



THE CONUNDRUM OF CHILDREN IN THE US HEALTH CARE SYSTEM

Wanda K Mohr and Sheila Suess Kennedy

Key words: children's rights; health care decision making; legal-ethical issues; professional ethics; UN Convention on the Rights of the Child

One area in which children's rights are rarely considered in the USA is that of autonomy over their bodies. This right is routinely ignored in the arena of health care decision making. Children are routinely excluded from expressing their opinions involving medical decisions that affect them. This article discusses the complex reasons why children's voices are typically not heard in the USA, the consequences of their disempowerment, and the ethical obligations of health care providers to advocate for the rights of children, even in the absence of a legal mandate to do so.

Introduction

In 1989, members of the United Nations (UN) held a landmark Convention on the Rights of the Child, affirming an international commitment toward safeguarding the physical, social, cultural and religious rights of children. The Convention was passed by the UN General Assembly, and then it passed out of the collective consciousness of the peoples of the USA. As a result, the children of the richest country in the world continue to occupy an indeterminate position between property and constitutionally protected citizen. This situation ensures that children in the USA are denied not only some of the basic rights available to adults in a free society but also rights that are arguably appropriate for all sentient beings, whether fully mature or not.

One area in which these rights are rarely considered is that of children's autonomy over their bodies. Nowhere is that right less respected than in health care decision making. Children are routinely excluded from expressing their opinions involving medical decisions that affect them.¹ In this article we discuss the complex reasons why children's voices are typically not heard in the USA, the consequences of their disempowerment, and the ethical obligations of health care providers to advocate for the rights of children, even in the absence of a legal mandate to do so.

Address for correspondence: Wanda K Mohr, 6441 Greenridge Drive, Indianapolis, IN 46278, USA.

In order to prevent redundancy we have used some terms interchangeably. These include the words pertaining to young persons who have not attained the status of being legal adults. In the USA, unless they are emancipated minors, this is the age of 18 years. Equivalent terms in this article are: child(ren), minors, young people or persons, and juveniles. When we use the word 'adolescent' we mean children or minors between the ages of 13 and 17 years.

The UN Convention on the Rights of the Child

The UN General Assembly adopted the UN Convention on the Rights of the Child in 1989.² The Convention appeared at a time when the need for improvement in the status of the world's children was painfully apparent.³ The Convention incorporates a number of components: (1) a set of standards in the form of stipulated rights and freedoms to be enjoyed by all the world's children; (2) a formal, legal commitment of state authorities to take such measures as are necessary in order to bring the quality of their children's lives as close as possible to that which is prescribed in the document; and (3) mechanisms and procedures to monitor the performance of states in relation to the Convention's standards, in order to call attention to places where corrective action is called for, and to provide some guidance and assistance to states desirous of improving their performance. The Convention consists of a preamble and 41 substantive articles. Article 1 defines what the convention means by 'child' and articles 2–41 extend civil, political, religious, economic, social, cultural and humanitarian rights to all children. The substantive articles each outline specific principles of rights: for example, the right to freedom of expression of opinion (article 12) or freedom of thought (article 14). By the same token, the document underscores that the degree of freedom granted to children should be guided by a consideration of their development and evolving maturity.⁴

Ratification status

Signing the UN Convention signals a nation's intent to pursue ratification. Ratification means that a nation agrees to be legally bound by the terms of the Convention. Since the Convention was opened for nations' signatures in 1990, only Somalia and the USA have failed to ratify.⁵ Somalia has no recognized government and thus is unable to proceed to ratification.

With respect to the USA, a number of reasons have been given for its failure to ratify the Convention. Official reasons include the unwillingness of the federal government to interfere with the discretion and power of individual states' power to create, amend and adjudicate their own laws concerning children.^{6,7} A second reason is that some of the rights accorded to children under the Convention are not recognized as rights in the USA. An example is the fundamental right to education set out under article 28.⁸ A rarely appreciated distinction between the legal system in the USA and those in countries with systems based upon the Romano/Germanic legal model is that 'rights' in America are generally negative in character; that is, they are rights to be free from certain types of state interference. Romano/Germanic systems view rights as positive entitlements *to* specific

treatments or goods; these systems are more consistent with many of the Convention's enumerated rights and do not present some of the legal barriers faced in the USA.⁹ For the one, justice is prevention of state oppression; for the other, justice is the orderly distribution of social benefits, both material and intangible (p. 4).¹⁰ A third explanation has to do with actual conflicts between laws in the USA and convention principles, for example, the articles forbidding corporal punishment in schools and the use of capital punishment. Other, less official, explanations involve widespread misconceptions about the convention's intent. For example, fears have been expressed that the convention's support of adoption will weaken the rights of parents.¹¹ Many of those misconceptions have been promulgated by opposition groups and political authoritarians. These individuals express concern that the Convention would usurp national and state sovereignty and undermine parental authority.¹² Whatever the reason, the lack of action is consistent with the USA's lacklustre record of ratifying major human rights treaties despite a political rhetoric extolling human rights. For example, the Convention on the Prevention and Punishment of the Crime of Genocide took more than 30 years to be ratified by the USA.¹³

How the UN Convention applies to the rights of children in health care settings

By asserting children's right to life as a distinct personality and a right to possess a legally recognized identity, the Convention is the first document to state explicitly that children have a right to 'have a say' in processes affecting their lives. The inclusion of identity as an element of children's right to life is grounded in the idea that, unless individuals possess identity as a legally recognized attribute, they are unable to claim the rights available to all persons residing within the jurisdiction of a particular state. These rights presuppose not only life itself but also the autonomy to determine what is to be done in order to sustain that life and enhance its quality.

