

Providing medical care for children

David Hull, *President of the British Paediatric Association*

This is the second in our series of papers showing the problems facing the medical services for children in different countries.

That 'enterprise' which brings the benefits of medical science to the British, the National Health Service (NHS), is undergoing a managerial reorganisation. The overall objectives of the 'health service industry' are stated in the white paper. Good management requires that there is something in it for those who own the 'factory' and something for the 'workers'. The owners also happen to be the customers, such is the nature of nationalised industries. For them the aim is to provide better health care and greater choice of the services. For the staff there is to be greater satisfaction and rewards for those working in the NHS who successfully respond to local needs and preferences. No one can take exception to either of these ambitions.

The NHS is not a manufacturing industry but a service. We do not have a product like a can of beans, we provide a service, the item of service is the interaction between the patient and a health professional. The problem with the current arrangement in the NHS is that those who 'lay on hands' aim to do the best for their patient and acknowledge no financial restraint, indeed they have little influence over those who allocate resources. Currently those who control the resources are unable to allocate them in a way that acknowledges the medical needs, however those are defined, of the people they serve. Health authorities, the purchasers, who buy the service on behalf of all of us, are required to ensure that (1) there are effective services for the prevention and control of diseases and the promotion of health, (2) their population has access to a comprehensive range of high quality, value for money services, and (3) they set targets for and monitor the units for which they continue to have responsibility.

In Nottingham those of us working with children have interpreted these notions with respect to the service we provide for children to give us the following objectives:

- To provide a quality service to all children when and where it is most appropriate
- To support families in the care of their children
- To take whatever actions we can to ensure that as many children as possible reach adulthood with their potential uncompromised by illness or environmental hazard
- To provide a single comprehensive service
- To introduce audit in the framework of quality management.

We have tried to spell out the implications of these objectives in our service statement.

It is inevitable that as we try to understand the new management arrangements and how they will affect the service we hope to provide

for children, that we will get entangled with the details and we will be frustrated and perhaps disappointed by the frameworks that are applied to control our own working practices. Notions like 'smooth take off', 'level transfer', 'letters of comfort', 'mission statements' have at least a certain 'Alice in Wonderland' charm. But we must not make the mistake that Alice did when she asked the Cheshire cat which way she should go. If we have no vision of what we want for the medical services for children then we must not complain about the way we are managed. How can the 'managers' know if we do not tell them.

1991 provides us with an excellent opportunity to consider what we would want, what changes we would like to see, and what problems we would like addressed. The situation requires that we are realistic and reasonable, this is not the time to dream of what might be if we lived in a community which shares our values or a UK with a flourishing economy and a world without war and famine. It does mean however that we need not bind ourselves to arrangements which have been hallowed by time. It is not self evident, as many of the proposed arrangements appear to envisage, that hospitals working on outpatient and inpatient activities are the best way to provide the service.

The 'balanced district general hospital', that egalitarian dream of the last reorganisation which resulted in the closure of many small children's hospitals, left those of us concerned with children repeatedly stating that children are different and need special consideration not because they suffer from *strange childhood illnesses* but because they are *children*.

We might be forgiven, but then again we might not, if we again state the obvious. Yes children are a burden, no they do not produce, yes they need care and protection whether they are ill or not, *but* they are the sowers and the gatherers of the future. They need a medical provision which is tailored to their special needs, it is nonsense to adapt services designed for adults by an adjustment in time or scale, that is usually as dangerous and misguided as reducing the height on 20% of the steps on the stairs in the hospital because 20% of those who use the stairs are children who have shorter legs.

The argument for giving the medical services for children the highest priority rests not on the emotional appeal of 'women and children first' but on the grounds that a healthy future generation is the best way of looking after the well-being of us all. Put in negative and harsh terms, a damaged child becomes a damaged adult and for the 'Medical Industries Inc' they are a long

Correspondence to:
Professor David Hull,
Department of Child Health,
University Hospital,
Queen's Medical Centre,
Nottingham NG7 2UH.

and expensive non-economic drain on resources. This is well illustrated by the size of the 'one off' pay settlements awarded by judges when doctors have been found at fault in the care they provided for a child who is left damaged. In such matters judges do not recognise the welfare state! What I propose in this brief statement is to highlight some of the challenges inherent in the proposed changes.

