

Bristol Royal Infirmary Enquiry

Position of Association of Directors of Social Services (ADSS)

Introduction

The ADSS recognise the importance of providing high quality healthcare for sick children and acknowledge that their illness may be of short or long term nature and/or may be a disability that requires adaptations to the lifestyle not only of the child but of their family.

We believe that it is important to recognise the rights of children and their families in planning children's healthcare services and would argue that to do so, may require rather more flexibility and creativity than has previously been the case.

This short paper looks first at the legislative basis for state intervention and then at the issues for the families of children in hospital. It explores the roles of social workers and concludes by seeking clarification of the respective roles of the health and Social Services.

Legislative basis

1. The principle legislation for childcare in England and Wales is the Children Act 1989. This promotes the upbringing of children by their families and gives Local Authorities a role in supporting and enabling parents to do so.
2. Only where it is clear that parents and/or the child's family cannot meet their needs, can the state intervene and there are a range of public law Orders that a Local Authority can ask the Court to make should it be necessary to do so.
3. The Children Act also contains a range of private law orders that are designed to facilitate the care of children within their families. In particular, to define the life arrangements for a child where it has not been possible for these to be agreed between their carers: most often their separated parents.
4. Section 8 of the Act contains provision for two Orders which are sometimes used to ensure that a child receives appropriate medical treatment: i.e. a Prohibited Steps Order and a Specific Issue Order.
5. These are available to resolve single issues and replace the previous procedure of using Wardship. For example, where a child is refusing treatment and thereby endangering his/her life, the hospital/Local Authority can apply for a Specific Issue Order which would require the Court to consider whether the treatment should proceed. Alternatively, in a situation in which a family wanted to remove their child from hospital when to do so would endanger their life, the hospital/Local Authority could apply for a Prohibited Steps Order which would prevent this, but would not otherwise intervene in their parenting.

6. The cardinal principle is that in any proceedings relating to children, the child's welfare shall be the Court's paramount consideration.

The law relating to children in hospital

7. Children in hospital are "children living away from home" and as such the provisions of the Children Act 1989 apply. Generally, children in hospital for a short stay would not be considered as living in alternative accommodation.
8. There are two key exceptions:
 - Section 85 of the Act covers children placed by health authorities in NHS hospitals and those placed by statutory agencies (e.g. a Social Services Department) in a private hospital.
 - Section 86 of the Act applies to children in private hospitals who are there to receive treatment, specialised care or Education "because they are handicapped, chronically ill or have special educational needs".
9. These sections were included because of concern that these groups of children often have little or no contact with their families, that their positions were not reviewed systematically enough or sufficient attention paid to their welfare needs.
10. The Act requires a health authority accommodating a child for more than 3 months to notify the Local Authority who must then satisfy itself that the child's welfare is being met.
11. It is rare for the section to be used, as the majority of children in hospital long term have families who spend as much time as possible with them. Where the child is already "looked after" (in care) by the Local Authority, the child's foster carers are likely to spend time at the hospital with them.

Quality of Children's Health Care Services

12. The NHS Trust holds responsibility for providing children's hospital healthcare services. It may undertake this in partnership with others e.g. other Trusts; Primary Care Groups.
13. Local Authorities are required to produce a Children's Services Plan at intervals (the Guidance is currently being revised) and the local Health Authority is a key partner in the multi-agency fora which develop these. The extent to which the Health Authority will involve individual Trusts will vary: Many have standing Children's Services Groups which aim to co-ordinate children's hospital services and ensure consistency across the Authority and feed into joint planning processes.
14. Local Authorities are also required to establish Area Child Protection Committees (ACPC) to co-ordinate child protection activity and Hospitals should be represented on these.

Issues to be considered to ensure good quality care in children's hospital services.

