PERSONAL PRACTICE

Paediatrician to a special school

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The work of a paediatrician in a special school has several components. It is about providing health care to individual children and support to their families. This entails working in a team with nurses and therapists based at the school, it entails understanding how schools work, and the anxieties of staff about the children they teach. It also demands the ability to think of a child's medical condition in terms of how it affects his life in school, and to interpret this to his teachers both individually and by taking part in formal in service training courses for teachers and other education staff. The paediatrician must be ready to provide support and counselling both to health care and to education staff who work with children with disabilities. Finally, but by no means the least important, is cooperating with health service managers in planning for better provision of health care services within the school, and advising education authorities on the adaptation of the school environment to children's needs.

The work demands above all excellent communication. All paediatricians need to communicate both with the children they serve and with their families. Any paediatrician working with children who have disabilities works as part of a wide network of providers of services from a variety of professions and trained in a variety of disciplines. Paediatricians who work in the community have a specialised knowledge of the neighbourhood in which they work, its environment, and the opportunities and constraints for children and the professionals who work with them. The paediatrician working in a special school must relate to individual children and their families, to the education staff and health care team within the school, to colleagues within the health service outside the school, to other professionals in the education and social service departments of the local authority, and to voluntary bodies in the local community who care for children with disabilities.

Special educational needs

All children attending special schools have special needs over and above those that can be met in a mainstream school. The Education Act 1981 stated that children should no longer be put into categories such as 'physically handicapped', 'delicate', or 'educationally sub-normal', but that their needs should be individually assessed. Every child who undergoes assessment must have a health report, which is collated by the school medical service. This is added to the educational reports and the education authority then produces a 'statement of

educational needs', which details how those needs should be met. All the reports and the statement itself are available to the parents. The act was intended to give impetus to the movement to cater for children with special needs within their neighbourhood school, or in a unit attached to a local school. How far this has succeeded has depended largely on local political will. The effect on this process of the most recent Education Reform Act has yet to be ascertained.

The work described in this article is that of a paediatrician whose special responsibility is for children with learning difficulties.

Children with moderate learning difficulties

Most of the children identified as having special educational needs have mild to moderate learning difficulties which, combined with the problems they have in socialising, make them difficult to teach. These children may attend a special school or be catered for (more or less effectively) in their local school. Recent studies, such as that of Lamont and Dennis, have drawn attention to the need for careful medical evaluation of these children.¹ The paediatrician caring for children in this group is not only aware of the need for diagnosis of possible handicapping conditions, but also of the need to look for undiagnosed or undertreated ill health and secondarily handicapping conditions, as these may be inhibiting the child's ability to benefit from and enjoy his education even more. Once these unmet needs are identified, the paediatrician can work towards the provision of appropriate remedial services. Many of the children who have moderate learning difficulties come from the most deprived families in the community who find it hard to use conventional health services. Provision of appropriate health services for these children in their schools may reduce their vulnerability and their need for the services in adult life. Parents and the public enthusiastically support attempts to provide more services for children with severe and complex handicaps, but the professionals campaigning for services for children with moderate learning difficulties do so with less public support.

Working in a special school

The special school that I visit weekly is a day school for 180 children, all of whom have severe learning difficulties. The children's ages range from 3.5 to 19 years, and their range of ability is quite as wide as that met in a comprehensive

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school. More than 50 of the children are in classes for those with special needs within the school. About half of these need special care because of profound mental and physical disabilities. These children make painfully slow progress, perhaps never gaining the ability to sit unsupported to feed themselves, or to communicate their needs reliably. A small group of children have profound learning disabilities, but have motor abilities within the normal range. Some of these children are hyperactive and have severe behaviour problems because of the discrepancy between their physical and mental development. A further group have physical disabilities and a learning disability, but are able to make some progress with suitable teaching and treatment. The remaining children are in the mainstream of this special school.

