

“Competence” and “Consent”

Doctors concepts of competence or ideas about consent of children are often based on a training session on Gillick and contain the idea of the “magic birthday”, after which a child of 16 becomes “competent” to decide for him or herself things that they were apparently not able to decide a month or two beforehand. This is obviously nonsense when one takes into account other factors such as a child’s natural intelligence, previous experience, ability to articulate and general world view. Nevertheless, many doctors will tailor information given according to whether the child is 16 or over. If a child is under 16, many doctors feel that they do not have to be meticulous in considering the child’s own views, as “they can’t consent for themselves anyway, it’s up to the parents”.

Many adults would consider that health care and treatment choices which have a chance of averting the possibility of eventual death would be the obvious ones to make. Many are concerned and uncomfortable that children and young people lay much more emphasis, particularly if they have had previous experience of the kind of treatment offered, on quality of life rather than eventual outcome of treatment. Doctors may express concern that the child hasn’t “fully understood” the implications of their decision if they seem not to wish to avert death at all costs, and will often wish to re-give information until the child “realises”.

Assessing children’s information needs

Children must be listened to and respected just as their families must, and an infallible way for parents and health care professionals alike to know that they are giving children the right sort of information in the right amount is to listen to the child and be led by the child’s questions.

Children will ask about what they want to know, and, if what they want to know is answered truthfully and clearly, the adult will not be “putting their foot in it” or introducing topics that the child is not ready or willing to hear. There is confusion in the mind of some adults about being truthful and being brutal; a problem for doctors who are not experienced or confident in talking with children. There are people within the health care team who can advise and guide, for example play specialists, social workers, psychologists and school teachers, but there may be a reluctance among some clinicians to turn to these psychosocial professionals for advice in these kind of matters, as there is a strong culture of the doctor knowing best and being the lead decision maker of the health care team. This is an inappropriate culture within paediatrics where a holistic focus on the needs of the child within his or her family and a multidisciplinary multi-professional approach to the care of the child is likely to deliver the best outcome in terms of decision making and ultimate compliance.

Methods of information delivery

There are various means by which information is conveyed and delivered. The most usual way, initially, is verbally, with all the possibilities and pitfalls as described above. There is also, and importantly, written information, often in the form of pamphlets provided for parents, families and children about specific disease entities or procedures which they may undergo. There are vast libraries of books and information videos about specific procedures, diseases or situations designed both for the child patient and for the adult patient or parent, and there are of course increasing numbers of patients who use the Internet to gain access to factual information, research reports etc... There may be pitfalls here as much of the information posted may be unfiltered and potentially misleading, and written information in any form cannot be appropriately used in isolation from individual discussion between doctor and patient.

Parents like to have written or recorded information to back-up their discussions with the doctor, and usually welcome the practice being initiated by some doctors of tape-recording initial or diagnostic discussions.

Language and cultural issues

Most Hospital Trusts who prepare their own information, would hopefully pay attention to the fact that very many of their patients, depending of course on the area of the country in which they are sited, will not have English as a first language and many of the large, particularly inner city, Hospital Trusts have specialist staff to advise on language and cultural matters, particularly around the giving of information, whether oral or written. The use of translators and interpreters is fraught with potential difficulty and misunderstanding in terms of ability to convey nuance and uncertainty as well as "straight fact". An interpreter is still vastly preferable to the still all too frequent practice of using a patient's family member (often a child), who may be asked to interpret with no attention paid to the cultural or personal impact of what they are being asked to do. In these situations, confidentiality is also impossible to maintain.

Finally, several health care professionals who contributed their ideas to this paper mentioned the very important way of conveying information which is often missed out of consideration; that is unspoken information, body language, gesture, facial expression. There is ample information on this topic, particularly in relation to the terminally ill patient who understands very well what is happening from the behaviour of the staff towards him. Children are particular past masters at picking up unspoken information and this is universally astonishing to parents and staff who have persuaded themselves that the child does not know what is the matter with her, or "he doesn't realise that he is dying and we don't want him to". The child makes it very clear by his or her own questions or remarks that he or she has known perfectly well what is going on and has complied with the parents (and often health care professionals) in the operation of mutual pretence.

Self help and volunteers

Almost all families value the information exchange and mutual comfort and support which they find within specific support groups, and research shows that some families, have gleaned most of their information about their child's situation, likely future and support available to them from other experienced parents in self help groups or organisations. Some doctors are quite vociferous about not using self help groups (mentioning such concepts as "winding up" parents, "frightening them" etc) but as parents have said, "if the doctors themselves don't tell us, what can we do?"

