

## **The Experiences of Children and Young People with Complex Needs Being Cared For Away from Home: A Cross-Border Study**

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### **Introduction**

This paper reports some key findings from a two year study, commissioned by the Joseph Rowntree Foundation, which focused on children with complex needs being cared for away from home for one month or longer. Morris (1995), in a review of policy and research concerning disabled children living away from their families, concluded that these young people experienced 'patterns of care which would never be tolerated for non-disabled children' (Morris, 1995, p. 89). She suggested that a major barrier to meeting these children's needs lies in the hidden nature of their experiences, with little information available about who they are and what their lives are like. Other studies had shown that young people with serious or complex medical conditions spent long periods in healthcare settings when they could perhaps have been at home, or at least in 'homely' settings (Eyre, Thomson & Gilroy, 1999; Social Services Inspectorate, 1998; Noyes, 1999; Stalker & Hunter, 1999). Discharge was often delayed for social rather than medical reasons or because the services needed to help families support young people at home were not available. In relation to residential schools, the children in Abbott, Morris and Ward's (2001) English study had very mixed feelings about going away to school: homesickness was common. At the same time, some children enjoyed aspects of residential school, including the opportunity to make friends and have more independence than they did at home. Overall, however, the authors concluded that, because of wide variation in the implementation of the Children Act 1989 and its accompanying guidance (for example, relating to the circumstances in which children were treated as 'looked after' or 'accommodated'), it was not possible to be confident about the pupils' welfare.

Against this background, our study aimed to explore the numbers, circumstances and careers of children with complex needs within institutional settings, primarily healthcare. Within this broad framework, the study had a number of objectives but we wanted to explore in particular the young people's experiences of day to day life away from home: this is the focus of the current paper. The full results are reported elsewhere (Stalker et al., 2003).

Deciding on an acceptable definition of 'complex needs' proved a difficult task. There is no commonly agreed definition of this term. In practice, the study focused on three groups of children: those with acute and chronic medical conditions; those with multiple and profound impairments; and those with both learning disabilities and psychiatric diagnoses. While all these young people have some characteristics and needs in common by virtue of being children first and foremost, each group also has distinctive requirements and experiences.

## **Methods**

This was a complex study which used a mixture of quantitative and qualitative methods. There were five different aspects to data collection:

- analysis of NHS statistics relating to everyone discharged from hospitals in Scotland and England during a 12 month period (ending 31 March 2000), who had been aged 19 or under on admission.
- a review of relevant legislation, policy and research north and south of the border
- semi-structured interviews with key informants in health authorities/boards, social services, and parents' organisations. These were mostly middle managers with responsibility for matters relating to children with complex needs, and were drawn from the areas covered by two Scottish health boards and five English health authorities (giving similar population sizes north and south of the border)
- interviews with children, parents and keyworkers in various institutional settings in these health authorities/ boards
- a case study of a discharge service attached to one children's hospital.

The study was approved by the Multi-Centre Research Ethics Committee for Scotland, although not without some difficulties and delays (see Stalker, Carpenter, Connors & Phillips, 2004). Throughout the study, careful attention was paid to ethical issues, including gaining the children's informed consent to interviews. In the presentation of findings, real names have been changed.

We explored the experiences of fifteen children in three different settings: acute medical wards; a long-stay learning disability hospital; and a residential school. We were only able to talk to five of these young people: some were too young (aged two and under); some were too ill (sadly, one of the children died during the course of the research); others had very high support needs with little or no speech; and one did not wish to be interviewed. Where the children themselves were unwilling or unable to participate, we spoke to parents and keyworkers.

Discussions with children were partly based on schedules used in a previous study exploring the experiences of disabled children living at home (Connors & Stalker, 2003). They included activities and exercises for younger children and those with learning disabilities, using accessible and colourful materials. With respondents' permission, the interviews were tape-recorded, transcribed and subjected to a content analysis. Pen profiles were developed for each child, drawing on data collected from different respondents. Emerging themes and patterns were then identified and brought together, within the framework of the research aims.

In the rest of the paper, we focus on certain aspects of the care and treatment of children in acute medical wards and those at residential school. We have not included the findings relating to three teenage boys living in a secure unit within a long-stay learning disability hospital. The reasons for their admissions, and the regime in this setting, were very different from those experienced by other young people in the study. The final section of the paper draws out the policy and practice implications of the findings.

