

The role of children's hospices in providing respite care

Children's hospices are growing in number in the UK. They care both for disabled children who have severe impairments and children who are expected to die in childhood. Research into the role of hospices as providers of short-term (respite) care found that they are filling a gap in statutory provision by looking after children who cannot easily be accommodated elsewhere. However, the current regulation of hospices as nursing homes which are exempt from the Children Act is unsatisfactory. The research found:

- f** There is a broad mix of children using hospices in terms of age, behaviour and level of impairment. Very young or vulnerable children were occasionally at risk of injury from other children.
- f** Twenty per cent of children being accommodated were unlikely to live into adulthood.
- f** Not all hospices have the same eligibility criteria: newer hospices tend to have looser criteria whereas older, more heavily subscribed ones, tend to provide only for children who are likely to die in childhood.
- f** Some children were staying frequently in hospices but these placements were not monitored under the Children Act. Only a minority of families had had meetings with hospice staff and other professionals to discuss their child's care.
- f** Many families regarded hospice care as a life-line: usually because they could not obtain elsewhere the specialist care their child required or because other support services could not provide enough breaks for them.
- f** The researchers noted a lack of planned activities and stimulation for children, especially those who have severe or multiple impairments.
- f** No one external to the hospice was responsible for taking a holistic approach to supporting these families so few had a coherent package of short-term care.
- f** Some local authorities had policies which prohibited some children with extensive needs from using social services facilities or carers.
- f** Most professionals and families thought that hospices were staffed by qualified nurses. However, the staff teams often comprised people from a wide range of professional backgrounds, some of whom had no formal nursing qualifications.

Introduction

Both government and families recognise short-term care as an important resource for families caring for someone at home. It is especially important when the carer has to provide care day and night, as is the case with many of the children involved in this study. Children's hospices are relatively new providers of short-term care but they are increasingly important. There are currently eighteen children's hospices in the UK, with a further eleven being planned. At the outset, little was known about the children who use hospices or about the quality of the care they receive. This research sought to address these issues by studying how four hospices were operating.

Which children were staying in hospices?

Most children's hospices accommodate a wide age range from young babies to young adults but the average age of children accommodated was 9 years, 7 months. However, one hospice only catered for children of four years and under. Nearly two-thirds of children in this study were boys (64 per cent). Twelve per cent of children came from minority ethnic backgrounds. The majority of these attended one hospice.

The children had an enormous range of diagnoses including some very rare syndromes. However, over half had diseases of the nervous system and amongst these, over one-third had cerebral palsy. As expected, many children needed high levels of nursing care but some young people needed no assistance of any kind.

On the basis of the study's estimated prognosis, only one-fifth had conditions which are likely to lead to death in childhood although 52 per cent may die in childhood if the condition takes a severe form or involves medical complications. The remainder were expected to survive into adulthood.

Detailed information about socio-economic factors was generally not available on hospice records but on the basis of information gathered from families interviewed, poorer families are using hospices in significant numbers.

How much care was provided by hospices?

The amount of care that hospices could offer varied, with newer hospices able to provide more stays than

older, more heavily used ones. On average, across all four hospices, children were accommodated for 20 days a year. However, there were some examples of children receiving much more than this, with one young child having had 32 stays (98 days) in a hospice. Another child had been away from home for 133 days or approximately four months.

Such extensive or frequent stays away from home are likely to heighten children's insecurities, especially amongst very young children. At present, there is no formal, agreed system for reviewing the suitability of a hospice placement and therefore no alternatives are likely to be considered.

Why were families using hospice care?

There were three main reasons why families were using children's hospices:

- **A positive recommendation by a professional or another family.** Most professionals interviewed thought that the service provided by children's hospices was superior to that provided elsewhere and some families said they had been encouraged to use hospice care by hospital doctors, social workers and community nurses.
- **Poor experiences of, or inadequate support from, other short-term care services.** Of the families interviewed who had used other 'respite' care services many found that they received inadequate amounts of help from them or considered them to be unsatisfactory for their child. This was particularly true of hospital wards and local authority residential services. Family-based provision was well-liked but offered insufficient breaks.
- **Lack of suitable alternative provision.** This was a particularly important factor in some areas especially where local policies prohibited children who were unwell or who required nursing care from entering either social services establishments or staying with a short-term carer on a family link scheme.

Use of other support services

A third of families interviewed had not used any other service to obtain a break from caring. However, a third had used a family link scheme and most of these were continuing to use the service, albeit to a

limited extent. In only one instance had a short-term carer been unable to care for a child because of the child's extensive needs.

Nearly two-thirds of families were using at least one other service and two families were using as many as three additional services, including family link, residential care, holiday playschemes and sitting services.