Article 12 of the Convention provides that children who are capable of forming views must be assured the right to express them on all matters affecting them, and these views must be given due weight. In addition, under article 3, the Convention provides that a child 'considered by internal law as having sufficient understanding' is to be granted and is entitled to request the right to receive all relevant information, to be consulted and to express his or her views, and to be informed of the possible consequences of compliance with these views and the possible consequences of any decision.

The American legal context

In the USA, the right of a competent adult to bodily autonomy is taken very seriously; there are even criminal penalties against physicians who violate it.¹⁴ Likewise, competent individuals have the right to refuse treatment, a right that courts rarely extend to minors. Children are not recognized as competent under US law, so their due process privacy rights may be infringed on the showing of a 'significant' state interest, while the state must show such a compelling interest

to justify similar infringement of the rights of an adult.¹⁵ Moreover, children are naturally dependent on their parents or guardians, who are legally presumed to have their best interests at heart.

Competency in the USA in terms of decision making capacity over one's health care decisions is defined by reference to the legal concept of competency. Competency is one of three components (together with voluntariness and information) necessary for a patient's treatment decision to be considered legally valid.¹⁶ Legal scholars have included several components that are necessary to meet the test of competency. These are: (1) evidence of choice; (2) reasonable outcome of choice (this option corresponds to the choice that a reasonable person might make); (3) rational reasoning (in making the decision); and (4) understanding of the risks, benefits and alternatives.¹⁷

In the USA, children are generally considered to be incompetent to give voluntary consent to what is done to their bodies by way of medical procedures.⁸ In a review of cases involving life-sustaining treatment, Evans found that only 13% of children's stated wishes were considered.¹ Moreover, in the USA, parents continue to invoke the right to make medical decisions for their children on the basis of their constitutional right to privacy, which has been held to include the right to raise their children in accordance with their own beliefs and values. These rights have often been interpreted in ways that effectively disempower children. In order to understand why the USA addresses the rights of children as it does, it is necessary to understand both the history of children's rights and the ambiguity of the term 'children's rights' as it has been used and understood within legal discourse.

Walker, Brooks and Wrightsman have described the historical reality of childhood in a brief, but quite telling passage:

Until modern times, childhood was an almost universally grim experience. For hundreds of years, children were treated primarily as chattel. They were bought, sold, cared for and abandoned in much the same way as a pair of shoes (p. 20).⁸

In English common law, children were considered to be the property of the father, who could dispose of them in his will like any other property.¹⁸ It was not until the sixteenth century that children's status began gradually to improve; indeed, the very *idea* of childhood did not develop until that time.^{8,19} The emergence of a concept of childhood that recognized vulnerability and acknowledged special needs requiring nurture and protection also gave rise to the legal and ethical dilemmas faced by proponents of children's rights today. If, as many commentators have noted, the USA lacks a coherent policy on children's rights, much of the problem is that different people use the term 'rights' to mean different, and often contradictory, things.

American laws concerning children have been informed by two very distinctive approaches: a paternalistic, or progressive, approach, which focuses on nurturance and protection; and an individual rights approach, which emphasizes the child's age-appropriate right to personal autonomy.²⁰ To the first approach can be attributed legislation making school attendance compulsory, establishing juvenile courts, and prohibiting child labour. These are measures that assume a large degree of dependence by children on adult society. In the second category can be listed court cases such as: *Brown v. Board of Education*,²¹ which recognized

children as rights-bearing individuals; *Re Gault*,²² which entitled juveniles to court-appointed counsel; or *Tinker v. Des Moines*,²³ which protected the right of minors to express political opinions in a nondisruptive manner in a public-school setting.²⁰ Studies have shown that, in the USA, there is strong political support for the extension of the protective, 'nurturant' rights, but far less support for rights of self-determination.²⁴ If these two approaches are to be rationalized and a comprehensive framework within which to discuss both the social and individual rights of children is to be created, decisions must be made about when it is appropriate to treat a given individual as a dependent child requiring nurturance, and when as an adult, entitled to individual autonomy and voice. The legal system has struggled with that core question, which is made more difficult because the rights and duties of parents and (to a lesser but not inconsiderable extent) the interests of the State are also implicated. As one commentator has noted, the courts have struggled to mediate the conflict between 'democratic ideals of individual freedom and the sanctity of the family unit (p. 461).²⁵ The result is a framework that rests on a sharp distinction between public and private responsibility for children's welfare, with the public assuming responsibility only when the private actors have defaulted. The primacy of the power given to parents and family rests on a belief that children need authority rather than autonomy, that 'rights' so understood are not in the child's best interests.²⁰