## **The children**

Eight children were currently, or had been, in medical wards (in three different hospitals). There were four boys and four girls, aged between 10 months and 16 years. They had a variety of serious illnesses, such as cancer and renal failure; one had sustained extensive injuries in a road traffic accident. The longest continuous stay in hospital for individual children ranged from two months to six months but they had all experienced repeated admissions. Indeed, several had spent the majority of their lives in medical wards. We interviewed two young people after they had been discharged home, eight parents and one 'named nurse' (a nurse assigned to work closely with a particular child, intended to ensure continuity of care and good communication with the whole family).

There were four young people at the residential school, three girls and a boy, aged 16 to 18. All had high support needs, each having a number of impairments and/or medical conditions. Three had 'severe learning disabilities' while the fourth had acquired brain injury. None had any speech: we were told that

their communication consisted mainly of facial expressions, body language, laughing and crying. They had been at the school for between one and eleven years. The reasons for attending residential school were given as their high level of dependency, the inability of their own families to care for them at home and/or the lack of adequate community support. We were not able to talk to any of the young people at residential school but we did interview two parents and four keyworkers.

## Findings

### *Choice and Consultation*

The importance of involving children in decisions affecting them is emphasised in current legislation and policy guidelines. The principle is enshrined in the UN Declaration on the Rights of the Child, the Children Act 1989 and the Children Scotland Act 1995. In addition, the *Patients' Charter on Services for Children and Young People* (Department of Health, 1996) sets out children's rights to access their records and be involved in decision-making. Nevertheless, a number of recent studies have shown that authorities often fail to meet their duties in this regard, particularly when children with complex health care needs and /or communication impairments are involved (Murray, 2003; Watson, Townsley, Abbott & Latham, 2002).

The young people who had been in medical wards emphasised how important it was for them to have some say in their day-to-day lives. Although their medical conditions imposed some restraints, they had been able to make choices about what to wear, how to spend their time, when to have visitors and how to decorate their room. However, 16-year-old Stephen reported that frequent staff changes meant that nurses were not always aware of his preferences:

*Because you've got to explain everything to them again and they've got to get to know you. You've got to get them round to your way of thinking.*

His preferences included having blood taken from his arm rather than the back of his hand, as favoured by some doctors. He had asked for - and been given - sedation to have a stent removed rather than stay a few extra days in hospital when it could be removed without pain. His nurse commented:

*He's always been quite sensible about his treatment. He did his own care. He did his own dialysis, dressings and personal hygiene... On the ward it was Stephen who spoke to as well as his mother: he was the one who asked the questions.*

However, Sophie, aged 12, was less satisfied with the outcome of making her wishes known:

*They have to ask me [if they can carry out a procedure] but they don't listen to what I say.*

On one occasion, she had been so upset following what she considered to be rough treatment from a radiologist that she refused to speak to anyone, except her mother, for several days.

Both these young people commented on the standard of hospital food, Stephen reporting that 'some of them [dishes] were more appetising than others', Sophie describing the food as 'rubbish'. However, they had been able to make some choices about meals, since they could go to the canteen or ask their parents to bring in food from local restaurants and delicatessens. One hospital provided a hostel where relatives could stay, and this enabled some children to eat a meal, cooked by their parents, in a more 'normal' environment.

One mother emphasised how important it was that her 11-year-old daughter be consulted about her wishes:

*Occasionally we come across particular nurses who don't really know Rachel very well who try to, maybe, say, like force her into doing things and there's certain ways of...dealing with Rachel. Like I say, she knows her own mind; she knows what's good for her.*

However, there were occasions when parents felt that staff had allowed their children to make decisions, or do something for themselves, inappropriately. For example, Rachel's mother had found that, when her daughter was eight, the nurses were leaving the child to take her own medicine. Rachel was suffering from an undiagnosed complaint which made taking medication, or swallowing anything, very uncomfortable. As a result, she had been hiding her medicine and pouring it away. Another parent recalled how she had been unhappy about doctors allowing her son, then aged 12, to decide against having an operation which she felt would have benefited him.

