

Children's rights

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A practice perspective

The year 2004 marked the 15th anniversary of the UN Convention on the Rights of the Child, which has had a remarkable impact on the position of children in society both in the UK and internationally. To bring the concept of children's rights alive for practising paediatricians, we requested articles from a number of professionals including an academic, a general

paediatrician, a paediatric surgeon, and a nurse.

We requested they give their own personal perspective on what children's rights meant to them, and were not too prescriptive in our invitation. They were also asked the reasons why they think children's rights are important, how the concept enters their ordinary work including academic work, and any

proposals to make children's rights central to paediatric practice.

Additionally one young person (a member of the Young National Children's Bureau) was asked for her comments on two of the articles, and these are included in an attempt to add a different perspective in order to identify key issues. We hope you enjoy...

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Children's rights

Children, rights, and responsibilities

D M B Hall

Helping young people make the distinction between wants and needs

The images are heart-breaking, the statistics mind-numbing:¹

- UNICEF estimates that 1 million children are trafficked each year for sexual exploitation²
- There are 300 000 child soldiers in 30 conflicts around the world³
- In 23 countries more than 30% of children under 5 years of age are moderately or severely underweight
- There are at least 25 countries where more than 15% of children die before they reach the age of 5
- UNICEF puts the number of primary school age children out of school worldwide at 121 million, with a marked excess of girls—65 million girls and 56 million boys.⁴

A recent review on the impact of the United Nations Convention on the Rights of the Child (UNCRC) on these statistics reveals little progress or even regression in some countries, but real change in others.¹ For example, there is significant improvement in the proportion of girls enrolled in school and in the number of children completing primary school.

The UK is a signatory to the Convention and although UN Conventions do not have the force of law, countries do report at regular intervals to the relevant UN Committee on their progress in implementation. The UNCRC does not have the same force as the Human Rights Act,⁵ although it is widely quoted in policy documents.⁶ The concept of "Rights" cannot change human behaviour, but it "adds an element of accountability and a legal framework that can be used to make governments wake up to their obligations to make things happen".⁷

The Convention contains some Articles related to civil and political rights which are deemed to be absolute and others dealing with economic, cultural, and social issues, which each country should implement progressively according to its stage of development. In poor countries, many of the Rights set out in the Convention are a distant dream for many millions of children. In the western democracies the need for and potential impact of the Convention may seem less obvious to UK professionals, many of whom are ill informed about its provisions or are ambivalent

about its value. It has much to say that is relevant to the delivery of health care,^{8,9} but in this article I will take a broader approach to the concept of Rights and argue that we should teach children—by public example and in school—to understand the intimate relationship between Rights and Responsibilities, whatever the stage of development in their home country.

THE CONCEPT OF "RIGHTS"

Moral dilemmas occur when there are good moral reasons in support of two opposing and mutually incompatible courses of action. Within ethical theory, the notion of "rights" sits somewhat uncomfortably.¹⁰ Who confers these rights? How are they defined and on what basis? Can they be taken away or forfeited? Rights movements—Civil Rights in the USA, the anti-apartheid struggle in South Africa, and many others—have justifiably used the language of rights to further their cause. For the modern Western democracies, this language reflects the pervasive culture of liberal individualism. In a post-modern society the concept of rights has taken the place of absolute, externally defined, moral and religious principles.^{11,12}

If someone has a right to a service or a good, then someone else has an obligation to provide it. Usually, as in the case of the UNCRC, these obligations are placed primarily on the State.¹⁰ The 41 articles that make up part 1 of the Convention place two kinds of obligations on governments.¹³ Positive rights entail an obligation on the part of authority to provide a service or good; negative rights entail an obligation to refrain from doing something.

Box 1: Sort it out

Three thousand children responded to a questionnaire about children's rights, citizenship, and their priorities for change in London. Their ages ranged from 5 to 18 with a peak around the 10–12 age group. The list shows their top five priorities, followed by many other issues they raised.

- Violence and safe streets
- Abuse
- Drugs
- Bullying
- Racism
- Other: good and bad schools, crime, poverty, jobs and work, having fun and the cost of going out, space to play, health care, particularly emotional caring including elders, homelessness, traffic, filthy streets

Negative rights, for example the requirement that governments not permit or resort to torture (Article 37), or interfere with freedom of worship (Article 14), are justified in ethical theory by reference to the principles of respect for autonomy, non-maleficence, and justice. Non-interference by the state is stressed by individuals and countries with a strong philosophy of personal responsibility and independence.

Positive rights and obligations are justified in particular by the principle of beneficence—one ought not merely to refrain from causing harm but actually to do good. Positive rights carry more weight in societies with a long tradition of welfare and state support. By their nature, they require action by government, leadership, a degree of state control, and substantial state expenditure. Thus Article 23 refers to special provision for disabled children, Article 24 to access to health care, Article 26 to insurance and social security, Article 27 to an adequate standard of living, and Article 28 to education. The exercise of these rights and obligations depends on resources—people, skills, and finance. In a democratic society they need the support of the majority of the population who must meet the cost through taxation.

Statements about rights have some inherent problems as well as benefits. They can discourage or override the development of cogent moral arguments for or against a particular course of action in a given set of circumstances. They can be used to distort judgments as to how resources ought to be used. They can encourage selfishness by placing excessive emphasis on the rights of individuals. And it is too easy to pay lip-service to rights without any real commitment to action.

