ABC of 1 to 7

H B VALMAN

THE HANDICAPPED CHILD

	Rate per 1000 children
Mental handicap	25
Cerebral palsy	4.6
Epilepsy	6.4
Asthma	23
Blindness	0.25
Hearing defects	
Mild usually due to glue ear	40.0
Moderate (need hearing aid)	2
Severely deaf	1

The parents of a child who may be abnormal will want to know what is wrong, the treatment required, the prognosis, and the chances that a future child will have a similar problem. The experience of managing handicap or chronic disability will vary from doctor to doctor. Although about 5% of preschool children in a general practice have a chronic disability most have asthma or behaviour disorders. Nevertheless, there are many more children who may be brought by parents worried about developmental variations and learning difficulties, and a general practitioner can help parents considerably if he has an interest in and experience of the normal range of abilities.

A general practitioner is likely to see one new case of Down's syndrome every 10 years and a new case of cleft palate once every 20 years. A district unit for the assessment and care of handicapped children may have about 60 with cerebral palsy and 80 with mental retardation without cerebral palsy attending the centre.

About one in 1000 children have severe hearing loss and are managed mainly at special centres, but many children in every general practice have fluctuating or persistent hearing loss due to secretory otitis media. Severe visual defects are often associated with other abnormalities, but defects in visual acuity which could be corrected by spectacles often pass undetected for long periods. Although a family doctor may have only two children with epilepsy in his practice a consultant paediatrician may be following up about 50 in the general outpatient clinics.

Chronic handicaps affecting the central nervous system or special senses are rare in general practice; they are not simply medical problems and for adequate assessment need the help of workers from several disciplines, including social and educational. Most of these children are now referred to their local district paediatrician. This group will be discussed in detail because management illustrates important aspects of child care.

Discovery

Abnormalities may be noted at birth—for example, Down's syndrome or myelomeningocele. A neighbour, relative, or friend may notice that an infant is not performing like her own child of that age and may point it out to the mother. A doctor may discover that the child has developmental delay at a local routine assessment clinic, during a consultation for an acute illness, or while following up children of low birth weight. The mother may have read books on child development and realise that her child is not behaving normally. Unless a doctor discovers the disability there may be a considerable delay before the mother summons up the courage to seek appropriate advice. If the mother suspects that her child is abnormal she should be referred to a consultant paediatrician or a clinical medical officer with special experience in assessing handicap. Mothers are usually correct in their assessment. Once a mother has shown this initiative any delay may make her distrust later medical advice.

First consultation

Patients are referred to consultant paediatricians by family doctors, but the community paediatrician (clinical medical officer) receives some referrals from health visitors or community clinics by agreement with family doctors. The family is seen by the consultant alone at the first visit, or at most by three members of the staff (consultant, psychologist, and physiotherapist), as the presence of a large team may prevent the mother from expressing her worries. After taking the history and examining the child the doctor should tell the parents the possible diagnosis. He should explain that this is a provisional diagnosis and that relevant blood, urine, or radiographic tests will be carried out and assessments performed by various members of the staff in the day care unit. These results will be discussed with the parents in the presence of all the therapists at the second visit, so that a programme of management can be agreed.

Assessment and treatment

The appropriate members of the team can then be selected and asked to see the child before the second visit. Most of the children will need to be seen by an ophthalmologist and also need a hearing test. Only a minority need the opinion of a neurologist. As the physiotherapist, occupational therapist, and speech therapist often assess a child together they learn part of each others' jobs and can advise whether help from another discipline is indicated. Therapists often taken two to three hours to assess a child, taking the opportunity to assess him during a meal and at play as well as by formal tests. Assessing patients without having a part in their further management can be frustrating for therapists, but they are seeing more patients in their own homes, nurseries, and schools to advise on practical management. Formal exercises in hospital are avoided and an attempt is made to teach mothers, nursery supervisors, and teachers how to help the child. A community occupational therapist who also has a session in hospital may help considerably. Taking children out of school for treatment in hospital has the disadvantage of accentuating the stigma of being different.

Second consultation

Just before the family is seen on the second visit the therapists and consultant meet to plan the child's management. A "key worker" should be selected to avoid duplicating treatment and give the parents a person to latch on to and telephone in a crisis. The whole team then sits down with the parents and the consultant discusses the diagnosis, management, and prognosis. The parents should be given an ample opportunity to discuss their worries and they often bring a list, which saves forgetting important points. Some parents may wish to discuss these points with the consultant alone as they may be intimidated by the large team.

In some units the medical social worker sees the parents between the two visits but in others she sees them at the second visit or afterwards. Most families with handicapped children need social work support at some stage. All parents should be offered a consultation with a geneticist even if they are not contemplating a new pregnancy in the near future.

