Do children’s rights to health care in the UK ensure their best interests?

Milroy Lecture

There has been enormous growth in our knowledge and understanding about childhood and the experience of children. Three years ago, the United Kingdom signed up to the 1989 United Nations Convention on the Rights of the Child which places in international law, for the first time, a duty upon States to accord children’s rights on a par with adults. It may be no coincidence that, at this time, the British Paediatric Association is seeking approval from the Privy Council to become a college independent of this College.

During Dr Gavin Milroy’s lifetime (1805-86), one child in five died within a year after birth and one in three before the end of their fifth year [1]. Milroy’s life’s work was devoted to the control of communicable disease and to improving sanitary conditions. These were the major causes of mortality not only of infants and children, but also of mothers; even though maternal mortality was of the order of one for every 200 live births, ten times as many women of child bearing age died of other causes, most commonly pulmonary tuberculosis [2]. Many children then grew up without their mothers.

During Milroy’s lifetime, Dickens was campaigning for improvement in the living conditions and treatment of children. Control of communicable disease and improved hygiene are well understood concerns of public health and of the State—as is access to health care for children. Such campaigns have however, helped to bring about smaller families, less overcrowding, better nutrition, a huge drop in infant mortality rates (Fig 1) and an increase in life expectancy (Fig 2). The high rates of death in children led to a widespread feeling of indifference towards this fragile childhood (Fig 3) [3]. But as it became less likely that children would die in infancy, ideas changed and there was a ‘connection between progress in the concept of childhood and the progress of hygiene, between concern for the child and concern for his health’. By the end of the eighteenth century the health and education of middle class children had become a prime concern of parents. Childhood became in essence the period in which schooling took place; because of their limited opportunities for schooling, the concept of a brief childhood lasted much longer among the lower classes.

Twenty years ago, the Court Committee spelled out the implications of the ways in which we view childhood for health care practice and services: ‘In the last two or three generations we have come to realise their needs as being different from those of adults. At one time . . . childhood was thought of as an inadequate and incomplete form of the adult state. By contrast, we have become increasingly aware of childhood as a separate state, as a period of human experience in its own right. And more important still, we have come to realise the extent to which experience in childhood determines adult outcome’ [4].

Lawrence Stone, in his history of the family in England, states that ‘the only steady linear change (of the family) over the last four hundred years seems to have been a growing concern for children, although the actual treatment has oscillated cyclically between repression and permissiveness’ [5]. Thus children are considered more or less as the property of their parents. So there is no need to account for children in their own right, either in terms of collecting information directly about their status or of targeting policy and action consistently towards their best interests. In addition, assumptions about parental responsibility for children mean that society takes the responsibility to interfere only in exceptional cases, when children are endangered [6]. The good of children depends upon paternalistic and benevolent attitudes of parents, of the State, and of professionals.

Just as parents influence the development of their children, so their personal development is influenced by having children. The distinction between adulthood and the more recent traditional characteristics of childhood is becoming less clear. Because adults now reckon to go on learning all their lives, being educated is certainly not uniquely a function of childhood. Adults will move more and more in and out of periods of work; therefore, not being in the job market or world of work will no longer be a defining characteristic of childhood either. While it is becoming increasingly common for children to look after or care for their parents or other adults, it is also increasingly common for children not to be cared for by them. However, older members of families and of
society dominate social policy. In Britain, a primary school child now can normally expect to live longer as a grandparent than as a parent only or as a child [7]. In addition, today's parents have become adults over a time during which enormous encouragement has been given to the idea that personal development and self-fulfilment should continue throughout life—tending to produce a cult of individualism which conflicts with the parenting role.

Children have always been targeted by health care programmes, more in the spirit of charity or the interests of adult society than of entitlement by rights. Voluntary bodies and local education boards provided meals and milk at school when the introduction of compulsory schooling in Britain in the nineteenth century revealed the extent of malnutrition and physical defects for the first time. In response the State set up the School Medical Service in 1907 to carry out health inspections on all children and later to ensure treatment. Maternity and child welfare services were established after the First World War and were taken over from local authorities by the NHS following the National Health Service Act of 1974. Under the 1991 Patients' Charter (as in the first NHS Act of 1946) 'every citizen has the right

- to receive health care on the basis of clinical need, regardless of ability to pay
- to be given a clear explanation of any treatment proposed, including any risks and any alternatives, before you decide whether you will agree to the treatment’ [8].

The NHS Patients’ Charter rights are based on the Citizens’ Charter [9]. A ‘citizen’, as applied to all public services, is a taxpayer and can vote. Children under the age of 18 cannot vote; therefore, by definition, in this country they are not citizens in this sense and it has become clear that children’s interests have been largely regarded as covered by the 1989 Children Act.

