972 figure[68] of 1200 persons with impaired speech in a population of 250,000 (the size of the average Health District) is now thought to be an underestimate as a current review[69] suggests that the average Health District contains 800 persons with severe communication disorders with a further 1600 with less severe but significant problems.

Table 3. Medical diagnoses of 193 patients referred for, and recommended aids, at the Frenchay Communication Aids Centre in 1984/5.

	Number	%
Progressive Neurological Disease—Motor Neurone Disease, Parkinson's Disease and Multiple Sclerosis	68	35
Stroke	29	15
Cerebral palsy	29	15
Head injury	23	12
Miscellaneous (Including Laryngectomy and Glossectomy)	44	23

Communication aids are of particular use to patients whose language function is intact, but who, for some reason, cannot speak and/or write. They are not usually of use to patients with dysphasia, where there is a disturbance of linguistic ability.

The main communication systems in use are:

1. Sign and letter systems—e.g. Deaf Alphabet, Makaton, and Amarind.
2. Symbol systems—e.g. Bliss Symbolics (the patient points to a symbol to represent an expression).
3. Low technology aids to communication—e.g. pointing boards, pictures and word charts.
4. Medium technology aids—e.g. Canon Communicator and the Cambridge Lightwriter.
5. High technology aids for communication such as speech synthesisers and computers.

It is clearly important that patients should not be supplied with equipment which is inappropriate. Each patient must be individually assessed and this will involve an analysis of the precise type of communication defect, physical, visual and cognitive abilities, as well as his educational background and the prognosis of the underlying disease. The following are the suggested criteria for an adequate Communication Aids Service.

Recommendations

Assessment

It should be possible for all patients to be assessed by a speech therapist, and sometimes by other professional staff, including an occupational therapist, teacher, and sometimes an engineer.

Equipment

1. A wide range of equipment should be available for trial purposes.
2. The patient must be able to acquire the requisite equipment quickly. This is particularly important for patients with rapidly progressive disorders such as motor neurone disease.
3. Each patient and his family should be properly instructed in the use of the equipment.
4. Most patients require prolonged follow-up to ensure that their equipment is functioning properly and is the most suitable and up-to-date device. Different aids may be needed as the patient's environment or condition changes.

Hospitals

Sign, letter, and hospital picture boards should be available in wards and Intensive Care Units where there are patients with major communication difficulties—for example, after a tracheostomy. Assessment of each situation by a speech therapist is desirable.

Regional and District Services

Ideally, all patients should be within a reasonable distance of a Centre that can provide a Communication Aids Service. We recommend that each District should have the ability to undertake simple assessments. More complicated needs would be dealt with at a Regional Centre. Some Health Districts should consider establishing a mobile Communication Aids Service for patients in isolated rural areas.

Regional Unit

The Regional Unit should be situated in the speech therapy department in a major hospital. It would ideally have links with the university, occupational therapy, and an engineering department. It should be staffed by two full-time speech therapists, and there should be some occupational therapy sessions and appropriate clerical help. Each Centre would have the capacity to assess patients with a wide variety of communication disorders, and have available a wide range of communication aids to be tried out by each patient. In addition, the Centre would hold a limited number of aids available for immediate loan (whilst the equipment was being ordered from the appropriate firm).

Because many patients have to travel a substantial distance—we recommend that there should be three or four residential places (some of which could be in hostels) so that patients could attend the Communication Aids Centre over a number of days. The Regional Communication Aids Centre would have an important educational function and run courses for professional staff.

Services in Individual Health Districts

There should be a small Communication Aids Centre, offering specific expertise, somewhere within each Health District. In certain areas it might be possible for this facility to be shared between Health Districts. This limited Communication Aids facility would be contained within a speech therapy department. One of the speech therapists would be expected to have a sessional commitment to the subject, and there would need to be appropriate cover for sickness and leave. A small amount of equipment would be held—including the more commonly used communication aids. The District Communication Aids Centre should have a close link with the Regional Centre. At both Regional and District levels, the Communication Aids Centre could be combined with a Disabled Living Centre (see page 173).

Funding

The setting up of a Communication Aids Service will inevitably involve some expense. It is likely that some additional staff will be required. Equipment for demonstration purposes will need to be provided. We also think it highly desirable that each Communication Aids Centre should hold a 'bank' of the more commonly used aids. These could be loaned out to patients and recalled when no longer required. Some of the cheaper aids could be purchased by patients themselves.

Aids may be funded for individual patients by Social Services, Manpower Services Commission, or the Education Department. More frequently the patient would qualify for an aid, on consultant prescription, from the NHS. Each Health District will have to ensure that the necessary funds for these aids are available. A list of

Communication Aids Centres in England and Wales is given in Appendix 5.

Wheelchairs

The provision of wheelchairs is the responsibility of the Artificial Limb and Appliance Service (ALAC), which is directly responsible to the DHSS. In Scotland, this service has been incorporated into the Health Boards. An enquiry into the future of the ALAC Service has recently been published[50].

Wheelchairs are provided for people of all ages and sizes, and for widely disparate patterns of disease and disability. Data collected during 1973–1976 suggest that about two thirds of users of wheelchairs are above retirement age; 5 per cent are in paid employment; 5 per cent of wheelchairs are privately acquired, and one person in five will have two or more wheelchairs, with about 20 per cent requiring non-standard chairs[70]. Figures derived from the Scottish Home and Health Department[71] indicate that the number of chairs per 1,000 population increased from 1.2 in 1960 to 4.0 in 1970. Recently the Report on ALAC Services in England[50] found that 362,000 people have a wheelchair. Most elderly use a chair once a day; 15 per cent were totally reliant on the chair, using it on average for 64 hours a week. If these latter figures are accepted, the average group practice (with a list of 10,000) will have 72 persons with a wheelchair and there will be 1,810 persons with a wheelchair in each Health District with 250,000 people.

Audit

Fenwick[70] found that 9 per cent of his sample were 'not very satisfied'. Moreover, the longer a chair was used the more dissatisfied the user. Delay in the provision of wheelchairs was unsatisfactory for some people, 22 per cent waited for more than eight weeks.

The Association for Spina Bifida and Hydrocephalus told the recent ALAC Review Committee that nine out of 10 of all young people with spina bifida are in wheelchairs which are unsuitable, needing adjustment or repair. A representative from Mary Marlborough Lodge told the Review Committee that 10 per cent of severely disabled people have wheelchairs which are unsafe or completely unsuitable. A recent survey in Leeds[72] showed that 77 per cent of hospital wheelchairs were defective; 57 per cent had tyres which were soft or flat, and 61 per cent had defective brakes. Similar results were found by Young *et al.*[73].

Needs of Wheelchair Users

Wheelchairs are required to fulfil a number of functions, which include mobility within the home, within the immediate vicinity of the house including the garden, and also for longer distances, including travelling to and from shops and public houses. Many patients need to be able to travel in a car, and so will require a chair which can fit into the boot. Comfort is important; some patients are likely to spend a large proportion of the whole day sitting in their chair.