A SELF-CENTRED SOCIETY?

We should not blame the language of Rights for the pervasive individualism, indeed selfishness, that characterises many current debates, but difficulties arise in a society whose members have become more preoccupied with their rights than their duties to fellow citizens. Article 24 refers to the right to “the enjoyment of the highest attainable standard of health”. If a society wants its children to enjoy that right, there is a reciprocal obligation on its members to make that possible—especially when there is no conceivable risk to themselves. Some recent controversies illustrate this:

- Should organ donation for transplant should be based on an opt-out

system? Our government has been reluctant to back the opt-out approach to organ donation, or to give strong leadership in that direction, so those who might claim a right to health care by organ transplant are often denied that right.

- In response to public anger over the organ retention issue and the Redfern report, a Bill on tissue and organ retention is now going through Parliament that is draconian in its provisions and is predicted to seriously damage research and the training of the next generation of pathologists, with unpredictable effects on the quality of health care.^{14 15}
- Parents refuse immunisation on the grounds of perceived risk, however minimal, while their child enjoys the benefits of herd immunity conferred by the immunisation of other children.^{16 17}
- Children have difficulty in finding places to play or in going out, because of traffic speed, the use of small local roads as rat runs, and their parents' well-founded anxieties about pedestrian road accidents. But speed cameras and 20 mph limits produce a massive reaction from the powerful motoring lobby and the media.¹⁸
- Data protection legislation protects the privacy of individuals at the price of making epidemiological research and public health increasingly difficult (though policy makers and civil liberties lobbies may have misinterpreted the public mood on this issue).^{19 20}

LISTENING IS GOOD, ACTION IS BETTER

Article 12 says: “States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child”. Consultation with children and young people is important,²¹ but becomes insulting if there is no commitment to respond to what they say. Children are very aware of their environment and surroundings and are quick to realise that what adults say is not necessarily supported by what they do. Professor Ann Oakley wrote in 1996 a stinging commentary on the gap between rhetoric and reality.²² She refers to:

“... the hollowness of the rhetoric of that politically correct term—the Health Promoting School. There is not very much about most of these

Box 2: Examples of educational objectives from *Talking rights; taking responsibility*

- To help young people make the distinction between wants and needs
- To realise that every child has rights and they must respect each other's rights as much as their own
- To understand that rights bring responsibilities
- Seeing things in common with peers who they perceive as different in terms of gender, race, ethnicity, and social class
- To understand the concept of stereotyping
- Learning to solve conflicts responsibly

schools that is perceived by children as promoting their health. By the time children go to school they have picked up the major health education messages about a good diet, but the diet provided at school is often far from good. Playtime and the playground emerge as uncomfortable and dangerous for many children, particularly for younger children and for girls, who reported negative experiences of playground dominated by boys practicing their infant masculinity. Contrary to adults' beliefs, Playtime is not the best thing about school for one in two children and for one in three bullying is the worst. The problem is that national educational policy is not based on what children value, but on a particular view about what they ought to have and become".

An interesting example of wide consultation with children in accordance with Article 12 is the report *Sort it out*.²³ Their responses in priority order are summarised in box 1.

The Mayor of London in 2004 responded in detail to the points made by children in the consultation.²⁴ While much of what he said is aspirational, he also made a commitment to bring about changes.

HOW CAN THE CONVENTION BE IMPLEMENTED?

If we want a society in which the rights of every individual are respected, perhaps the place to start is with the next generation. Children will naturally assume the attitudes of their parents and of adult society in general unless efforts are made to capitalise on their real interest in these issues. Recent partnerships between educators and children's rights experts offer encouraging examples of what could be achieved. A programme for Key Stages 3 and 4 entitled *Talking rights; taking responsibility*²⁵ refers to the recommendation of the Advisory Group on Citizenship that "young people should

understand their legal rights and responsibilities [author's italics] with particular reference to the UNCRC". The programme provides teachers with materials to develop these ideas (see examples in box 2). The "Child to Child" scheme is an approach to health promotion and community development led by children and "aims to encourage children to play an active role ... for development of themselves, their families and their communities". The evaluation confirmed valuable benefits but also stressed the need for a considerable investment of time, leadership, and professional expertise to achieve these.²⁶ There are no quick fixes in promoting citizenship and responsibility.

HOPE FOR THE FUTURE

The UN Convention on the Rights of the Child has had a major impact in many parts of the world. It provides a gold standard and stimulus that will encourage countries at all stages of development to improve the lives of children. But the concept of rights brings with it a number of challenges as well as some very obvious benefits. Will our society acknowledge and act on the reciprocal relationship between rights and responsibilities? We need a less strident and more thoughtful media approach to the kind of moral dilemmas outlined above, and strong, principled leadership from government, the professions, and all those who want a more fair and just society.

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Children's rights

R Wheeler

A surgeon's view

Children's surgeons are rarely described as "champions" of children's rights. That is not to say we are oblivious or indifferent to them. With some honourable exceptions, surgeons tend not to perform the vital task of ensuring that rights are kept in the forefront of the public conscience. In contrast to paediatricians, who are not infrequently labelled "champions", our involvement is usually limited to the daily consequences of rights.

