MEDICAL EDUCATION

Teaching junior staff about caring for handicapped children

L Rosenbloom, N Marlow

During the past 10 years the care of children with handicaps has assumed an increasingly important role in paediatric practice. This is reflected in the recent expansion and reorganisation of the community child health services and of training programmes and professional examinations. Caring for families who have a handicapped child entails a delicately balanced partnership between parent, child, and a potentially large multidisciplinary team, including a paediatrician. Within this team the doctor is not necessarily the most important person in terms of the family's perception of their child's care nor in terms of the delivery of that care, which distinguishes it from most other areas of paediatric practice. This paper reviews the important areas of philosophy and practice underlying the training we offer to junior staff in the care of children with long term neurological disabilities.

The context of training

A number of important principles form the background to our programme. First, trainees must be aware of the balance between investigational, diagnostic, and therapeutic paediatric medicine on one hand, and family relationships, children's needs, and parental adjustment on the other. They must also recognise the gulf between ideal and practical provision of community and other support services. Secondly, they must appreciate that handicapped children and their parents relish continuity of care with a doctor with whom they have an established relationship. Thirdly, the trainee should be aware that the main contributions to the management of handicapped children are normally made by people other than doctors, and—lastly—that care for such children only rarely takes place within the hospital.

Content of training programme

Within these contexts a mixture of experiences should be provided to make the paediatric trainee aware of:

- (i) the range of neurological disabilities that may have to be faced in childhood and adolescence;
- (ii) the range and usefulness of the clinical and developmental examinations and investigations that are available in paediatric neurology;
- (iii) the fact that most childhood neurological disorders are not curable, implying that their management includes counselling of parents and an understanding of family relationships;
- (iv) the range and relevance of provisions for children with disabilities provided by health, educational, and social services;
- (v) the therapeutic options available for outpatient and inpatient management;
- (vi) the role of medical and other staff in providing services for handicapped children—what is feasible, how they work together, and the view that other staff have about the role of the paediatrician (including the trainee); and
- (vii) the changing needs of children and their families as they get older, as their disabilities evolve, and available resources change.

We take the view that the best way to offer the trainee appropriate experience is to encourage them to take part in the sequential procedures that are followed when children are referred.

SERVICE BACKGROUND

Most children with neurological impairments who live within the Mersey region are at some time seen in the department of neurology of the Royal Liverpool Children's Hospital Alder Hey. This offers a comprehensive range of inpatient and outpatient services, including the regional child development centre, in which multidisciplinary services are available for the assessment and care of disabled children. Junior medical staff who are part of the regular rotation through the department comprise a part time senior registrar in community paediatrics, a senior registrar in paediatrics (for one year), a paediatric registrar (for six months), and a senior house officer (for three months). During the tenure of each post an attempt is made to make sure that the doctor takes part in the whole range of services provided. Thus the care of the children is placed within the context of the individual's training programme.

REFERRAL

All referral letters are seen by one of us, and

Regional Child Development Centre,
Royal Liverpool Children's Hospital
Alder Hey,
Eaton Road,
Liverpool L12 2AP
L Rosenbloom
N Marlow

Correspondence to:
Dr Rosenbloom.

where it seems that the child may have a chronic neurodevelopmental disorder the referral information is discussed at a weekly multidisciplinary meeting. This meeting is attended by staff from both the child development centre and the community service. Decisions can therefore be made for individual cases about which staff members will see the child and family at their first visit. The fact that community based staff take part from the start allows for the provision of additional information from, for example, the child's school or day nursery, and also ensures as far as possible that duplicate assessments do not take place.

The exposure of paediatric trainees to the range of staff and services at these meetings—medical, physiotherapy, occupational therapy, teaching, psychology, and social work—is often their first introduction to multidisciplinary practice.

INITIAL CONSULTATION

There are many advantages to the initial consultation being undertaken by a trainee, and this is done whenever possible. The need for a full social and family history is stressed: if this information is not obtained at the time when relationships are first established it may be difficult to obtain later. In the first weeks of an attachment to the department the trainee is joined by the consultant or senior registrar towards the end of the consultation, during the formulation of a list of problems, and the planning of the initial management. This frequently entails making decisions about investigations and referrals to staff in other disciplines for assessment and treatment, and is therefore a good time to introduce both families and junior staff to the concept and practice of a multidisciplinary team.

Whenever possible a full discussion of the implications of the child's disorder is postponed. This delay is usually possible because of the obvious need for further information and the more subtle but equally acceptable need for a more established relationship with the family. This is especially so if, as frequently happens, only the mother attends the first consultation. After the first attendance parents of some of the children take home a questionnaire on which they can indicate their concerns and record a developmental profile.

