How to choose delivery devices for asthma

The inhalation route has many advantages in the treatment of diseases of the respiratory tract. Medication may be delivered directly to its site of action, giving a faster onset and allowing smaller doses of drug to be administered. Systemic absorption of the drug is diminished, reducing systemic side effects. The drug treatment regimen for the vast majority of patients with asthma is straightforward and is documented in recent guidelines. The choice of which drug delivery device to use is less straightforward and is documented in recent guidelines.1

Spacer devices, used with facemasks for children unable to breathe reliably through a mouthpiece, are the first choice of device for children younger than 5 years. Nebulised delivery of bronchodilator and prophylactic medications is inefficient and expensive, and nebulisers should be reserved for those unable or unwilling to use metered dose inhalers and spacers. The use of metered dose inhalers alone, breath actuated devices, and dry powder inhalers should be discouraged in this age group. It is important to read studies pertaining to this age group with care, as conclusions of a device’s suitability may be generated across a wide age range, despite inclusion of a small number of subjects younger than 5 years chosen for their ability to undertake advanced respiratory manoeuvres.

For children older than 5 years, bronchodilators may be given via a breath actuated metered dose inhaler or a dry powder inhaler. We recommend a spacer device for the administration of inhaled steroids at any age. These are normally given twice a day, for instance on waking and retiring, so arguments that the spacer is not portable are not relevant. However, for low dose steroids, if the child is unwilling to use a spacer, breath actuated or dry powder devices may be chosen in preference to the metered dose inhaler alone. There is no evidence that changing to these devices improves compliance.

### Drug delivery device

There are three main types of inhalation drug delivery device, grouped by the drug dispersion method that they use: pressurised metered dose inhalers, containing a mixture of propellant and drug under pressure; dry powder inhalers, utilising the patient’s inspiratory effort to disperse medication; and nebulisers, using compressed gas or the vibration of a piezo electric crystal to aerosolise liquids. Adjuncts—such as spacers or holding chambers—may also be used to improve inhalation treatment.

**PRESSURISED METERED DOSE INHALERS**

Pressurised metered dose inhalers are easy to actuate, but difficult to use properly. Drug is emitted at high speed and most impacts in the oropharynx. Many adults and most children use their metered dose inhalers incorrectly,2 and the necessity to coordinate inhalation with metered dose inhaler actuation means that they are not suitable for use on their own for most children.

Metered dose inhalers with extended mouthpieces, such as the Spacemaker (Evans Medical, Leatherhead, UK), are designed to reduce the speed of the emitted aerosol, reducing oropharyngeal deposition. There are no published studies of this device used by children.

Breath actuated metered dose inhalers incorporate a trigger that is activated during inhalation. In theory, this reduces the need for the patient or carer to coordinate metered dose inhaler actuation with inhalation.1 However, patients may stop breathing when the metered dose inhaler is actuated (the “cold freon effect”) or have suboptimal inspiration.4 Evaluation of their efficacy in children under the age of 6 years is limited,7 and their use should be restricted to older children and adults. Oropharyngeal deposition of steroids using these devices is still very high, and some devices incorporate a short open tube spacer. This addition may be expected to reduce extrathoracic drug deposition, although there are no published evaluations of its use.

Spacer devices were developed to overcome some of the problems of metered dose inhalers. There are two main types.

