

Helping looked-after children and young people cope when they are ill

Ann Wilson
Development Officer
Action for Sick Children (Scotland)

Introduction

Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity
(World Health Organisation, 1948).

While everyone would wish that all children should be in a state of physical, mental and social wellbeing, this should apply even more to children and young people who are looked after away from home. Unfortunately, research shows that they are among our most disadvantaged young people in terms of their health and wellbeing (Scott and Hill, 2006). There are problems with longer-term preventive care in the form of health surveillance and routine immunisations (Residential Care Health Project, 2004). It should also be recognised that they may face difficulties in the shorter term, when they are ill. Corporate parenting is one way that should ensure that looked-after children who become ill are helped. This paper seeks to explore the views of some of those involved in corporate parenting when a child is ill. It will outline some of the findings of a project by Action for Sick Children (Scotland). This project looked at the healthcare needs and priorities at times of illness for children and young people who are looked after away from home. As part of that work we surveyed a range of health professionals who may be involved in corporate parenting at times of illness. We also obtained the views of young people regarding their treatment.

Policy and Corporate Parenting

In recent times, there has been considerable concern about the less than favourable outcomes for children and young people who are looked after, both at the political and the practice level. This has given rise to a number of Scottish Government reports which strive to set out strategies and standards to help local authorities, health boards, schools and social work departments to rectify this situation and to improve the outcomes for this vulnerable group. One area which has been emphasised is that of collaboration between professionals and agencies, in the form of *corporate parenting*. In considering how hard it can be to collaborate over decision-making or reach a consensus in ordinary families, we may wonder how possible this will be within the corporate family.

In thinking about what corporate parenting will mean for a sick child, we can all cast our minds back to times of childhood illness and reflect on how comforting it was to have a caring figure at our bedside. If being a good corporate parent means giving our children and young people the love, security and care that any good parent would give their own child when they were sick, how does the local authority fulfil this role for children in care? The Scottish Government document *These are our bairns* (2008) has set out a range of responsibilities for each of the partners in corporate parenting, including health services. A health care professional may say that they cannot possibly provide an overview of everything that is going on in the young person's life and that it is beyond any one individual to be all things to that young person. Yet it is everybody's job to identify an area in which they can intervene and to make sure that whatever needs to be done is carried out by them within their role. In thinking about the corporate family in health, one wonders just how the whole concept of the corporate parent would work in relation to healthcare provision given the very considerable range of different professionals who can be involved, particularly in complex cases.

The project

The project discussed in this paper is looking at the healthcare needs and priorities at times of illness for children and young people who are looked after away from home. A range of health care professionals have been approached to take part. The project began in March 2009 and is still continuing. This paper refers to telephone responses obtained during the early part of the data collection. In the interviews, we wanted to establish:

1. How the health professional saw their role in relation to the looked-after child;
2. The challenges presented;
3. The part they play in the corporate family regarding the important role of caring for the child when they are sick.

We also wanted young people to tell us what actually happens and then say what they wanted to be provided for them when they are ill. Three of their experiences are included in this paper highlighting some of the concerns and issues (identifying details are not included to preserve anonymity).

Findings

Professional awareness about looked after children seems to vary considerably but active discrimination appears to be reducing as more and more examples

of good practice become the norm. At the start of the project we were made aware of examples of poor practice which stigmatised and discriminated against children and young people who are looked after away from home. For example, there was the general practitioner who refused to register a young person saying

Well look at his mum, there is no way we are having him!

In another example, an optician refused to visit the young people in a secure unit on the grounds that

We do not attend inmates in penal institutes!

Finally, there was the suicidal young man who presented at an Accident and Emergency department within a hospital, only to be turned away as he was not registered with a general practitioner.

These stories are neither apocryphal nor historic, and they acted as a further impetus for the project, in which we examined the role of each health professional and highlighted the important part they play in the healthcare of looked-after children and young people.

