Continuing care—a continuing dilemma

Medical advances in paediatric care have resulted in an increase in the number of children needing long term medical and nursing care. These children are dependent on complex technological devices such as mechanical ventilation, tracheostomies, and artificial feeding. Most technologically dependent children live at home with parents as the main carers. The complexity of caring for these children in the community demands that statutory and voluntary agencies work together effectively to provide coordinated services.

Background

HEALTH
In 1995 the Department of Health issued guidelines to all health authorities clarifying NHS responsibility for meeting continuing care needs. The guidance confirmed the NHS responsibility to meet the continuing care health needs of individuals and set out a process for health authorities to agree local criteria for access to this care in collaboration with health providers and local authorities.

The documents were detailed about the process to be followed but left establishing criteria to local discretion. The structure and framework advised in the guidelines related primarily to the needs of the elderly population. The needs of children were acknowledged but detailed guidance was not given.

EDUCATION
The 1993 Education Act required the Secretary of State to issue a Code of Practice giving practical guidance to local education authorities regarding their responsibilities towards children with special educational needs. Section 3:89 considered children with medical conditions and mentioned “consultation and open discussion” between education and health agencies. The financial framework for joint collaboration between health authorities and local authorities was not acknowledged or established. There appear to be wide variations nationally in the interpretation of the relative financial contribution between the two authorities in terms of the Code of Practice.

SOCIAL SERVICES
The Children Act 1989 provides for collaboration and interagency approach in the provision of services to families and children. The Act states that “to work in accordance with the spirit of the Act” the following should occur:

- Interagency cooperation is required, both in providing services to children in need and in the protection of children
- Greater collaboration is required between social services departments (SSD), health professionals, parents, and others in meeting health needs of children looked after by SSD and other agencies.

The Act outlines the holistic approach involving health, social services, education, and often the voluntary sector in planning for children who are sick or have very complex disabilities.

The Ealing/Hammersmith/Hounslow experience
In 1998 a series of meetings were convened between the three local authorities, the three health trusts, and the health authority to discuss the following:

- Defining children eligible for continuing care funding
- Understanding the current provision and funding
- Establishing principles, criteria, processes, and assessment procedures
- Setting up a multi-agency panel to discuss cases where no agreement can be reached.

The health contributions were defined; table 1 gives examples. The categories are based on recognition of shared responsibilities across agencies and an attempt to use the same terminology. A process of assessment using standardised referral forms and referral pathways was agreed. Despite this, issues regarding the amount contributed by each agency have not been resolved. With increasing demand and limited funding there are tensions about whose responsibility it is to pay for children with complex medical problems in school, at home, and in respite care.

Nationally the funding and coordination of complex packages of support for these families continues to present a major challenge. Parents are often caught up in the “haggling” process. A recent report found that few families received adequate and well coordinated services. They perceived poor communication between health and social services, with parents often having to pass information between professionals and coordinate services themselves.

Short term break facilities were difficult to find because of the specialist skills needed. Disputes between health and

<table>
<thead>
<tr>
<th>Band</th>
<th>Unipartite funding—health</th>
<th>Bipartite funding—health and social services</th>
<th>Tripartite funding</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>Children whose medical condition is so unstable that they require round the clock nursing care and whose health needs are such that alternatives are not appropriate</td>
<td>Children with severe challenging behaviour due to a psychiatric/medical condition or with severe physical disabilities whose needs cannot be met at home without additional professional/respite support</td>
<td>A child needing a combination of 2A and 2B</td>
</tr>
<tr>
<td>2A</td>
<td>Children whose medical condition is so unstable that they require round the clock nursing care and whose health needs are such that alternatives are not appropriate</td>
<td>Children with cerebral palsy and gastrostomies or autismic children with challenging behaviour who need respite care either at home or in an “out of home” scheme</td>
<td>Children with tracheostomies or other medical problems needing a carer in school</td>
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<tr>
<td>2B</td>
<td>Children with tracheostomies or other medical problems needing a carer in school</td>
<td>Children with tracheostomies or other medical problems needing a carer in school</td>
<td>Children with a medical diagnosis such as cerebral palsy or severe learning disability and challenging behaviour or epilepsy, where local placement has broken down and residential placement is needed</td>
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social services were common and could delay hospital discharge. There were wide variations in the amount of home support and short term care, depending on local policies. Funding for support workers to enable children to attend mainstream nurseries and schools was a further source of interagency disagreement.

The future
In 1994 the Audit Commission report, *Seen But Not Heard*, made the following recommendations:

There should be joint policies, strategies and operational arrangements between agencies. This represents the biggest challenge ... Joint funding should be used to break down barriers between agencies and disciplines and change current systems. This is ambitious. A good place to start is the provision of joint funding equipment budgets and shared respite budgets ... Unless the system for supporting disabled children is approached in this radical way then experience suggests that their needs will not be met in a comprehensive and wholehearted fashion.

Interagency joint funded equipment budgets have been achieved in one district. The 1999 Health Act makes provision for NHS bodies and local authorities to establish and maintain a fund which is made up of contributions by one or more NHS bodies and one or more local authorities, out of which payments can be made for health related functions.

There is an urgent need for health and local authorities to take advantage of the 1999 Health Act flexibility to pool budgets, delegate commissioning to a single “lead” agency, or integrate services within a single organisation. To achieve this goal in an economy of cost savings will require much ongoing work. There is a lack of understanding that in the end money will be used more efficiently and may provide overall savings. The decision lies at chief executive officer level for the three main agencies, but as paediatricians we should be key in influencing these changes.

D LESSING

The Thelma Golding Centre, 92 Bath Road, Hounslow TW3 3EL, UK
daniela.lessing@hscmh-tr.nthames.nhs.uk


Very small Australians . . .

The outcome of extremely low birthweight survivors born during 1979 and 1980 has previously been reported by the Victorian Infant Collaborative Study Group at the ages of 2, 5, and 8 years. In this month’s issue of our Fetal and Neonatal edition (*Arch Dis Child Fetal Neonatal Ed* 2001;85:159–64) the neurosensory outcome of 90% of the 88 survivors to 14 years is reported. Only ten percent have cerebral palsy but including visual, hearing, and cognitive impairments, 14% were judged to be severely and 15% moderately disabled. Mild disability (defined as ambulatory cerebral palsy with minimal limitation of movement or an IQ between 1 and 2 standard deviations below the mean for normal birthweight controls) was present in 25%, and 46% were normal. The moderate and severe disabilities were all identified at earlier ages, and it is reassuring in this respect that only one of the 9 children who could not be assessed at 14 years had a severe or moderate disability when assessed at age 8. Information from another era of neonatal intensive care, of course, but important longitudinal information on this cohort. On the whole disability “tracked” reliably during childhood, but interestingly this cohort showed no significant increment in recognisable cognitive impairments between the age of 2 and 5 years, and 4 children classified as having mild/moderate cerebral palsy at 2 years were subsequently classified as having no motor deficit.