It is arguably misleading even to suggest the existence of an American jurisprudence on children's rights; it is more accurate to say that there are a number of court decisions that have affected the legal rights of children. As Minow has noted,²⁰ children have no political power and are not usually the focus of laws and decisions that affect them. Child labour laws achieved nothing until labour unions decided that such laws would be economically beneficial to their members. Similarly, court opinions affecting children typically arise in the context of other conflicts: child custody disputes, religious liberty cases, the criminal justice system, and conflicts around medical treatment and intervention. Those disparate cases provide the underpinnings of the legal system's current jurisprudence on the relationship between children, parents and the State, and even a brief and necessarily incomplete overview illuminates the need for a normative theory to bring order to this chaotic area of the law.

The earliest cases to focus on conflicts between parents and the Government established parental prerogatives as constitutionally protected privacy rights. In 1923, *Meyer v. Nebraska*²⁶ considered, and overruled, a state law prohibiting parents and schools from teaching children in the German language. The case was decided largely on First Amendment freedom of expression doctrine. *Pierce v. Society of Sisters*,²⁷ decided in 1925, established the right of parents to remove their children from the public school system. The decision also upheld the right of the State to mandate education through a particular age, or for a particular number of years. The court recognized the right of parents to instruct their children in a manner consistent with their own values and beliefs, but also recognized that society in general and government in particular has a vital interest in assuring an educated citizenry. Not until *Wisconsin v. Yoder* in 1972²⁸ (and then only in a dissent by Justice Douglas) was there an explicit recommendation that the interests of the children involved be given any consideration.

In *Prince v. Massachusetts*,²⁹ in 1944, the court upheld the constitutionality of

child labour laws and penalties for parents who violated them. This case signalled that parental rights, while still paramount, could and would be limited when socially determined interests of children required such limitation.

In the late 1960s, three cases sent mixed signals about the rights of young people: *Re Gault*, handed down in 1967,²² required the State to provide legal representation for children facing criminal proceedings, extending to juveniles a right previously enjoyed only by adults. The next year, however, in *Ginsberg v. New York*,³⁰ the court upheld a law prohibiting the sale of 'girlie' magazines to a 16-year-old, over objections based upon adolescents' free expression rights. Then, in 1969, in *Tinker v. Des Moines*,²³ the Supreme Court issued the now-famous (and routinely disregarded) edict that children 'do not leave their constitutional rights at the schoolhouse gate', and permitted the plaintiffs to wear black arm-bands to class to express disapproval of the Vietnam War.

In 1971, retreating from the promise of *Re Gault*,²² the court declined to extend the right of trial by jury to young people (*McKiever v. Pennsylvania*³¹). In 1972, it handed down another case involving the education of young people, *Wisconsin v. Yoder*.²⁸ The court in *Yoder* held that Amish parents had First and Fourteenth Amendment rights to withdraw their children from formal schooling after completion of the eighth grade. The case continues to be widely discussed and analysed because it addresses the persistent tension between the free exercise of rights of minority religious sects and the interest of the State in fostering civic cohesion and citizenship education. What it did not address, as Justice Douglas pointed out in dissent, was the possibility that Amish children may have rights distinct from those of their parents, which the State may have a duty to consider.

If parents have often been accorded unreasonably wide latitude over child-rearing decisions, the court has just as steadfastly refused to limit the scope of state interference with children's liberty interests. In 1979, in *Parham v. JR*,³² the court declined to require that a hearing be held before a child could be institutionalized; and, in 1984, in *Schnall v. Martin*,³³ it permitted the 'preventive' detention of juveniles said to 'pose a risk' of committing crime. The court in *Schnall* held that a minor's liberty interest was subordinate to his 'best interests' as the State may define them.

The trend since 1980 has been to diminish even such children's rights as the court had previously established.²⁵ *Hazelwood School District v. Kuhlmeier*,³⁴ a 1988 decision, upheld the right of public school officials to censor student newspapers. In the infamous *DeShaney v. Winnebago County Department of Social Services*, in 1989,³⁵ the court declined to find county social workers liable for severe brain damage suffered by a child at the hands of his father, despite the fact that the agency had been aware of the situation for months, had removed the child from the home at one point, had returned him to the father's custody, and then allowed him to remain despite the father's noncompliance with required counselling and documented evidence of continued abuse. This case stands as a stark example of current legal principles favouring the rights of even abusive parents and sharply limiting the state's affirmative responsibility for the well-being of children.