There are many fundamental obligations incorporated in surgical practice that could be said to flow from children's rights. However, in practice, the reverse occurs. What came first was a genuine concern to address the panoply of issues around hospitalisation and treatment, and to deliver the optimal outcome for the child and their family. Many would see the development of the subspecialty of paediatric surgery as a manifestation of this. Realisation of the need for, among other things, an appropriate environment, symptom control, and a coherent consent process has coincided with recognition of the obligations we have towards paediatric patients.

The advent of the patient and public involvement pillar of clinical governance is articulated as "Children's Voices".¹ This may be seen as the further evolution of the rights of children, or a cynical ploy for votes, depending on your views.

In any event, this progress towards optimising the outcome for the child has all been the result of clinicians striving for improvement.

Whether it will fit neatly into the rights based vocabulary remains to be seen. To what extent does this progress in surgical practice correspond to any recognisable system of rights, and are these moral, or ethical, or legal rights?

Although the United Nations Convention on Children's Rights (1989) cannot be directly applied in UK courts, we are under an obligation to honour it. As a codified objective standard, it provides for comparison with our current performance.

The main thrust behind establishing paediatric surgery as a specialty was to ensure that only doctors who had been specifically trained, treated children.

This principle had already been firmly established in paediatric medicine and nursing, and anaesthesia was soon to follow suit. It remains to be seen whether further subspecialisation will perpetuate this trend. The surgical management of rare structural anomalies, for example, biliary atresia is being concentrated in a reducing number of centres. It is argued that this may enhance outcome but certainly will reduce access (in a geographical sense) to health care. Subspecialisation into system specific groups, such as paediatric urology, may reverse the trend towards pure paediatric care. Paediatric urologists are already rejoining their adult colleagues professionally, and may yet offer their services from within urology, rather than child health.

The Convention² provides for children's health services to conform to standards set by competent authorities, adding validity to our own efforts to specialise as children's doctors. At the same time, if the trend to reconfigure services on an organ-system basis were seen to compromise the paediatric element of care, it would be inconsistent with this section.

In UK society, the most profound considerations of the Convention seem secure. All children's doctors would endorse the right to life, and the need to maximise survival and development.³

As with our own legislation, and in concordance with the efforts in paediatric surgery to optimise the outcome of the child's surgical management, "the best interests of the child shall be the primary consideration".⁴ That is not to say that best interests always corresponds with optimal surgical management. A neonate with Hirschsprung's disease may ideally be managed in hospital while awaiting the definitive surgery. There may be significant benefits in the reliability of colonic washouts and the early recognition of enterocolitis. However, the best interests of the child, in terms of the benefits of maternal bonding and being absorbed within the family dynamic, may outweigh the benefits of prolonged hospitalisation. The "health rights" of the child must be balanced against the

rights of the child to benefit from family life.

If children have to remain in hospital, the Convention also reminds us that accommodation must be provided so that the parents can accompany them, to prevent separation.⁵

Considering that pain relief is as favoured by adults as it is by children, it is remarkable that analgesia following neonatal surgery is a relatively novel concept. During the late 1980s, there was still debate among some clinicians concerning the necessity for postoperative pain relief in neonates, and various groups took on the mantle of "advocates for the child" to ensure that it was provided.

Improvements in the understanding of neonatal physiology, rather than acceptance of the rights agenda, led to the diligent management of postoperative pain in all ages of children that should be the standard today. Our continuing efforts to provide symptom relief find no direct support from the Convention, but are clearly consistent with other forms of rights legislation.⁶

The association of fear with treatment is not exclusively due to the possibility of pain. There is a widespread perception that fear is rooted in ignorance (although one wonders how that stands up to the evidence test). Paediatric surgical nurses deserve credit for striving to ameliorate such fears by supplying an enormous amount of information concerning surgical diseases, procedures, and postoperative outcomes. Such information goes way beyond the literature available merely for the disclosure for the purposes of consent.

Day case "clubs" are widely employed to familiarise children with the process of day surgery, and play therapy together with specifically designed toys introduces the bizarre world of postoperative tubes, stomas, and long term implants that might otherwise horrify a child and his parents.

The issue of disclosure during consent is also pertinent, for both children and their parents. The strict legal doctrine of informed consent has not been accepted into English law.⁷ However, we have an obligation to disclose anything which the reasonable patient (or parent) might wish to know in terms of the procedure itself, together with any alternatives, benefits, risks, and complications, so that the consentor can make an informed and balanced judgement as to whether they should proceed with surgery.

It is hoped that surgeons welcome this provision of information. It reflects the ascendancy of the principle of autonomy, as paternalism falls from favour. However, one is not infrequently

faced with a parent or patient who explicitly declines such information. Perhaps they privately consider that possession of the information will do them more harm than good. They may be discouraged or made afraid by the disclosed information, and prefer to rely on the doctor to act in their best interests, while personally remaining in ignorance. This is a difficult situation to resolve. The autonomists may respect the patients right for self-determination, but at the same time be concerned that the patient is missing an opportunity to be informed, "which must be in their best interests". And so the arch autonomist becomes a paternalist. CHAI may well be worth watching from this point of view.

The importance of involving the child in decision making conforms explicitly with the Convention⁸ and to our common law, which ensures that children who are capable of forming views are given the opportunity to express them, and to influence decision making. Whether the reluctance of the courts to permit dissent of the child who otherwise is judged to have capacity will continue, remains to be seen.