Specialist, high tech care

Here we must face some painful choices. We should not complain too much for in most of the world they do not even have the choice. What should be the 'outcome measures' against which we audit our expensive high tech medical services like intensive neonatal care, cardiac surgery, neurosurgery, oncology services, etc? The outcome measures which are most easily measured are mortality rates. For example perinatal mortality has been a popular measure of health service provision in the past, the first UK Perinatal Mortality Survey had a major impact on the future provision of services: women went to hospital to have their babies, and each maternity unit has a neonatal unit.

And yet it has not been a primary objective in Nottingham for us to reduce our perinatal mortality rate for some 10 years, though obviously we would like it to be nothing (or at least better than anyone else's!). Of more concern to us is the handicap rate. Given the current technology for the care of infants on the edge of viability we often achieve survival with the near certainty of handicap. It is an unhappy fact that doctors who specialise in neonatal medicine rarely have to face up to the consequences of their 'success'. The legal position is no protection, the law by its very nature follows events, here whether we like it or not we have to decide what is good and what is bad. But the moral debate is no easier, destruction in utero four weeks earlier in gestation is desired by many families if the fetus is abnormal. We provide a service to our customers, is the customer always right? Can we find refuge in the thought that it is what we would want for our own child. What would you want if your child, born at 24 weeks' gestation, was ventilator dependent on day 7 with grade 4 intraventricular haemorrhage? If you controlled the budget would you invest more and more in the sophisticated tools of neonatal intensive care when there is good evidence that gentleness and minimal intervention causes less damage? It might be difficult to establish one way or the other whether taking control by active interventions or by judicious but selective support leads to the lower neonatal mortality rate. Doing and trying always seems the more commendable approach.

The time has come when we have to make some difficult choices. The control of services for the special and intensive care of newborn infants must stay close to the people who are served, the purchasers must know about the people, their concerns, their hopes and their dreams, and they must learn what happens to the fragile creatures that are handed to their parents when they leave such units. It is wrong

to give parents a responsibility they, with the best will in the world, cannot carry. We must not be surprised to be told yet again that premature birth and low birth weight are good indices of disadvantage, nor should we pretend that it is not so. Ordinary folk in distress or passing through troubled times have different priorities to the noble well resourced.

So the future of intensive neonatal care needs to be examined carefully. Small units are unlikely to do it well, technically or economically. Regional health authorities have shed their responsibility for intensive neonatal care, they appear to have left it to 'market forces' to establish new networks. It seems to me that all maternity units need level 1 and 2 neonatal services, and that *they* should control the transfer to and from a level 3 centre whose quality management, system, control and assessment, are public knowledge and subject to external audit from the beginning. The UK has too small a population and our resources are too limited to allow everyone who wishes to do level 3 care to do it. It should no longer be the stalking territory of the enthusiastic neonatologist.

Debate along similar lines could be followed for most of the specialist tertiary services for children, as well as for the intensive care of older children.

Family care

Once infants leave the hospital in which they have been born their care is the responsibility of their parents. Initially parents may need support and help in their new task, and this is the time when any support is most welcome and is likely to be most effective. Help with early rearing was one of the main reasons why health visitors were appointed and the child health service (infant welfare clinics) were established. Very quickly the parents become the experts in the care of their child. Infants are very dependent on their parents' awareness and skill in attending to their needs. When an infant falls sick, those skills become especially important, the art of caring for sick children is to make optimal use of this awareness and skill for the child's benefit. Again this is not just a soft cuddly notion about the sanctity of the family, or an example of parents' 'rights'. Examination of hospital statistics shows that the majority of children admitted to hospital with medical conditions are under 2 years of age, they have acute illness requiring emergency admissions, and that they are in hospital for one or two days only. Given that scenario, it is unthinkable, if we aim to provide a quality service, not to have adequate and acceptable accommodation for the child's parents, and not to accept that it is the primary duty of the staff to support the parents in the care of their child. In Nottingham we explored the concept of 'parent care units' and concluded that it was inappropriate for our service, parent care is not an extra for some children, nor an economic option, it is central to the care of all children. We are, of course, aware that it is sometimes the parents who need the care, we only wish we were able to address that need

more directly. Our primary responsibility is to the child, it has taken longer than could possibly have been imagined to persuade hospital management that parents staying in hospital need resources. Any contract for hospital services for children should include a clear statement of what is provided for parents to assist them in continuing their vital contribution to the care of their sick child.