### Table 1 Age specific recommendations for drug delivery devices

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>First choice</th>
<th>Second choice</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>0–2</td>
<td>MDI + spacer and facemask</td>
<td>Nebuliser</td>
<td>Ensure optimum spacer use Avoid “open vent” nebulisers</td>
</tr>
<tr>
<td>3–6</td>
<td>MDI + spacer</td>
<td>Nebuliser</td>
<td>Very few children at this age can use dry powder inhalers adequately If using breath actuated or dry powder inhaler, also prescribe MDI + spacer for acute exacerbations May need to adjust dose if switching between inhalers Advise mouth rinsing or gargling</td>
</tr>
<tr>
<td>6–12 (bronchodilators)</td>
<td>MDI + spacer, breath actuated or dry powder inhaler</td>
<td>Nebuliser</td>
<td>Ensure optimum spacer use and appropriate dosing Nebulise for a set period of time Written instructions for what to do in acute asthma</td>
</tr>
<tr>
<td>6–12 (steroids)</td>
<td>MDI + spacer</td>
<td>Dry powder inhaler</td>
<td>May need to adjust dose if switching between inhalers Advise mouth rinsing or gargling</td>
</tr>
<tr>
<td>12+ (bronchodilators)</td>
<td>Dry powder inhaler or breath actuated MDI</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>12+ (steroids)</td>
<td>MDI + spacer</td>
<td>Dry powder inhaler or breath actuated MDI</td>
<td>–</td>
</tr>
<tr>
<td>Acute asthma (all ages)</td>
<td>MDI + spacer</td>
<td>Nebuliser</td>
<td>–</td>
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</table>

MDI, pressurised metered dose inhaler.
Valved holding chambers (for example, Volumatic (GlaxoWellcome, Uxbridge, UK), Nebuhaler (AstraZeneca, Kings Langley, UK), Babyhaler (GlaxoWellcome), Aerochamber (Trudell Medical, Ontario, Canada) are what most practitioners refer to as spacer devices. They allow the patient to breathe tidally from a reservoir of drug. Facemasks allow spacers to be used by infants and children too young to use a mouthpiece. However, delivery of drug by a mouthpiece is more efficient, and patients should use this in preference to a facemask as early as possible.

Extension devices may be used with pressurised metered dose inhalers. They provide a “space” between the inhaler and the patient, allowing the aerosol to slow and propellants to evaporate, reducing the size of drug particles from metered dose inhalers, and trapping large particles in the spacer. Examples include the Integra for beclomethasone, the Optihaler, and ACE spacer. Coordination is still required for optimal drug delivery. Because of this, these devices are not suitable for young children and may be inappropriate for the large number of patients, of any age, who have difficulty in coordinating actuation of a metered dose inhaler and inhalation.

The size of the spacer may also affect the amount of drug available for inhalation, and this will vary with the drug prescribed. The clinician should be aware that data about a spacer derived from studies with one drug might not apply to others. Similarly changing from one spacer to another may be unimportant with some drugs, but be critical for others, leading to overtreatment or treatment failure. Output from spacer devices may vary greatly depending on static charge. Drug output from a spacer lined with an antistatic agent may increase by a factor of 3 or more. Static charge of polycarbonate spacers will vary greatly depending on the washing procedure used and the use of the spacer. Although non-electrostatic spacers should overcome this variability they are not currently available in the UK.

DRY POWDER INHALERS
Dry powder devices do not have the associated problem of coordination difficulties experienced when a metered dose inhaler is used. However, oropharyngeal deposition of inhaled drug is high, and spacer devices are still advocated for patients requiring higher doses of inhaled steroids. In the UK, the Accuhaler (Discus (GlaxoWellcome)) and the Turbohaler (AstraZeneca) are the most popular. Comparative studies of these two multidose devices are confusing. The Accuhaler is twice or equally efficient at delivering medication as the Turbohaler. In vitro studies suggest that the Accuhaler is more consistent in the dose delivered at different flow rates, although it has a reduced fine particle mass and emits more large particles than the Turbohaler. Again the number of dry powder inhalers are continuing to increase. The Clickhaler device (Medeva, Leatherhead, UK) is designed to look similar to a metered dose inhaler, even mimicking the press down action of a metered dose inhaler to load a unit dose for inhalation.

NEBULISERS
Nebulisers are mentioned only briefly because of their decreasing role in asthma management. Many new designs have been introduced without formal information on the output of drugs such as steroids being available. This is of concern as recent laboratory studies have shown that the amount of budesonide a child is likely to inhale from different devices may vary by up to 400%. Most of the prescribed medication for nebulisers never reaches the lungs. Of the dose placed in the nebuliser chamber, perhaps two thirds remains there at the end of nebulisation. Two thirds of the dose released from the nebuliser may be released during expiration and passes into the surrounding air. With many nebulisers less than 10% of the prescribed dose reaches the lungs. The nebuliser does not rely on patient cooperation or coordination to work, although deposition is improved by the use of a mouthpiece rather than a facemask, by holding the facemask close to the patient, and by the patient breathing quietly, rather than crying or rapid breathing.