The Children Act reinforced the underlying ethos of the Court Committee, embodying the view of the child as ‘subject’ as opposed to ‘object’. The Act primarily seeks to support parents and takes ‘as the fundamental task of parenthood, the duty to care for the child and to raise him to moral, physical and emotional health. The Act seeks to strike a balance between the need to recognise the child as an independent person and to ensure that his views are fully taken into account, and the risk of casting on him the burden of resolving problems caused by his parents or requiring him to choose between them’ [10]. The Children Act makes radical changes in the law relating to children and their families, and states that in all matters of law, ‘the child’s welfare shall be the court’s paramount consideration’.

New duties are placed upon local authorities to promote the upbringing of children in need. A child should be taken to be in need if:

- he is unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining, a reasonable standard of health or development
- his health or development is likely to be significantly impaired, or further impaired
- he is disabled (Section 17(10))
‘Development’ means physical, intellectual, emotional, social or behavioural development; and ‘health’ means physical or mental health (Section 17(11)).

Rights to health care are only important to the extent that they have a bearing on rights to health. It often comes as a surprise when one has reviewed all that has been done and is in place for the promotion of health in children, that in the UK today, large numbers of children remain vulnerable. There may be fewer deaths among children and young people but the incidence and prevalence of chronic medical conditions such as asthma, diabetes, cerebral palsy and cystic fibrosis are rising, as are all types of disability [11]. Between 10 and 20% of children and young people show significant emotional and behavioural disorder at any one time and this proportion is on the increase [12]. In addition, there is a continuing and widening discrepancy between the health experience of children living in poor as compared to affluent socio-economic conditions with clear indications that

Fig 3. Images from contemporary documents showing feelings for children and their place in the Middle Ages. Reproduced from: Riché P, Alexandre-Bidon D. L’enfance au Moyen Age. Bibliothèque Nationale de France. Paris: Seuil, 1994.
health care, among other services, is inadequate [13]. There is also good evidence that the number of children in this country at serious risk of ill health because they are living in families with below half the average income, is growing [14,15]. These indicators of conditions under which the risks to health of children are shown to be greatly increased tend to rely on relative measures, but attempts have been made to describe the extent of need for a number of basic conditions for health by establishing a 'bottom-line' level below which health would be impaired.

The basic needs of children are those that are necessary for physical survival, for the avoidance of ill health and ignorance, and for preparation for an independent, autonomous role in adult society. Needs such as:

- adequate diet
- adequate housing
- adequate income
- a stable, continuous source of affection and care, together with protection from physical, emotional and sexual abuse
- cognitive stimulation and adequate education
- a safe environment
- access to preventive and curative health care [16].

In each of these areas, clear cut failure to meet the need will result either in death, physical impairment, intellectual retardation, disturbed behaviour or emotions, or will subsequently lead to failure to lead an independent existence. Further, in each of these areas, the processes whereby failure to meet the need impairs physical or mental health are at least partially understood. To establish a standard for each of these basic needs below which there is an unacceptable degree of deprivation, is more difficult but we do know that significant numbers of children are living in conditions where their basic needs cannot be met (Fig 4).

As a framework for ensuring equity and quality in health care, the Children Act has limitations. In law, services are to be available for disadvantaged children—an attempt to give an equitable share to those who suffer inequalities and an exercise in positive discrimination, in that those who are covered by the Act have a right to services while others may be by-passed. But the Children Act does not cover all children, and the criteria for categorisation as eligible for services—as a child in need—vary widely between different authorities; and in a number of instances, services are not available even for children who do meet the criteria [17].

The extent of local discretion on the point at which intervention in the family is thought necessary is variable. There are no explicit national and accepted parenting standards which can reasonably be used to measure the success or otherwise of the Children Act in operation. Links with health services are problematic under the Children Act because, as stated in Section 27 of the Act, a health authority must comply with the request for help from a local authority only provided that the request is compatible with its own

Fig 4. Photograph taken as part of a project on child poverty in modern Britain: one of six children in a family sitting down after school, to her largest meal of the day.
statutory or other duties and does not unduly prejudice the discharge of its function. This implicitly recognises the likelihood of differing priorities between health and local authorities. A wide range of needs for health care is not included under the Children Act definition of a child in need and many are also in danger of not being recognised in this frame of duties for local authorities.