The General Practitioner (GP)

The GPs' views presented the relationship with a patient in care as being more complicated than may be imagined. They reported that they were more likely to see children and young people on their own than with a carer. When they did see a young person with their carer, however, the relationship was different from the one where they saw the child with the birth parent, in that the GP was less likely to assume full knowledge on the part of the carer. They also felt that there were more complex issues of consent and confidentiality when the birth parent was not involved. Some of their comments revealed that they were still likely to take the young person seriously:

I try to treat them as if they were in their birth home, in fact as I would treat anyone else

We try to focus on the child and I think we need to empower them to have an understanding of their own health and how to take responsibility for that

The Community Paediatrician

The community paediatricians felt that they provided the overview of the young person's health and were often the only health care professional to see the young person when they came into care. This was clearly the case in health boards where community paediatricians assess all children when they first

become looked after. Their role included:

- Providing a global view of health;
- Initial health checks for looked-after children;
- Chasing important health information;
- Carrying out 'detective work'.

They reported that they had to acquire forensic abilities in tracking previous records for such children. Although a great deal of time was spent chasing information, this was reported as being vital work, as missing records or an incomplete picture of past procedures can pose a real danger to the health of a looked-after child (for example if severe allergies or past procedures and illnesses are not recorded).

The Community Psychiatric Nurse (CPN)

The CPNs, based in the community adolescent mental health services, reported operating in a role in which they were caring for young people in situations where the following were often prevalent:

- Basic healthcare gaps – dentist/GP/immunisations;
- Medical records not keeping up with the young person;
- Young people self-harming and residential units unable to cope;
- 16 year-olds functioning at a much younger cognitive age level yet being admitted alone to adult psychiatric wards;
- Mental health issues and behaviours not understood by carers;
- No treatment in accident and emergency departments if they are not registered with a GP, yet not able to get GP registration if they are homeless.

The commitment to care and to take on a real role as a corporate parent is shown in this professional's words:

I could not have left her there (A&E)..... There was no-one else for her.

They're absolutely terrified, it freaks them out (in relation to the young person in an adult psychiatric unit.)

The Hospital Paediatrician

Many children and young people are looked after because they have long-term conditions or complex healthcare needs and the birth family cannot sustain them at home. The main concerns for the hospital paediatrician centred round the giving and obtaining of consent. A question arose whether looked-after children and young people are being expected to self-manage by asking them to make decisions just because legally they can, when many of them are afraid of being handed that responsibility. Who advocates for these young people when they are in hospital and there is no-one there to support them? Practical hospital admission procedures can be hurtful when a child who is looked after is asked 'Who is your next of kin?' and they do not know or do not have anyone to name. How can this question be asked more sensitively?

Helping a looked-after child or young person to cope in this situation requires a seismic shift in the mind set of all clinicians looking after a child. A person is not just a case. This paediatrician was clear in defining two guiding principles:

The organisation has to be flexible to the needs of vulnerable children and young people and make rules appropriately.

The child's eye view..... keeping the child in mind treatment should be individualised to each - one size does not fit all.

The LAC Specialist Nurse

The LAC nurses perform a multifaceted role and take an holistic approach to the healthcare of children and young people who are looked after away from home. They carry out a range of interventions and activities. These include health assessments and reviews, identifying previously unmet needs and compiling individual Health Action Plans. They are involved in both health education and promotion for carers, young people and residential unit staff. They track the movements of children and young people as they change placement and attend LAC reviews. Foster carers considered the support of the LAC nurse to be a lifeline and, in a few areas, the LAC nurse role extended to providing advice to residential unit staff caring for children and young people with complex or exceptional healthcare needs. One of the main challenges reported by the nurses is gaining the trust of young people who may be wary of authority and unwilling to engage in relationships with anyone.

Case studies

The following three case studies illustrate some of the issues which have arisen for ill children who are looked after away from home.

Case Study One

This is taken from the case load of a community children's nurse (CCN). It illustrates perfectly the importance of information-sharing when working within multi-disciplinary teams and the need for real collaborative working amongst professionals so that the baton of care is not dropped.

Craig was a young boy with a complex disability who was in voluntary foster care. He had regular contact with his birth family but was now in the palliative phase. Birth parents, foster carers and health professionals had agreed that his quality of life was paramount and that further invasive treatments would not take place. Craig entered a respite unit to give his foster carer a break. The foster carer gave letters and the care pathway to the respite unit. While there, a gastrostomy problem arose and Craig was admitted to hospital, where he was placed in the High Dependency Unit (HDU). The foster mum was informed but when she contacted the hospital, they refused to give her any information. She contacted the birth father who contacted HDU, and was told everything, although he did not have day-to-day care of the child. As a result of this, the foster carer returned from holiday. In the meantime, the HDU contacted the hospital's ear, nose and throat surgeon who had previous knowledge of the child and the care pathway. Only when they had spoken to the surgeon did they accept the care pathway agreements. There was then a discussion with the birth family and foster family. At that point, they finally agreed to carry out no further intervention, as per the original instruction to the respite unit. A long way round for a short cut? Where was the vital stitch dropped? The CCN is very clear about the challenges of her role. Here are some of the CCN's comments:

The sharing of information, and the way in which we do that, is vital when working with multi-disciplinary teams.

