

# BRISTOL ROYAL INFIRMARY INQUIRY

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## PHASE TWO

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### **Acute Healthcare Services for Children**

#### **Summary Report**

This is a summary report of the key points emerging from the seminar discussion on *Acute Healthcare Services for Children* which took place in Bristol on 12 January 2000.

The following are points put to the Panel in discussion; they do not necessarily reflect the views of the Panel.

#### **Summary of the discussion**

The seminar was designed to cover a series of discussion points suggested by the Panel and supplemented by seminar participants in invited papers prepared for the occasion. The seminar began by considering why children and young people have needs that are different from those of adults and why particular priority should be given to their needs. The subsequent discussion focused on two key aspects of children's healthcare needs: (1) integrating children's services within and beyond the health service and achieving an appropriate configuration of specialist paediatric care and (2) meeting the needs of children and their families for appropriate information and involvement in decision-making with regard to their care. For each issue discussed, consideration was given to defining what the needs are, identifying barriers to meeting those needs and discussing potential solutions to the problems. The key points emerging from each of these topics are summarised below. Many of these issues are elaborated further in the position papers that were submitted in advance of the seminar. These papers may also be accessed on the Phase 2 section of the website.

## **1. Why are the needs of children and young people different?**

Views advanced included:

- (i) Children differ from adults in terms of physiological, psychological, intellectual and emotional development. As a consequence they see and experience the world differently. Their smaller size and relative immaturity has practical implications for treatment and the physical environment of care. They come as part of a family and their needs are often mediated by their parents who are usually the primary providers of their care.
- (ii) There are important differences *between* individual children (and their families) and between children at differing developmental stages. Children should not therefore be regarded as a homogeneous group.
- (iii) Children's needs require particular attention because they are a relatively powerless and subordinate group within society and do not have a vote. They are heavy users of public services but have no direct access to influence over service policy. Their needs are almost always addressed through a tripartite model which has their parent/carer at the apex. They are a sizeable group, representing 25% of the total population. Good care in childhood produces long term benefits and can be seen as an investment in the future.

## **2. Children's needs, in terms of acute health care and health generally**

- (i) Discussion focused on the need:
  - for specialist paediatric care and children's services in both secondary and primary care
  - to concentrate specialist services in designated centres
  - to achieve a child health service that is vertically integrated between primary, community, secondary and tertiary care
  - to ensure that there is also appropriate horizontal integration of children's services across health, social services and education
- (ii) Various implications of these objectives were discussed. These included: the need for the training of specialist paediatric staff and for maintenance of their skills; the need to consider the appropriate balance between sub-specialisation and the ability to offer general paediatric care; the need to clarify the relationship between paediatrics and other services and specialties such as obstetrics and A&E; and the need to achieve an appropriate balance between centralisation of care out of concern for quality, and the need and desire of parents and siblings for reasonable access.

## 2.1 Barriers to implementing change

There is considerable and longstanding consensus among experts on the appropriate organisation and provision of children's health services. This is reflected in extensive nationally agreed standards for children's care. Nevertheless, many of the recommended standards have not been achieved. Seminar discussants identified a wide range of barriers to implementation.

These included:

(i) *lack of political pressure*

Children's services have a low profile among the media and the public, as well as in the political arena. Paediatric care is not generally thought of as a problem area, being more often heard about for its successes. Consequently there is relatively little pressure on politicians to press for change.

(ii) *lack of evidence*

Evidence about children's health and healthcare is inadequate, both in terms of local epidemiological databases and information about the processes of care. The information that does exist is often poorly coordinated and sometimes of doubtful quality. There is a need to ensure that the right questions are being asked of the right people, including children and their families, and also to make better use of the extensive information about their experiences already held by voluntary organisations.

(iii) *absence of incentives*

Standards for children's services are not performance managed and there are no incentives, financial or otherwise, to improve them. They tend therefore to be seen as less of a priority than the many other areas of healthcare provision which are subject to performance management. There are generic problems of articulating, conveying and monitoring standards within organisations and of ensuring that accountability systems are effective, and these apply to the standards for children's service also.

(iv) *fragmented responsibility*

At both national and local levels, services tend to be managed functionally, particularly by reference to specialty, rather than by client group. Thus children become a minority in an adult-focused service. Responsibility for their health care is a part of many people's jobs, but there is often no-one with overall responsibility for this area.

(v) *shortage of appropriately trained staff*

There continues to be a shortage of staff with appropriate specialist training for children's care. These staff are often in a minority and may have relatively junior status and limited influence at organisational level. The tendency for paediatricians to be "nice people" may be a handicap in respect of fighting organisational battles. Particularly for interagency and multidisciplinary work, staff turnover leads to a lack of continuity of people with appropriate knowledge and expertise.

(vi) *generic difficulties with achieving change*

There is a need for changes of attitudes and ethos as well as structural and organisational change. Altering the culture of professions and organisations takes time and is not easily achieved. Reorganisation at local level is not necessarily costly in resources overall, but may be unpopular with local people and with primary care, if it impinges on existing local services.