The Halo-lite (Medicaid, Paghams UK) is the only nebuliser currently able to release a predetermined dose with accuracy. It monitors the breathing pattern of the patient, generates pulses of aerosol during early inspiration only, and allows titration of the inhaled drug dose. As the patient’s breathing pattern is known to affect the delivery of drug from nebulisers, this type of device may prove more efficient and reliable than conventional nebulisers, although no published studies have examined this device when used by children. The inclusion of electronic devices used to monitor compliance, currently used in research trials, would be of great help in monitoring asthma patients who are responding poorly to treatment.

DOSE VARIABILITY WITH AGE
The patients’ breathing pattern will affect the dose of drug delivered from a nebuliser or spacer device. The amount of drug delivered from a polycarbonate spacer increases with tidal volume, and more drug may be delivered from small rather than large volume spacers when these are used by infants and young children.

From nebulisers, the inhaled dose increases with age up to the point where inspiratory flow exceeds nebuliser output, and the dose inhaled per kilogram is constant up to 6 months of age, declining after this. Only infants will inspire with a lower flow than that of the nebuliser output, and only then will the dose received be affected by the child’s size. The importance of this observation has been highlighted in relation to bronchoprovocation studies in infants and young children. Data from Salmon’s study suggests that up to 1.5% of the dose of nebulised sodium cromoglycate will be deposited in the lungs of children from 6–36 months of age. Assuming approximately 10% of a nebulised dose is deposited in the lungs of an adult, the dose per kilogram body weight can be calculated. For example, a 70 kg adult will receive 0.14%/kg (10% ÷ 70), whereas, using Salmon’s data, young children will receive up to 0.15%/kg (1.5% in a 10 kg infant). This suggests that although there may be poor drug deposition in infant lungs, this is compensated for by their small size, so that the final dose reaching the lungs per kilogram body weight may be very similar to that of an adult.

There have been few clinical studies of lung deposition of nebulised aerosols in children. Alderson et al found that lung deposition increased with age, whereas others have found no relation between age and total lung deposition of nebulised aerosols.

COMPLIANCE
The most effective inhaler for any given patient is the one that the patient will use on a regular basis and in an effective manner. Patient compliance with inhaled medication is poor. In studies using electronic timer devices attached to metered dose inhalers, where subjects knew that compliance was being monitored, on only half of the study days was the prescribed medication taken, whether this was self administered by adults or children or where administration was supervised by a parent. Poorly compliant
Conclusions

Age and drug specific recommendations can be made (table 1), and are a useful starting point. At present clinical management should be based on prescribing a device that the patient will use, and encouraging adherence to prescribed treatment. Clinicians should be aware of the limitations of each type of device, and the optimum methods of use for each. They should then pick one or two of each type of device for use in their practice and become completely familiar with these, using table 1 as a guide. When considering new devices, clinicians should ask how the devices were tested, and whether the tests are appropriate to estimate lung deposition. Whichever device is used the dose of drugs, such as corticosteroids, should be titrated to the lowest dose required to control symptoms.

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Pectus excavatum: studiously ignored in the United Kingdom?

Pectus excavatum describes a malformation of the anterior chest wall characterised by a hollowing over the sternum and an associated prominence of the costochondral junction. The resulting depression in the chest wall, the opposite situation to pigeon chest (pectus carinatum), is variable in severity, ranging from a mere indentation to an extreme form where the sternum lies within a few centimetres of the vertebral column. The reported incidence is eight per 1000 population, more commonly in boys. It might be anticipated that such a deformity would have significant implications for cardiopulmonary function and pose a cosmetic challenge.