The 1995 case of *Vernonia v. Acton*³⁶ is the most recent of a series of cases considering and substantially restricting the Fourth Amendment rights of youngsters. In contradistinction to adults who may not be subjected to searches if authorities deem that there is a 'probable cause' to do so, minors may be searched under the

lower standard of 'reasonable suspicion'. Students may even be searched at random and without suspicion in school settings. In *Vernonia*, the asserted pervasiveness of drug use in the school was held as sufficient grounds to justify random, suspicionless drug testing that would clearly be unconstitutional if conducted on adults.

A comparison of the juvenile justice system with health care law provides numerous examples of the legal system's ambivalence about the rights and capacities of children. As prosecutors are waiving more and younger juveniles into adult courts, insisting that they be held legally and morally responsible under adult criminal standards, other courts are tightening parental notification laws based on the assumption that female adolescents are incapable of assuming responsibility for their own reproductive decisions.³⁷ Children's voices are routinely and legally ignored in medical situations directly affecting them.⁸ As Minow has noted, there are states in which an 18-year-old can obtain an abortion without parental notice, but cannot legally miss school for a doctor's appointment without a note.²⁰

It may be in the abortion context that these competing considerations are most starkly revealed. The Supreme Court has attempted to mediate among the values involved by constructing a mechanism by which the states could be informed of a minor's desire to have an abortion, and could authorize in conformity with that desire without notice to the minor's parent. This judicial mechanism signalled the court's recognition and protection of children's constitutional rights, and its willingness to circumscribe those rights in the light of children's particular vulnerabilities, impaired decision making, and dependence upon their parents. The court has recognized a minor's right to have an abortion, even without parental consent, but has also allowed the State to impose limits intended to encourage intrafamilial resolution of the issue. States have been required to develop a judicial by-pass procedure allowing a minor to establish her maturity in the event that attempts at intrafamilial resolution prove impracticable. This represents a recognition of the (admittedly limited and contingent) rights of children to make certain important personal decisions; but it also opens the door to inconsistencies of application, in large measure because courts are not well equipped to deal with issues of intellectual competency and emotional maturity, and because lack of competency is a convenient proxy for other, more authoritarian, concerns.²⁰

Health care decisions and children's rights

As Woodhouse³⁸ has suggested, one reason for the inconsistent nature of children's rights jurisprudence is that US law is forged out of crisis intervention. The Constitution requires the existence of a 'case or controversy', a conflict implicating real interests and affecting real parties, as a condition to court action. Advisory opinions are not part of our legal tradition and, if a real case has not forced a court to address an issue, there is no case law on that issue. As a result, the guidelines we have for allowing children to participate in medical treatment decisions are more suggestive than determinate.

Probably the most litigated area involving children's right to self-determination is abortion and required parental notification. Parental notification laws are an example of legislation directed at politically powerless constituencies, and courts

have 'reinforced the state's power to curtail the rights of minors when it acts in the guise of a protector of minors from their lack of capacity to fend for themselves (p. 1127).³⁷ In addition to the presumed diminished capacity of minors, deference to the integrity of the family is often cited as a justification for parental notification requirements. Although it is true that the due process clause's liberty interest protects parental authority over children, it is also true that, even in cases upholding parental rights, the courts frequently distinguish between the rights of the father and mother, suggesting that 'family integrity' is a more nuanced issue than proponents of parental notification legislation may recognize.^{38,39}

In order to pass constitutional scrutiny, parental notification laws must contain by-pass provisions that allow a young woman to demonstrate that she has sufficient capacity to make an informed and responsible decision. The guidelines usually applied to determine capacity are very similar to those that the courts have applied in cases involving general medical care and informed consent. The older the girl, the more nearly emancipated, the more likely it is that a court will respect her decision. A typical case is *Re Mary P*,⁴⁰ in which a Queens County, New York, court issued a protective order against a mother who was insisting that her daughter should undergo an abortion. The girl was aged 15 years and wanted to carry her child to term. The judge ruled that 'it is the child who has the right to decide'. Of course, there is a strong concern when dealing with polarizing issues like abortion that judges will be influenced by their own strong beliefs, and will tend to see as 'mature' those adolescents who make decisions with which they agree. In order to guard against that danger, it has been suggested that the burden of proof in such cases be placed on whoever is *opposing* the minor's decision. Parents or others who wish to substitute their judgment for that of the young woman involved should have to demonstrate by clear and convincing evidence (a high legal standard) that the decision is not in the minor's best interests.³⁷

In a legal system that accords so much power to parents, courts have been called upon to decide whether parents may give consent to a child's participation in medical research, or may authorize transplantation of their minor child's organs and, if so, under what circumstances. In *Strunk v. Strunk*,⁴¹ a court allowed parents to consent to the transplantation of a kidney from an institutionalized 27-year-old with an IQ of 35. The recipient was his brother, a married university student. In *Hart v. Brown*,⁴² a court allowed a similar transplant from a healthy 7-year-old to her sibling, but only engaged in a searching examination of the risks and motives involved. In several other reported cases, permission has been denied.⁴³