A number of patients have particular problems, such as:

1. Gross trunk instability—necessitating side supports.
2. Scoliosis, requiring a moulded cushion.
3. Hemiplegics, with only one functional arm and leg, have difficulty propelling the chair themselves.
4. Incontinence.

Common Problems

Experience indicates that problems with the Wheelchair Service include:

1. Slow provision.
2. Lack of instruction in usage and maintenance.
3. Difficulty with obtaining non-standard wheelchairs; it can take many months to get an appropriate chair.
4. Some chairs are unsuitable for the needs of the patient.
5. Maintenance of wheelchairs in hospitals seems to be particularly bad. Common problems include sagging seats and backs, worn brakes and unsuitable cushions.
6. Non-NHS chairs. There is at the moment, in most areas of the country, no way of obtaining an unbiased assessment for a non-NHS chair.

What should be done by Health Districts?

The Wheelchair Service is currently under review but we feel that some comments are desirable. We suggest that Health Districts might consider the following actions:

1. Set up a factual review of wheelchairs within the Health District. Information would need to be collected relating to the numbers of chairs, and the diseases encountered. It might be helpful to undertake an 'in depth' assessment of a sample of wheelchair users—examining such matters as:
   a) How well the various mobility needs are met—e.g. getting to the shops.
   b) General suitability for the patient's needs, e.g. foot supports, reclining back-rest, etc.
   c) How many wheelchairs each patient has, and whether this number appears to be appropriate.
   d) State of maintenance of the chairs.
2. Within the Health District there could be a Wheelchair Clinic attended by a doctor and an occupational therapist. This Clinic should cater particularly for patients with severe deformities who are likely to require special chairs. Advice on non-NHS chairs should also be given at such a Clinic.
3. Each Health District should ensure that chairs are maintained, and arrange for all wheelchairs to be reviewed at regular intervals—at least twice a year. Within each hospital there should be a nominated person with responsibility for the maintenance of hospital wheelchairs. The Health District should consider setting up a small workshop where all but major repairs could be effected.
4. Health Districts should make some provision for advice to be given on non-Statutory chairs—particularly electric chairs for outdoor use.

Children

Standard wheelchairs do not always fit the patient properly. Special chairs and modifications are needed in some cases. Chairs need to be changed frequently—because of the varying requirements of the growing and developing child. The wheelchairs are needed for use at home and at school, and the problems arising from transporting chairs between home and school should be remembered. The possibility of holding an occasional Paediatric Wheelchair Clinic should be considered.

Prosthetics and Orthotics

The term 'prosthesis' is applied to equipment which replaces a lost part (e.g. an artificial limb). The term 'orthosis' is applied to equipment which can be attached to the body (e.g. a splint or collar).

Amputations and Prosthetics

The ALAC (Artificial Limb and Appliance Centres) Review Committee[50] reported that in 1984 there were 51,130 (285 per Health District) lower limb amputees in England and Wales. There were 11,813 (60 per Health District) upper limb amputees in England and Wales. There were approximately 5,000 (28 per Health District) new amputees each year. The vast majority of patients had lost limbs as a result of peripheral vascular disease and 78 per cent of new patients were over the age of 60.

The vast bulk of patients are thus in the older age group, and they present with multiple problems, which include cardio-respiratory disease, arthritis, and sometimes the effect of a stroke. Ideally, these patients need the services of a multi-disciplinary team for the assessment and management of multifarious disability problems. The loss of the limb is only one facet of their overall problems.

At present, patients with amputations attend one of the DHSS Artificial Limb and Appliance Centres (ALAC) for fitting of the limb. There they are seen by a medical officer, employed by the DHSS, who acts as an interface between the surgeon at the hospital and the prosthetist at ALAC. This service was originally set up in 1945 to provide limbs for otherwise healthy war veterans, whose total number was in the order of 45,000. The Service now has to deal with a much larger number of older patients.

Unfortunately, the training of ALAC medical officers has not always kept pace with recent advances, and this criticism has been voiced by the medical officers themselves, amongst others. There is also widespread criticism of the delays in the provision of limbs, and the long waiting time the patients have to suffer at the ALACs. Another important aspect is that there seems to be evidence that British manufacturers have not caught up with the technical developments in artificial limbs that have occurred in the USA and in Europe. Also, while most ALACs are supplied by two or more firms providing prostheses under contract to the DHSS, there are several Centres where no choice is available as only one firm is represented.

Thus, there is considerable evidence that the services for patients who have sustained the loss of a limb are not, in general, satisfactory. It seems clear that the ALAC system requires modernisation. A Working Party was set up by the Secretary of State to look into the present ALAC Services and make recommendations, and this reported in January, 1986. The Report recommends the establishment of Regional Centres where primary amputations would be undertaken wherever possible. It also envisages that the ALAC facilities would be incorporated into a Regional Disability Centre where a whole range of disability problems could be catered for (including those of mobility, communication, continence and special senses). Prosthetists would work as part of the team at the hospital and a much wider range of artificial limbs would be available. In this way, hopefully, the present physical isolation of ALAC's would be overcome, and the Service would be largely incorporated into the overall disability facilities of the Region. These recommendations are very much in keeping with our own view, which we set out on Page 166.

Orthotics

Background

The number of orthotic devices (orthoses) is large. The commonest are special footwear, spinal supports, lower limb splints and abdominal appliances, e.g. trusses. Less commonly prescribed orthoses include elastic stockings, collars, breast prostheses and wigs.

Costs

The costs are apparently unknown, but must be very considerable. The British Orthopaedic Association (BOA) Engineering Subcommittee[74] estimated in 1978 that two million orthoses are prescribed commercially each year. The DHSS does not produce any consumption figures and Districts do not usually keep detailed figures.

Private contractors supply 97 per cent of orthoses; only 2.5 per cent are supplied by the very few hospital workshops in existence.

Dissatisfaction with Orthotic Services

Criticisms include:

1. Many orthoses are old-fashioned, ugly and ill-fitting.
2. The supply of orthoses is often slow and erratic—particularly when the device has to be specially made.
3. Lack of competition. Most Health Authorities deal with only one, or possibly two, commercial firms for the supply of equipment. They rely on the orthotist employed by the firms for advice as to the most suitable equipment. This orthotist thus becomes partly a salesman and partly a professional. Clearly, his main allegiance is likely to be to the company who employs him. So it is difficult for the patient to obtain independent advice regarding the most suitable orthosis.
4. There is no incentive for contractors to undertake research and development—hence the fact that many devices are clearly out-dated.

Short-Term Recommendations

Ideally, the whole Service needs to be re-organised. In the short-term, however, it will be necessary to work with the system as it exists, however imperfect. Only prescribers (and patients) can make sufficient demands on the sytem to ensure that the correct equipment is supplied on time. This implies particularly that the prescriber (i.e. the doctor) is properly informed and educated as to what should be available and provided.