It's often a case of playing detectives and terriers.

The follow-through is vital.

Case study two

The following is a moving account of the part played by a foster carer in the life of an ill child. David was a 14 year-old boy with developmental delay who attended a special school. He needed treatment for dental abscesses. He was refused dental treatment and anaesthetic on three occasions, because the dental team refused to proceed in the absence of his consent. The help of a play specialist was sought to try and encourage the young person to give his consent, but to no avail. The foster carer knew that a member of David's family had died as result of a ruptured, untreated abscess, so the foster carer

used this to persuade him to have the treatment. The foster carer was faced with an almost impossible choice. Do they let the child suffer or do they use all persuasive means at their disposal to obtain consent, in the face of the refusal of the dentist to proceed with treatment? Having the courage and commitment to take this responsibility is the mark of a true carer. The way that this foster carer, and perhaps many other such carers, see their role is encapsulated below:

You wouldn't stand by and let your own child refuse treatment you knew was in their best interests.

Case study three

Lesley was 14 year old when she was admitted from her care placement with severe abdominal pain. Lesley was admitted to hospital in a mixed adult ward alongside much older patients with end-stage cancer. The hospital admission lasted for three weeks. Tests were carried out at various times but no explanation was given as to why. There was also a question mark about consent. Doctors said they could not find out what was wrong but in the meantime, Lesley was overhearing patients talking about how long they had to live. On discharge, there was no follow-up. The young person's own words are best left to speak for themselves:

I felt frightened – the doctors kept saying they didn't know what was wrong wi' me so I thought, 'am a in the same situation as them?'

I wanted them to tell me what they were doin' and why they were doing it and what they were doing it for. Nothin – just your goan doon!

When asked what helped gain their confidence during an appointment with a healthcare professional they said:

I like it, ken, when they tak time tae explain an they've got that look on their face that says we do care what's going on wi people

Some concluding remarks

Article 24 of the United Nations Convention on the Rights of the Child (1989) says that:

State parties recognise the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health.

For this right to become a reality for children and young people who are looked after away from home, all of the good intentions enshrined in policy, research

and practice need to come together so that they can enjoy the standard of health that we would aspire to for all our children and young people.

The challenge now and in the future will be to make children and young people in care as healthy as their counterparts who are raised outwith the residential care sector. In order to compensate for some of the deficits outlined in the introduction to this paper, it is vitally important for professionals to recognise the poorer health background of those more vulnerable children and act accordingly. This will mean prioritising their needs, and promoting coordination and communication between the relevant agencies. It will also mean implementing a robust record-keeping system which follows the young person through any placement moves. Finally it will mean encouraging the young person in any opportunities to build their resilience and promote their ability to take greater responsibility for their own health.

Action for Sick Children (Scotland) Children and the *Young People's Healthcare Resource Pack* has been used successfully with young people and staff in residential units. It provides workshop sessions for staff to use to help children and young people understand the nature of healthcare services available to them, how to access these and what their rights are in relation to them. For further information on our work and publications, the website can be accessed at www.ascscotland.org.uk.

References

Residential Care Health Project. (2004). *Forgotten children: Addressing the health needs of looked after children and young people*. Edinburgh: NHS Lothian.

Scott, J. & Hill, M. (2006). *The health of looked after and accommodated children and young people in Scotland: Messages from research*. Edinburgh: Social Work Inspection Agency.

Scottish Government. (2008). *These are our bairns: A guide for community planning partnerships on being a good corporate parent*. Edinburgh: The Scottish Government.

United Nations Convention on the Rights of the Child (1989). Accessed on 27th June, 2009 at www.unicef.org.uk/tz/rights/convention.asp.

World Health Organisation (1948). *Definition of health*. Preamble to the Constitution of the World Health Organisation as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948. Accessed on 29th June, 2009 at www.who.int/about/definition/en/print.html