Children with complex support needs in healthcare settings for long periods

Anecdotal evidence suggested there may be significant numbers of children and young people spending long periods in healthcare settings such as hospitals and nursing homes. This study, by a research team from the Universities of Stirling, Durham, Newcastle and York, explored the experiences of 15 children and young people in a variety of healthcare settings. The team also mapped all discharges of children and young people from birth to 19 years of age from all NHS hospitals and healthcare settings in England and Scotland during a twelve-month period. The study found that:

- During the twelve months studied, this age group accounted for over two million 'bed days' in England and 115,000 in Scotland. Teenagers with 'mental health and behavioural problems' in England were the group most likely to have been in hospital for one year or more.
- A few children and young people were found in nursing homes and children's homes registered with health authorities.
- Confusion exists among some service managers and providers in health and social services about the legal status of children and young people in healthcare settings for more than three months.
- There was no agreed definition of 'complex needs' among professionals, and thus no clear picture of the numbers of people who might fall into such a group. It was not possible to identify children with complex needs from the data provided by hospitals.
- Within the learning disability hospital and the residential school in the study, little evidence existed of clear procedures for consulting children and young people, particularly those with communication impairments, about aspects of their care and treatment.
- Few of the young people involved had access to a social worker. None had an independent advocate. Parents and professionals identified several barriers to discharge from healthcare settings, including lack of funds for housing adaptations, and a shortage of occupational therapists and specialist nurses in the community.
- New services designed to facilitate the discharge of children and young people from medical wards and to support them in the community had been set up in three of the fieldwork areas.

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Background

The study was carried out between October 2000 and December 2002 in five English health authorities and two Scottish health boards. The main aims were to examine the number, characteristics and circumstances of children between birth and 19 years in healthcare settings in England and Scotland, and to explore the reasons for their admissions and any barriers to their discharge. The study also examined the children's day-to-day lives within these settings, as far as possible from their perspective.

Hospital data

There are difficulties comparing data from Scotland and England, as collection and classification methods are different. However, data provided by NHS Hospital Episode Statistics in England and the Scottish Morbidity Record from 1st April 1999 to 31st March 2000 were analysed. These showed that over 16,000 children and young people in England and over 1,400 in Scotland were discharged from healthcare settings following an admission of one month or more. The most common diagnoses for children admitted to hospital in both countries were:

- conditions arising shortly after birth;
- injury and poisoning; and
- 'mental and behaviour problems' (including mental health problems and learning disabilities).

In England, almost half of the children and young people who had been in hospital for more than twelve months had a diagnosis of 'mental and behavioural problems' – 79 per cent of this group had been admitted as teenagers. Over 200 children, adolescents or young adults were discharged after spending between one year and four years in hospital. In Scotland, 21 individuals were discharged after an average of four years in hospital. It is not known if these children and young people had stayed in hospital for non-medical reasons.

Data concerning ethnicity was of poor quality. In over 40 per cent of cases in England, no information about ethnicity was recorded. In Scotland, these data were not collected.

There was no way to identify children and young people who had multiple admissions to hospital during the data collection period. However, data from a children's hospital in Scotland (analysed in a separate exercise) indicated that eight per cent were re-admitted in the same year following discharge.

Nor was it possible to identify children and young people with complex needs from hospital data.

Other healthcare settings

Besides hospitals, information was sought from non-NHS establishments in the fieldwork areas. Nineteen children and young people were found to be living in nursing homes, private children's homes and a residential unit registered with the local health board and social work and education departments. They had lived in these establishments for between two months and ten years.

Legal status

There are therefore significant numbers of children and young people staying in healthcare settings for long periods. It became clear during the study that their legal status is confused. Professionals from health, social work/services departments and voluntary organisations variously described children in healthcare settings for more than three months as:

- 'looked after' under the terms of the Children Act 1989 or the Children (Scotland) Act 1995; or
- not 'looked after' but treated as such.

Some professionals were uncertain about the children's status.

In reality, the Children Act 1989 states that a health authority must notify local authorities of any children who have been living in healthcare accommodation for three months or more. The Children (Scotland) Act 1995 requires the same action when children in healthcare settings have not had contact, or are unlikely to have contact, with their parents for three months or more. In neither case do children automatically become 'looked after'. Both north and south of the border, the local authority then has a duty to determine whether the child's welfare is being adequately safeguarded and promoted, and whether to exercise any of its welfare functions under the Acts.

Children with long-term illness and impairment are 'children in need' under both Acts and as such are entitled to an assessment of need. Good practice suggests they should be offered appropriate services and support to meet any needs identified.

Little evidence exists that this was happening in the study. Except for those children in medical wards who had access to a hospital social worker, very few of the other people involved had a designated social worker – those who did had, for the most part, limited contact with their social worker. Nor were there examples of children and young people having access to independent advocacy. All these findings point to the need for a procedure whereby professionals could identify individuals who may be 'lost' in the system, in order to make plans to assess and discharge them.

'Complex needs'

There was also confusion about the meaning of 'complex needs'. Both in the literature and in interviews with professionals, there was no commonly agreed definition. The difficulty in providing one became obvious as the study progressed. The children and young people encountered had very differing needs and circumstances. The project involved three specific groups of children; those with:

- acute and chronic medical conditions;
- multiple and profound impairments; or
- learning disabilities.

However, some individuals belong to more than one of the above categories and others move in and out of them at different times during their lives.