A number of courts have had to weigh the rights of terminally ill minors against the wishes of their families and the advice of medical professionals. A case in point was 15-year-old Benny Agrelo, who was born with a malfunctioning liver. He had a transplant at age 8, which failed when he was 13. After another transplant and treatment with experimental drugs, he could not lead a normal or comfortable life. When he refused to continue his drug regimen (with his parents' concurrence), his doctors went to court to compel treatment. In a widely reported case, the judge ruled that Benny was capable of informed consent, and he died as he had wished.¹⁵

Informed consent implies a right of informed refusal. Competent adults have that right, not only under common law but as a part of their constitutional right

to privacy. That right, however, has not been generally extended to minors, owing both to their presumed incapacity to make such decisions and to the intervening rights of parents.¹⁵ However, some courts have recently begun to extend the right to refuse treatment to 'mature' minors. The burden of proof is on the minor to demonstrate maturity. Standards applied by different courts vary, with some using a common-law 'rule of sevens' to support a presumption that children aged over 14 years are competent, and others taking a case-by-case approach. Two decisions, one issued in 1989 and the other in 1990, illustrate some of the complexities of these cases. In *Re EG*,⁴⁴ a 17-year-old Jehovah's Witness refused transfusions that were necessary to save her life. The trial court disregarded her wishes, despite finding her to be mature and informed. That decision was overturned by the Appeals Court, which ruled that her right to make her own decision must be balanced against the importance of preserving life, the need to protect the interests of third parties (usually parents), society's interest in preventing suicide, and maintenance of the ethical integrity of the medical profession. In this case, the mother supported the decision, and the balance was struck in favour of respecting the minor's right to self-determination. *Re Long Island Jewish Medical Center*,⁴⁵ decided the following year, is an example of the fact-sensitive nature of such enquiries. As with *EG*, the case involved a 17-year-old Jehovah's Witness (in fact, he was only seven weeks short of his eighteenth birthday). His parents, too, supported his decision to refuse transfusions, but the evidence demonstrated that he was highly dependent, that he considered himself still a child, and that his connection to the religious beliefs compelling his decision was tenuous, at best. He repeatedly testified that it wouldn't be 'his' sin if the court ordered the transfusions. The court found that he was not a 'mature minor', and that he lacked legal capacity to make the medical decisions involved.

The issue of children's competence

The body of scholarship on children's competence is sparse indeed, with much theoretical or expository posturing, but little in the way of empirical study. Realizing the limitations and recent challenges to the theories of Piaget, we limit our discussion to his theoretical framework because the few studies that have been carried out have used his concepts to inform their enquiry. From a theoretical perspective, Piaget describes the ability to posit general logical rules through internal reflection, that is, hypothetico-deductive reasoning as the capacity that evolves during the formal operational stage of development.⁴⁶ During this stage abstract thinking appears and, when faced with a problem, a child will think of all the possibilities and outcomes, including those that are not obvious, weigh the alternatives, and test them against reality in an orderly fashion. In addition to voluntariness, this is precisely the skill that is required in the process of informed consent. The presence of formal operational thought is necessary in order for one to be able to appreciate the nature and consequences of a proposed treatment, to reflect on these rationally, and to reach a reasonable decision.^{47,48} Extensive evidence exists to suggest that developmental stage is a more accurate determinant of cognitive ability than is chronological age, thereby indicating that at least some persons below the age of 18 years are intellectually capable of giving truly informed consent to treatment. By the same token, some persons over the age of

18 do not reach the formal operational stage, a finding that has been substantiated by research.^{49,50}

There are only a few major attempts to apply cognitive developmental concepts to analyses of minors' capabilities to make independent decisions about their own health care. Grisso and Vierling, who examined the extant research in developmental psychology, concluded that the moral and intellectual maturity of most 15-year-olds was usually at least equal to that of most adults and that most 11–14-year-olds would be capable of consenting in some selected instances.⁵¹ In 1982, Weithorn and Campbell empirically tested the law's presumption about the competence of minors to make decisions affecting their own health care. The study compared the performance of persons ages 9, 14, 18, and 21 years on a measure developed to operationalize legal standards of competency. Their findings supported predictions of Piagetian concepts of cognitive development. Minors aged 14 were found to demonstrate a level of competency equivalent to that of adults. Younger minors aged 9, however, appeared less competent than adults.⁴⁷

Only one reported study exists to date that considered the issue of informed consent and children's ability to participate in a clinical trial. Lewis and Lewis found that after explaining the nature of the research and its risks and benefits, children aged 9–12 years were capable of understanding the process and consequences of participation.⁵²

Despite there being few empirical data establishing competence and the capacity to engage in decisions, there is little doubt that nervous systems and cognitive structures mature. Although maturation and the acquisition of stage-salient competencies may theoretically be attenuated by certain factors, such as physical injury or exposure to noxious environmental influences, maturation nevertheless proceeds incrementally. The law finds it convenient to specify age cut-offs, with which abilities are presumed to correlate. However, neither developmental theory nor empirical evidence support this position. Clearly both predict and demonstrate that children who at one time cannot comprehend the facts and issues on which consent must be granted do become able, or at least as able as adults, by some time in their adolescence.