It has become clearer who may consent for surgery in a child. Even surgeons knew that the adult consentor had to have parental responsibility. However, one suspects that many adults who accompany the child for day surgery may blithely consent for a step child or niece/nephew for whom they have no parental responsibility, and neither they nor the consenting doctor know any better. Natural fathers now obtaining parental responsibility simply by appearing on the birth certificate⁹ may reduce the number of these non-consents.

This potentially rather casual attitude to who is consenting on the behalf of a child would be directly contrary to the Convention.¹⁰ The significance of such a breach of rights is self-evident; the best interests of the child are most likely to be served by ensuring that the decision maker is also the person with parental responsibility. Research may soon quantify this issue, and if it proves to be significant, Trusts should be able to rectify this relatively easily.

The situation where children can give their sole consent is also becoming clearer. Although statute¹¹ recognises the validity of the consent of 16 and 17 year olds, it is clear that the courts do not intend to allow such children to refuse surgery when the treatment will preserve life or health. Equally, Gillick¹² competence can allow some younger children to consent for themselves,

depending on the gravity of the procedure and their familiarity with the details surrounding it. Recognition of this competence necessitates the provision of appropriate patient information.

It therefore may be acceptable for a 13 year old leukaemic to provide consent for his third central venous catheter within 18 months, while in a newly diagnosed child of the same age, such consent could be invalid. Despite the theoretical applicability of the Gillick judgement to any sphere of decision making, it seems unlikely that a court would find any child competent to provide sole consent for surgical research.¹³

With these parameters in mind, it is hoped that surgeons are making more informed judgements about what to tell, and who to ask, when handling the consent process, and that rights based training is incorporated in the surgical curriculum.

Such skills become relevant when considering the potential conflicts of rights posed by such issues as the need for dual consent for religious circumcisions.¹⁴ This begs the question as to whether a single parent can be relied on to act as proxy for the child. Furthermore, it brings into sharp relief the issue of whether consent is being given in the best interests of the child, or of the community. This article is not the place to address the ethics of dual consent; merely to use it to illustrate that the surgeon has to consider the rights of the child in the context of the rights and codes of the society in which he or she is being raised.

Dual consent is also of interest because it implies that there may be two valid yet contrary views, both held by people entitled to give proxy consent. It follows that one view may be more in the best interests of the child than the other. The law has given those who hold parental responsibility equity of influence. Yet we have allowed a situation to develop where, with contrary parental views, the fate of the child will depend on the outcome of the dispute between the parents.

This amounts to "rights" that a parent has over the child. It is recognised that a right to raise children according to the parents' religious preference was codified within the Children Act 1989. However, this falls short of legitimising excisional surgery. One purpose of the Act¹⁵ was to shift the emphasis from parental rights to responsibilities, and the "dual consent" approach is inconsistent with this shift.

The "white board" is another example of this conflict of rights that impinges

on surgical practice. There have been recent concerns that the use of the white board on the hospital wards, where children's full names and bed locations are written in public view, was undesirable. The concerns were based on important issues of data protection and child protection. However, these conflict with concerns for patient safety, for a variety of reasons, which include patient tracking and certainty of identification.

On the basis that the location and correct identification of patients is an integral part of patient care, it is arguably no different from any other aspects of medical treatment. The benefits to the patient must be balanced against the risks, to determine whether the intervention is in the patient's best interests. The result has been a consent based process, allowing the parent and child to determine whether they should appear on the board or not.

I conclude that the recent development of children's surgery within the UK is largely consistent with the spirit of the Convention, and by extension, with the respect for children's rights. These examples serve to illustrate the balancing of conflicting rights that forms the daily work of paediatric surgeons; although it is unlikely that they generally consider the problems they face as explicitly rights based.

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Challenges and outcomes of working from a rights based perspective

G D Brook

With comments from a young person's perspective

Rights, what are they and who has them? Alderson¹ describes rights as "equal entitlements for all members of the human family to respect their worth and dignity..." as a reflection of the preamble stated in the United Nations Convention on the Rights of the Child 1989.² The Convention reflects the philosophy that children too are equals, having the same inherent value as grown-ups. The value of childhood itself is emphasised by the child's right to play within Article 31 of the Convention.³ The Articles of the convention have been divided into three sections:

- Provision: setting the rights to the provision of necessary goods services and resources that will help them reach their potential. This includes the right to food, health care, education, etc.
- Protection: the right to be protected from neglect, abuse, exploitation, and discrimination.
- Participation: the right to be respected; being active participants in the family, in the communities in which they live, as well as in organisations that provide services for them.

This includes being informed and having access to information, to the opportunity to express their views, and to have those views and wishes taken seriously in all matters that affect them (Articles 12, 13, and 17). In a health care setting these rights are especially challenging in relation to consent to treatment.

Working from a rights base perspective is important to my personal and professional accountability in my role as a nurse and manager within the NHS. All rights are applicable in health care but it is **the application of the participation rights that are perhaps the most challenging because they challenge our power and**

This article has been read by a young person, Hannah Gibney, who has provided her comments (see box).

authority. A rights based approach requires that we examine and understand our power and influence in the roles we have with children. As a health professional I hold power and authority by the nature of my specific nursing/medical knowledge and skills. I have access to resources and I can define what happens where, when, how, and by whom to a lesser or greater degree as can other professionals. The more authority one has in the team or the organisation, the greater the power and influence. If that power is used in a unilateral and paternalistic manner, then the patient (the child) and parent can become passive recipients of care organised and delivered by professionals. The UN Convention challenges our view of childhood and our power base. It can be seen as a "benchmark for a change of priorities in our relationships, professional and otherwise, with children".⁴ The focus of nursing "is the whole person and the human response...". Nursing interventions "are concerned with empowering people and helping them achieve, maintain, or recover their

independence".⁵ Nurses often have the greatest time in direct contact with the patient compared to other staff involved in their care. They are therefore able to identify the needs, wishes, and concerns more readily, and are in a unique position to influence the child's empowerment through participation and indeed have a responsibility, with others, to do so.