Patients with pectus excavatum have a mild restrictive ventilatory defect, but functional impairment is difficult to demonstrate, appearing at only the extreme limit of exercise tolerance. Despite an increase in the intrathoracic volume postoperatively, there is no substantial associated improvement in pulmonary function.

The North American and [continental] European literature abound with references to various aspects of this condition: the possible benefits of surgical treatment, the complications of such operations, and the psychological burden associated with the condition. Such literature reveals that pectus surgery is commonplace in these societies, with series of many hundreds of cases being reported.

The British literature is strangely silent, contributing fewer than 5% of articles cited in MEDLINE in the past 10 years. Equally, the referral rate to paediatricians and paediatric/thoracic surgeons appears to be very low, although we are currently conducting a survey of paediatricians with a respiratory interest in Wessex and the South West to quantify this.

It is undoubtedly true that, unlike their North American colleagues, British paediatric surgeons see very few children with chest wall deformities and there is an overall impression that patients are simply advised to put up with their deformity.

While obviously disfiguring, even the most trenchant pectus surgeons recognise that correction of the deformity will not usually give significant physiological benefit. The fact that in the face of this North American surgeons are prepared to perform extensive surgery with significant complications implies that they recognise the psychosocial burden of such an obvious abnormality. While formerly, the cynic might have pointed to a fee for case arrangement as a motivating factor, modern risk management would, the cynic might have pointed to a fee for case arrangement as a motivating factor, modern risk management would have curtailed such activities—but on the contrary, pectus surgery is flourishing.

The surgery of gynaecomastia in adolescence bears comparison. This condition is known to resolve spontaneously in the vast majority of cases, but the psychosocial limitations of each type of device, and the optimum methods of use for each. They should then pick one or two of each type of device for use in their practice and become completely familiar with these, using table 1 as a guide. When considering new devices, clinicians should ask how the devices were tested, and whether the tests are appropriate to estimate lung deposition. Whichever device is used the dose of drugs, such as corticosteroids, should be titrated to the lowest dose required to control symptoms.

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burden it places on the child makes subcutaneous mastectomy a recognised necessity in many cases. Pectus, on the other hand will tend to worsen throughout childhood and with the pubertal growth spurt, yet is apparently treated by camouflage rather than correction.

Historically, the enormity of the necessary surgery may have encouraged surgeons to discourage all but the most severely affected from undergoing an operation. The traditional surgical approach involves a submammary transverse incision, followed by elevation of the skin, subcutaneous tissues, and pectoral muscles to give access to the thoracic cage. The defect is usually corrected by resection of costochondral junctions and multiple osteotomies, although some surgeons advocate physical disconnection of the sternum from all of its cartilage joints, and replacement of the sternum back to front.5

The traditional surgical approach involves a submammary transverse incision, followed by elevation of the skin, subcutaneous tissues, and pectoral muscles to give access to the thoracic cage. The defect is usually corrected by resection of costochondral junctions and multiple osteotomies, although some surgeons advocate physical disconnection of the sternum from all of its cartilage joints, and replacement of the sternum back to front.5

The refashioned anterior chest wall is then held in place with sutures, struts or rods. All of this occurs through a substantial incision, with significant blood loss and postoperative pain. There have been attempts to minimise the incision and the associated trauma, but this remains major surgery with abundant complications.

At least 15% of patients will get recurrent excavatum, the more immediate complications include the iatrogenic perforation of any feasible local intrathoracic structures during surgery. Later, migration of supporting metal work into adjacent sites is reported, together with the significant problem of an asphyxiating osteodystrophy, particularly if the surgery is too extensive or performed at too early an age.6

Therefore, one can sympathise with the reluctance to refer or operate on a child for a “cosmetic” indication. This has led to alternative approaches, such as merely filling the defect with a subcutaneous mould of silicone to abolish the hollow contour.

However, the “beach” societies such as USA and Australia have not been reluctant to operate for this indication—although in the meantime, have searched for an alternative to a major intervention. This has particularly been driven by the fear of asphyxiating osteodystrophy, where the segment of thoracic cage that has been resected fails to grow, and acts as a constricting band in the mid-zone of the developing chest.