Ethical practice within the confines of the conundrum

One might well enquire what this lengthy discussion of children, their psychosocial competence and their legal rights, has to do with ethical practice of health care professionals in the USA. All of the preceding discussion relates to the nature of the relationship and is built on trust. Patients trust professionals and entrust themselves – their bodies and well-being – to the professional. Participatory rhetoric notwithstanding, this is an unequal relationship at best, and patients are unavoidably situated within various forms of vulnerability and uncertainty with respect to this relationship.⁵³ The bioethicist Pellegrino underscored this uneven power distribution when he wrote that patients are 'condemned to a relationship of inequality with the professional healer, for the healer professes to possess precisely what the patient lacks – the knowledge and the power to heal (p. 161).⁵⁴

Given this asymmetrical relationship, professionals are under a special obligation to be strictly at the service of patients and to use their power in the interest

of their well-being. In the case of children, this obligation is more daunting in that children constitute a special class of vulnerable patients. They generally do not initiate the professional relationship and they are disempowered because of their presumed incompetent status under the law.

It does not actually take very long to identify a series of decisions that ought not to be left to a child. Irreversible surgical procedures are one example. By the same token, parents may deprive children of rights and in other ways exercise authority over them that would be impermissible in other contexts between citizens. One example is the situation that occurs when a child is critically ill and the only potentially hopeful means of saving the child is to remove a kidney for a transplant from a healthy sibling. Such a dilemma is bound to provoke moral distress in the thoughtful practitioner who sees a child experiencing coercion, albeit benign coercion. The child in this instance experiences both impotence and powerlessness against a coalition of adults acting in traditional adult roles.

As evidenced by the few studies available on the subject, much empirical work remains to be done to further the study of children's competency. Nevertheless, a foundation for ethical decision making already exists for health care professionals. Principles of beneficence and nonmaleficence are central to the ethical standards that regulate health professionals. The maxim *primum non nocere* (above all do no harm) is at the core of the Hippocratic oath and foundational to western medicine. In the American Nurses' Association *Code of Ethics*, the very first provision states: 'The nurse provides services with respect for human dignity and the uniqueness of the client, unrestricted by considerations of social or economic status, personal attributes, or the nature of the health problems.'⁵⁵

An ample body of psychological literature points to the positive value of allowing human beings to exercise choice. Moreover, patient choice appears to be an important determinant of treatment success.⁵⁶ Thus, both medical and nursing ethics point strongly in the direction of recognizing the right of persons to be given choice and sufficient information to make reasonable choices, to participate in treatment decisions and to be engaged in the process of their care.

Conclusion

What are we to conclude from this discussion? It is obvious to anyone who has seriously approached the issue of children's rights that it is a nuanced and multi-dimensional issue. It is also one that spans the paradigms of ethics, social and developmental sciences, and the law. Our codes of ethics suggest that professionals must ensure that children, as human beings, should have the opportunity to be informed and to consent to medical treatment. Social and developmental sciences suggest that children have incremental capacities for decision making that depend on a number of ontogenetic and ecological factors. Yet, for the most part, the highest court in the USA has little faith in minors' competence and capacity to make informed decisions.

Children's capacity for decision making and the exercise of meaningful autonomy over their bodies depends upon socially constructed definitions, observations, attitudes and values, which, unfortunately, are not informed by hard data. There is a clash between the sciences and the law, with the law relying more on

logical analysis and the sciences on empirical analysis. This is unfortunate; both law and public policy would be better served if this discontinuity were bridged, and legislation was based on a better grasp of empirical data. The current situation leaves the professional having to decide what is morally acceptable and yet legal at the same time.

In addressing this issue, Rodham suggests that legal competency be presumed unless proved otherwise. She called upon the law to be as discriminating in its application to children as it is with adults and argued that children should be presumed legally competent unless proved otherwise.⁵⁷ Winick, among others, has argued that the jurisprudence of children's rights rests upon questionable presumptions about capacity, and the issue of capacity is at the heart of much of the difficulty that the courts have with these cases.⁵⁶ As one judge has observed:

While mature children may not have the political autonomy that an adult possesses, they still possess the personal autonomy possessed by all human beings. The specter of a judge ordering such a drastic intrusion into the personal autonomy of a cognitively competent, socially mature adolescent, who for personal or religious reasons chooses to reject treatment, ultimately repulses most individuals. Power has its limits. Our society has recognized those limits where adults are concerned. While the result in children's cases is not altogether satisfying, the alternatives are worse (p. 1914).⁵⁸