Children and young people from three settings – acute hospital wards, a learning disability hospital and a unit attached to a residential school – were studied. Despite their diverse needs, they expressed many wishes in common. These included:

- being treated as individuals;
- being consulted about their medical care, listened to and having their wishes acted upon;
- exercising choice on a daily basis about both serious interventions and everyday aspects of life;
- being clear about which staff were involved in their care;
- maintaining good contact with family and friends;
- having continuity of education; and
- having access to the wider community.

Whatever their illness or impairment, the participants had similar interests to any other children and wanted to do similar things in their spare time.

Consulting children

None of the three healthcare settings involved in the study had procedures for routinely consulting children and young people. Those in medical wards stressed the importance of being able to make choices in their lives. Although they did not feel their wishes were always acted on, they did have more say in their day-to-day lives than young people living at the residential school. These young people had significant degrees of learning disability which, according to professionals involved, made choice-making difficult. However, staff in the residential unit did not use communication aids to which young people had access in their classrooms.

Young people in the learning disability hospital seemed to have the least choice of all. Discussions about their future placements seemed to take place without their knowledge. Professionals involved felt that they would not be able to cope with the uncertainty inherent in such discussions.

Education

The education the children received while in hospital, especially in acute wards, tended to be limited and fragmented. One teenager experienced significant difficulties returning to her own school when she went home. Children and parents greatly valued continuing contact, both educational and social, with their local school during hospital admissions. These could be enhanced, for example, through the Internet, emails and by lending laptop computers to children in hospital.

Barriers to leaving

Most of the children and young people interviewed wanted to go home. Parents and professionals identified a number of barriers to this:

- insufficient provision and support in the community;
- lack of funds for housing adaptations;
- a shortage of occupational therapists; and
- problems securing appropriate nursing care.

Some professionals identified 'parental readiness' as an issue. That is, the stress of parents looking after very sick children at home, or anxiety about doing so, sometimes led to consultants keeping children and young people in hospital longer than necessary. Also, several health professionals suggested that children and young people were admitted to hospital for social reasons, such as giving parents a break, which could result in multiple admissions for a child during a relatively short period of time.

Discharge planning

Three of the fieldwork areas had new services specifically designed to facilitate the discharge of children and young people with complex needs. The study took a detailed look at one discharge planning service.

This service was offered by a children's community nursing team which formed part of a multi-disciplinary team, led by a social work manager. Information provided by the nursing team showed that, of the 82 children who had used the service in 2001-2002, 16 had long or repeated stays in hospital. Six of these were further identified as doing so for social reasons, such as:

- unsuitable living accommodation;
- inadequate short break provision; or
- difficulties in setting up suitable care packages.

Nurses from the team maintained contact with

children's wards in local hospitals. Children were sometimes referred to the service by ward staff directly, sometimes more formally by ward managers. Planning the discharge of an individual from hospital involved a series of meetings with key personnel from hospitals, social services, Primary Care Trusts, discharge planning nurses and parents. Care packages were designed for each, potential carers given training, and medical equipment purchased or borrowed from the hospitals.

There was no agreed stream of funding for discharge. Community nurses had to negotiate a budget for each child with the local Primary Care Trust. Substantial funding was often required to discharge children with complex needs from hospital and to support them in the community.

Discharge planning nurses continued to work with families after children and young people had been discharged from hospital, within the community nursing part of their remit. It was said that the clearest predictor of a successful discharge was the presence of a supportive family network. When a supportive family was evident, community nurses were able to reduce contact a few weeks after discharge.

Parents' needs

Although the main focus of the study was on children's needs, several areas were identified where support to parents could be improved. These included:

- accessible information about their child's condition and treatment and the services available;
- partnership working with professionals, including involvement in future care planning;
- comfortable and convenient overnight family accommodation within or near the hospital; and
- pleasant, relaxed visiting facilities in longer-stay residential settings.

About the project

The research used a mixture of qualitative and quantitative methodologies. There were five separate elements:

- literature search - this drew on relevant research, policy documents and good practice guidelines from England and Scotland;

- key informant interviews – 13 semi-structured interviews were conducted with key people in health boards/authorities, social work/social service departments and parents' organisations in the fieldwork areas;

- mapping exercise – data were collected about the numbers and characteristics of children and young people from birth to 19 who had been discharged after an admission lasting more than one month in NHS hospitals in England and Scotland during the year ending 31 March 2000. These data were analysed separately and the results for Scotland and England compared. Admissions statistics for one large children's hospital during a twelve-month period were also examined. A postal audit of non-NHS healthcare settings in the fieldwork areas was carried out to ascertain how many young people had spent more than one month in these settings during a twelve-month period;

- interviews with children, parents and key workers – guided conversations took place with five young people, spread over two visits (for a variety of reasons, including age, level of learning disability and degree of ill health, it was not possible to interview the other ten children). Semi-structured interviews were carried out with 13 parents and eight key workers or named nurses;

- a case study of a discharge planning service – information was collected about the numbers and characteristics of young people who had used a Children's Community Nursing Service during a twelve-month period. A senior nurse running a discharge planning service (part of the Community Nursing Service) was interviewed.

How to get further information

Further information about the study is available from Kirsten Stalker, Social Work Research Centre, University of Stirling, Stirling, FK9 4LA. Tel: 01786 467729; email: kos1@stir.ac.uk

The full report, **Care and treatment? Supporting children with complex needs in healthcare settings** by Kirsten Stalker, John Carpenter, Rena Phillips, Clare Connors, Charlotte MacDonald and Janet Eyre with Jane Noyes, Stephen Chaplin and Michael Place, is published for the Foundation by Pavilion Publishing (ISBN 1 84196 054 3, price £16.95).

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