

The identification of children in need and disabled children in particular will require close collaboration between health, social services, and education agencies. Procedures whereby information is shared will have to be carefully designed. If they are to be effective more accurate and accessible information systems will have to be developed. Children move in and out of the category 'in need' so the exercise of identification will have to be kept under regular review. To facilitate an integrated approach a common health pathway will have to be established in each health district. Many local authorities will look to the community child health services for an adviser in this matter. Whoever is ultimately identified will need time designated to meet the commitment and adequate administrative support.

Care orders

The act clearly states that compulsory intervention must be fully justified. Care and supervision orders will require demonstration of 'significant harm'. Harm is defined in the act and consists essentially of a deficit in or detriment to the standard of health, development, and well being that can reasonably be expected for the *child in question*. The court will have to decide what is 'significant' and will be able to draw on expert advice. Paediatricians, among others, can be expected to be involved in this advisory process. In order to do so they may need training in order to draft clear, accurate reports and advice about presentation in court.

The status of voluntary care will be abolished. A child will be 'looked after' when in the care of a local authority or when provided with accommodation, which may be in a foster home or children's home or some other appropriate arrangement. A higher profile is given to identification of the health and developmental requirements of these children, many of whom will come into the children in need category. Many local authorities already rely on a medical adviser, frequently recruited from the community child health services, to coordinate identification of needs. Good practice such as this will be expected on a more regular basis and will have resource implications for paediatricians.

Child protection

The Children Act introduces new protection orders that also have implications for paediatricians. An *emergency protection order* will replace a place of safety order. It will be made when there is reasonable cause to believe that the child is likely to suffer significant harm if not made 'safe'. The court can give directions for a medical or psychiatric examination or other assessment. As the order can last for only eight days

and be extended only once for a further seven days, health agencies will have to be able to react promptly.

Under a *child assessment order*, which will last for seven days, a court can authorise a health or developmental assessment. The order will be able to specify what is to be done, when the assessment should start, and who should do it. Again, the health professionals involved will have to be reactive, possibly at the expense of other commitments.

Under all these orders a child with sufficient understanding to make an informed decision can refuse to undergo an examination or assessment.

Money from central government has been made available to promote training programmes about the act within social services departments. Regrettably this has not been so for doctors, although individuals have benefited from multi-disciplinary training opportunities organised at local level by social services departments. There is still time for this deficit to be corrected.

Assumptions have been made that there will be no significant health resource implications flowing from implementation of the act. Clearly from what has been discussed above this is not true. Even if health agencies wanted to restrict their contributions, it would not be possible to do so as Section 27 of the Children Act allows a local authority to request help from a health authority. Having received a request that authority must comply.

As the act provides an excellent opportunity for better service planning between social services, health, and education, paediatric services will be eager to participate. Coordination of the health participation should be easier in those districts where an integrated child health service has been introduced. Other districts where integration has been rejected or fleetingly discussed could take the opportunity to reconsider their decision.

In all circumstances the health resource implications of implementation of the act must be acknowledged and accommodated within the purchaser and provider plans currently under consideration. Similarly relevant, and possibly new, service commitments should be identified when contracts for consultant paediatricians are agreed.

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1 Department of Health. *An introduction to the Children Act*. London: HMSO, 1989.

2 National Children's Bureau. *Working with the Children Act*. London: NCB, 1990.

See related article on p536.

Social and emotional impact of childhood asthma

Recent research suggests that asthma morbidity in children is on the increase.¹ This is particularly worrying in the light of evidence that asthma is often poorly managed both by general practitioners and in hospital.²⁻³ Patients and their carers, for their part, have been criticised for failing to comply with prescribed treatment or to manage attacks appropriately.⁴ Not all the problems, however, are due to poor management: for some patients, asthma can be very difficult to control.⁵⁻⁶

Any disease is likely to have some impact on the social and emotional lives of sufferers and their carers. That impact may be greatest where symptoms are not adequately controlled. But even the underlying presence of disease can

cause distress and concern. Prevention, avoidance, and management strategies can themselves create difficulties in people's everyday lives. It is also important to recognise that, although sufferers and carers may sometimes claim to lead 'normal' lives, such 'normality' may be based on adjustments and restrictions that they have already incorporated into their lifestyles: their redefinition of normality enables them to emphasise the positive aspects of those lifestyles and avoid focusing on any underlying problems.⁷

In the case of children and their families, the social and emotional impact of asthma can be subdivided into four main categories: social and leisure pursuits, schooling, practical aspects of daily life, and emotional effects.

Social and leisure pursuits

The extent to which asthma affects children in their social and recreational activities largely depends on how well their symptoms can be controlled. Although some studies suggest that children experience few difficulties in these areas,⁸ others highlight the problems that some children do suffer.