Longer-Term Action

1. The majority of orthoses will be prescribed at District level and therefore it is clear that Districts themselves should employ some orthotists. This will mean substantially increasing the salary of orthotists so that the NHS can compete on equal terms with the private contractors. Some arrangement with private contractors will have to be made and proper audit arranged.
2. There should be a proper career structure for orthotists and prosthetists within the NHS. This will involve the development of training facilities. Action in this area is urgently required.
3. There should be Regional (and probably sub-Regional) Orthotic Centres with appropriately equipped workshops and equipment stores as an integral part of the Regional Disability Centre. At each major Centre there should be a display of the principal orthotic devices.
4. The Regional Centres would act as a major focus for staff training and for research (see below). Health Districts at a distance from the Centre might need to combine in the establishment of smaller satellite Centres which would be linked organisationally with the main Centre.
5. A consultant in disability medicine would be in charge of the Regional Orthotics and Prosthetics Service. He should be supported by other Health Service professionals, including physiotherapists, occupational therapists, and orthotists.
6. Each Region and District should publish records of the number and costs of orthoses supplied each year.
7. The DHSS should sponsor research into the development of new and improved orthoses, using modern materials and modular systems. The Regional Disability Centres, with their university links, would be the ideal sites for such research.

Urinary Continence Service

Incontinence is defined as a condition in which involuntary loss of urine is a social or hygienic problem and is objectively demonstrable. Thomas *et al.*[41] estimated that about 11,000 people (2,000 men and 9,000 women) could be anticipated to experience some degree of urinary incontinence in a Health District of 250,000. Of these, 1,000 would be under supervised care, but 10,000 would not be receiving any services. Incontinence increases with age. Common causes include prostatic disease in men, weakness of the pelvic floor in women, multiple sclerosis and mental subnormality.

The cost of incontinence, both to individuals and the community, is high. Exton-Smith *et al.*[75] showed that incontinence accounted for 25 per cent of nursing time on a geriatric ward. Frost and Sullivan[76] in 1979 estimated that the current UK market for incontinence pads and appliances was in the order of 12 million pounds. Incontinence is often a reason for patients not being accepted into residential accommodation.

General Principles for the Operation of a District Continence Service

1. Every Health District should operate a Continence Service. There should be a written District policy.
2. The Continence Service should be the responsibility of a designated consultant clinician with a particular interest and appropriate training in the subject. He would have one or more designated sessions. The consultant would frequently be a urologist, but in some cases could come from another discipline, such as gynaecology or geriatrics.
3. Each Health District should employ a full-time nursing sister as a continence adviser (see below). This person, together with the consultant, would together be responsible for running the District Continence Service.
4. The District Continence Service should be centred on a permanent site. This would be manned during working hours, and telephone enquiries would be welcomed. An automatic telephone answering service could be in operation at other times.
5. There should be a regular Continence Clinic in the Health District—held as often as necessary—perhaps weekly. This Clinic would have open access and patients would be able to refer themselves, or could be referred by any caring agency. The Clinic should be able to advise on all aspects of incontinence and it should be the focus of clinical assessment.
6. Each Health District should have a supply of basic equipment, including catheters, pads, and incontinence garments. These would usually be held at the permanent site.
7. There should be a permanent display of incontinence equipment—at the permanent site. This would include catheters and protective garments. Links would need to be forged with the local Disabled Living Centre, which could also have a static display, if this were felt to be appropriate.
8. There should be a plentiful supply of literature covering common topics such as the prevention and management of incontinence, and catheter care. This literature should be widely available—in the Continence Clinic and elsewhere.
9. There should be training and educational facilities for professional staff—nurses, doctors, medical students, and others. These facilities are probably best centred at the District base.
10. Urological Assessment. Facilities must be available for the expert assessment of bladder problems, usually by a urologist. It should be possible to get urodynamic studies undertaken without difficulty, in order to measure pressure changes in the bladder and urethra during the

passage of urine, and urinary flow rates. We envisage that the urodynamic facilities would be sited in the District Urological Centre, and they might need to be shared between two or more Health Districts. Current evidence is that about six patients per week will require a urodynamic investigation[77].

11. Surgery. Facilities for urological and gynaecological surgery will be available in most Health Districts as part of the routine health service. Facilities for the implantation of artificial sphincters should be available in a limited number of Centres, as implantation is a very specialised technique.

Staffing

Medical

As mentioned above—we are suggesting that there should be a consultant in each Health District with designated sessions in the management of incontinence. He would be responsible for:

1. Organising and running the Service (in conjunction with the nursing sister).
2. Producing, and updating at regular intervals, plans for the District Continence Service.
3. Running a regular Continence Clinic in the District Continence Centre.

Consultant time would need to be available for urodynamic studies.

Clinical Assistant

We suggest that the consultant input could be augmented by one or two clinical assistant sessions per week—depending on local needs.

Nursing

The nursing involvement will require a proper structure. There is now an Association of Continence Advisers with a particular responsibility for Continence Services. A high standard of training is now recognised as being necessary and the English National Board have established a Continence course to promote this (ENB Continence Course 941).

It is suggested that each Health District would employ a full-time nursing sister (Grade 1) or nursing officer, as a continence adviser. He/she would supervise the hospital and community care of incontinent patients. The continence adviser would work in close collaboration with the responsible medical staff (particularly the consultant) and would require support from resource nurses who have also undertaken some specialist training. A close link should be established with the Stoma Service in the Health District.

Other Staff

The help of a secretary and a medical physics technician would be required (the latter to help with the running of the urodynamic assessment facilities).

Stoma Care Service

The term 'stoma' in the present context, is applied to any artificial external opening into one of the abdominal organs. For practical purposes, the principal stomas are ileostomy and colostomy for a bowel diversion, and urinary conduit. Other forms of stoma include gastrostomy, jejunostomy, pharyngostomy, and suprapubic urinary catheters.

The number of permanent ileostomies for colitis is falling.[78] There is a male-female ratio of 1:1.2. The number of permanent colostomies for rectal cancer has remained constant—5,510 operations in 1968 to 5,635 operations in 1980, with a male-female ratio of 1.5:1. Thirty per cent of all stomas are constructed in emergency situations—ileostomies for acute fulminant ulcerative colitis and a variety of stomas for intestinal obstruction, trauma, and other causes.

Prevalence data are sparse. Devlin[45] estimated that there are about 100,000 patients in England and Wales with a permanent colostomy (i.e. approximately 4–5 per general practitioner and 400 per average Health District). The comparable figures for permanent ileostomy is probably about a tenth of this figure. The number of urinary conduits per Health District is not known.

Rubin[79] estimated that the average cost of equipment for colostomy patients was £496. This works out at about £200,000 annually for each Health District (assuming 400 patients with a colostomy per Health District). There will be a smaller sum for patients with other types of stoma. In addition, there are substantial staffing costs (mainly nursing and medical).