As a practical matter, ignoring children's strong preferences may well undermine the enforceability of a court order. Noting that the rhetoric of 'best interests' provides inadequate guidance to jurists, Mlyniec makes several recommendations for ethical decision making: judges should be aware of the importance of good legal representation in these cases; they should be familiar with scientific research and child development theory; and they should be required to demonstrate expertise about children before trying cases involving them. Judges should be willing to evaluate cognitive competence, particularly in juvenile criminal proceedings, where children aged under 15 years rarely understand their rights and their IQ will affect their ability to do so. They should also look carefully for evidence of undue influence. Subject to these variables, Mlyniec gives no weight to the preferences of children aged under 10 years, and applies a refutable presumption favouring the preferences of children over 14. Whatever the age of the child, however, Mlyniec is adamant that the child should be *heard*.⁵⁸

We suggest a similar approach to health care professionals concerned with the issue of children's voices in decision making. Difficult cases such as the bone marrow donation dilemma will be rare but, in view of children's vulnerability and powerlessness, professionals have an obligation to empower rather than further to disempower children. Thus we propose no algorithm for health care professionals in their practice with children, but rather urge the adoption of empowerment-based practice. Empowerment suggests that children should be heard, their interests advanced, and their rights determined on a case by case basis that takes context and competency into account. It suggests that the practitioner, as both advocate and fiduciary, will ensure that children have as much information and decision making power as is consistent with their age and capabilities.

At the heart of empowerment practice is the idea that professionals value children's autonomy and uniqueness, no matter what their chronological age. We recognize that the exercise of more mature and informed decision making is

necessary in order to protect children's futures as adults, nevertheless, with respect to day to day practice, children should at least be consulted about the major decisions that they cannot make independently, such as life-saving chemotherapy.⁵⁹ They should also have age-appropriate autonomy over matters that they can control, for example, who can visit them in the hospital. Nurses and other health care professionals can make clear to children what is outside their realm of responsibility and what is within their control.

The USA may or may not ratify the Convention on the Rights of the Child, but the health care professions should not wait for ratification and legal mandate in order to implement the Convention's central insight: children are individuals whose personhood deserves respect. Empowerment practice is a demonstration of that respect.

Wanda K Mohr and Sheila Suess Kennedy, Indiana University Purdue University Indianapolis, Indianapolis, IN, USA.

References

- ¹ Evans JL. Are children competent to make decisions about their own deaths? *Behav Sci Law* 1995; **13**: 27–41.
- ² United Nations High Commissioner for Human Rights. *Declaration on the Rights of the Child*. Proclaimed by General Assembly resolution 1386 (XIV) 20 November 1989, New York, UN.
- ³ Freeman M. *The moral status of children: essays on the rights of the child*. Cambridge: Martinus Nijhoff, 1997.
- ⁴ Mower AG. *The convention on the rights of children: international law support for children*. Westport, CT: Greenwood Press, 1997.
- ⁵ United Nations Children's Fund (UNICEF). *Child rights: about the Convention*. Available at: <http://www.unicef.org/crc>
- ⁶ Cohen CP, Davidson HA. *Children's rights in America: UN Convention on the Rights of the Child compared with United States law*. Chicago, IL: American Bar Association, 1990.
- ⁷ Limber SP. Universal rights for children. *Soc Psychol Stud Soc Issues Newsletter* 1994; (193): 10–11.
- ⁸ Walker NE, Brooks CM, Wrightsman LS. *Children's rights in the United States*. Thousand Oaks, CA: Sage, 1999.
- ⁹ Nauck BJ. Implications of the United States ratification of the United Nations Convention on the Rights of the Child: civil rights, the Constitution and the family. *Cleveland State Law Rev* 1994; **42**: 675–703.
- ¹⁰ Lucier JP. Unconventional rights: children and the United Nations. *Fam Policy* 1992. Cited in: Nauck BJ. Implications of the United States ratification of the United Nations Convention on the Rights of the Child: civil rights, the Constitution and the family. *Cleveland State Law Rev* 1994; **42**: 675–703.
- ¹¹ Donnolo P, Azzerelli K. Ignoring the human rights of children: a perspective on America's failure to ratify the Convention on Human Rights of the Child. *J Law Policy* 1996; **5**: 203–21.
- ¹² Purdy LM. *In their best interest? The case against rights for children*. Ithaca, NY: Cornell University Press, 1992.
- ¹³ United Nations Children's Fund (UNICEF). *Child rights: how to help the US ratify*. Available at: <http://www.unicef.org/crc>
- ¹⁴ Skeels JF. The rights of minors to refuse medical treatment. *Loyola Univ Law J* 1990; **23**: 1199–230.
- ¹⁵ Lonowski SC. Recognizing the right of terminally-ill mature minors to refuse life-sustaining medical treatment: the need for legislative guidelines to give full effect to minors' expanded rights. *Univ Louisville J Fam Law* 1996; **34**: 421–45.
- ¹⁶ Meisel A, Roth LH, Lidz CW. Toward a model of the legal doctrine of informed consent. *Am J Psychiatry* 1977; **134**: 285–89.