For the family, subsequent contacts at the child development centre may be with medical or other staff, although joint appointments are encouraged. It is helpful for children needing a range of assessments to be seen in multidisciplinary clinics, either informally or in more formal team sessions. These appointments take place in a clinic and observation room to which other interested staff, including those referring the child, can be invited. This forum is a most valuable training exercise as the sectarian interests of each member of staff are pooled during the series of assessments, and a plan of care or continuing assessment developed, which has to be communicated to the child and family. Again the peripheral role of the paediatrician in terms of continuing treatment and care is

emphasised although as a doctor, coordinator and—on occasions—investigator, an important contribution can be made.

DIAGNOSTIC CONSULTATION

Although by implication the arrangements to investigate a child's neurological state or to arrange further assessment by the multidisciplinary team assume there is a continuing problem, there is a need for explicit discussion about the nature and implications of the child's disabilities with members of the family. It is preferable to have only one other member of staff present during this discussion, and for training purposes this should be a junior doctor. On occasions it is essential, however, that other key personnel are available (for example, social worker, nurse, or physiotherapist), especially if one of them is to assume the role of key worker with the family. At the time of this discussion we attempt to explain to the parents the neurological origin of their child's difficulties, the results and the relevance of investigations, and the implications for the future as far as they can be seen. We give labels if it is clear that they are needed (and we know them). We discuss what we can do to help, and what we cannot. This painful interview is usually not very long, but is followed by a period when the parents are allowed to be by themselves or are joined by a member of the team they have already met. Further explanatory visits are often necessary and may be undertaken by the trainee after discussion.

As a teaching exercise for junior staff we consider that the greatest value for the trainee is as a participant in the consultation rather than as a witness using a one way screen or videotape, even given the limitations that this inevitably produces on their opportunities for learning and analysis. Conversely, the individual junior doctor should be equipped to continue his or her active participation with the family.

After this series of consultations a member of the team is asked to prepare a report that will be sent to the parents to provide a record of the assessments and of the plan of management, an established practice with clear training implications for the development of communication skills.

HELPING THE CHILD AND FAMILY

Given the plethora of staff and facilities that are available to help handicapped children and their families, it is not surprising that a hospital based paediatrician (senior or junior) can become lost and confused. It is therefore helpful to give new staff a brief summary of the community and hospital services available, and introduce them to all members of staff. In our department this is combined with an invitation to be personally responsible, under supervision, for the medical management of selected disabled children while they are attached to our department.

The summary is given by one of us and by a senior clinical medical officer, whose duties are shared between the community services and

the child development centre. We try to emphasise in this that community provisions are complemented by what goes on in hospital or the child development centre rather than the reverse, and make available to the trainee reports about how the various services work and interrelate. This information is supplemented as non-medical staff members explain their own roles, and, more importantly, as they are available to explain and discuss their management of individual children. Against this background the paediatric trainee is encouraged to select a small number of children with chronic handicaps and to take an active part in their management. Often such children are self selected, the junior doctor having met them at the time of their initial consultations, or during an inpatient stay, and taken part in the diagnostic consultation.

We then not only expect the trainee to see the family at each subsequent medical consultation but also to be present, when possible, at other attendances—for example, for psychological assessment, physiotherapy, or during team discussions about the child's and family's continuing needs, including the important discussions concerning placement at school. Ideally we encourage the trainee to visit any special nursery or school that is attended but this is rarely possible regularly. We would also like him to make a home visit, but this has so far only been possible as part of research projects.

RESEARCH AND AUDIT

Increasing pressure is being placed on junior medical staff to undertake clinical and laboratory based research. Caring for handicapped children is one area in which there is a wealth of subjects around which small and large projects can be designed, most of great relevance to practising paediatricians. Many areas of clinical practice are based on scanty scientific data and the collection and publication of such data provides the trainee with an additional qualification

for caring for children, whether handicapped or not.

In the child development centre we therefore encourage research into areas that are truly multidisciplinary. For example, we are currently evaluating the work of a paediatric head injury rehabilitation service, a hospital respite ward, and a joint language clinic (speech therapy, psychology, and medical) in addition to investigating motor and information processing skills in liaison with the neonatal service.

Auditing the workload of a child development centre is also an important area to which the trainee can contribute and from which he can learn. Outcome measures are difficult to establish in an area where few therapeutic interventions have been rigorously tested. Because of the variation among units, such performance indicators must be defined locally and upgraded regularly as experience increases. Research into the work of the multidisciplinary teams helps to define their individual roles more precisely, and allows tighter auditing of performance, unit meetings, such as our weekly referral meeting and monthly academic meeting, provide a forum for discussion and audit of performance. Our inpatient work is additionally pooled in the hospital clinical audit system to which our junior staff contribute. Individually, the parents of our handicapped children are rarely reticent in providing instant audit of the performance of staff members.

Conclusion

The aim of the training is to make junior doctors who are heading for either general practice or general paediatrics aware of our service. It can also be seen as an introduction and orientation towards paediatric neurology. If trainees leave the service with some understanding of the complex relationships in families who have handicapped children, of the role of staff working in a multidisciplinary service, and with some knowledge of community services, then our training aims will have been achieved.