In the main it has been the participation rights of children that have been the focus of my work, but no right can be seen in separation from another.⁶ While working in the role of Clinical Nurse Specialist within the Liver Unit (1988–2002), I established, with the multidisciplinary team, a framework of practice to help children with their parents to make choices in their care and treatment. Children's participation rights in relation to consent or refusal of treatment were the key drivers in this work. Involving children in decision making on their treatment is one of the greatest challenges in paediatric practice, and in a rapidly developing, highly technological service, it was important to ensure there was a process from which the whole team worked to empower children and young people to share in decisions with their parents, enabling them to gain greater competence and confidence over time in decision making.⁷ Principles of practice were defined and objectives agreed.⁸ The process starts at the point of referral and applies to all children who attend the Liver Unit. The initial stage of the process involves identifying what children and young people already know about their health problem and treatment, as well as finding out about

Young person's commentary

I have highlighted certain areas of the article: bold is what I disagree with and italics what I agree with.

I feel that in certain aspects of this piece of work the author is looking at the rights of the children from the wrong perspective—who has the most power in the relationship. It is not really about who has the power or intelligence, it's about the mutual respect within the relationship and how this empowers and allows participation to flow naturally. I also feel she holds a slightly tokenistic view when she says nurses are in a good position to influence and therefore gain consent. This is almost as if the decisions have already been made for the young person, and so although there is consultation, what they say does not really affect their own treatment and their own body.

However, there are many positive areas of this piece. I agree with the author in saying that although parents are an important and crucial part of the child's life, in the child's decision-making they should not necessarily have the final say. And that this particularly leads to patient centred care.

I feel that there isn't really a lot missing from this article, except possibly a short paragraph from a young person that has been treated in the ways explained. This would illustrate either its effectiveness or what could be changed about the methods used.

Hannah Gibney

their experience of living with the disease/condition. An opportunity is provided for the child to share as much as they want to about themselves through various activity sheets. Information can then be shared by the team within the context of the child's life experience and concerns.

Whenever possible, information is shared with the child at their own pace. In order to achieve this, time for information sharing and listening to the child needs to be built into the care and treatment plans and care pathways. Opportunities to share and discuss information with their parents are provided, as well as the chance to make real choices. It is important to be clear about the limits of choice and why that is so.

Supporting parents in this process is crucial. Many parents wish to protect their child from difficult information. This is only natural; however, it is our role to help them understand that informing children and giving them a chance to participate, when undertaken sensitively by skilled people and in an age appropriate manner, is preferable to unexpected unpleasant experiences in which the child has no control.⁹⁻¹¹ This is respectful to the child. Many parents require support and guidance to prepare them to answer difficult and emotional questions from the child and their sibling(s) in a sensitive and truthful way.⁸ Supporting parents in their parenting role upholds Articles 5 and 18 of the Convention.

Runeson and colleagues¹² identify in their research on children's participation, the role of parents in upholding the views, concerns, and needs of their children, and indicates that parents may not always uphold these in a health care setting. Earlier research by Arronson¹³ identified that parents often take the side of physicians. Leikin¹⁴ states that parents may have "interests separate to those of the child, including fulfilling their own needs and desires and those of the staff". This emphasises the importance of listening and responding to children, and not only acting on what the parent says. Our advocacy role on behalf of the child may be imperative.

The Department of Health Consent Policy¹⁵ reflects the partnership of choosing. In Consent Form 1, a place is provided for parents to sign when a 'competent' child is signing. Consent Form 2 similarly has a place for the child to sign in agreement alongside the parent's signature. **Nurses are in an excellent position to influence this, and indeed to become trained communicators in gaining consent to treatment.**

While working with children, they themselves asked how they could make sure that the choices about the way they wanted to be looked after could happen in the planned episode of care in the intensive care unit (where they had no physical voice!). Together we came up with the idea of having a brightly coloured piece of paper headed "Things you need to know about me" or "How to look after me". An example of the content of such a sheet is given below; an 8½ year old girl writes:

"I would like to have clip-on bag please, on my ileostomy. They are easier to change. I would like to take 'Big Rabbit and Teddy' to ITU with me. Please always tell me what you would like or need to do to me before you do it and how it will feel. Please talk to me even when I'm having my 'special rest' in ITU. I might be able to hear you but be too sleepy for you to know that."

Sharing information, listening, and responding to children and young people requires time and skill and commitment. This can only happen if a process for this to be achieved is defined within teams and the skills of the different professionals are used (for example, play specialists with medical or nursing staff). How, where, and when children can access information and address their concerns should be defined, as well as identifying who will coordinate this process and ensure it happens. Within the Liver Unit team, this has mainly been the Liaison Nurse or Nurse Specialist. A whole team approach and commitment is required for this approach to be successful.