It appears that a solution has been found.7 Through 2.5 cm incisions on each side of the chest wall, a curved steel bar, moulded to the anticipated anterior thoracic contour is passed between the posterior aspect of the sternum and the pericardium, using direct vision from a thoracoscope. Once in place, the bar is rotated to its final position, forcing the concavity of the sternum anteriorly and abolishing the deformity.

As with all procedures there are associated complications of infection and postoperative pain, but these are not significantly different from the conventional surgery. However, the lack of any costochondral resection removes the fear of late osteodystrophy. The procedure is minimally invasive taking less operating time than the conventional technique and leaving insignificant scarring. Furthermore, should the procedure fail to achieve the desired cosmetic result, or the deformity recur at a later date, the option of conventional surgery remains.

It can only be hoped that this advance persuades those caring for patients with pectus excavatum to reconsider the management options. The excuse for persuading a young person that keeping his shirt on at the swimming pool is a better alternative than facing surgery is fading.

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Public health

Establishing an interagency equipment fund for children with disabilities

“We were concerned to hear that the provision of equipment for sick children is beset by difficulties. We recommend suitable mechanisms to improve the overall management and coordination of the purchasing, utilisation, maintenance and evaluation of equipment by health, social and education services and the voluntary sector.” House of Commons Health Committee [edited]

Children with disabilities often need specialised equipment to enable them to make the most out of life. Despite its importance, provision of this equipment is often poorly coordinated with no consistency in what is provided nor how it is funded. In East Norfolk we have developed an interagency group to address this problem. It includes members from the three main agencies (health, social services, and education) encompassing a range of professional expertise in assessing children’s equipment needs. It funds equipment that is not routinely provided by one or other of the statutory agencies, and is financed by equal recurring contributions from all three agencies. This article describes how we got there.
It was a public health exercise in that it is based on a health needs assessment, it covers an administratively and geographically defined population, it required multiagency collaboration, and is subject to ongoing monitoring and evaluation. It also depended on those other essential criteria for a successful public health initiative: luck, opportunism, and compromise.

Background
In the past 10 years the complexity of equipment has increased dramatically, with advances in computer technology and in the application of ergonomic and orthotic principles. As a result, the potential benefits to children have increased, as have the costs. Parents have become more assertive, and organisations in the voluntary sector have become more effective in applying pressure on the statutory agencies. There has therefore been a rising demand on therapists, paediatricians, social workers, and educationalists to supply appropriate, high quality equipment for disabled children.

The response from the statutory agencies has been characterised by lack of agreement over common assessment procedures and ambiguous lines of responsibility for funding. Barriers to a coordinated response are:

- the tight constraints on public sector budgets
- the less than high priority that disabled children have among the agencies
- the devolution of budgets within all these agencies so that any collective action needs agreement across a large number of units
- the fragmentation of care both between and within the different agencies
- and the different cultures and professional backgrounds of workers at all levels within the three agencies.

In consequence individual professionals have had to use ingenuity and persistence in seeking funding. This includes having to solicit money from charities, and having to tailor assessments to what they know is likely to be available. Meanwhile, pieces of unused equipment are “lost” in school cupboards and stores because no-one knows who owns what or where it is located. Managers are uncertain about which agency is responsible for what type of equipment—for example, specialised seating could be seen as a health need, a social need, or as an educational need depending on the circumstances. Equipment is, in effect, rationed by procrastination. The whole process has been aptly, if cruelly, summed up by the expression “the tripartite bum” to describe the child at the centre.

Until 1994 this was the situation in the area of Norfolk covered by the former East Norfolk Health Authority (some 80% of the county). Elsewhere in East Anglia there were examples of more successful interagency work. In neighbouring Suffolk a group of senior managers from the three agencies processed requests for equipment, and a communication aids assessment centre was being developed. In the west of Norfolk (a different health authority) a multiagency group of professionals administered an equipment fund and it was their work that acted as the prototype for east Norfolk.