There has been increasing emphasis, now embodied in the Children Act, on the involvement of parents in decisions about children’s health care. Parents generally provide practically all the care for their children’s health, although they may be irresponsible in this respect. A number of studies have demonstrated how differently health professionals and parents (chiefly mothers) view their respective roles in parenting and in the health care of their children, and about the relative importance of particular health care problems or aspects of management [18]. Parenting education is being developed apace, with the aim of better equipping parents to act in the best interests of their children and recognising that if parenting and the role of the ordinary ‘good enough’ mother were more highly valued, children would also fare much better [19,20].

It has become clear that skills and a particular approach, with generous allocation of time, are required to ascertain children’s wishes properly, especially those of very young children, and to tread the delicate line between listening to the child and listening to the parents. Little attention has so far been paid to this aspect in this country, perhaps because it has been thought that the multidisciplinary approach to care would ensure that all contexts and considerations for the good of the whole child would be taken into account. However, we now have good evidence that decisions about individual case management and about common standards of practice and service protocols often are different according to the views and personal values of different members of a clinical team, of different professional groups and even of members of the same professional group [21]. A great deal of attention has been paid in America, notably at the Yale Child Study Centre, to training multi-disciplinary teams in working outside their individual professional interests, but together for the best interests of the child [22]. In Britain, this approach has for the most part been seen as perpetuating the power of professionals and if not, of parents, in deciding children’s best interests. There is valid criticism about the difficulty of identifying the criteria that should be used to evaluate alternative options that are open to a decision maker seeking (or purporting) to act in the child’s best interest. That the child’s wishes be taken into account in all matters of serious concern to him or her is written into the Children Act and is one of the cardinal principles in the Department of Health’s 1991 guidance on the Welfare of children and young people in hospital [23]:

‘Like all other patients, children have a right for their privacy to be respected and to be treated with tact and understanding. They have an equal right to information appropriate to their age, understanding and specific circumstances’.

Further guidance is given that:

‘young people should be kept as fully informed as possible about their treatment so as to enable them to exercise their rights. Even where young children do not have the required understanding, they should be provided with as much information as possible and their wishes ascertained and taken into account’.

Both the Act and the Department of Health guidance build on the pioneering work of the National Association for the Welfare of Children in Hospital (NAWCH), a parent-led organisation which was set up because of the distress experienced by parents and children when children were admitted into hospital to unfamiliar, often uncomfortable surroundings and removed from their parents. The parents’ views were greatly supported by a filmed record made by James Robertson of the largely unspoken messages of distress in a five year-old in hospital. It is interesting to note how humane treatment of children has been introduced on the basis of evidence of the deleterious effects of neglect—and often depends on this evidence.

The chief barrier to taking full account of children’s views and wishes in regard to health care is the presumption upon which so-called ‘Gillick’ competence is based. This is the evaluation of the ability of a child under the age of 16 to make his or her own medical decisions, according to age but considered in conjunction with the child’s mental and emotional maturity, intelligence and comprehension—each of which requires fairly expert assessment to establish a level of competence (Fig 5) [24]. We will learn more if we turn around the starting point—in other words, we should presume that the child is competent unless he proves to be otherwise, not that he is not competent unless he shows himself to be competent. The key to children’s rights is respect for their competence and acceptance that they can be as rational as adults. The ‘non-competent child’ who figures in the legal imagination is treated as rational rather than irrational. This leads to the recent uneasy swing between defining ages for the attainment of criminal responsibility [25]. But we must now build on the increasing evidence that children are capable of being moral agents; that they can voluntarily seek to promote the well being or freedom of others [26]. It is also being shown now that even primary school-age children are interested in and capable of philosophical argument [27].

In consideration of consent, competence is seen to depend almost entirely on the understanding of medical and legal information; professional, textbook
knowledge is highly valued, personal experiential knowledge is discounted. Children are assumed to be ignorant except in so far as they can recount medical information. There is an onus on professionals to take proper time and to develop their skills in giving information to patients. On the whole, they do not do this well, particularly with children and young people [28].

The balance between professional, parental and the child’s duties, responsibilities and rights is currently being redistributed and the boundaries between these and the child’s best interests are still uncertain. There are differing considerations for the best interests of very young children, for progressively older children, for teenagers and for young people, which cannot be discussed in this article.

The capability of vocal, energetic parents to win resources and influence policy may be laudable in the individual case but, as ever, those who are most vulnerable are at risk of losing out. Some argue that ill-health is due primarily to a failure of entitlements such as immunisation rather than to inadequate overall provision [29]. Strengthening entitlements can be done through the law. True implementation of a right means assuring that every individual who is entitled to it gets his or her full share of it. Interests in promoting health can be pursued in many different ways, but to use the language of rights about these interests means that one is going to use the law. But ‘ethics cannot be reduced to law’ [26].

