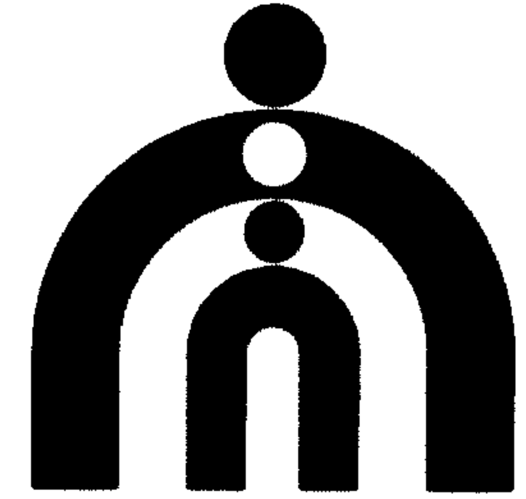
SEM1 0002 0477



INSTITUTE
OF FAMILY
THERAPY

Institute of Family Therapy
24–32 Stephenson Way
London NW1 2HX

Telephone 0171 391 9150
Fax 0171 391 9169
E-mail ift@psyc.bbk.ac.uk

12 January 2000

A 'Position Paper' – On behalf of the Institute of Family Therapy, in response to Phase Two of the Bristol Royal Infirmary Inquiry.

Introduction

The Institute of Family Therapy is a multidisciplinary organisation, with particular expertise in the areas of family relationships in relation to children, as well as children in relation to the wider contexts which may impinge on their development. However members of the Institute are drawn from a wide range of professionals which allows access to expertise in a wide range of related areas of concern.

In this position paper all 10 points raised about Acute Health Services for Children and the wider issues affecting the quality of children's health care services will receive **some** response, albeit minimal in areas which are outside the remit of the Institute.

Acute Health Services for Children

1. The changing priority accorded to acute health care services for children.

Planning for acute health services for children can no longer be thought about in isolation from the relevant community services in general, and from specific follow-up services particularly in relation to the treatment of cancer. Although there are resource concerns throughout the health service in relation to the provision of the most efficacious treatment for all who require this, in general these are not usually a particular problem for children, who's needs are appropriately prioritised. However the above may only be valid for the acute phase of treatment. Given that the 5 year survival rate for children suffering from cancer has dramatically improved over the past 20 years, and on most estimates approximately 80% of children suffering from cancer can expect to develop into adulthood, services to treat and respond to the long term effects of cancer, and specifically of cancer treatment, are in their relative infancy. Many children treated for cancers, for other life threatening illnesses, or treated for other conditions (such as lupus erythematosus) with cytotoxic drugs, may have long-term physical and psychological needs. At University College London Hospitals the first consultant paediatrician with special responsibility for the long-term effects of cancer treatment has only recently been appointed and the range of back-up services required is only increasingly becoming apparent. Therefore we would recommend;

That in relation to all acute children's services for major disorders, (certainly including cancer treatment, and all major surgical interventions – particularly major cardiothoracic surgery) a long term follow-up team needs to be established who will liaise with, work directly with, and strive to create a 'seamless' service in association

Director: Barry Mason
BA, ACTFT, DipSW (CQSW), Cert Ed

Assistant Director: Judith Lask
BA, MSc, CQSW, ACTFT

Chair of Council: Dr Ivan Eisler
MA, DipPsychol, CPsychol, PhD

Consultant for Training: Gill Gorell Barnes
MA, MSc, CQSW

A Company Limited by Guarantee
Registered in England at the above address
Company No.: 1621020
Registered Charity No.: 284858

SEM1 0002 0478

with acute treatment facilities. This team should include and/or have direct access to relevant specialist paediatric knowledge, psychology, psychiatry, family psychotherapy, and child psychotherapy.

2. The debate about how children's health care services are organised, in order to improve access to children's hospital services.

Whilst the Institute does not have a specific view about how specialist services are to be accessed by more generic children's hospital services, we do believe that general paediatric services should be sufficiently local for them to be familiar with, and for them to be able to be in close collaboration with, the local primary care services. Whilst, in our opinion, all general practitioner group practices should include at least one partner trained in paediatrics, at least one partner and/or senior member of ancillary's staff should have particular training in talking with children directly about their experiences and needs in relation to health and illness.

3. The development of paediatrics as a clinical speciality.

Whilst the Institute does not have a view on the future shape of paediatrics as a speciality, we would strongly urge that there needs to be joint working between paediatricians and their adult colleagues in relation to a range of sub-specialities, (such as endocrinology, rheumatology, oncology, urology etc.) where children's care may need to be followed up into young and late adulthood. Flexible arrangements are required so that some children may be followed up by the paediatric team into young adulthood, whilst others may transfer to the adult service in adolescence. Such flexibility requires both close working relationships between the child and adult facets of specialist services, as well as in care of the child in the hospital from an integrated bio-psychosocial team. This should be the model for what is usually referred to as a 'Paediatric Liaison' team, and should include the following components;

Availability for consultation about and/or assessment of children seen at outpatient clinics or inpatient paediatric wards.
A range of interventions from brief consultation to on-site mental health treatment provided by the team.
Structures, (such as joint clinics) designed to provide a broad psycho-bio-social framework for a child's disorders and/or treatment.

4. The changing nature of children's medical surgical intensive care and nursing services.

In our opinion 2 key changes should be taken into account in organising future services:

Greater awareness of the psychosocial factors in relation to children's health, and specifically the connection between these and family health and/or disturbance.
The increasing need for centralisation of highly specialised services, because of the increasing specialist knowledge base and technical facilities required.