Present Pattern of Stoma Care

Most stoma care in the United Kingdom is hospital-based. It has grown up in a haphazard manner, often with one surgeon showing a specific interest in the problem, and perhaps having a clinical assistant to help him run a Stoma Clinic with dedicated nurse involvement. Stoma nurses are generally hospital-based, though extension of their activities into the community is increasing. Since the early 1970's—Stoma Nurse Training Centres have provided the ENBCC 216 Clinical Course in Stoma Care Nursing for registered general nurses, usually lasting eight weeks, and including the physical, physiological, psychological and social aspects of stoma care. Some Centres provide a shorter (eight day) course on principles of stoma care (ENBCC 980); this course is available for all qualified nurses.

The improvement in stoma care in the last 8–10 years has largely been the result of endeavours to train nurses to give them a greater facility for counselling and to provide them with reasonable hospital premises. There appears to be a deficiency in the service—principally in the lack of continuity that often occurs between the hospital, where the stoma is created, and the community, where it has to be managed. The small number of stomas in the average general practice means that few general practitioners have any direct knowledge of stoma care and are not usually in a position to provide detailed advice.

The voluntary organisations, the Ileostomy Association, the Colostomy Welfare Group, and the Ileal Conduit Association, have provided much support.

Other Background Information

There is widespread recognition of the enormous psychological consequences of the establishment of a stoma. Patients require continuing advice about a number of problems, including types of equipment, irrigation of the bowel, avoidance of leakage, skin protection, avoidance of odour, diet, clothing, alcohol intake, and taking of medication; employment, foreign travel, sexual activity and pregnancy. A number of complications can occur, and these need to be dealt with effectively. These complications include leakage, sore skin and contact dermatitis, herniation around the stoma, prolapse of the stoma, depression and impotence. Particular problems are likely to be encountered by patients who have visual problems, defective arm function (e.g. after a stroke), and where there is intellectual deterioration. Considerable expense is involved in the running of a Stoma Service. Appliances are expensive and should be used effectively.

Suggested Criteria for the Operation of a District Stoma Care Service

Our recommendations are very similar to those which we have made in relation to the District Continence Service. Indeed, we consider that there is some scope for fusing the two Services. Certainly, we think that it should be possible for the two services to use the same building and probably the same secretarial staff.

The overall objective is that all stoma patients should have pre- and post-operative counselling, informed and sympathetic medical and nursing care, and support. The general practitioner should have an important role. He is usually the first person to whom the patient turns when problems arise[80].

1. Every Health District should operate a Stoma Care Service. There should be a written District policy.
2. There should be a consultant with designated responsibility for the running of the Stoma Care Service. The consultant will need to give enthusiastic and informed leadership. He will also need to develop links with other departments, including psychiatry and dermatology. The consultant input might need to be augmented by one or two clinical assistant sessions per week.
3. There should be a full-time stoma care nurse, with the grade of sister. She, together with the consultant, would be responsible for the operation of the District Stoma Care Service. There is probably need for a part-time staff nurse to provide back-up.
4. The Stoma Care Service should have a permanent Centre within the Health District (possibly shared with the District Continence Centre).
5. It will probably be desirable to run a regular Stoma Clinic—this would be the responsibility of the designated consultant and the nurse.
6. Within the Stoma Centre there should be a room which is comfortable, so that the medical staff can sit and counsel patients and their relatives about stoma care. There is also need for a room where clinical examinations can be undertaken, and this room would require sluice facilities so that patients can be taught how to change appliances and, for instance, irrigate a colostomy.
7. All patients undergoing elective colostomy or ileostomy should receive pre-operative counselling. They should be put in touch with patients in whom the operation has been satisfactorily completed. In this way, confidence may be gained.

The Stoma Centre should hold a supply of basic equipment and have a permanent display (as discussed in relation to the Continence Service), and also a supply of literature for lay and professional staff. The Centre would be used for training and teaching. Careful records should be kept of the incidence, prevalence, and type of stomas within the Health District, and this information should be published in the annual Report of the Health Authority. There should be a record of equipment used, and of the costs of running the Service.

Pressure Sores

Pressure sores are life-threatening, unpleasant, socially undesirable and expensive. It was estimated in 1973 that hospitals were treating some 60,000 sores annually at a cost of around 60 million pounds[81]. A survey in Glasgow found that 8.6 per cent of patients in hospital or community care had tissue damage, from superficial skin effects to necrosis and cavitation[82]. A review of four published hospital surveys found the prevalence of pressure sores to range from 3 to 8.8 per cent[83]. Thus it appears that at least 5 per cent of patients in general hospitals will have one or more sores. A survey of all patients in the Bath Health District showed a prevalence of sores in hospital patients of 6.17 per cent compared with 1.27 per cent for patients in the community[84]. Pressure sores are an increasing problem with age so that the number of patients at risk will inevitably increase.

Suggested Criteria for Operation of a District Service

The current evidence indicates that pressure sores are common, frequently preventable and probably are costing each Health District hundreds of thousands of pounds each year. On both humanitarian and economic grounds we recommend that every Health District should have a properly organised and audited Pressure Sore Prevention and Treatment Service set up with the following outline criteria—

1. There should be a written District policy for the prevention and management of pressure sores.
2. There should be a designated member of the medical staff in the District General Hospital who should be knowledgeable about medical aspects of pressure sore prevention and treatment.
3. There would be a designated senior member of the nursing staff who would have responsibility for running the District Pressure Sore Service (in conjunction with the designated member of medical staff). This person should be properly trained and informed on all aspects of

pressure sore prevention and management, and would be available to advise and train hospital and community staff. He/she should know about the various types of weight dispersal cushions and beds.
4. Training. District and ward nurses would be expected to have training in pressure sore prevention and management; this would be one of the responsibilities of the designated nurse.
5. A regular survey of the incidence and prevalence of pressure sores, both in the hospital and in the community, should be undertaken. The annual cost (particularly of admission to hospital) to the Health District should be calculated and reported in the District annual Report.
6. Patients at risk of developing pressure sores should be identified routinely by means of a pressure sore prediction system, e.g. Norton[85]. There is an argument to be made for some form of enquiry whenever a major pressure sore occurs. The subject of pressure sore prevention has been discussed by Scales[86].
7. Plastic surgery help should be available when required.
8. There should be a readily available supply of beds, mattresses, and weight dispersal cushions. The most commonly available equipment should be available for demonstration and trial.

APPENDICES

1. Definitions Used Throughout The Report

Medical Disability Services—This term is used in the Report in relation to NHS Services that are required in order to prevent or minimise disability resulting from the disorders under discussion.

Rehabilitation—The term 'Rehabilitation' has been used widely for many years and has proved to be virtually incapable of definition. We have not found it possible to entirely avoid using this term. However we broadly agree with the 'Mair Report'[5] which stated:

> Rehabilitation is a concept whose meaning varies from the precise to the vague, according to individual taste, practice and experience. In the past, it was frequently taken to mean the application of physical methods of treatment aimed at restoring local function and general fitness after disease or injury. In recent times, a much broader meaning has been given to the word, which now implies the whole complicated process of the restoration of individuals rendered unfit from any cause to a degree of social and economic independence, within the limits imposed by any residual restriction of function. For the purposes of this report, the following simple definition was adopted:
>
> Rehabilitation implies the restoration of patients to their fullest physical, mental and social capability.