In the mainstream the infant classes are taught a wide range of preschool social and cognitive skills. In the junior classes (9 to 13) the children are taught elementary reading and number skills. In the senior school a wide curriculum is slanted towards living in the community. Social skills are necessarily the basis of the curriculum for the 16 to 19 group.

About a quarter of the children in the school have Down's syndrome. Many of the rest have other chromosomal or single gene disorders; other children have abnormalities, but have not yet been diagnosed as having any particular syndrome. A few children had prenatal infections, and a few perinatal asphyxia. A small but appreciable proportion of the profoundly disabled children had postnatal brain injuries or infection. The cause of disability of about a quarter remains unknown.

A multidisciplinary health care team is being gradually built up as funds allow, and as the case can be made for care in the community. Two school nurses share the day to day health care of these children. This entails giving regular medication including nebulisers, care of the children when they have severe fits, and advising about the care of those whose health causes anxiety. Those with severe heart disease, and those whose profound disabilities make it difficult to know if they are unwell or merely unhappy, pose particular difficulties.

There are two full time physiotherapists, a part time occupational therapist, and a half time speech therapist, all of whom work closely with teachers and parents. We offer all the children in the school regular health care reviews, which provide an opportunity for parents to discuss their child's health and progress, for monitoring of physical and sensory problems, and for relating their health care and educational needs.

HEALTH CARE REVIEWS IN SCHOOL

Each review starts with a discussion between the parents, the doctor, and the nurse about the child's health and progress. If she is treating the child, the physiotherapist joins them. When appropriate, other therapists also take part. After discussion the child joins the review, and receives the full attention of everyone. When the child has been examined, there will be more

time for talking and for clarifying plans. Sometimes parents like to see the doctor, nurse, or therapist separately, but we find that usually having all three present is helpful to parents and children because parents, doctor, nurse, and therapist can combine their knowledge of the child and their professional expertise to solve problems and make plans. Parents take the opportunity to see their child's teacher while in school for the medical review. Sometimes it is helpful for the teacher to join the general discussion that takes place after the child has been seen.

THE FIRST CONSULTATION

The first consultation takes place during the term before the child starts at the school, and is an opportunity for parents and the health care team to meet and exchange information. Summaries of medical assessments made in the community, or at the child development centre, must be available.

Starting the discussion with 'Tell me about . . .' and recording the parent's description of the child in their own words as far as possible gives valuable information about how the parents see their child—often quite a different picture from that of the professionals. After this a more formal medical history is taken, including discussion of the parents' understanding of the cause of their child's disability.

The history must take note of the parents' unique knowledge of their child's medical condition, his abilities and disabilities, his strengths and needs, and his reactions when unwell or uncomfortable. Parents' knowledge of how their child behaves when unwell is important, especially if the child is unable to communicate.

It is useful to have a checklist to cover useful points, such as self help skills—a description of a day spent with the child gives insight not only into skills but also into the gaps to be tackled by treatment or teaching. It is important to find out about the child's mobility both indoors and out, and what aids to mobility are used. What expressive language does the child have, how does he communicate his needs, and how do the parents know what the child wants? Does he use words, gesture, or make signs? What do parents think that their child understands?

It is important to know about hearing and vision, including the date and results of the last formal tests. Is the child's vision under review? What do parents think that their child can see? Does the child have epilepsy? What is the current medication? Has rectal diazepam been prescribed? (The use of rectal diazepam revolutionised the lives of many of the children who have epilepsy that is difficult to control, and it also helped the school nurse, who had previously had to take children into hospital for emergency treatment almost every week.) Is there an emergency admission card for a particular hospital?

Are there any problems at home with physical care, behaviour, or parents' or siblings' health? Does the family use any respite care facility? This is an opportunity to outline local facilities that are available to families when they wish to

take advantage of them. Does anyone visit the family at home—community nurse, specialist health visitor, or social worker? Bad mistakes are made by well meaning doctors who are unaware of what these professionals do for families, and who confuse the issue by introducing yet another visitor to possibly already overburdened families. Is the family aware of their welfare rights?