SEM1 0002 0479

Potentially the above 2 needs may sometimes appear to be in conflict. The following will tend to mitigate against this pattern and encourage co-ordination:

That children should only be admitted and/or treated by dedicated paediatric, 'child trained' staff. Such staff should also be provided with intensive training on communicating with and accessing the thinking capacity of children of all ages. Further comment on this is included under section 5 below.

The increasing use of centralised highly specialised units **increases** the need that such units should respond to the overall needs of the child and family, both in terms of medical treatment and care of the child, explanation to the child and parents, and psychosocial support for the child and family. This needs to be provided by an integrated team to include the various professions noted under 1. This team needs to be responsible for very close liaison with the local services, particularly when the child's treatment is transferred back to his or her locality.

5. Communicating with children and parents and seeking and achieving consent to treatment.

Skills in talking with children and their families are both different from, and complementary to, skills in talking with children. However talking with young children requires a professional;

To have a clear understanding of the child's level of development, and use of language.

To recognise and counteract the child's assumption that he or she must be compliant to the professional.

To elicit the 'thinking' aspects of a child in situations in which he or she may be frightened, and/or may believe that he or she is expected to be passively acquiescent.

The necessity to ensure full parental understanding and consent in relation to all treatments of children has been widely discussed in the public domain. When fully informed, parents very rarely oppose the most appropriate treatment for their child, and when they do such opposition is usually based on specific religious or other belief systems. However there was evidence from the case of child 'B', who was not adequately consulted about the choice of continued treatment in the face of medical advice to the contrary, that this child would have chosen to reject the additional and painful treatment. Although under English law the concept of 'Gillick competence' gives the child the right to consent to treatment, it is usually seen as not giving the child the right to refuse. With the increasing range of complex and difficult decisions resulting partly from the availability of more radical treatment approaches, children may need to play an increasing part in decisions about their own treatment.

6 Reasons for increasing need to access children's informed consent.

Because this would be in line with the implementation of article 12 of the United Nations Convention on the Rights of the Child.

Because it seems likely that children will have the right to legal redress against practitioners implementing treatments which may have led to subsequent harm to

SEM1 0002 0480

the child's future life.

Because there is reasonable evidence that when patients in general, and children in particular, have 'agency' or an element of active participation in decisions about their treatment, then their adjustment to the treatment and its consequences is greatly improved.

7. Issues in elicitation of informed consent from children and young people.

Quite young children are able to understand considerable degrees of complexity of their illness and treatment, (often more than their parents). Children may choose not to 'know' things about their illness, and delegate the responsibility to their parents, but it is the responsibility of hospital staff to ensure that the child has genuinely chosen this, rather than it has just been assumed.

In order for a child to be able to engage in an appropriated dialogue about his or her illness and treatment, the child needs to be in a state in which he or she is thinking actively.

8. A thinking child versus a passively responding child; what makes a difference in achieving the former ?

The level of anxiety needs to be at a level that the child can manage.

The child needs information in which to base a choice.

The information needs to be understandable and 'imaginable'.

The professional needs to ensure that the 'image' in the child's mind which is elicited by the words is close enough to that being used professionally.

The relationship with professionals, and his/her way of defining questions and giving information needs to challenge the expectation that the child should comply to all the adults wishes.

The child may be assisted by constructing a 'pros and cons' list, (this is found to be particularly useful when children with cancer are offered sperm banking or storage of gonadal tissue).

Professionals also need to recognise that children often make relatively little use of metaphors. Although adolescents may be highly verbal, and may even make much of play on words, for their understanding they commonly rely on visual images. Some adults do likewise. Thus in understanding a disturbing idea, if the child does in fact choose to try and understand ideas about his or her illness, usually requires that he or she achieve some visual representation of what has been described. The child may need for example to develop an actual picture of the cells in the body, or of a tumour, and an apparent understanding by the use of words without any reference to the pictures it conjures up for a child, may mean no real understanding.

SEM1 0002 0481

Wider issues affecting the quality of Children's Healthcare Services

The rights and needs of children and families in relation to children's healthcare services.

Whilst the Institute does not have a view on the political structures which may be set up to regulate health services in general, such as possible alternatives to Community Health Councils, we are strongly committed to the need for active participation of parents and children in the accessing of consumer satisfaction about services. Whatever structures are finally instituted should include opportunities for regular and detailed feedback from families.

The changing nature and scale of inequalities in children's access to healthcare services, and in provision of children's healthcare services as compared to services for adults.

Because, at least in some areas, children's specialised services have been protected from the drains on, and lack of resources, those in the best resourced areas should be rapidly established as the benchmark of services, and realistic short term targets set to equalise these.

How to achieve better co-ordination across the range of children's healthcare services.

This question has to some extent been addressed the 'Acute' section.

How to improve co-ordination of children's healthcare services with other services for example education and social services.

It is difficult to know how to address this question adequately whilst Social Services, whose activities may so immediately impinge on health care services, remains answerable to local political pressures. The inclusion of Social Services with enlarged authorities, similar to Current Health Trusts could provide a radical solution. In these circumstances good liaison with Schools would be greatly facilitated.

Who speaks for children and for children's healthcare services at a policy level?

The government has so far rejected to proposals for a Minister for Children, and to our knowledge there are not yet any firm plans for the appointment of a Children's ombudsman. We support those groups who have publicly and privately pressed for the creation of such bodies, and in fact believe that both the above are required.

Dr Alan Cooklin

Institute of Family Therapy