2. Prevalence of Physical Disability

Estimates of the prevalence of physical disability and of the numbers of disabled people in the population vary according to the criteria used. In an effort to standardise definitions, the World Health Organisation has introduced a Manual of Classification—the International Classification of Impairments, Disabilities and Handicaps (ICIDH)[87]. This classification, based on the work of Wood[88], distinguishes between impairment, disability and handicap as different dimensions of the consequences of disease.

Impairment is defined as any loss or abnormality of psychological, physiological or anatomical structure or function; *disability* as any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being; and *handicap* as a disadvantage for a given individual, resulting from an impairment or a disability that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual. The following example illustrates the differences between these three definitions:

A building labourer of 40 undergoes a below-knee amputation as a result of an accident. The term 'impairment' refers to loss of part of the leg. The disability refers to his inability to walk quickly or to climb ladders. The handicap refers to the fact that he can no longer undertake his previous work because of his inability to climb ladders.

To date, no results have been published of a survey of a large, defined population which identified impaired, disabled and handicapped people using the definitions and criteria of the ICIDH. It was necessary, therefore, to estimate numbers using data from surveys which used different definitions (Table 1).

3. Evaluation of the Service Provided by Mary Marlborough Lodge

(Based on a Report to the Oxford Regional Health Authority; January, 1985, by G. M. Cochrane and G. I. Hughes).

Mary Marlborough Lodge (MML) was established in 1960 as a Disabled Living Research Unit by the National Fund for Research into Poliomyelitis and other Crippling Diseases. In 1964 it was absorbed into the National Health Service. The Unit was under the direction of Dr. Philip Nichols from 1964 until his death in 1979. Dr. George Cochrane was appointed Medical Director in 1980.

The principal function of the Unit is the assessment of severely disabled persons, and the provision of appropriate equipment, which is not readily available in other Centres. A wide variety of skills are available, and there is a comprehensive Workshop.

A study was undertaken of all new in-patients and out-patients attending MML during the three month period September to December 1983. In this period 81 new patients were seen and 42 (52 per cent) came from outside the Oxford Regional Health Authority. Patients were referred from as far away as Cumbria and Cornwall. Extrapolation of the figures for one year gives 325 new referrals in a year. Further examination of these figures shows:

1. The Oxford Regional Health Authority itself generated a substantial number of patients during this study period—equivalent to 156 annually.
2. Each year 168 patients will have come from beyond the Oxford Regional Health Authority catchment area. This indicates that the need is not being met by the other Regions.

What Diseases are Involved?

Details of the five principal diseases are given in Table 4.

Table 4. Medical diagnoses of 81 patients seen at MML over a three month period.

Diagnosis	Number	%
Cerebral palsy	19	24
Amputees	10	12
Multiple sclerosis	10	12
Motor neurone disease	9	11
Spina bifida	7	9
Miscellaneous	26	32

Miscellaneous disorders (none of which comprise more than 5 per cent of the total) included stroke, muscular dystrophy, skeletal conditions (e.g. osteoarthritis) and spinal cord injury.

Principal Problems

Many patients were referred with a mixture of problems; 33 per cent of patients presented with five or more difficulties. Table 5 gives details of some of the main problems.

Recommendations Made and Advice Given

In all 412 recommendations were made—the median number for a single patient being five (range 1–13). Table 6 gives details of some of the recommendations.

Particular Skills Available at MML

The staff are fully trained in the understanding and management of the problems of patients with multiple handicap. Particular skills include:

1. The making and fitting of orthoses.
2. Customised seating.
3. Wheelchairs—advising on special types, alterations, and controls.

Table 5. Patients' problems at MML (% of total).

Problem	%
Wheelchairs and seating	58
Pain/weakness/joint contracture	44
Difficulty with transferring	36
Activities of daily living	30
Mobility	26
Psychological	19
Housing	16
Communication/speech	6

Table 6. Recommendations made at MML.

Recommendation	Number
Wheelchair/seating	79
Medical	66
Transfer aids	51
Orthoses	27
Exercises, including limb training for amputees	26
Small aids	26
Mobile arm supports	7

4. Special items of equipment for personal care and recreation.
5. Moulded thermoplastic trunk supports.
6. Design and mounting of special switches for patients with absent or defective limb control.
7. Mobile arm supports for patients with severe proximal arm weakness.
8. Gardening for the severely disabled.

Audit

An audit was conducted of the patients who had attended MML. At follow-up after three months, 90 per cent of patients remained satisfied with the help that they had received. More than 80 per cent of the principal professional carers were satisfied with the service, information, and recommendations made.

4. Assessment and Training Facilities For Re-learning Driving Skills

Assessment of the possibilities for driving must be carried out by an expert in this field whose recommendation as to suitability to drive will be accepted by the Licencing Authorities. Assessments can be provided by some branches of the British School of Motoring. If there is no local school prepared to offer help, enquiries should be made to the British School of Motoring, Disabled Drivers Section, 81/87 Hartfells Road, Wimbledon, London SW19. Assessment and driving instruction courses, and advice on conversion, are given at the Banstead Place Mobility Centre, Park Road, Banstead, Surrey, SM73 3LE, who specialise in the difficult case. Enquiries for driving test and licencing should be addressed to the Medical Officer, the Medical Advisory Branch, Department of Transport, Oldway Centre, Orchard Street, Swansea. To claim exemption from Road Fund Tax on account of disability, enquiries should be addressed to the DHSS, Department DSB, 7a Warbreck Hill, Blackpool.

The introduction of Mobility Allowance has marked a considerable advance for disabled patients who cannot use public transport. The criteria are strict and laid down in Leaflet L1211/April 1983. They comprise inability or virtual inability to walk or to make the exertion needed to walk, creating a serious risk to life or health. The allowance is £20 per week, and this may be spent in any way preferred. Application is made on this form obtained from the local DHSS Offices and forwarded to the Mobility Allowance Unit, Norcross, Blackpool, FY5 3TA, to arrange a medical assessment. If an award of Mobility Allowance has been made, clients are eligible for the Motability Scheme. The Motability Scheme offers leasing or hire purchase of a vehicle, or purchase outright. Leasing can be a most effective method, for a small car can be leased for seven years for a down payment of as little as £13.00 and the Mobility Allowance assigned to Motability. There is an annual insurance premium of £80. All servicing costs and repairs are paid by Motability, except the first four new tyres and with a mileage ceiling of 10,000 miles a year. Outright purchase is possible on low interest rates, but adaptations duty and comprehensive insurance must be paid. VAT exemption, however, is allowed on adaptations at competitive rates. There is a Disabled Drivers' Insurance Association address; 292 Hayle Lane, Edgware, Middlesex. It is well worth joining the Disabled Drivers Association, which offers benefits and advice. Its address is: Ashwell Thorpe Hall, Ashwell Thorpe, Norwich. Motability's address is: Boundary House, 91/93 Charterhouse Street, London EC1.