EXAMINATION

We do not always examine the child at the first consultation, especially if he is shy and nervous, but leave it until the first review, by which time both he and his parents will be more confident in school.

The paediatrician and team end the consultation by explaining the health care available in the school and negotiating communication between health care team and teaching staff, as well as keeping the family doctor and hospital paediatrician informed.

The next stage is a discussion with the head teacher and with the class teacher about how the child's health is likely to affect his schooling.

FIRST REVIEW

A review is arranged when the child has been at the school for a few weeks. This is a time to discuss any unforeseen problems that have arisen, and to make plans for the child's future medical care. This care is always shared with the family's general practitioner, and good communication is essential. It may be useful to share care with a colleague in hospital paediatrics if a child needs frequent inpatient treatment. The practice of subjecting families to long waits in hospital outpatient departments, however, just so that they may spend three to five minutes with a doctor (often a different one at each visit) is one that has little to recommend it. Regular review of children who are in special schools is best carried out in the school, by a doctor who is a part of the school team as well as the health care team, and who can see the child's health care in the perspective of the school and the community.

FURTHER MEDICAL REVIEWS

Further medical reviews can be tailored to the needs of each child and family. I arrange with the school nurse that no longer than a year goes by without the parent being given an opportunity to come to see me in school. A few parents never come; if their child is receiving all the services he needs, I feel that they have every right to make that choice. I do not see children without their parents unless the head teacher (who is acting for them) has immediate concerns, and the parents cannot or will not come.

Community paediatricians provide an on call service to their special schools. Some calls concern medical emergencies but most are for advice about children with unexplained bruising. The diagnosis of non-accidental injury is fraught with danger when a child is hyperactive, is unable to speak, and the family is under stress; much harm may come from a mistaken

assessment. The head teacher and school nurse decide between them what is the appropriate action to take in most cases, but when in doubt they need the experience and authority of the paediatrician.

The advantage of working in a school and visiting it regularly is that the paediatrician can see children when problems arise. Parents, teachers, the school nurse, the therapists, and sometimes an older child may ask for a review. This child does not seem quite his usual self; these parents need medical help with housing or allowances; the staff have noticed a possible deterioration in a child's work; the therapists need to discuss a child's motor function. In this way the children with the most complex problems, and whose parents have the greatest need for support, are seen most often. This allows prompt medical advice and intervention when the need arises.

REGULAR REVIEWS

It is nevertheless useful to have regular reviews to update records. This begins with finding out the parent's view of the child's current health, as well as that of the school nurse and the teacher.

The child's growth chart should be updated. Movement should be reviewed with the physiotherapist; are there any problems with chairs or other appliances, any handling problems at present, and any foreseeable problems as the child grows? One person may be able to carry the child upstairs now, what about next year? Organising funding for adaptations to homes takes about two years.

What progress has the child made in self help, speech, and language? When was the last hearing test? An annual hearing test is recommended for children who have Down's syndrome. For other children testing should be undertaken if there are any concerns from staff or parents, or if the child has frequent ear infections. Vision should be checked in school if possible. If the child does not attend an ophthalmology clinic, vision should be tested at the ages of 7, 11, and 15.

Does the child's behaviour cause concern? Does the child (and thus the family) sleep well? Receipt of benefits, relief care, and home visits must be checked.

On examination children with multiple handicaps should have their hips and backs checked. Children with Down's syndrome should have their walking and reflexes checked because of the possibility of atlantoaxial instability. Any other clinically relevant examinations should be done.

Who else sees the child? Is this appropriate? Others should be kept informed, and there should be discussions with school staff as appropriate.

THIRTEEN PLUS REASSESSMENT

The Education Act 1981 states that all children who have a 'statement of educational needs', should undergo reassessment between the ages of 13+ and 14+. This is an opportunity for the paediatrician to take extra time to look at each child.