The lack of a coherent, planned package of care which is designed to meet the needs of children may create problems for families. Apart from the complications associated with dealing with a number of short-term care providers, families may find that their child's behaviour deteriorates as a result of changes of environment and carers. Hence, short-term care may be damaging to some children's prospects of staying within the family home.

Families' views and experiences of hospice care

Some families said they had initially felt anxious about using a hospice because the word conjured up a morbid place where people go to die. However, first impressions of hospices were generally favourable and families appreciated:

- the non clinical environment;
- the informality and friendliness of staff; and
- the good facilities

Parents tended to expect good quality care and frequent breaks but not all felt their expectations had been met. Usually this was because hospices, having become so popular, were no longer able to provide so much care as they had at first.

Few parents had complaints about the service provided but the most common ones were:

- the hospice was not sufficiently local and so involved long journeys to transport the child and any equipment that was required;
- the poor availability of breaks.

Children's experiences of hospice care

Eighty-two per cent of parents thought that their child enjoyed staying at the hospice and the researchers' observations confirm that this was generally true. However, nearly half the parents

interviewed mentioned changes in the child's behaviour or physical condition on returning home from the hospice. Many of these changes appeared to indicate homesickness.

The researchers observed that there were times in all but one hospice when the staffing levels were inadequate to meet the diverse needs of the children who were resident. Indeed, on occasion, young or very vulnerable children were considered to be at risk of injury from other, more boisterous, children.

There was a lack of planned activities for children in all hospices especially for those who had severe or multiple impairments. Some parents also expressed concern about this aspect of the care provided. It is especially important as less than half of the school-age children in the families interviewed were able to attend school during their hospice stays. This was largely because of the distance between the hospices and schools concerned.

A more professional service?

Families and some professionals assumed that all hospice staff were qualified nurses but this was not the case in any of the hospices visited. However, there was always one trained nurse on duty. At times, staff in three hospices seemed under severe pressure and the arrangements for securing extra help were sometimes inadequate and may reflect resource constraints.

In general, staff appeared to work very long shifts (up to 12.5 hours) and often had no lunch break or rest period. This seemed to be part of the philosophy of trying to reduce the effects of a shift system on children but took its toll in terms of staff energy levels and effectiveness. On the whole though, staff worked well as teams unless they were under undue pressure.

At times, in three of the hospices, staff were observed to be under a lot of pressure especially when the mix of children was challenging or a child was very ill or had died. Occasionally, a shortage of care staff meant that parents were forced to become involved in caring for children.

Volunteers made an important contribution to the working of all hospices although the level of their involvement was much greater in some than others. Most often, volunteers undertook practical tasks around the hospice although in some, they were involved in direct work with children and families.

Regulating children's hospices

Children's hospices are autonomous, charitable bodies which are not within the remit of the Children Act. They rely heavily on fund-raising and are not subject to the kinds of scrutiny which are associated with commissioned or 'purchased' services.

The only statutory regulation to which they are subjected is six monthly visits to check whether they fulfil the limited requirements of nursing home registration. These requirements are not geared towards children's services and focus heavily on the provision, and safety, of facilities. Many senior hospice managers thought the current registration status of hospices was unsatisfactory.

Moreover, in keeping with other domiciliary services run by local authorities or voluntary organisations, the community-based support services which some hospices have developed are not open to scrutiny by registration and inspection units nor are they subject to contract compliance processes.

Children accommodated within hospices are not protected by the Children Act, Placement of Children Regulations and only a minority of families had ever had a meeting to discuss their child's care at the hospice.

Whilst some professionals had a good working relationship with hospice staff, others found that the flow of information about families was poor, making it difficult for them to work effectively with families. Lack of external professional input may mean that children's welfare is compromised. It can also leave hospices in a difficult position especially if they consider that hospice care is no longer appropriate.

About the study

Four hospices were involved in the study. They were selected to give a spread in terms of the amount of time they had been functioning; urban and rural settings; size of establishment and the age of children accommodated. Basic data were extracted from records of all children who had stayed in the four hospices between 1 April 1995 and 31 March 1996. Thirty-eight families were interviewed about their experiences of using hospices. During 1997, a three-

day period was spent observing in each hospice by one of the researchers and a co-observer. Twelve hospice staff were interviewed about their role and the running of the hospice in which they worked. Quantitative data were analysed using SPSSpc and qualitative data were content analysed.

How to get further information

The full report, **Children's hospices: a lifeline for families?** by Carol Robinson and Pat Jackson, is published for the Foundation by the National Children's Bureau (ISBN 1 900990 26 1, price £11.95 or £8.95 for NCB members, plus £3 p&p for orders under £28).