Demography and administrative boundaries
A further barrier to local multiagency arrangements was the overlap of administrative boundaries. The local authority responsible for education and social services covers the whole county of Norfolk (population 775 000). There were two health authorities, one in the west also included part of neighbouring Cambridgeshire. The health authority in the

east of Norfolk had a total population of 620 000 of which around 105 000 were aged 0–14 years, with 6600 births per year. This health authority was served by seven National Health Service (NHS) trusts (three acute, two community, one mental health, and one joint) of which four provided services to patients in other health authorities (and counties) as well. To add to the confusion, the boundaries and responsibilities of the health authorities and some of the trusts had changed just prior to this project and have subsequently changed on more than one occasion.

Setting up the fund
In 1994 a £10 000 bid to “joint finance” was made to set up an equipment fund. (Joint finance is a scheme administered by health authorities for pump priming multiagency developments.) The extent of unmet equipment needs were unknown and the first year was intended to allow preliminary development work. This included establishing criteria for which equipment would be eligible to be provided, the mechanism for processing applications, and the development of a bid for continued financing of the group.

The following year we made a further bid for three years’ funding, again through the joint finance scheme. At this time NHS boundary changes had brought a neighbouring trust within the control of the health authority. After some negotiation between the trusts, the health authority, and the social services and education departments of the local authority, an annual grant of £21 500 was made to set up a scheme covering the whole health authority area.

Membership of the group administering this fund was designed to provide the widest representation with a minimum number. It includes speech therapists, occupational therapists, and physiotherapists, paediatricians, a social worker, and an educational psychologist who provide professional expertise and also represent their agencies. The health professionals have been chosen to include representatives of each of the NHS trusts. It is chaired by a senior social services manager who holds the budget.

The criteria for funding have been continually developed and those currently used are shown in table 1. The general principles are to fund equipment that meets needs in different settings, and which is not the clear responsibility of one of the statutory agencies. Requests

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Criteria for funding equipment</th>
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<tr>
<td>A thorough assessment of need must have been undertaken by a member of sta <strong>f</strong></td>
<td><strong>f</strong></td>
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<tr>
<td>Where appropriate consultation with colleagues in statutory or independent agencies should have taken place</td>
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</tr>
<tr>
<td>In exceptional circumstances, applications may be made for part or matched funding (for example, in conjunction with parents or charity funding), as well as for the full cost of equipment required</td>
<td></td>
</tr>
<tr>
<td>If children have received insurance or other financial settlements for their disability, therapists should check whether the equipment can be funded from this source</td>
<td></td>
</tr>
<tr>
<td>Equipment requested should not otherwise be the responsibility of any specific agency to supply. The joint equipment scheme should not be used to compensate for a budgetary deficiency on the part of any agency</td>
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<tr>
<td>As a general rule, equipment should assist with more than one function, or be for use in more than one setting</td>
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<tr>
<td>The intended location of the equipment must be specified</td>
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<tr>
<td>When a buggy or other item of equipment is requested as a form of restraint, this should be part of a broader programme of behaviour management, ideally with clinical psychology input</td>
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<tr>
<td>New situations arise and practice develops. The joint equipment group is always prepared to consider applications that do not appear to “fit” elsewhere. However, it cannot guarantee to offer a solution</td>
<td></td>
</tr>
</tbody>
</table>
data.3

The process of coming to this consensus has thrown up some interesting dilemmas. The scheme has not funded equipment such as lycra body suits, orthoses, keyboards for classroom work, or specialised toileting facilities as these were felt to be the responsibility of single agencies. The group has also relied heavily on therapists’ expertise and, where possible, on evidence of effectiveness. Hence, certain types of walking aids and communication aids have not been funded because they were felt to be either clinically inappropriate or ineffective. On the other hand, discussions between the group, parents and voluntary organisations have led to a protocol for the supply of buggies as part of a package for children, such as those with autism, whose behaviour results in severe mobility problems for them and their families.