A look at the past notes is a chance to review the ascribed cause of the child's disability. If a likely cause was found during earlier assessments, does it still seem as likely? Sometimes medical understanding has progressed since the tentative diagnosis was made. Sometimes abnormalities become more obvious as a child grows up. It may be appropriate to repeat chromosome analysis or other tests, or to refer the family to a clinical geneticist for further appraisal. If a cause is already known, do the parents understand its implications for their child as an adult and are the family fully aware of any genetic implications?

Looking at the present entails a thorough look at all aspects of caring for the child (as in previous reviews), paying special attention to testing of hearing, vision, and to the development of self help skills.

Looking towards the future means that the paediatrician must help the family in beginning the difficult adjustment towards perceiving their disabled child as an adult. One of the reasons that this is difficult is that while young people are becoming physically mature and going through the emotional changes of puberty, they remain dependent and immature in other ways. It is difficult to grasp just what being an adult means for each of these young people, and they and their parents need to be given a chance to start talking this through.

It is also a time for starting to build up a picture of what the young person's adult life will be like. The school staff and their colleagues in careers and social service departments will at this time be beginning to talk about prospects for training for employment, and about structured day care. The health care team may need to introduce discussion about where the young adult will live and whether he, or his parents, have yet thought about him leaving home. Consideration of this may lead on to further discussion about the parents own feelings as their child grows up.

The Disabled Persons Act 1986 comes into force this year. Under its provisions, social service departments are required to make an assessment of the needs of any school leaver who is likely to be substantially and permanently disabled. I hope that these assessments will be the precursors of comprehensive provision for the needs of adults with disabilities. In this health district we have taken the view that the establishment of social service assessment teams provides an opportunity for the child health services to look at their assessment procedures for school leavers, and to draw up new guidelines for health records; these will be the property of the young person, or the carer, but will give information both to social service departments and to those who will be caring for the health of the young adult. We already have a group of parents and professionals who have started to write these guidelines.

SUPPORT FOR STAFF

Working in the way I have outlined means providing day to day support for both health care and school staff. Staff who work full time with children with disabilities have particular needs

for support. Working with children with profound disabilities who make desperately slow progress can make staff uncertain of their own abilities and worth. They need to be able to talk through the goals of their work and its benefits to both child and family. The illness and death of a child arouses feelings of grief, not only for the child's death but also for his life. The paediatrician has a part to play in the support of the bereaved family and of those who cared for the child in school.

Planning health care provision in schools

I have already mentioned the work of the paediatrician in identifying unmet needs and bringing appropriate health services to children with moderate learning difficulties. Effective planning demands a knowledge of the changing prevalence of disability within the community, and an understanding of the burden. I am at present looking at services for children with profound multiple disabilities. In common with all children, they are receiving better medical care and living for longer. The numbers of children with multiple disabilities in local special schools have risen gradually; many of them had previously been cared for at home or in institutions. Health care provision in schools has not kept up with their needs. Our team in the special school is developing a regimen to measure the health care needs of this very dependent population, while in the joint education and health service planning body we are working out how to recruit and train the staff to provide that care.

The future

Are we the last generation of paediatricians in special schools? The Education Act 1981 looked forward to appropriate provision for children with special needs in their neighbourhood schools. Progress towards this goal has been gradual and uneven, and at present it is difficult to predict the effect of current legislation. Many children with physical disabilities and others with sensory impairments, however, are already in normal schools. Assessment units are to be taken out of special schools. It seems likely that fewer children will go to special schools, which may come to be used as resource centres for all children with special needs.

I have described how a paediatrician in a special school works with a child and his family, and takes part in the planning of resources to bring health care to the children in the school. This is also the way paediatricians in the community need to work with the children in mainstream schools, if they are to gain the full benefit of integration into mainstream education. Parents of disabled children who are in ordinary schools are pleased with the social and educational integration, but regret the lack of support and difficulty of access to health care services. This is the challenge for the paediatrician working with children with special needs in mainstream schools.

¹ Lamont MA, Dennis NR. Aetiology of mild mental handicap. *Arch Dis Child* 1988;63:1032-8.