In relation to choice-making at the residential school, staff reported that three young women, all aged 16, had developed ways of communicating whether or not they wanted something, for example, by pointing, blinking, rubbing their nose, and through sound and facial expression. In the staff members' view, this allowed the young people to exercise some degree of choice about what they ate or wore, what they did and who supported them. However, John, aged 18, was apparently less able or willing to express preferences—except at mealtimes. We were struck by the fact that the residential staff did not use any communication aids with these young people, especially as teachers in the same institution apparently used picture cards during lessons. One keyworker suggested that such aids were not required because she understood everything said by Louise, the young woman she worked with: 'I can practically tell what she's thinking'.

However, we do not know if Louise shared this view.

The keyworker for another young woman, who had been seriously injured in a road traffic accident, reported that the girl understood everything said to her and showed her feelings by laughing or crying. However, there were clear limitations to this method of communication:

*Interviewer: How do you know that she is happy?*

*Keyworker: Well, she laughs. There are times when she cries.*

*Interviewer: What does she cry about?*

*Keyworker: When she first came here, she cried quite a lot. Maybe it was about pain or remembering how she was before she had her accident.*

None of the young people appeared to have had much choice about going to residential school. However, each of the girls' keyworkers expressed the view that the young people were distressed about being separated from their families. When Louise first came to the school, she apparently 'scratched and nipped' her keyworker. The latter thought this was because:

*She was so unhappy away from her mum and her family. You can understand that. She was 15 and she lived at home... she knew what she wanted; she couldn't communicate and that's what she used to do – if she was unhappy she would scratch you.*

Louise's mother described her daughter's reactions when she visited:

*I mean I know she feels it. She cries quite often when I leave and her face sparkles when you go in and so it guts you.*

### *Health care and personal support*

All the children in hospital found some aspects of their treatment painful and distressing. Several had used a nasal gastric tube which they found very unpleasant. Stephen said 'I hated that. I absolutely hated that.' Both young people we spoke to were well informed about their treatment and prepared to put up with it in order to get better. Stephen did not enjoy being in hospital but said, of one admission for life-saving surgery,

*It was only two weeks out of your life, you know – for to get ten years back, it's a small price to pay.*

Sophie especially disliked having a scan:

*It's a big long tube and you have to go in and it's really noisy and you have to*

*wear headphones...I'm very, very claustrophobic...I had to throw up so that they wouldn't give me an MRI [scan].*

She was annoyed that on one occasion when she had pressed a button to stop the procedure, it seemed the staff 'weren't bothered', leading her to believe that the scan she had so dreaded was not really necessary.

Overall, the children had good relationships with nursing staff. Where they had known the child for years, sometimes since he was born, relationships could be very close. The children and the parents appreciated staff who 'went the extra mile', for example, bringing in a child's favourite cake or video. Sophie said, 'I like people who speak to me like I'm normal and act as if I wasn't ill'. Stephen remarked, 'Oh, Jane's a good nurse. I'd give Jane about an eight or nine [out of 10].' One mother described how her baby son responded well to a particular nurse, and she had asked that this nurse prepare him for an operation:

*She would always, like, talk away or...sing wee nursery rhymes to him...I always used to watch his [heart rate] monitor and it was always dead peaceful when she was there.*

Few of the children appeared to have a 'named nurse'. Parents reported that where this system was supposed to be in place, it did not operate well, since the designated individual did not work any more closely with their child than did other staff.

Children expressed mixed views about doctors. Some were seen as good fun, for example, 'chucking pillows about'; others were said to talk over the children's heads to their parents.

In the residential school, the young people's support needs were met by their keyworkers and other staff working on shifts to provide 24 hour care. Staff reported that they encouraged the young people to do as much as possible for themselves, including eating, drinking and getting dressed. Since arriving at the school from home two years earlier, one young woman had mastered using a spoon and was learning to use the toilet. John was said to become agitated and violent at times, but the staff had developed ways to help him calm down, such as relaxing in a bath and leaving his bedroom door open at night to avoid him feeling shut in. He was also learning to dress himself and use the toilet.