Parental reactions

Initially young parents or parents of first-born children may have difficulty in persuading a doctor that the child is abnormal. This may delay the diagnosis or cause frustration and considerable subsequent hostility to all medical advisers. Parents deserve to know the truth about their child and all aspects of the prognosis should be discussed honestly. Most parents are shocked when the diagnosis is discussed and feel detached. The reality of the symptoms may be denied, the doctor's competence questioned, and the parents may search for an alternative opinion. Both parents should be present when the diagnosis is explained so that they can support each other. They usually need to be seen again shortly afterwards because they may be too stunned at the initial interview to understand what is being discussed and may later deny that important aspects were mentioned at all.

The parents become increasingly dispirited and lacking in self-confidence and mourn for the normal child they have lost. They may blame themselves for the child's problem and feel guilty about their inability to protect him from the event or come to terms with reality. Some parents deny the diagnosis for some time but others continue to do so for several years. Some become unable to understand anything but the simplest information. A social worker may help to interpret to the parents aspects of the diagnosis and management which they do not understand.

Both parents may develop symptoms of grief: depression, sighing, crying, preoccupation with the child, loss of appetite, and sleep problems. Often these symptoms lead to irritability and the parents may be hostile towards the child, the medical staff caring for him, and even their other children. The other children may develop behaviour problems because their parents appear remote and uncaring.

Training junior staff in the management of handicapped children is difficult. Most registrars can see a child only over a year, and families usually need support for much longer. Confidence in the doctor and ability to discuss problems with him is attained only after a long period and is not easily transferred.

Early and appropriate treatment helps to support the parents and is therefore indirectly beneficial to the child. More research is needed to determine the effects of various treatments on the long-term prognosis. Research is also needed into the effects of the treatments provided by physiotherapists, occupational therapists, speech therapists, social workers, and child psychiatrists, so that they may use their resources rationally. At present some of their work is interchangeable.

Parents' groups

There are several associations of parents of children with various handicapping diseases and many have local branches. Most associations raise money for research and enable parents with children with similar problems to make best use of local resources and discuss mutual problems. Social workers usually have a list of the addresses of local groups. Some groups are arranged by the social services department in each district and may be organised by a social worker with the help of an occupational therapist or physiotherapist.

Education

For preschool children with handicaps the opportunity playgroup has great advantages. Up to a third of the children are handicapped and the rest normal. Children with and without handicaps can mix, and the parents of handicapped children are brought together for mutual support. These groups have a high staff:child ratio, and an occupational therapist or physiotherapist should have a regular commitment to advise on the management of handicapped children. The object is to enable the child to reach his maximum potential and to enable him to attend the most suitable local school. Close observation in this setting, a knowledge of local facilities, formal testing by an educational psychologist, and discussion with the parents will help to make the transition to a school. Local education authorities have to provide some form of education for handicapped children from the age of 2 years and to provide the necessary transport.

Most children with handicaps will go to normal primary schools and an increasing number with learning problems will also go there. For example, children with Down's syndrome always used to go to special schools, but a few could be admitted to normal primary schools as a pilot scheme. This would require more staff with special training and abilities together with extra facilities for small classes. Some education authorities may find it difficult to find the extra resources or change staff attitudes.

Regional centres

Regional centres for the assessment and care of the handicapped have many advantages, including the ready availability of paediatric ophthalmologists, neurologists, and ENT and orthopaedic surgeons. But parents may find it difficult to travel to a regional centre often. The strengths and weaknesses of local facilities for treating and educating handicapped children are usually known best by the paediatricians and clinical medical officers working locally. If they are in clinical charge of the patient they are likely to press for the provision of local services. Assessment without appropriate care increases the frustration of parents with a handicapped child.

Dr H B Valman, MD, FRCP, is consultant paediatrician, Northwick Park Hospital and Clinical Research Centre, Harrow.

The second part of this series will continue in the new year, after which the whole series will be published in book form.

Some useful addresses

Association for Spina Bifida and Hydrocephalus
Tavistock House North
Tavistock Square
London WC1
Tel: 01-388 1382

British Diabetic Association
10 Queen Anne Street
London W1M 0BD
Tel: 01-323 1531

The Coeliac Society of Great Britain and Northern Ireland
PO Box 181
London NW2 2QY
Tel: 459 2440

Cystic Fibrosis Research Trust
5 Blyth Road
Bromley
Kent BR1 3RS
Tel: 01-464 7211

Disabled Living Foundation
346 Kensington High Street
London W14 8NS
Tel: 01-602 2491

Invalid Children's Aid Association
126 Buckingham Palace Road
London SW1 W9SB
Tel: 01-730 9891

MENCAP (National Society for Mentally Handicapped Children)
117-123 Golden Lane
London EC1Y 0RT
Tel: 01-253 9433

Muscular Dystrophy Group of Great Britain
35 Macaulay Road
London SW4 0QP
Tel: 01-720 8055

National Deaf Children's Society
31 Gloucester Place
London W1H 4EA
Tel: 01-486 3251/2

The Royal National Institute for the Blind
224-8 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

The Spastics Society
12 Park Crescent
London W1N 4EQ
Tel: 01-636 5020