A hierarchy of responsibility for a child’s best interests has been described [30].

Child
Family
Community
Local government

State government
National government
International non-governmental organisations
International governmental organisations

Ideally each agency supports those that are closer to the child but does not substitute for these other agencies.

The principle of ‘best interests’ is complex and is inextricably linked to the cultural context in which it is invoked. At each level in the hierarchy shown above, there may be tensions between the views about children’s best interests and the legal constraints; these tensions exist also between levels. Because of the role of government agencies in health care in deciding on priorities and determining the context in which clinicians treat patients, civil and political rights cannot be divorced from economic, social and cultural rights. The United Nations has always sought to resolve this link which can seem to be overbalanced in one direction or the other, by insisting upon the equal importance of the two sets of rights.

The UN Convention on the Rights of the Child is a much broader instrument than the Children Act. Ratification does not automatically mean that the Convention becomes law in the UK. The situation is different in the USA for example, where ratification of International Treaties automatically brings them into Federal Law.

The UN Convention itself establishes only what have been called ‘soft’ rights [29]. They can be transformed into ‘hard’ rights if national and local governments create suitably strong national and local laws along with effective agencies to implement the rights. ‘Hard’ rights have a history of case-law through which the meaning of the right is tested and refined.
The Convention covers three broad themes: participation, based on the concept of the child as an active and contributing participant in society and not merely as a passive recipient of good or bad treatment; provision, which covers the child’s right to survive and develop in an environment that allows this, with resources such as food, clean water, shelter, and services such as education and health care; and protection, which deals with all forms of abuse, discrimination and mistreatment, and exploitation of children at work. The Convention is clear that the best place for a child is with its parents, and that the State has a duty to support and assist parents in this responsibility where necessary [30].

These principles are laid out in three Articles which are of fundamental importance in the implementation of all the others: Article 2, whereby the State must ‘respect and ensure’ the rights in the Convention for all children without discrimination of any kind on grounds such as disability, race, colour, sex, religion, language, national, ethnic or social origin, birth or other status; Article 3, which states that ‘in all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration’; and Article 12, whereby ‘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’. Article 5 underlines the responsibilities of State and parents to ensure that children are provided with guidance appropriate to their evolving capabilities.

There are also Articles setting out the dimensions of other rights for children. Those regarding health and health care principally concern the child’s inherent right to life and the State’s duty to ensure to the maximum possible extent the survival and development of the child (Article 6) and the child’s right to enjoy the highest attainable standard of health and to facilities for the treatment of illness and for rehabilitation (Article 24). In the three years following ratification of the Convention by the UK, a great deal of work was undertaken, much of it by the non-State funded Children’s Rights Development Unit, to find out how current policy and practice fits in with the principles of the Convention [31]. The UK government was required at the end of this period to report on this to the UN Committee on the Rights of the Child.

The UN Committee has now commented upon the UK government’s report, noting positively the adoption by ‘the State party of a Children’s Act applicable to England and Wales …’ [32]. It expresses particular concerns about the absence of any independent mechanism for the purpose of monitoring developments in relation to the rights of the child; and that the principle of the best interests of the child appears not to be reflected in legislation in such areas as health, education and social security which have a bearing on the respect for the rights of the child.

Covering a whole range of concerns, the UN Committee has identified that in Britain, negative, or at least not positive, attitudes to children are widespread and that their best interests are pursued or perhaps merely safeguarded in ways that are neither comprehensive nor coherent, indeed often conflicting.

In the government’s strategy for health in England published in 1992, the importance of the health of infants and children for making progress towards the national targets was highlighted thus: ‘Success in meeting the targets will improve the health of children, for example in reducing low birth weight associated with expectant mothers smoking during pregnancy, and success with children—for example in establishing healthy lifestyles at a young age—is crucial to the long-term success of the strategy’ [33]. This strategy has a crucial influence on the priorities for NHS attention and on the markers for achievement in the health service but the health of children is included almost exclusively in relation to its effect on the future health of adults.

One comparative example is France where family policy and legislation have long been centred on the child’s best interests [34]. Maternity and welfare benefits are tied to the child’s attendance for health-related preventive and surveillance services. France claims to be the country of human rights par excellence, but originally it was the best interests of childhood rather than of the child as such that were served by the legislature. What was lacking in the French system was the right to be heard. However, legislation in recognition of this has now been put high on the national and political agenda. France’s report to the UN Committee describes how on every school board there are two children who are trained to ensure that children’s rights to express opinions about the running of the school are fully enacted.