There is an increasing tendency now to supplement the clinical care of families with social and emotional support from volunteers, who have experienced similar situations. Examples of such initiatives would be the volunteer support given at the Twins and Higher Order Birth Clinics at Queen Charlotte's, run by the Multiple Birth Foundation, and, for bereaved parents, the Child Death Helpline.

It is very important that such volunteers are trained and supported appropriately in their work and not used as "cheap alternatives" to professional staff. It is also important not to confuse the concept of "volunteer" with "amateur", but to recognise the very valuable and unique contribution made by those who communicate empathically with patients and families who are experiencing similar situations.

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Final note

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**EXECUTIVE GROUP
THURSDAY 31ST AUGUST 2000**

THE CHILD IN THE FAMILY - A VISION FOR FAMILY SERVICES

Sally Nethercott - Director of Nursing and Family Services

1.0 INTRODUCTION

The following paper describes the development of Family Services in relation to the NHS plan and issues identified by users of our services. A concept of the **Child in the Family** is suggested as a suitable philosophy to underpin the work of GOS.

2.0 THE NHS PLAN

Three of the **CORE PRINCIPLES** of the plan, underpin the work for Family Services:

The NHS will:

- **Shape services around the needs and preferences of individual patients, their families and their carers.** This statement covers discrimination, dignity and patient and citizen involvement.
- **Work continuously to improve quality services and to minimise errors** - in addition to clinical quality this includes quality of life and the entire patient experience.
- **Work together to ensure a seamless service for patients** - There will be partnerships at all levels - between patients, their carers and families and NHS staff; between health and social care; between the public sector and voluntary organisations - to ensure a patient centred service.

These themes are further developed in Section 10, **Changes for Patients**. The relevant themes for Family Services are:

- **More information for patients**
- **Patient advocates and advisers in every hospital**
- **Patient's forums and citizens panels in every area.**

3.0 A CHILD AND FAMILY CENTRED GOS

The NHS plan challenges us to involve and empower users of our services i.e. children and their families, to create a Family Centred Service. The National Center for Family Centered Care in the USA has given a useful description of a Family Centred Service:

The name given to a constellation of new philosophies, attitudes and approaches to care for children with special health service needs. At the very heart of family-centred service is the recognition that the family is the constant in a child's life. For this reason, family centred service is built on partnerships between parents and professionals. (Rosenbaum et al., 1998)

However, an emerging sociology of childhood, sees children as *"actively constructing their own lives, participating in and negotiating their own health care.....having*

knowledge and skills that often go unrecognised, and being competent reporters of their own experiences". (Green,1997; Mayall, 1998).

In addition, the UN Convention on the Rights of the Child, states "*Children have the right to seek, receive and impart information and ideas and the right to express their views and to be heard.*"

Through our motto, **The Child First and Always**, we are challenged to have the child at the centre of our services, recognising the child as an individual rather than a "future adult". A concept of **The Child in the Family**, provides a slightly different framework that sees our partnership with the family as being in the interest of the child. This would enable the responsibility of the family for meeting the needs of their child to be described. In addition the child would be seen an individual with a right to information concerning their health and a rights to have their views heard.

Underpinning Child in the Family is the acceptance of the diversity of values and cultures found within our multi-ethnic society . This challenges us to be culturally aware in providing services to meet these needs.

4.0 FAMILY SERVICES - THE VISION, THE STRATEGY AND THE PLAN

4.1 THE VISION

The Vision is of a hospital that lives by its motto **The Child First and Always** and where staff and parents/carers work in partnership to maximise the health and well-being of the child. The principle of the Child in the Family will underpin and inform all services, developments and staff behaviours.

4.2 THE STRATEGY

Through the development of a Directorate of Family Services, working in partnership with other directorates and linked to the Clinical Governance work of the Director of Clinical Services, the hospital will:

- **Meet the every day needs of resident and visiting families by providing appropriate Family Support services.**
- **Actively seek the views of children and their families and use these to inform changes in service delivery and professional practice.**
- **Recognise the special expertise of families in caring for their child and seek to work in partnership with the family.**
- **Work in partnership with others to ensure a seamless service across professional and service boundaries.**

This will be achieved by:

- Leadership for the **Child in the Family** as provided by DNFS, the Executive Group and Family Service Steering Group.
- Management of Family Support Services.

- Listening to and acting upon the views of children and their families using a variety of methods.
- A Family Forum.
- Empowering children and their families through communication and information.
- Developing the skills of staff for working in partnership with children, their families and other professionals.

4.3 THE PLAN

The following plan details the work needed to achieve a focus on the Child in the Family with the resulting service improvements. It encompasses the requirement of the NIS plan.