Orange Badge Scheme

Most people in receipt of Mobility Allowance will qualify for the Orange Badge, which allows special parking. This is issued by the Social Services Department. Application should be accompanied by a medical report. The system has been much abused, and the issue of the badge is strictly controlled.

5. Communication Aids Centres

BRISTOL
Assistive Communication Aids Centre,
Speech Therapy Department,
Frenchay Hospital,
Bristol BS16 1LE.
Tel. 0272-565656 Ext. 2140.

LONDON
Communication Aids Centre,
(Speech Therapy)
Charing Cross Hospital,
Fulham Palace Road,
London W6.
Tel. 01-7482040.

NEWCASTLE
Communication Aids Centre,
Royal Victoria Infirmary,
Queen Victoria Road,
Newcastle-upon-Tyne.
Tel. 0632-325131 Ext. 455.

SANDWELL
Communication Aids Centre,
Sandwell Health Authority,
Boulton Road,
West Bromwich,
West Midlands B70 6NN.
Tel. 021-553 0908.

WALES
Communication Aids Centre,
Rookwood Hospital,
Fairwater Road,
Llandaff,
Cardiff.
Tel. 0222-566281.

LONDON
Communication Aids Centre,
Wolfson Centre,
Mecklenburgh Square,
London WC1N 2AT.
Tel. 01-8377618.

6. List of Demonstration Centres

CENTRE	CONSULTANT IN CHARGE	SPECIALITY
1. Addenbrooke's Hospital, Hills Road, Cambridge CB2 2QQ.	Dr J. R. Jenner	General Rehabilitation Rheumatology
2. Crawley District General Hospital, West Ham Drive, Crawley, Sussex RH11 7DH and Horsham Hospital, Hurst Road, Horsham, Sussex.	Dr J. A. Hicklin Dr A. Martin Dr R. Bailey	General Rehabilitation Geriatric Rehabilitation Geriatric Rehabilitation
3. Derbyshire Royal Infirmary, London Road, Derby DE1 2QY. and Derwent Hospital, Derby, Kings Lodge Younger Disabled Unit.	Dr C. F. Murray Leslie	Rheumatology & Rehabilitation Orthotics & Disability Research Rehabilitation Engineering & Disabled Driving Centre

4.	Devonshire Royal Hospital, Buxton, Derbyshire.	Dr E. P. Copp	Rheumatic Disease: Rehabilitation of Severe Locomotor Disorders
	Young Disabled Unit, Withington Hospital, West Didsbury, Manchester M20 8LR.	Dr P. H. Merry	Arthritis, Stroke and Geriatric Rehabilitation
	Wythenshaw Hospital, Southmoor Road, Manchester M23 7LT.	Dr H. N. Misra	General Rehabilitation Rehabilitation after Trauma
5.	Garston Manor Medical Rehabilitation Centre, Garston, Watford, Herts. WD2 7JX.	Dr A. P. H. Randle	Residential Rehabilitation
6.	Guy's Hospital, St. Thomas Street, London SE1 9RT.	Dr R. Grahame	Rheumatology Rehabilitation of Locomotor Disorders
7.	Medical Rehabilitation Unit, RAF Headley Court, Leatherhead, Surrey.	Group Captain A. F. Tredre	Orthopaedic Rehabilitation Rehabilitation of Hand and Head Injuries
8.	Kings College Hospital, Denmark Hill, London SE5.	Dr E. B. D. Hamilton	Rheumatology and General Rehabilitation
9.	The London Hospital, Whitechapel, London E1 1BB.	Mr B. Roper	Rheumatology: Joint Replacement Surgery and Orthopaedic Rehabilitation
10.	Mary Marlborough Lodge, Nuffield Orthopaedic Centre, Headington, Oxford OX3 7LD.	Dr G. M. Cochrane	The Severely Disabled: Daily Living—Rehabilitation Research Unit
11.	Medical Rehabilitation Centre, 152 Camden Road, London NW1 9HL.	Dr F. R. Middleton	Day Rehabilitation Centre
12.	Middlesbrough General Hospital, Ayresome Green Lane, Middlesbrough, Cleveland TS5 5AZ.	Dr J. Fordham	Rheumatology: Rehabilitation of Locomotor Disorders
13.	Norfolk & Norwich Hospital, St. Stephens Road, Norwich NR1 3SR.	Dr W. G. Wenley	Rehabilitation Rheumatology Sub-Regional Service
	Mundesley Hospital, Mundesley, Norfolk.	Dr. J. R. Burrows	
	St. Michael's Hospital, Aylsham, Norfolk.	Dr N. Cardoe	
14.	Pinderfields General Hospital, Aberford Road, Wakefield, Yorks WF1 4DG.	Dr A. A. Burt	Neurology
15.	Robert Jones & Agnes Hunt, Orthopaedic Hospital, Oswestry, Salop SY10 7AG.	Prof. B. T. O'Connor	Orthopaedic Rehabilitation Rheumatology
16.	Royal East Sussex Hospital, Cambridge Road, Hastings, Sussex.	Mr S. C. Gallennaugh	Orthopaedic Surgery Joint Replacement Surgery and associated problems of rehabilitation
17.	Royal National Hospital for Rheumatic Diseases, Upper Borough Walls, Bath, Avon BA1 1RL.	Dr A. K. Clarke	Rheumatology
18.	Regional Rehabilitation Unit, Salisbury General Hospital, Odstock Branch, Salisbury, Wilts. SP2 0BJ.	Dr R. M. Ellis	General Rehabilitation
19.	Westminster Hospital, Dean Ryle Street, London SW1 2AP.	Prof. D. A. Brewerton	Rheumatology and Rehabilitation
20.	The Wolfson Medical Rehabilitation Centre, Atkinson Morley's Hospital, Copse Hill, Wimbledon, London SW20.	Dr D. G. Jenkins	Neurological Rehabilitation
21.	Fazakerley Hospital, Longmoor Lane, Liverpool L9 7AL.	Dr E. Williams	Rheumatology and Rehabilitation; Neurology
22.	Royal National Orthopaedic Hospital, 234 Great Portland Street, London S1N 6AD. Stanmore Branch, Brockley Hill, Stanmore, Middx. HA7 4LP.	Dr C. B. Wynn Parry	Pain Rheumatological Rehabilitation Orthopaedic Rehabilitation Neurological Rehabilitation