- 17 Meisel A. The 'exceptions' to the informed consent doctrine: striking a balance between competing values in medical decision making. *Wisconsin Law Rev* 1979; **1979**: 413–88.
- 18 Wilkin J. A time for change: re-evaluating the constitutional status of minors. *Florida Law Rev* 1995; **47**: 113–46.
- 19 Jackson R. The war over children's rights: and justice for all? Equalizing the rights of children. *Buffalo Hum Rights Law Rev* 1999; **5**: 223–51.
- 20 Minow M. Rights for the next generation: a feminist approach to children's rights. *Harvard Wom Law J* 1986; **9**: 1–24.
- 21 *Brown v. Board of Education* 347 US 483 (1954)
- 22 *Re Gault* 387 US 1 (1967)
- 23 *Tinker v. Des Moines* 393 US 503 (1969)
- 24 Rogers CM, Wrightsman LS. Attitudes toward children's rights: nurturance or self-determination? *J Soc Issues* 1978; **34**: 59–68.
- 25 Rush SE. The Warren and Burger Courts on state, parent and child conflict resolution: a comparative analysis and proposed methodology. *Hastings Law J* 1985; **36**: 461–513.
- 26 *Meyer v. Nebraska* 262 US 390 (1923)
- 27 *Pierce v. Society of Sisters* 268 US 510 (1925)
- 28 *Wisconsin v. Yoder* 406 US 205 (1972)
- 29 *Prince v. Massachusetts* 321 US 158 (1944)
- 30 *Ginsberg v. New York* 390 US 629 (1968)
- 31 *McKiever v. Pennsylvania* 403 US 528 (1971)
- 32 *Parham v. JR* 442 US 584 (1979)
- 33 *Schnall v. Martin* 467 US 253 (1984)
- 34 *Hazelwood School District v. Kuhlmeier* 484 US 260 (1988)
- 35 *DeShaney v. Winnebago County Department of Social Services* 489 US 189 (1989)
- 36 *Vernonia v. Acton* 515 US 646 (1995)
- 37 Katz K. The pregnant child's right to self-determination. *Albany Law Rev* 1999; **62**: 1119–66.
- 38 Woodhouse B. Children's rights: the destruction and promise of family. *Brigham Young Univ Law Rev* 1998; **1993**: 497–515.
- 39 Woodhouse B. Hatching the egg: a child-centered perspective on parents' rights. *Cardozo Law Rev* 1993; **14**: 1747–75.
- 40 *Re Mary P* 444 NYS2d 545 (Fam. Ct Queens County, 1981)
- 41 *Strunk v. Strunk* 445 SW.2d 145 (Ky 1969)
- 42 *Hart v. Brown* 289 A.2d 386 (Conn. Sup. Ct 1972)
- 43 Wadlington W. Medical decision-making for and by children: tensions between parent, state and child. *Univ Illinois Law Rev* 1994; **1994**: 311–36.
- 44 *Re EG* 549 NE.2d 322 (Ill. 1989)
- 45 *Re Long Island Jewish Medical Center* 557 NYS2d 239 (Sup. Ct 1990)
- 46 Piaget J. *The construction of reality in the child*. New York: Free Press, 1954.
- 47 Weithorn LA, Campbell SB. The competency of children and adults to make informed treatment decisions. *Child Dev* 1982; **53**: 1589–98.
- 48 Billick SB. Developmental competency. *Bull Am Acad Psychiatry Law* 1986; **14**: 301–308.
- 49 Keating D. Adolescent thinking. In: Adelson J ed. *Handbook of adolescent psychiatry*. New York: Wiley, 1979: 211–46.
- 50 Morrison K, Morrison JK, Holdridge-Crane S. The child's right to give informed consent to psychiatric treatment. *J Clin Child Psychol* 1979; **8**: 43–47.
- 51 Grisso T, Vierling L. Minors' consent to treatment: a developmental perspective. *Prof Psychol* 1978; **9**: 412–27.
- 52 Lewis MA, Lewis CE. Consequences of empowering children to care for themselves. *Pediatrician* 1990; **17**: 63–67.
- 53 Zaner RM. The phenomenon of trust and the patient–physician relationship. In: Pellegrino ED, Veatch RM, Langan JP eds. *Ethics, trust, and the professions*. Washington, DC: Georgetown University Press, 1991: 45–68.
- 54 Pellegrino ED. Trust and distrust in professional ethics. In: Pellegrino ED, Veatch RM, Langan JP eds. *Ethics, trust, and the professions*. Washington, DC: Georgetown University Press, 1991: 69–92.

- ⁵⁵ American Nurses Association. *Code of ethics with interpretive statements*. Washington, DC: ANA, 1987.
- ⁵⁶ Winick BJ. On autonomy: legal and psychological perspectives. *Villanova Law Rev* 1992; **37**: 1705–77.
- ⁵⁷ Rodham H. Children under the law. *Harvard Educ Rev* 1973; **43**: 487–514.
- ⁵⁸ Mlyniec WJ. A judge's ethical dilemma: assessing a child's capacity to choose. *Fordham Law Rev* 1996; **64**: 1873–915.
- ⁵⁹ Ladd RE. *Children's rights re-visioned: philosophical readings*. Belmont, CA: Wadsworth, 1996.