There is potential for a research base to develop in all activities within these key themes.

4.3.1 Leadership for the "Child in the Family"

Key objective

- The DNFS will seek opportunities to develop Family and Child Centred services and user involvement strategies assisted by the Family Services Steering Group and Quality and Clinical Governance Committee, Executive Group and Management Board.

4.3.2 Management of Family Services.

Family Services comprise Accommodation, Chaplaincy, Bereavement Services, Family Resource Centre, Play Department, Volunteers, Administrative Support to Social Work Department, Radio GOSH.

Key Objectives

- Provide a comfortable supportive environment for visiting families through the effective management of the Family Support Services.
- Improve the provision of identified services e.g. food, telephones and recreational facilities for resident parents and siblings.
- Develop a Patient Advocacy and Liaison service in line with the NHS plan.

4.3.3 Listening to and acting upon the views of children and their families.

Trusts will be required to ask the views of patients and their carers on the services they have received, with all patients being given the chance on discharge to do this either in writing or electronically.

Key objectives

- Obtain the views of children and families by the use of surveys, focus groups, staff/parent conferences, comments scheme.
- Develop and implement a user involvement strategy in partnership with key support groups and families.
- Ensure the user perspective is reflected in all aspects of service delivery and development.
- Ensure the Trust fulfils the requirements of the Annual Patient Survey.

- Develop children, parent and staff charters in line with the new NHS Charter to be published in 2001.

4.3.4 A Family Forum

Each Trust is expected to establish a Patient's Forum to provide direct input from patients. For GOS this should include a forum for children, possibly linked through the internet or intranet.

Key objectives

- In partnership with support groups, describe the role and responsibilities for a Family Forum.
- Establish the Forum and its working relationships, providing necessary administrative support.
- Describe and develop a Children's Forum.
- Develop and maintain a data-base of families and support groups.
- Co-ordinate trust-wide initiatives to involve families.

4.3.5 Empowering children and their families through communication and information.

The Patient Information Group acts to continually assess and improve information for children and families.

The NIIS plan describes a patient advocate team who will act as a clearly identifiable welcoming and information point for families. Patient advocates will handle patient and family concerns, with direct access to the Chief Executive.

Key objectives

- Further develop information for families regarding clinical care and service delivery.
- Develop child-focused information.
- Identify and meet the needs of families who do not speak English and those with impaired speech, hearing, sight.
- Enable families and children to access to information via the internet.
- Describe and cost an appropriate model for welcoming, information and advocacy, to be situated in the main reception, in preparation for introduction of the Patient Advocacy and Liaison Service.

4.3.6 Developing the skills of staff for working in partnership with children, their families and other professionals.

- Assist and advise managers and clinical staff in ascertaining user views and working in partnership
- Identify areas where families can appropriately work in partnership with managers and clinical staff.
- Identify the core and specialist skills needed for effective partnership working between families and staff.
- Devise and implement appropriate training programmes for partnership working, in conjunction with Training Department, PGME and Clinical Governance.

5.0 FUTURE WORK

Last year the Trust Board agreed to development of charters for children, parents and staff. The NHS plan states that a new NHS charter will replace the existing Patient's Charter in 2001. Well-established Family and Children's Forums will achieve this work.

6.0 WORKING PRACTICES

The Directorate is to work with other groups to achieve change. This will include clinical and non-clinical directorates; Social Work Department; GOS School; parent support groups; as well as children and their families.

In particular, there will be a close working relationship with the **Clinical Governance and Clinical Improvement teams, Training Department and PGME.**

The **Family Services Steering Group** will continue to assist the Director in setting the agenda for change through offering advice and leading some aspects of the work.

7.0 RESOURCES

The work for Family Services is considerable. The posts available to meet this agenda are identified below:

Director Of Nursing and Family Services	
Assistant Director - Clinical Support	Post vacant when Clin Support transfers
Secretary	To Director, Assistant DoN, Senior Nurse Advisor, Senior Nurse Child Protection, Professor of Nursing Research
Secretary	Works to support Clinical Governance and Risk Management Books interpreters

7.1 Other costs

The involvement of children and families and increased information will incur costs associated with surveys, travel and possibly child care for participants. A bi-monthly Family Forum, for example, is estimated to cost £3,000 p.a..

8.0 SUMMARY

From our work with families including the OP survey, we know that they often experience frustration when attending or dealing with the hospital. They comment adversely on communication with professionals, balancing hospital and home and the lack of support on discharge. These difficulties add considerably to the burden carried by a family with a child with a complex disease. The development of Family Services offers the opportunity to provide a focus for the child in the family and to create opportunities for the voice of the user to be heard.

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