6. List of Demonstration Centres (continued)

CENTRE	CONSULTANT IN CHARGE	SPECIALITY
23. Royal Devon & Exeter Hospital, Heavitree, Exeter, Devon.	Dr J. S. Watkins	Geriatric Medicine and Rehabilitation in the Elderly
24. Humberside National Demonstration Centre in Medical Rehabilitation of the Elderly, Kingston General Hospital, Beverley Road, Hull HU3 1UR.	Dr J. McV Loudon	Geriatric Medicine
25. Northwick Park Hospital, Watford Road, Harrow, Middx. HA1 3UJ.	Dr A. Frank	Childhood and Adult Rheumatic Disorders. Provision of a Service to the Health District including Domiciliary and Coronary Rehabilitation
26. Newmarket General Hospital, Exning Road, Newmarket, Suffolk CB8 7JG.	Dr B. Hazleman	Rehabilitation of Rheumatic Diseases
27. Rehabilitation Unit of Western District of Leeds, plus Younger Disabled Unit, plus William Merritt Aids Centre. Correspondence to: Leeds General Infirmary, Great George Street, Leeds LS1 3EX. Tel. 0532-4322799.	Dr M. Anne Chamberlain	Rheumatology and Rehabilitation
28. Queen Mary's Hospital, Roehampton, London SW15 5PN.	Dr I. H. M. Curwen	Rheumatology and Rehabilitation
29. Rookwood Hospital, Fairwater Road, Llandaff, Cardiff CF5 2YN.	Dr J. C. Chawla	Neurological Rehabilitation Neurosurgical Rehabilitation

7. Some Useful Addresses from the Disability Rights Handbook

British Sports Association for the Disabled: Hayward House, Barnard Crescent, Aylesbury, Bucks. HP21 8PP. Tel. 0296-27889.
DEMAND (Design and Manufacture for Disability): 99 Leman Street, London E1 8EY. Tel. 01-488 9869.
Disabled Drivers Association: Ashwellthorpe Hall, Ashwellthorpe, Norwich NR6 1EX. Tel. 050-841 449.
Disability Alliance: 25 Denmark Street, London WC2H 8NJ.
Disabled Living Foundation: 380–384 Harrow Road, London W9 2HU. Tel. 01-289 6111.
Disablement Income Group: Attlee House, 28 Commercial Street, London E1 6LR.
Leonard Cheshire Foundation: 26–29 Maunsel Street, London SW1P 2QN. Tel. 01-828 1822.
Motability: Boundary House, 91–93 Charterhouse Street, London EC1 M6BT. Tel. 01-253 1211.
National Bureau for Handicapped Students: 40 Brunswick Square, London WC1N 1AZ. Tel. 01-278 3450/3459.
PHAB: Tavistock House North (2nd Floor), Tavistock Square, London WC1H 9HX. Tel. 01-388 1693.
John Grooms Association for the Disabled: 10 Gloucester Drive, Finsbury Park, London N4 2LP. Tel. 01-802 7272.
Radar: 25 Mortimer Street, London W1N 8AB. Tel. 01-637 5400.
REMAP (Rehabilitation Engineering Movement Advisory Panels): 25 Mortimer Street, London W1N 8AB. Tel. 01-637 5400.
Riding for the Disabled Association: Avenue 'R', National Agricultural Centre, Kenilworth, Warks. Tel. 0203-56107.
Royal National Institute for the Blind: 224 Great Portland Street, London W1N 6AA. Tel. 01-388 1266.
Royal National Institute for the Deaf: 105 Gower Street, London WC1E 6AH. Tel. 01-387 8033.
SPOD (Sexual and Personal Relationships of the Disabled): 286 Camden Road, London N7 0BJ. Tel. 01-607 8851/2.
Winged Fellowship Trust Holidays for Disabled People: Angel House, Pentonville Road, London N1 9XD. Tel. 01-833 2594.

Note: The Disability Rights Handbook is published each November, and has a comprehensive list of organisations, including those for particular conditions. It is available from the Disability Alliance.

SUMMARY

This Report puts forward a plan for the management of physical disability. It recognises that the subject is administratively complex and that many different organisations, including Social Services, are involved. The Report concentrates upon the role of the NHS in general, and upon the position of physicians in particular.

The Report starts by reviewing some of the evidence that services for the physically disabled are in many respects deficient. The evidence includes accounts given by disabled people themselves, the fact that many patients are 'followed-up' by inexperienced junior hospital staff, and the lack of agreed standards of provision in many areas (see Section 3) such as pressure sores, incontinence, wheelchairs, and the care of head injured patients. Disabled people between the ages of 15 and 65 are identified as requiring particular attention (Paediatric and Geriatric Services probably cater reasonably well for the young and the old). The 'size' of the problem of physical disability is examined. For instance, the average Health District (of 250,000 persons) will contain 25,000 physically disabled people, of whom 6,250 will be severely, or very severely disabled; and 1,800 will have a wheelchair; 40 per cent of disabled people are under the age of 65.

The Working Party on Rehabilitation Medicine of the Royal College of Physicians (1978) was of the opinion that rehabilitation is an integral part of total patient care, and is therefore the concern of all clinicians. The implication of this view is that Medical Disability Services should be developed without a major specialty of Rehabilitation or its equivalent, such as exists in most western countries. The Report explores the practical implications of this principle in the light of evidence discussed above.

Research (Page 168)

There is a need for a major expansion of research. Priority areas include epidemiology (particularly of head injury), the physiology of recovery, and the evaluation of equipment, rehabilitation techniques, and different ways of providing care. We recommend particularly the setting up of units capable of investigating the many problems of neurological disability. Regional Disability Units should be important Centres of research.

Regional Services (Page 166)

Some Services will need to be organised at Regional level, some at District level, and, in other situations, two or three Health Districts may combine in the setting up of services. The principles involved are intended to be firm enough to provide a minimum standard of care, but sufficiently flexible to allow for local circumstances.

We recommend the setting up of a Regional Disability Unit in each Region in England and one in Wales. We agree with the ALAC Review Committee that it would be sensible to incorporate the functions of the ALACs into the Regional Disability Units. Each Unit would form close links with Health Districts in its Region, and would form an important focus for the development of Regional Disability Services. The Units would have research and training functions and would be attached to a major District General Hospital with, ideally, links with the medical school and/or university. Each Unit would include on its staff the equivalent of two full-time consultants in Disability Medicine. The functions that we envisage for the Unit are as follows:

1. The assessment of severely disabled patients—especially those with multiple problems.
2. Orthotics, Prosthetics and difficult Wheelchair problems. Appropriate workshops would be provided.
3. The Unit could include a Disabled Living Centre, where a wide variety of equipment is available for inspection and trial.
4. The Regional Communication Aids Centre could be included.
5. The Unit might incorporate the management of certain specific clinical disorders, such as spinal injury and/or stroke disability.

District Services (Page 166)

1. *Information.* Health Districts should maintain an up-to-date data base of facilities for the physically disabled locally. A booklet should be produced annually.
2. *Generic services.* Certain specific services (e.g. a District Continence Service) should be provided and minimum standards should be attained and maintained.
3. *Domiciliary Services.* Each Health District should ensure that there are adequate numbers of therapists and district nurses who are properly trained in the management of disability. These community workers should collaborate closely with general practitioners.
4. *Medical Staffing.*

(a) *Consultants.* We recommend that in each Health District there should be 10–11 disability sessions held by two or more consultants practising in a variety of specialities (e.g. general medicine or neurology). Each consultant would have certain specific designated responsibilities.