This approach has proved successful for children, young people, and their parents, as well as staff. Parents have said they have learnt with and from their children and gained greater confidence in their child making informed choices in their life. Staff are surprised by the knowledge and understanding that children can develop and are moved by the choices they make when given the opportunity. This in itself is an empowering and humbling process. Trust, respect, and commitment by the whole team to sensitive effective and honest communication between all parties, is the key to success.

While sharing this work with others I became motivated to explore the position of children's involvement in their care and treatment in an acute paediatric surgical setting. This is an Action Research project being undertaken as part of an MPhil degree.

In my current role as Head of Child and Family Centred Care I have the opportunity to influence the implementation of the rights of the child on a wider scale. One key area of responsibility is to develop policy and make reality within the Trust, patient and public involvement; that is:

- The involvement of patients in care and treatment decisions
- Their involvement in the review, planning, development, and delivery of services.

In paediatrics or child health services it can be all too easy to substitute the word patient for parent. Parents are of course vital to a child's life, but they are not the patients with their "unique" experience. Their child's experience and views need to be heard and respected alongside that of the parent if we are to deliver "patient centred" care and services.^{16 17}

Through and with the people and services I am privileged to manage, the implementation of the rights of children will become more of a reality. These services include Cultural Patient Advice and Liaison service (CPALS), Child and Family Information Centre, Interpreting Service, Bereavement Service, and the post of Arts Manager.

This year's objectives include:

- Through creative and participative methods, help children gain knowledge and understanding of the United Nations Convention on the Rights of the Child and its application in their care and treatment
- To develop and implement with colleagues, children, young people, and their families, multi-professional training and education on:
 - knowledge and application of children's rights
 - communication with children and parents
 - empowering children and young people, including the development of resources on creative methods of gaining children's and family's views.

Other opportunities include the chance to influence the trust's catering contract in the purchase of "Fair Trade"¹⁸ food products in support of Article 27 in the UNCRC: "the right of all children to a standard of living adequate for the child's physical, mental, spiritual social development".⁶

We live in exciting times. Children have never been so much at the centre of government policy and legal provision. The Children Bill¹⁹ "creates a

legislative spine for developing more effective and accessible services focused on the needs of children, young people and their families”.

As a part of this process an independent champion for children will be created in the form of a Children’s Commissioner. Their role will be to represent the views and interests of children, ensuring “they are at the heart of policy making and national debate”. The Bill also states that the UNCRC will “provide an important context for the Commissioner’s work”. A Director of Children’s Service and Lead Coordinator Council Member for children will also be created. September 2004 saw the publication of all 11 standards of the National Service Framework for Children, Young People, and Maternity Services, providing clear direction on the provision of care of children and young people. As health professionals it is our responsibility to take on the challenge of putting this into practice.

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Children’s rights

A general paediatrician’s practice in children’s rights

T Waterston

With comments from a young person’s perspective

In this paper I describe my own personal approach to children’s rights in health care. This has developed from apprenticeship to good role models, from listening to children, and from voluntary organisations which represent children. The National Children’s Bureau has been a valuable source of advice (www.ncb.org.uk).

The UN Convention on the Rights of the Child is an essential tool for individual health care as well as public health practice. Any paediatrician who peruses the Convention carefully will find many articles with health implications.¹ Table 1 lists the essential health care related articles. I have asterisked the articles which are of relevance to every consultation with a child. The other articles are important because they

This article has been read by a young person, Hannah Gibney, who has provided her comments (see box).

impose an advocacy function on us as paediatricians.

I will deal with paediatric practice in relation to the clinic consultation, to the provision of information, to advocacy for children in difficulty, and to participation. Finally a mention is made of teaching in this field.

CLINIC CONSULTATION

The chief principle underlying my practice is that of child autonomy and respect for the child’s separate identity. The child is as much a person as their parent and deserves respect and separate consideration. Children and young people (hereafter CYP) often say, “The doctor never spoke to me”. *The child is the primary client and the parents secondary, though essential to the child’s wellbeing.* This will not be new to most paediatricians.

Hence my aim is to communicate directly with the child in every consultation. This is *regardless of age.* The

conversation begins with the child, though this can be limited if he or she is under 3—and some children do not open up easily. However, it is good practice, if not always easy, to engage with every child. Some parents keep interrupting and would like to give the history themselves; they have to be persuaded to wait their turn.

The child him or herself can provide much of the history as well as interests and views about school, which is a core interest in children’s lives.

Children and young people are honest with the doctor and don’t hold back on confidences *as long as they trust you.*

What about seeing children/young people on their own? My practice is to do this after the age of about 12, but take each case as it comes. It is always helpful to see a young person on their own and should be the norm after about 15, though each should be taken on merits.

It would be useful to have a notice up in the waiting area about confidentiality or perhaps a leaflet to give out to the CYP when they arrive, as it can be difficult to explain this each time.

When I have completed the assessment, I will inform both the child and the parent of my opinion and plan. Certain other issues may come up which may require advocacy: for example, discrimination, lack of services for a disabled child, exclusion from school, emotional abuse, bullying. Assistance may be offered if appropriate.

Young person's commentary

I have highlighted certain areas of the article: bold is what I disagree with, italics what I agree with, and underlining something I have a question about.