The UN Convention on the Rights of the Child reflects sensitivity to the impact of contextual factors and cultural considerations on the norms it purports to set. As shown in the hierarchy of responsibility, the international community should help national governments in their work with children. This mirrors the requirements of comprehensive needs assessment in health care commissioning [35]. The tensions may seem so acute in the UK because the variation in the local situation is often so great and local administrative boundaries do not follow lines of population variation nor necessarily of political influence.

A large number of people and interests have the power to decide what is in children’s best interests. How can acting towards children with the objective of furthering their best interests (which the UN Convention says must be ‘a primary consideration’ in all actions concerning children) be reconciled with treating children as possessors of rights (which the UN
Convention clearly thinks they are)? These two bases for action require conciliation if the argument is accepted that it is right that someone should have complete power to determine what is in A's interests and to direct A accordingly, and leaves A without any rights at all. They can be reconciled by allowing scope for the child to determine what those interests are; this has been called 'dynamic self-determinism' [36]. It is more than merely the application of Article 12 of the Convention affording the child the right to express his or her views, and allows for changes in the child's views—or in children's views—over time. It must be an incremental and iterative process.

The dichotomy between protecting children and protecting their rights is clearly false. Children who are not protected, whose welfare is not advanced, will not be able to exercise self-determination. On the other hand, failing to recognise the personalities of children is likely to result in undermining their protection and reducing them to objects of intervention.

What can we learn from what children and young people tell us? First, a 14 year-old girl published an account in the British Medical Journal of the time she underwent chemotherapy two years previously [37]. She wrote of her feelings of isolation and terror each time she went for treatment:

'When that vile yellow toxin was linked to my arm I could make myself sick by just watching it ooze down the tube and into my body... On that table is the only time I can truly say that if I could have stood up I would have killed myself. The feeling of utter hopelessness, frustration, and boredom led to a desperation I never, ever want to experience again'.

She also described how simple measures, such as a video to help distract her during the treatment process and attention paid to the special needs of older children in the way the department was run, would have helped enormously.

Second, patients with brittle diabetes place an enormous burden upon the resources of the health service and cause physical, psychological and often financial strain to themselves and their families [38]. It is widely considered by workers in the field that maladaptive behaviour is the commonest cause of brittle diabetes, often remaining undetected after exhaustive investigation has excluded other potential causes such as inappropriate treatment of insulin dependent diabetes or undiagnosed intercurrent illness. The key element is extreme fluctuations in metabolic control sufficient to cause disruption to the lifestyle or to endanger the life of a patient. Young people with this condition indulge in potentially dangerous behaviour, partly because they are ignorant as to its consequences but more often because it 'pays' in the sense of fulfilling other needs whether for love, shelter, approval or escape from an otherwise insoluble conflict.

Third, deaf children in growing up may or may not make the choice to learn to speak so as to fit into 'normal' society—the hearing world—as their parents and professional carers almost inevitably would want. But within this hearing society, a deaf person is likely to remain disabled. The choice may be made to concentrate on learning to sign and to grow up as a fully competent member of the world of the deaf—in which those who cannot sign are disabled [39].

A final example comes from the work of the Council for Disabled Children [40]. Through a voluntary organisation, young people with disabilities were offered the opportunity to discuss with a peer group how they actually perceived themselves. These young people found it extraordinarily difficult to acknowledge their own disabilities. They all felt they had been given little factual information about their special health care or disability problems. When asked if they would make a presentation to their parents who were members of local voluntary organisations for carers, none of them felt confident to say what it had felt like growing up with a disability. However, they prepared a composite figure called Miss Can—with her alter ego, Miss Can't—to express what they felt, and these figures illustrate something of what we can learn about the needs of these young people and the requirements for disability services.

The director of Demos, an independent think tank, has recently commented that ours is an age where inherited duties and commandments have lost their pull [41]. Today, for better or worse, everyone is brought up to question and to contest, and to think about ethics in much more personal terms. This may be why a more personal language of responsibility, rooted not in duty but in individual choices, and the values each of us learns and experiences through school and life, fits much better with the times (Fig 6).

Children do not only tell us difficult things. We must not forget how much we have learned, in addition to disease processes and to impairments arising in...
childhood, about the magic in children, about their desire and energy for exploration, about their inventiveness and imagination. These are not only of incomparable value—if they can be expressed—to the individual, but to the capacity of the human race to adapt to a changing world, hopefully to enjoy greater richness in the experience of living. Above all, I believe that the essence of childhood exists in these qualities and that the human race depends on the continuing existence of such a childhood if it is to survive.

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Address for correspondence: Dr Zarrina Kurtz, 12 Blithfield Street, London W8 6RH.