(b) *Community Physicians.* We see an important role for a community physician who would be involved in collecting and analysing data and acting as a co-ordinator for certain clinical groups (particularly the disabled school leaver). We envisage that the community physician and consultants with Medical Disability sessions would work closely together.

(c) *General practitioners.* The GP has a vital co-ordinating and supportive function. This role is particularly important if the principle of maintaining disabled people in the community, rather than in residential care, is to be implemented. He should be able to 'plug in' easily to the wide variety of Disability Services provided within and outside the District.

Generic Services (Page 173)

The term Generic Services is used in respect of those services which are likely to be used by a variety of disabled patients, which are not obviously the responsi-

bility of a particular specialty. We have identified 15 specific areas:
1. Disabled Living Centres.
2. Housing, Housing Modifications and Re-Housing.
3. The Physically Disabled School Leaver.
4. Support Services for Younger Severely Disabled and Handicapped People.
5. Driving for the Disabled.
6. Sexual Counselling.
7. Head Injury Services.
8. Visual Impairment.
9. Hearing Impairment.
10. Communication Aids.
11. Wheelchairs.
12. Prosthetics and Orthotics.
13. Urinary Continence Service.
14. Stoma Care Service.
15. Pressure Sores.

For each of the 15 areas we have suggested some basic professional standards which can be used as a basis for audit. We anticipate that the establishment of these Services will make it easier for doctors to care effectively for disabled patients under their care. Some of the principles underlying these Generic Services include the following:
1. There should be a written agreed District policy.
2. There should be a series of simple audit criteria.
3. Areas of defined responsibility should be identified (e.g. a Consultant in charge of the District Continence Service).
4. For certain services (e.g. Continence and Stoma Care) there should be a permanent District site where clinics are held, equipment is available for trial and inspection, and where advice can be obtained and training given.
5. A plentiful supply of literature should be available for patients, relatives and professional staff.
6. Domiciliary facilities should be available for housebound patients relating to, for example, visual and hearing impairment.
7. Certain basic records and statistics should be kept (e.g. the number of pressure sores, and patients with a significant head injury occurring within the Health District).

Medical Staffing (Page 170)

The Committee makes its recommendations on the principle that each doctor is responsible for dealing effectively with the disability problems of patients under his care. Nonetheless, it is felt that certain defined consultant sessions in Disability Medicine should be established:

1. *Consultant Posts*

a) *Posts with Disability as the principal component.* We recommend that each Region should have two full-time, or equivalent, consultants practising in disability medicine. Their main work would be at Regional Disability Units.

b) Each Health District should have 10–11 consultant disabiity sessions which would be held by two or more consultants from a variety of specialties. We anticipate that these consultants would seek dual accreditation (e.g. neurology and disability medicine).

c) In each Health District there would be a community physician with specific responsibility for certain aspects of Disability Services.

3. *Training*

A certain number of 'one-off' senior registrar training posts will need to be created in order to achieve a target of 30–35 full-time consultants in disability medicine within five years. Once these consultant posts have been filled, then there will need to be a smaller number of permanent senior registrar posts.

A substantial number of posts involving dual training are required (e.g. general medicine and disability).

The SAC's are asked to draw up training schedules as a matter of urgency.

Undergraduate and Postgraduate Education (Page 171)

The management of disability should be an integral part of all undergraduate and postgraduate training programmes. The practical implications of these recommendations include ensuring that examinations include questions relating to disability, and the inclusion of the subject in vocational training schemes for general practitioners, and in medical textbooks.

Organisation and Administration (Page 169)

We consider that there should be a formal Committee structure at both Regional and District levels. Annual reports would be drawn up by Disability Committees, and these would be submitted to District and Regional managers. The Committees would also be expected to draw up short- and long-term plans.

Timetable (Page 171)

WE suggest a five-year timetable. At the end of this time the principal recommendations in this Report should have been implemented. A major review of Disability Services should be undertaken in the early 1990's.

Audit (Page 172)

This document contains a number of audit standards by which the quality of Disability Services can be judged. 'Internal' audit would be conducted by District and Regional managers. 'External' audit would probably need to be undertaken by some outside body not funded by the NHS.

Costs and Resources (Page 172)

Because existing patterns of care vary from Region to Region, no attempt has been made to 'cost' the proposals outlined in this document. We make the following points:
1. The current level of investment in Medical Disability Services is low.
2. It is essential to ensure that money is effectively spent (e.g. prevention and early treatment of pressure sores may be cheaper than lengthy stays in hospital).
3. Physical disability should be recognised by the DHSS as an area for top priority funding.

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Book Review

Interferons: Their Impact in Biology and Medicine edited by Joyce Taylor-Papadimitriou. Oxford University Press 1985. 148 pages. Price £20 (hardback), £10 (paperback).

It is just over a quarter of a century since Isaacs and Lindenman described the interferons (IFN)—a group of proteins produced by cells in response to virus infection. This concept was not immediately accepted, some critics even suggesting that the material found should really be called 'misinterpreton'. However, the skilled work of Isaacs and his colleagues has established beyond doubt the importance of IFN. These substances are involved in human immune responses, in growth regulation and differentiation, and may also affect the growth of malignant tumours. There has been an exponential increase in the amount of research done in the last few years, much of it due to the more ready availability of a host of interferons, and it is one of the most exciting fields of biology at the present time.

Joyce Taylor-Papadimitriou is to be congratulated on reflecting this sense of excitement in her book. Clinicians will, of course, be primarily interested in the role of IFN in viral infections (presented by Scott), and in malignant disease (described by Nethersole and Sikora), but they would be missing one of the most lucid accounts of the human immune system and the role of interferon if they do not read Balkwill's chapter on the regulatory role of IFN in these responses.

The early chapters on the genes of the IFN system and their expression are somewhat hard going for those not in the field of molecular biology, but good summaries and conclusions help to pave the way for understanding later chapters. It would be an advantage in a future edition to have an introductory chapter on the different forms of interferon and their derivation, in order to help the general reader.

The object of the book is to stimulate thought about IFN and to help with the institution of new trials. The chapters are well referenced, and undoubtedly the book will be of great help to those doing research on IFN. Wisely, no great claims are made for its clinical efficacy in either virus diseases or cancer. The editor stresses that careful, controlled clinical trials will be necessary to find the role of IFNs in therapy. The number of chapter authors working in institutions primarily concerned with cancer research indicates where experimental hopes have been over the last few years. Nethersole and Sikora have provided an excellent brief review of the present position with regard to interferons in malignant disease. There is no doubt that in a limited number of cancers a beneficial effect on tumour growth may be seen, and in one very rare leukaemia, hairy cell leukaemia, it may be that IFN will establish itself as a treatment of choice. As they emphasise, however, it is the insight that may be obtained into tumour cell growth and its regulation that may produce the greatest benefit from the study of the biology of IFN.

There is no doubt that in whatever field of medicine one's interest lies, IFN, but more particularly its biology, will be increasingly relevant during the next decade. This book provides a good introduction to the subject and a basis for further reading. J. S. MALPAS.