I completely agree with Dr Waterston about the need for the child to be the primary patient and not the parents. I also agree that information on confidentiality should be more readily available and easily accessible to children and young people (CYP); from my experiences I have found that this is not so and have often become confused about what the law says my rights are. From a political level I also agree that there should be a ban on smacking, and a close eye kept on health and travel aspects of life, as this greatly concerns CYP. I have found that many doctors or nurses don't know how to approach talking to YP—teenagers in particular—and I feel it should be an invaluable part of their training to look into things like this, as the author suggested.

However I did disagree on two points with the author. If a letter is sent out about someone who is 16 or older then I feel that it isn't right to send it to the parents. I feel that if the YP is able to give consent for treatment at that age they should have the decision about whether their parents are informed; this is a huge issue in confidentiality that needs to be addressed. Secondly, I disagree that schools should be contacted about bullying with the consent of the parent—what about the young person? They should give their consent as well, and what about if they want the school to be contacted and their parents don't—does that mean they therefore will not get the help?

Finally, in underlined text, I have questioned two aspects: whether or not the child should attend the meeting about their bullying problem (with the headmaster); and whether the CYP have any influence in deciding what happens if they are being abused or if there is not influence there.

I don't feel that there is anything missing from this piece about rights; they are clearly indicated at the beginning of the article that I found very helpful for reference.

Hannah Gibney

A full discussion would be held with the CYP if consent is required. Children should be asked for their consent to immunisation and there isn't normally a problem with them agreeing to do so.

The consultation may be used as a form of modelling to the parents about

child participation. This means treating the CYP as a person worthy of respect. I like to model positive regard, in particular for the child with low self-esteem and the child on the receiving end of negative attitudes from the parent. The child should leave walking on air

because they feel so good about themselves, and return happily on the next occasion. This means finding the right words to comment positively on their characteristics. Not all children have had this experience and they like it a lot. Remember they may use what you say with the parents afterwards, so one has to be sure not to say anything that isn't true.

PROVISION OF INFORMATION

It is desirable to provide written information for the CYP about their condition and its management. For conditions such as ureteric reflux, a drawing is needed. However, children may require a longer explanation and there is a shortage of written information. There are several websites which are good sources of information (for example, Contact a Family, and the American Academy of Pediatrics), but these are not written for children themselves. Useful sources of information for parents and children are:

- www.medem.com
- www.cafamily.co.uk

It is good practice to send a copy of the **GP letter to the parents, and if the child is over 16 then I send a copy to them too**. If the first language is not English, children should not interpret for their parents, even if they wish to do so.

CONTENT OF THE CONSULTATION

It is desirable to explore social issues in relation to children's rights. Discrimination is common. Possible issues are: asylum seekers not receiving benefits; a disabled child not allowed to go on a school trip; or a child with learning difficulties bullied at school.

Articles 24, 27, and 28 are also relevant to the consultation. Access to health care may appear adequate, but there may be constraints owing to expense of transport and child care considerations. Language differences and judgemental attitudes by health staff can also reduce access by parents. I hold clinics in the most deprived areas of the city in order to reduce these constraints; this also facilitates multi-disciplinary working. I will address Articles 27 and 28 in the next section.

ADVOCACY FOR CHILDREN IN DIFFICULTY

Advocacy is required in relation to bullying (Article 19), abuse and neglect (Article 19), provision of benefits and good housing (Article 27), and education (Article 28). The principles are the same for a number of other issues such

Table 1 Articles of the UNCRC which apply to health care work

Article	Purpose
Article 2*	Protection from discrimination
Article 3	Best interests of the child a primary consideration; the institutions, services and facilities responsible for the care or protection of children shall conform with the standards established by competent authorities
Article 5	Parents responsible for ensuring that child's rights are protected
Article 6	Right to survival and development
Article 9	Right of the child who is separated from one or both parents to maintain personal relations and direct contact with both parents on a regular basis
Article 12*	The right of a child to express their view: with weight given according to the maturity of the child
Article 13*	Freedom of expression including seeking, receiving and imparting information
Article 16*	Protection of privacy
Article 17	Access to information from mass media, with protection from material injurious to his or her wellbeing
Article 18*	Assistance to parents with child rearing responsibilities
Article 19*	Protection from physical or mental violence, abuse, or neglect
Article 20	Special protection for children deprived of their families
Article 22	Protection of children seeking refugee status
Article 23*	Rights of disabled children to special care
Article 24*	Right to health and access to health care
Article 27	Right to an adequate standard of living
Article 28	Right to education
Article 30	Right to own culture and religion
Article 31	Participation in leisure and play
Article 34*	Protection from sexual exploitation

Table 2 Tackling bullying: a graded response

Response	
1.	Advise the parents to take the matter up with the headteacher and offer support
2.	Write a letter to the headteacher outlining the health impact on the child (with parents' consent)
3.	Attend a meeting in the school about the child to assist in management
4.	If a particular school seems to be not tackling bullying, discuss this with other professionals involved in the school, e.g. educational psychologist, educational welfare officer
5.	Provide input to the local education authority on training in anti-bullying practice and the development of anti-bullying policies

as disability, racial discrimination, and refugee status. The list is almost endless and I can only take on what is realistic and achievable.

Bullying frequently comes up and is a significant concern. Do paediatricians have a role in tackling bullying? We have an obligation to do so and approaches are given in table 2.