Louise had particular dietary requirements and was reluctant to drink. Staff knew her favourite foods and tried to provide these at weekends. Initially, Louise's mother had been satisfied with the care on offer at the school but since a recent reorganisation, in which the young people had moved from one large residential unit into a series of smaller flats, she was less happy:

*If they had people employed who were cooks and they dealt with proper meals,*

*nutritious meals for the children, and the staff was there for taking them out and just making their life an enjoyment...I couldn't ask for anything more.*

One strength of the residential school was continuity of staff/client relationships. All the keyworkers interviewed had been linked to the same young person for at least a year. A further move was planned, from flats on the school site to ordinary houses in the community: wherever possible, the young people would be accompanied by their keyworker. One staff member commented:

*All the staff here get on very well with each other. We have a laugh, there is a relaxed atmosphere. It is important for the children that we get on.*

This positive view was echoed by one of the mothers:

*The staff that's looking after her are just lovely. They really take a great interest in her, like doing girlie things like taking her shopping for clothes and making sure her hair is all lovely...they take so much interest, and doing things that she likes to do.*

#### *Activities and social life*

Parents reported that there were good social and recreational facilities for younger children in hospital. Apart from toys and play materials, resources included a multi-sensory room, a children's radio station and dedicated play therapists. Provision for adolescents and teenagers was more mixed. Specialist wards which received charitable donations were able to provide every young person with a video and television at their bedside. One hospital had a computer room where teenagers could access games, email and the internet. Arts and crafts activities were on offer in one ward. Nevertheless, the two youngsters we spoke to had felt bored at times. Stephen commented:

*I would have liked more computer access, PC not a PlayStation, personal computers, not like 'beat-'em-up' games stuff...It maybe sounds stupid but more text, adolescents I think use text messaging a lot to keep in contact with your friends, so something. I know you can't use mobile phones in hospital but to find a way round that.*

As this quotation suggests, keeping in touch with friends from home was important to the young people. Sophie recounted how, on her birthday, the nurses had made a room available for her to have a party attended by family and friends. A close school friend had been able to stay with Sophie's mother in the family accommodation, keeping Sophie company in hospital.

*She used to come and sit on my bed and we'd read books and watch the telly and things and we once both fell asleep on my bed and the nurse came in and she didn't want to wake us up: she just left us.*



One hospital was located in a city centre. When the young people were convalescing, they had been able to go out with their parents during the day, visiting shops, museums and restaurants, which they enjoyed.

At the residential school, the young people spent a significant amount of their time in the company of staff and the two or three other youngsters, of the same sex, with whom they shared a flat. Two were said to get on well with their flatmates, one had little interaction with them, while the fourth had occasional visits from school friends and also went to see friends in other flats on the campus. Overall, it seems these young people had relatively restricted relationships compared to their non-disabled peers, or to disabled children living with their families (see Connors & Stalker, 2003).

Although the young people were said to have the same range of interests as many other teenagers, the extent to which they could pursue these interests depended on a variety of factors. The level of personal support required and the availability of staffing, and sometimes transport, were critical. The mother of one young woman reported that her daughter had plenty of opportunity to get out and about, going swimming, riding, bowling and to restaurants with staff. In contrast, Louise's mother was concerned that her daughter's need for social activity was not adequately met at the school and indeed the staff acknowledged this was sometimes so. John's keyworker commented:

*The good things about [the school] is he's got plenty of freedom in here... the place is big enough and we have our own pool, soft play and we've got a big hall... The way I don't feel it's really good is because we'd like to get him out more but we've never got the staff.*

Staff reported that the girls greatly looked forward to seeing their families, either when they visited the school or when the young people went home for weekends or short holidays. John, who had lived at the school from an early age, had little contact with his relatives and was said not to know his mother on her occasional visits.

## Conclusions and policy and practice implications

The young people in medical wards clearly differed in a number of significant ways from those at the residential school. Indeed it might seem there was more dividing than uniting them. Nevertheless, there were several common themes in reports about what the young people wanted, or what their parents wanted for them. The main points were:

- to be treated as individuals;
- as far as possible, to be consulted about their care and treatment, listened

to and have their wishes acted upon;

- to exercise choice on a daily basis;
- to be given information about what was going to happen to them;
- to be clear about which staff were involved in their care;
- for staff to show friendship in the way they talked to the children and by doing extra little things over and above their professional duties;
- to have good contact with their families;
- to have contact with their friends at home, for example through visits, email and mobile phone;
- to have access to a range of age-appropriate activities;
- to have access to the wider community.