The problem with the introduction of change is that managers and staff alike retreat into well tried (but not necessarily effective) arrangements understood by everyone. The government, and those who drafted the white papers on the Health Services Act are no exception. They speak of hospital trusts. It is not unexpected to find that those seeking such status are hospitals. No one doubts that hospitals are fine institutions in which to receive surgical attention. It does not follow that it is also the optimal environment to recover from surgery or be cared for when one falls ill with disease not open to surgical remedy. Over the last few years in paediatric medicine there have been many successful attempts to transfer the 'hospital care' of children, particularly those with chronic illness, from the hospital to the home and school. Thus services have been developed to support the family in the home and the teachers in the school. It would be a retrograde step to insist that this work takes the form of 'outpatient' or 'inpatient' activity so that the staff duties are accountable. For example, consultant 'fixed sessions' do not make much sense for a doctor who provides a service for families with a diabetic child, any more than they do for an inpatient service with an average length of stay of two days.

Health care

The medical services for the newborn are the entry point into the medical services for children, they are the point of first contact. In one sense they are a primary care service. In the UK we have a fine tradition of general practice. The proposed new arrangements are important because they introduce health promotion activities formally into family practice. How these will work out in the inner city areas where they are perhaps most needed remains to be seen. They may also bring with them 'duties' which are difficult to foresee: if a child is not vaccinated, is the family doctor liable? Has he failed in his responsibilities to the child. The World Health Organisation holds the view that no child should be denied the protection that an immunisation programme can give, and this is echoed in Department of Health advice. Doctors are being sued because they recommended against the pertussis vaccine and the child was subsequently damaged by the illness.

It would be as wrong in this matter, as it is in other areas, to run for cover just because the 'rules' are a little confused. We must do what we believe to be best for the child. In this matter as in the care of their children when they are ill, parents have the major responsibility. They will want to know what they can do to look after their child's interests. A major advance is the

introduction of a parent held record. There can be no doubt that this will increase in sophistication in the future. If I can go to cash dispensers in many towns and cities of the UK and find out how much I have in my account then it should not be long before we can set up a system that ensures all the children in our area of responsibility have had the necessary health checks and immunisations. Nor should it be difficult to introduce technology which gives parents access to information, in a form that they can understand, to assist them to make the necessary decisions about the health of their child. This will inevitably change the nature of the medical interview. The doctor's task will be as it has always been, to help his or her patient to make best use of what services are available.

Shared care

The newborn child becomes a separate individual with a 'right' to life. Talking about children's 'rights' always leads to problems, and there has been a lot of talking recently. However, it need not be made too complicated. Children need care and protection and it is the parents' responsibility to provide it. This is clearly stated in the Children Act 1991. Children also need to be respected for what they are and what they understand. Due regard must be given to any wishes or opinions that they have. It is awareness and understanding of these that is the special skill of those who work with children. There is however another aspect to all this which enlarges the duties of all professionals who work with children. It relates not to their professional skills but to the fact that they are responsible adults who are aware of a child's needs. The Children Act states that a child shall be taken to be in need if (a) he is unlikely to achieve or maintain . . . a reasonable standard of health or development without the provision for him of services by a local authority, (b) his health or development is likely to be significantly impaired . . . without such services, and (c) he is disabled.

A child is in need if his or her parents are not able to provide adequate care and protection. We too have a duty to do something if we have reason to believe that the parents are not able or willing to meet the needs of their child. In a later section the Children Act defines 'harm' as ill treatment or the impairment of health or development, which is not unlike the definition of need but the implications for those who become aware that the child is 'at risk' of harm are more prescribed. The Children Act was drafted by persons of great vision, no doubt the cynics will find their way through it, but we must not let them distract us. Children when they have need or are being harmed are often brought for medical attention. Thus our responsibilities extend well beyond the exercise of our craft. The medical services for children are a social agency and must work with the other agencies if we are to meet our wider responsibilities. Much has been said and written about interagency working. I suspect we would need far less if we could all remember that our purpose is to help the child and not to overstate our

own contribution or protect ourselves and our agencies from criticism.

Many of the outcome measures of the medical services for children are shared by the other agencies working with children, the law, police, social service and education, as well as many voluntary bodies. There is too much to be done for us to spend time competing or worse, squabbling.

In 1976, the Court report *Fit for the Future* set a vision for the future; perhaps its greatest contribution was to stress the importance of community services. In the 1990s we must aim

to provide a single comprehensive service for children which integrates medical care with health promotion and which does not allow management boundaries or professional self interest to diminish its effectiveness.

In this brief comment on the state of the medical service for children in the UK, I have tried to state the vision, and touched on some of the implications with examples from the primary, secondary, and tertiary services. We live in interesting times, they are the only ones we have, and it will be interesting to see what we can make of them.