Asthma can, for example, affect the ability to take part in sport. In one study, 61% of the parents of asthmatic children said their children's participation in sporting activities was restricted.⁹ Elsewhere, 22% of a sample of 111 children with asthma had been advised to avoid some sports, 25% had at times been unable to complete a game involving exertion, and 39% had occasionally missed sport due to their asthma.⁴

Some children have to avoid coming into contact with animals: one study of asthmatic children found that 20% of families had to get rid of pets.⁸ The need to avoid pollen and smoke may similarly restrict children's play and leisure activities. Holiday arrangements can be affected: in one study, 57% of families reported some degree of restriction⁹; in another instance, some families were prevented from going on holiday at all.¹⁰

In addition to having an impact on the child's own life, asthma can thus affect the social and leisure pursuits of the family as a whole. Siblings may be affected because of restrictions on the asthmatic child. And parents may be prevented from going out in the evenings or enjoying a life of their own.¹⁰

Schooling

Asthma is the most common reason for children's absence from school.¹¹ One study found that, since starting school, one in three 7 year old children who suffered from asthmatic symptoms had missed more than 50 days' schooling as a direct result of asthma: this represented more than three times the usual number of absences.¹² It is in their early years that children with asthma miss most days' schooling¹³: younger children are more likely to pick up respiratory infections which precipitate attacks.¹⁴ But another study found that half of a sample of severely asthmatic children aged 10 to 15 also experienced serious disruption to their education as a result of acute attacks.¹³

School absence can affect academic performance, and frequent short absences are generally more harmful in this respect than an occasional long one.^{15 16} School absence can also lead to psychological problems as a result of the child feeling different or inferior or being overprotected. These problems can in turn exacerbate the symptoms of asthma.¹⁷ The association between asthma and school absence, however, is not straightforward. One study found that school absence among asthmatic children was associated with parental separation, the non-manual occupation of the mother, having three or more children in the household, poor maternal mental health, lack of access to a car, and living in rented accommodation.⁸ Although the authors of this study did not attempt to ascribe any causal explanations for school absence, their findings did suggest that social circumstances and psychological factors play a part in determining whether children with asthma stay off school.

Within school itself, some children experience problems if they have to undertake activities that provoke attacks or—equally inappropriately—if they are not allowed to participate in normal physical activities.¹⁷ Such problems are clearly exacerbated where schools do not allow children to use asthma medication.¹⁷

Practical aspects of daily life

Depending on the specific factors which provoke attacks, children may have to avoid particular foods, stay away from

dusty or smoky environments, and be protected against catching colds insofar as this is practically possible.^{11 14} Parents are often advised to remove carpets, soft furnishings, and soft toys from bedrooms—even though this may remove an atmosphere of normality from the bedroom and deprive the child of sources of pleasure and comfort.

Parents of asthmatic children are often faced with extra housework in the form of additional cleaning, dusting, and washing in order to reduce exposure to potential irritants. Nocturnal attacks mean that parents will lose sleep and be physically exhausted.^{10 18} Parents may have to take time off work or give up their jobs; this can cause particular difficulties for one parent families.^{10 19 20}

Asthma can also involve financial costs. These result from time lost from work, transport to surgeries and hospitals, babysitter costs for other children (while the asthmatic child is at the hospital or surgery), and special purchases such as air cleaners, humidifiers, or special bedding.²¹ A study in the United States found that low income families bore a relatively greater financial burden, with an average of 1.5% of their income being spent on indirect costs.²¹ In one case, such costs amounted to 6.3% of the family income. If carers have to give up work altogether, serious financial problems can occur.^{7 10}

Emotional effects

Chronic illness can cause stigma, a loss of self esteem, and family strain.²² In one study, 41% of parents of asthmatic children said that asthma caused their children to feel self pity; 21% reported that their children had a poor self opinion, and 23% felt their children had poor relationships with their peers.⁹ It is certainly the case that restrictions on social activities can increase a child's sense of isolation and create further difficulties in establishing social contacts.¹⁵

Asthma can also have a major impact on family life. Parents of asthmatic children have stated that the asthma is 'a constant worry' for them, leaving them in a constant state of 'red alert' and unable to relax, even when the asthma is essentially under control.^{10 14 20} The emotional strain can be considerable: 34% of parents in one study felt that their child's asthma had an adverse effect on their own (parental) relationship.⁹ Parents may also feel a sense of guilt, whether or not this is justified: they may, for instance, feel they are to blame for their child's susceptibility to asthma attacks.⁷