Population needs assessment and evaluation of scheme

A textbook public health intervention is preceded by a population based needs assessment and followed by an evaluation. In this case, both were subsumed into one exercise. The initial £21 500 per year was based on little more than an educated guess of the funding requirements. Better evidence was required of the needs for equipment and the functioning of the scheme to justify recurring funding. Furthermore, much of the necessary information for a needs assessment became available as a result of the operation of the fund. We therefore set up a study to collect and analyse a range of quantitative and qualitative data.

Selected findings from this study included the following.

- Defining needs is a provisional and arbitrary exercise. From a professional and parental perspective there is always more or better equipment that might be helpful.
- Teasing out statutory responsibilities released a lot of worms from various cans! For example, the health authority believed trusts were responsible for providing standing frames yet none of the NHS trusts had a budget for these.
- Based on data from the OPCS (Office of Population Census and Surveys) disability surveys, information from therapists on equipment needs, and population estimates from the health authority patient register of 140 000 0–19 year olds (that is, 105 000 0–14 year olds), we estimated a total annual equipment budget of £157 000, of which £107 000 was for physical equipment and £50 000 was for communication equipment (1997 prices). This total includes equipment already supplied through the statutory agencies and so any extrapolation should take into account existing local funding arrangements.

Data from the five years of the fund’s operation show how the money was spent (table 2). The two main items of expenditure have been on specialised seating and communication equipment. The cost of seating is increasing rapidly and commercial practices such as preventing adaptations for one type of seat being fitted to other manufacturer’s seats are appearing. Communication aids fell into two main categories. A small number of sophisticated computer based aids were funded after careful assessment and evaluation. However, 80% of the items and 10% of the expenditure on communication equipment was on low cost aids and accessories. Other items included sleeping systems, standing frames, and even an electric toothbrush (for a child with a muscle disorder who could not brush her teeth independently).

Lessons learned from five years of running the scheme

The evaluation of the fund’s work helped secure recurrent tripartite funding on the basis that the provision of equipment is now more equitable, flexible, and responsive to families and users. However, this was only achieved after delicate negotiations with each of the three agencies in which we had to demonstrate simultaneously the value of the scheme, the prudency of our management, and the opprobrium they would receive from the other two if they did not contribute to continued funding. The evaluation has also enabled us to secure a further £60 000 over two years exclusively for communication aids, although we will again have to make a case for this to be continued after the grant runs out.

There are still gaps in the provision of equipment for disabled children despite our scheme. Administration of the budget and the supply of equipment are increasingly complex. We are also aware that the continued functioning of the group depends on the commitment of the individual members, none of whom has this specified in their “job description”. However, benefits include being able to keep track of equipment and provide an efficient system for recycling unused equipment. We have begun to rationalise systems of maintenance and insurance of expensive equipment. We have also found that requests for equipment that are clearly the responsibility of a single agency can be redirected and processed more rapidly.

Implications and conclusions

Multagency developments are difficult to implement, despite modest costs. Although money is used more efficiently and probably provides overall savings, the financing of such schemes remains vulnerable to restrictions in any of the participating agencies’ budgets, and to other unconnected interagency squabbles over resources. The viability of our scheme has, at times, depended on opportunism and compromise, even though the funding agencies have generally been very supportive. Ultimately, what has persuaded us all of the importance of this scheme has been the responses of parents who have welcomed the removal of bureaucratic hurdles in obtaining equipment for their children.
This paper is based on work largely carried out by Kathy Parker and members of the East Norfolk Joint Equipment Group, funded by a grant from Norfolk Social Services department, to whom we are grateful.

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STAMPS IN PAEDIATRICS

Thalassaemia

Thalassaemia is found only once on the world’s postage stamps, as part of the 1978 “anniversaries and events” issue from Cyprus. As is often the case, a stamp relating to a specific disease is most likely to appear from a country where the disease or condition is particularly prevalent. Examples come from Egypt (schistosomiasis) and Brazil (Chagas’ disease). In this instance, with thalassaemia being a major health problem in people of Mediterranean descent, the stamp from Cyprus is very appropriate to highlight its importance. The stamp depicts the blood film appearances in thalassaemia and is aimed at prevention. The stamp is relatively rare being overprinted “specimen”.

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