(Stalker et al., 2003, p. 78-9).

These findings have a number of significant implications for the care and treatment of children in healthcare settings and residential schools.

With regard to choice and consultation, Lightfoot and Sloper (2002) emphasised the importance of hospitals developing a 'listening culture', encouraging young patients to raise issues of concern at a time which feels right for them and not just when invited to do so by staff. Different children will feel comfortable with different staff members and thus it is important to promote an openness among all staff, rather than having one person with a designated listening role. However, it is not enough for staff to listen: they must be ready either to act on the child's wishes or, if that is not possible for good medical or operational reasons, to explain this to the child. Young people need reassurance that they will not suffer any unpleasant repercussions as a result of making critical comments. Staff could issue 'comments and complaints' forms to children from time to time to encourage and 'normalise' regular feedback, be it positive or negative.

Choice-making at the residential school was said to be encouraged within the limitations of the young people's cognitive impairments. However, we might speculate whether the young people would have been able to exercise more choice and control over their lives had greater attention been paid to developing keyworkers' communication skills. Staff in this setting, as in any other, need to develop a wide repertoire of skills for communicating with children with complex needs, especially those with communication impairments.

Parents can be powerful advocates for their children. However there are times, as seen in the case of the parents who felt their son should have had an operation

which he refused, when respective views will differ. Competence is usually judged on a child's perceived cognitive ability, not chronological age (Alderson, 1995). Nevertheless, there may be a need for children to have access to independent advocacy on occasion, an option which did not appear to be available in either the hospital or the residential school.

The young people in hospital had some good memories of being there, but aspects of their treatment had been painful and distressing at times. Children should be told in advance about the medical procedures they need and what these will involve. The appropriate type and level of information will vary according to an individual child's medical condition, age and ability to understand. Action for Sick Children (undated) urged parents and professionals to be as truthful as possible, although it may not be necessary to go into great detail. In addition, the 'named nurse' system should be implemented consistently in all wards: this is identified as a 'right' in the *Patients' Charter for Children* (Department of Health, 1996). The benefits of building up a close relationship with a trusted keyworker were evident at the residential school. At the same time, regular reviews of each child's placement should be open to considering new ways of relating to and supporting the young person where appropriate.

Some of the young people at residential school were said to be distressed about being separated from their families, and one had little contact with relatives. The study did not involve collecting case histories so we do not know the details of their past circumstances. Nevertheless, there is a clear need for better community services to support parents looking after children with complex needs at home (see Townsley, Abbott & Watson, 2004). Findings from other parts of our study highlight a particular need for housing adaptations, aids and equipment, as well as reliable domiciliary care schemes. Where appropriate, families with disabled children can be encouraged to apply for direct payments which will allow them to purchase their own support and have greater choice and control about the manner of its delivery. Where parents are unable or unwilling not only to care for their children but also to keep in close touch with them, there may be a case for considering substitute family placements.

Despite their illness and impairments, the children in hospital and at residential school had the same kind of interests as other youngsters of their own age. While facilities for younger children in hospital were good, there was a need to develop a wider range of interesting and age-appropriate activities for adolescents and teenagers, both on medical wards and at the residential school. For the former, access to email, the internet and computing facilities would be popular but other possibilities include discussion groups, library access and opportunities for the young people to do more for themselves, such as preparing simple meals. Staff in residential settings would benefit from training in new ways to stimulate children and involve them in a broader range of social and leisure activities.

Forging links with the wider community is also important. Consideration could be given to recruiting befrienders or community connectors to accompany young people to activities which interest them and promote their inclusion in local clubs.

Finally, the findings of this study, like many before it, strongly argue the need for children's views to be taken into account, and their needs treated as paramount, when decisions, small or large, are made about their lives. This is no less true for young people with impairments or serious medical conditions, who should be afforded the same standards of care, treatment and protection as non-disabled youngsters. Current legislation and policy already sets out a framework for achieving these goals: the challenge now is to implement them for children with complex needs.

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