(vii) *the scale of change required*

The complexity and scale of the change required may seem too daunting to take on.

## **2.2 Possible ways forward**

A number of potential ways of dealing with these barriers were identified and discussed. These included:

(i) *increasing visibility*

Children should be defined as a specific client group at every level and steps should be taken to ensure that children are considered in all decisions, perhaps through some form of "child health impact assessment".

(ii) *strategic planning*

At national level, there could be a National Service Framework for children's services, building on the work already done on paediatric intensive care. A coordinated overview of plans for children's services at regional or health authority level might be helpful locally.

(iii) *increasing accountability and incentives for change*

Children's issues should become part of performance management and be addressed explicitly within the process of clinical governance. Better information should be given about the reason for the need for changes. Efforts should be made to ensure that the process of change is owned by the relevant health care professionals and not regarded as a bureaucratic exercise. People should be engaged on the basis of their interests and given appropriate power and resources to implement change.

(iv) *focusing responsibility*

At both national and local levels, there could be someone with overall responsibility for children's services and with the appropriate knowledge, influence and resources to make things happen. Various models proposed for how this might work at national level included: the idea of an independent body or "children's commissioner" with statutory powers who could hold the government to account across a range of services, or an NHS commissioner specifically for children's health services; the question of commitment at Cabinet level to strategic cross-government planning for children; the possibility of giving one minister within the Department of Health overall responsibility for children's services.

(v) *defining manageable problems*

Progress in improving children's services will depend on a combination of social, political and organisational change. Within this, however, effort should be concentrated on defining focused and potentially soluble problems where real progress can be made and measured. Objectives should be divided into short, medium and long term goals.

### **3. Children's needs for information and involvement in decision making**

(i) The discussion focused on issues of information and communication, the process of achieving informed choice and consent in relation to treatment and research and on achieving a voice for children and their families at both individual and collective levels.

(ii) It was noted that consent is an ongoing and continuing process rather than a one-off event and that it is relevant to all encounters with health care professionals, not just hospital care. Attention was drawn to the importance of acknowledging individual and cultural variation, the complexity of interests and relationships within families and of the differing needs of young and older children and young people. There was also discussion of the regular use of drugs to treat children which were not licensed for use in children, and of the ethical problems and legal constraints associated with undertaking clinical research on children.

### **3.1 Barriers to involving children and ensuring that their voices are heard**

There was extensive discussion of the reasons why communication with and involvement of children in decisions about their treatment is often less than satisfactory. Problems identified included:

(i) *cultural assumptions*

Cultural assumptions about the need to protect children from painful knowledge are widespread, although there is evidence that these are not well-founded.

(ii) *fear and discomfort*

There may be fear and discomfort about talking openly with children about difficult topics, even among those professionals who work with children regularly. This unease is often not recognised or acknowledged.

(iii) *power differentials between children, parents and professionals*

There is little tradition of listening seriously to children, and sometimes a lack of respect for parents as experts on their children's needs. In healthcare settings, professionals are in a position of dominance. This may lead to professionals overriding parents' and children's concerns rather than acknowledging these and working cooperatively with families to address them.

(iv) *lack of professional knowledge*

Particularly in relation to adolescents and young people, health professionals may not be well-informed about the legal aspects of confidentiality, competence and consent and may not have day to day access to legal advice on such matters. There are no recognised training programmes for doctors or nurses working with adolescents in the UK.

(v) *lack of evidence about appropriate means of giving information*

Although research has been undertaken on various methods of giving information to children, such knowledge is not widely disseminated among healthcare practitioners. The process of giving information is not adequately monitored.

(vi) *lack of mechanisms for ensuring a children's voice*

At the collective level there are few mechanisms for ensuring that the voice of the child is adequately represented. Children are left out of the mechanisms for ensuring the accountability of public services. In general, parents do not become systematically involved in speaking out on their behalf, although there are examples of such involvement particularly in relation to children with chronic disease. The voices of the most vulnerable children and their families, for example those living in areas of social deprivation, are probably the least likely to be heard.

### **3.2 Possible ways forward**

A number of suggestions were made to help to address these problems. These included:

(i) *clarification*

There is a need to clarify relevant law and make sure it is widely understood.

(ii) *education and training*

Appropriate education and training should be provided for healthcare staff at all levels and stages, using effective methods such as role-playing. Competence in communication could be made a requirement for qualifications to practise.

(iii) *providing information*

There is a continuing need to develop, evaluate and disseminate innovative methods of providing information to children, and their parents.

(iv) *involving children*

There is growing recognition that children can make a valid contribution to monitoring, evaluating and designing services, but knowledge about how best to learn from children is at an early stage. Increasing attention is being given to involving adults in these areas and it is important to ensure that children are also included.

**Inquiry Secretariat, January 2000**