15. There is a range of issues to be considered in order to ensure good quality care in children's hospital health services.
16. A child with health related needs has enormous impact on family life. Thus, although the child is the patient, "care" is also needed for:
- Siblings
 - Parents
 - Extended family

Improvements needed

17. Observations of facilities for children in hospital and their families suggest that there is much which could be done to make the hospital stay more pleasant: for example:
- Improve hospital facilities (out and in patient): access to hot drinks/meals etc for family members
 - Consider the layout of wards and the impact on parents/sibling visiting an ill child and seeing other children in distress
 - Improve on ward facilities for parents/family
 - Recognise that wards are often understaffed and rely on parental input for care
 - Increase facilities for parents to stay.
 - Increase number of play leaders available and acknowledge that sometimes they should care for siblings as this may be the only way a parent can stay with a sick child.

Issues specific to Regional Hospitals

18. Where a child is admitted to a hospital a long distance from their home, this obviously creates greater pressures for the family: e.g.
- Family likely to be split for long periods: one parent staying with the child in hospital whilst the other stays at home looking after their other children
 - Travel costs can be considerable to enable all members of the family to keep in contact with each other
 - Travel time can take its toll, especially for young children
 - The child and parent in hospital can become isolated from their own community
19. There can be considerable financial consequences for the family if a long hospitalisation is required e.g. one parent would probably not be able to work
20. The state system currently offers little assistance:
- Benefits – e.g. Disabled Living Allowance– Parents report difficulty in making applications

- Forms require them to provide “worst case scenario’s”
- State offers limited assistance with travel costs
- There is limited help with child care for other children

21. Although Department of Health Guidance requires Health Authorities to agree Criteria for Continuing Health Care in respect of those people who have a medical need, these seldom offer a structure for providing for children’s continuing health needs after discharge.

22. Rarely is there a Joint Assessment of Care Needs between the hospital and Local Authority: and this can often mean that children with chronic health needs are discharged home without appropriate support.

Social Work Role

23. Local Authorities provide a social work service to hospitals in partnership with the appropriate NHS Trust.

24. The role of social workers on Paediatric Wards is to:

- Facilitate hospitalisation: ensure that arrangements are in place for a child to be admitted
- Facilitate parental/family contact with the child
- Assess the ongoing needs of the child, and where appropriate their family, and seek to arrange services to address these
- Ensure that there is a planned discharge.

Social Work Role in Specialist Multi-Disciplinary Team:

25. Social workers may also be based in multi-disciplinary teams e.g. working with children with disabilities or children with life-threatening illness.

26. They can provide:

- Initial assessment at time of diagnosis of parental strengths and weaknesses
- Information and support regarding services available as child grows
- A non discriminatory service – as available to all families as part of Hospital Team
- Ability to offer services at appropriate points
- Identifying and facilitating change at known crisis points (change of schools/change to adult services)
- Liaison role with education and community health services

27. Social workers are key players in the provision of Child and Adolescent Mental Health Services: although such work is often of a longer term nature, some children will be in-patients and they and their families will experience the same issues as those whose children have a physical illness. The general lack of understanding of the issues and the associated stigma which can arise can make this an even more stressful situation for all involved.

28. Tensions between Health and Local Authorities often arise when long term solutions for children with a mental health need are considered. This is because residential placements are often seen as the “answer”, at considerable cost and often fuelling debate as to whether the child will receive clinical or care treatment. (the answer thereby determining which agency should foot the cost).

Looking forward

29. In our view, responsibilities for ongoing complex health care needs of children need to be clarified and Government guidance would be helpful. Clarification of the respective roles of health and welfare staff is necessary, especially in situations which have traditionally caused dispute between the two e.g. children with ongoing treatment needs which have been deemed to be therapeutic rather than addressing clinical needs.

30. Recognition of the financial costs for parents and some flexibility in the Benefits system to accommodate this, especially where a child has a life threatening illness, would be welcomed.

31. Experience suggests that much needs to be done to raise the profile of children’s health care generally. This includes prioritisation of these services in the context of various regional and sub-regional planning processes, as well as adequate resourcing of both primary and secondary care services. The new flexibilities under the Health Act 1999 may provide an opportunity for the respective agencies to jointly commission services and to establish pooled budget arrangements.

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