Another concern is emotional abuse by a parent. As I see many children with emotional difficulties, I encounter parents who are extremely negative about their children. When does this become abusive? There needs to be some evidence that the child's wellbeing is affected, either through behavioural difficulties which interfere with education, or through the development of symptoms such as self harming. The first approach should be to support the parents to help them to change their responses to be more positive towards the child while not condoning bad behaviour. Some parents, owing to their own poor experiences as children, are unable to do so, and then social services need to be brought in to assess the overall functioning of the family. In my experience this should be done sooner rather than later. Smacking is potentially

abusive, but it is very common; advice on alternative non-violent means of discipline² should be readily available.

Education is another key area for advocacy. Two key issues are the exclusion from school of a child with challenging behaviour, and the support of children with special educational needs. I have seen children who have been out of school not receiving significant education for over two years because of their behaviour. This is not acceptable. Such issues should be raised with the local education authority at a senior level. The same is true for children with disability, where an alliance with the educational psychology service is crucial.

Advocacy is also desirable at a political level. I have covered this elsewhere,³ but current issues where *national advocacy is required are in legislation to ban corporal punishment of children in the home,⁴ curbs on the marketing of convenience food to young children,⁵ and traffic calming and traffic reduction programmes in residential areas.⁶*

PARTICIPATION

Promoting CYP participation is a central area within the UNCRC but still little practised in child health care. The

current initiative of the RCPCH Research Unit is very welcome and a good example for others.⁷ Figure 1 illustrates the ladder of participation, which is a valuable aid.

The chief opportunity for most paediatricians to promote participation is in relation to the health care process. Is the young person asked for their opinion about treatment, and are they encouraged to make their own choice within a range of options? The parent may not always demonstrate this approach, so we need to assist them in this direction.

Participation in health care means that *we should consult young patients about out patient and hospital provision and in particular, about the development of new facilities.*⁸ This issue is highlighted in standard one (child centred services) of the National Service Framework on hospital services.⁹

There are many other opportunities for participation which will be organised outwith the health service: for example, in Newcastle a young people's organisation carried out a consultation on young people's views on health and health services in schools. This was published as a report which illustrated their view that organisation within the school was a greater threat to health than infections or cigarettes.¹⁰

TEACHING CHILDREN'S RIGHTS

It is essential that these ideas are incorporated in the theoretical and clinical teaching of paediatricians. Teaching material is now available¹¹ and can be covered in a two hour teaching session; there is a need for videos on how to communicate with children.

The pursuit of children's rights allows paediatricians to follow a practice of health care which is child centred, respectful, and promotes wellbeing. It makes the relation with our client group more satisfying and ensures that we are considerate of global and national societal needs. The work is best conducted in a team with other health professionals who have similar approaches in their respect for children's rights.

ACKNOWLEDGEMENTS

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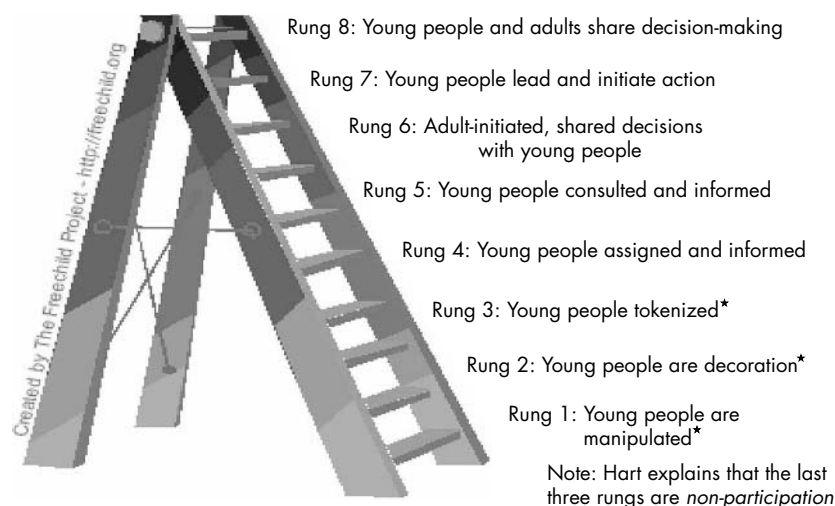


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Committee on Publication Ethics Seminar 2005 Friday 11 March 2005, 9.30 am – 5 pm, BMA House, London

This year's seminar will focus on COPE's new Code of Conduct for Editors and interactive workshops on common ethical and editorial dilemmas. The seminar is for editors, authors, and all those interested in increasing the standard of publication ethics.

The Code aims to set a new basic standard for the ethical conduct of editors and sets out guidelines for quality and correcting the record, standing by decisions made, ethics committee approval, consent for publication confidentiality of submitted material, guidance to authors, pursuing misconduct, relationship to publishers, owners, and advertisers, and conflict of interest. The code also creates a mechanism to refer a complaint to COPE if an editor has breached the code.

The seminar will include:

- The new Code of Conduct for Editors
- Dr Iona Heath, Chair BMJ Ethics Committee—research, audit, and ethics committee approval
- COPE's new website—full text and keyword searching for COPE's advice on specific issues, for example research misconduct, conflict of interest, and deception
- Interactive workshops—common ethical and editorial dilemmas for editors
- Opportunities to network with other editors and share your experiences and challenges

The seminar is free for COPE members and £30.00 for non-members. Numbers are limited and early booking is advisable. For registrations or more information please contact Sam Knottenbelt at cope@bmjgroup.com or call 020 7383 6602. For more information on COPE see www.publicationethics.org.uk/