In some cases, anxiety on the part of the parents of asthmatic children can lead to over protectiveness and/or to a failure to exercise adequate discipline.²³ Where family life is centred around the asthma, this can create a sense of oppressive closeness for the child.¹⁸ It can also mean that other children receive less than their fair share of parental attention: some parents feel it is often the other children who suffer most.¹⁴ In other instances, the fear resulting from observing the symptoms of asthma, and an awareness of its potential consequences, can cause the families of asthma sufferers to deny the existence of the condition and to pretend it does not exist. Such families will find it hard to offer sufferers any support or comfort and may instead become hostile and accuse the sufferer of manipulation.²³

Children, for their part, may react to their asthma by using it to seek attention or avoid unpleasant activities.²⁰ Some children have been reported to be able to play football at school while claiming to need a wheelchair at home.¹⁸ In some instances, parents have felt totally unable to control their child's 'tyranny' and physical aggression and have only obtained help through psychiatric intervention.²⁴

It should be recognised, however, that asthma does not always or only have negative effects. Many parents have found that asthma has brought their families closer together and that they now undertake more activities together.^{9 20}

Conclusions

Although treatment for asthma has improved considerably over the past 30 years, many sufferers and carers continue to experience problems in their everyday lives. This may in part reflect the difficulty of fully controlling the disease; further work is certainly needed to examine the precise relationship between symptom control and social and emotional problems.²⁵

In the meantime, parents state that the impact of asthma on themselves and their children is seldom fully recognised.⁷ They often encounter scepticism or incredulity when they describe their problems; indeed, they are often blamed for causing those problems themselves. A better appreciation of the social and emotional impact of asthma is essential if children and their families are to receive the care and assistance they need.

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Hyperexplexia or stiff baby syndrome

The stiff baby syndrome or hyperexplexia is an unusual neurological disease, occurring via dominant autosomal transmission, and distinguished by a permanent hypertonia that is heightened by the slightest stimulus. The diagnosis can further be ascertained by the clinical and electromyographic aspects, as well as the occurrence of a family history. The evolution of the disease is benign with myorelaxing treatment. The recognition of this syndrome is of great importance in order to avoid an erroneous diagnosis of epilepsy, to warn the parents against the risk of recurrence in case of later pregnancies, and to indicate the necessity of constant supervision during the neonatal period as attacks of hypertonia may lead to apnoeas that can endanger the child's life.

Hyperexplexia was described for the first time in 1962 by Kok and Bruyn in 29 members of one family.¹ The disease was characterised by the occurrence of a hypertonia from birth, which became less pronounced during the first year of life but could later lead to repeated falls. Those characteristics were later reported by Suhren *et al* on 25 members of a family.² In 1972, Klein described a family of 10 who presented with a syndrome distinguished by attacks of hypertonia heightened by the slightest physical stimulus and in whom an electromyogram showed a persistent activity even on resting; this activity vanished on treatment with diazepam.³ In 1981, Lingam *et al* described the same symptoms and named the disease: stiff baby syndrome.⁴ Another case was reported by Melki *et al* in 1988.⁵ In all cases a muscular stiffness appearing from birth is reported, which gives the child a peculiar attitude described as 'fetal', and there is a flexion of the forearms and legs and closed fists. The expression of the child is also characteristic: the stare is

fixed and gives the child an expression of anxiety. The hypertonia diminishes during sleep but increases with the slightest psychic or tactile stimulus. Attacks of hypertonia can involve respiratory muscles and lead to apnoeas, endangering the child's life. Digestive troubles, such as vomiting, are also reported. Vomiting is, in most cases, in association with a hiatal hernia. It is also noted that umbilical, inguinal, and diaphragmatic hernia are more frequent; they are attributed to the hypertonia.

Electroencephalography is normal but electromyography gives a characteristic result and shows an almost permanent muscular activity with, however, periods of electric quietness.⁶ The nerve conduction velocity is normal. The evolution of the disease is characterised by a delay in reaching motor 'milestones' (for example, walking). The hypertonia is reduced during the first two years, but abnormal reactions such as involuntary starts remain after the slightest stimulus. There is neither mental nor neurological deficiency.⁷

It is important to distinguish the stiff baby syndrome from other neurological diseases manifest by an increase in muscle tone. First, this syndrome must not be confused with the stiff man syndrome described by Gordon *et al* in 1967.⁸ The stiff man syndrome is not hereditary and appears at the age of 40 to 60; evolution is slow and progressive. It is distinguished by a permanent contracture, an intense dysphagia, the electromyogram shows a permanent electric activity, even during rest, and it is magnified by the slightest tactile or nociceptive stimulus.⁹ The Isaacs-Mertens syndrome, usually occurring around the age of 30, and for which neonatal forms have been reported, presents a mostly distal hypertonia, accompanied by fasciculations; the