

**Voices, choices and law: weighing children's views in justice proceedings**  
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**Giving children's views "due weight" in medical law**  
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**Abstract**

Article 12 with its concern to give "due weight" to children's views involves potential contradictions between human rights to self-determination and children's rights. A set of conditions in Article 12 turns rights into highly qualified permissions that can transfer agency and control from children onto adults. These are further complicated by reports by the UN Committee on the Rights of the Child and others that position children's best interests against their expressed views, and by contrasting standards set by national laws and guidance. Theories about children's rights in medical law differ from actual practice in reported cases, which are influenced by long-standing theories about childhood in philosophy and psychology that disregard realities in children's lives. Barriers to due respect for children's views in medical law and practice that need to be addressed are summarised.

**Keywords**

Article 12, assent, child development, competence, consent, evolving capacities, Gillick, human rights, mature minors, surgery

## **1. Introduction**

Although Article 12 is often seen as the jewel in the crown of the UN *Convention on the Rights of the Child* (UNCRC) (UN, 1989), would any adult want to be blessed - or cursed - with this right? The UN Committee on the Rights of the Child (2009) described Article 12 as a "unique provision in a human rights treaty". While some commentators see the Article as an advance on other Conventions, questions are raised as to why, if Article 12 is so vital, it appears in no other treaties.

This paper reviews how Article 12, with its concept of giving "due weight" to children's views, is fraught with splits and paradoxes, which are highlighted in medical law. There are potential contradictions between human rights to self-determination and children's highly qualified rights when Article 12 turns rights into conditional permissions. These are further complicated by the children's rights literature and reported medical legal cases, by an assumed opposition between children's best interests and their expressed views, and by conflicting standards set by national laws and guidance. Theories about children's rights in medical law differ from actual practice, which is influenced by long-standing theories about childhood in philosophy and psychology that disregard realities in children's lives. In conclusion,

barriers to respect for children's views in medical law that need to be addressed are summarised.

## 2. The invisible key to human rights: self-determination

Today's international human rights treaties began as responses to atrocities during the 1930s and 1940s, to the Holocaust and abusive medical experiments reported during the Nuremberg trials. The *Nuremberg Code* (1947) that sets international standards for medical research, the *Universal Declaration of Human Rights* (UDHR) (UN, 1948) and the *European Convention on Human Rights* (EC, 1950) were all designed to prevent these crimes against humanity from ever recurring. Although they do not mention "self-determination" their whole aim is to remove avoidable constraints on self-determination and to respect and promote many ways in which it can be exercised. One clear example is UDHR Article 3, "Everyone has the right to life, liberty and security of person" and, as stated in other Articles, freedom from servitude, torture, discrimination and all other unjust constraints.

Kant (1984) saw self-determination or autonomy in terms of individuals setting their own goals, being ends in themselves and not being used as the means to other people's ends. This freedom has also been envisaged as each of us being the author of our own life, not being forced to act out other people's scripts though we may willingly choose to follow some of these, while equally respecting everyone else's self-determination in solidarity. There are many critics of this "Western" aspiration. Yet the critics tend to claim that other people do not want these freedoms, and seldom if ever ask that their own autonomy rights be denied, while frequent public protests around the world demonstrate universal desires for freedom and justice.

Kantian autonomous self-determination is so much assumed and taken-for-granted as the moral basis of all adult rights and freedoms that it is not explicitly mentioned in rights treaties, though it implicitly pervades them, for example:

No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks (UN, 1948, Article 12; and see CE, 1950, Article 8).

One version of non-interference is the English common law of battery that prohibits unlawful touching, so that clinical staff should be careful not to touch patients in any way against their will and not simply request consent for major interventions. Another version is respecting the privacy and confidentiality of patients' records, including children's records.

Human agency is very limited by *unavoidable* natural and social constraints, such as illness and disability, gaps in medical skill and knowledge, and finite healthcare resources and services. The rights treaties, however, guard against *avoidable* and deliberate constraints. The *Nuremberg Code* (1947), aiming to promote "freely made" decisions about medical research, begins: "1. The voluntary consent of the human subject is absolutely essential...to exercise free power of choice, without the

intervention of any element of force, fraud, deceit, duress, overreaching, or ulterior form of constraint or coercion.”

Isaiah Berlin (2004) considered “negative liberty” rights to non-interference, to freedom of speech, information, thought and conscience, with the absence of constraints, as more powerful than weaker “positive liberty” rights, which rely on goods and services being provided by others, including education, healthcare, and an adequate standard of living, which all promote freedom and fulfilment. Among the criticisms of Berlin’s dualism is the point that to realise all their freedoms, positive or negative, individuals partly depend on other people’s active support and often on public funds. Today’s right to life often depends on the right to the highest attainable health services (UN, 1989, Article 24), for instance.

Beyond necessary supports for the free exercise of human rights, however, UNCRC adds further supports to be discussed. In some ways these turn children’s stronger “negative” freedoms (now packaged as participation rights) into a set of weaker “positive” rights or recognitions largely provided and controlled by others. And the UNCRC positions adults and not children as the main agents, as reviewed in the next section.

### **3. Article 12: agency or dependency? Redefining children’s daily activities into conditional permissions**

The “universal human rights” in UDHR (UN, 1948) that in theory are held by everyone will be contrasted in this section with children’s rights in the UNCRC (UN, 1989). UDHR Articles, and also the main Articles 6-27 in ICCPR (UN, 1966) are phrased as factual statements: “Everyone has the right to/ is entitled to...” or “No one shall be subjected to...” The statements are validated by our “inherent dignity and...the equal and inalienable rights of all members of the human family” (UN, 1948, Preamble).

UNCRC Articles, however, begin “State parties shall assure/undertake/respect...” There is strength in making authorities responsible and accountable for seeing that children’s rights are recognised and respected. Yet the phrasing risks also making children’s rights seem provisional, and not irrevocable and indubitable like human rights. If authorities can assure that rights are respected, as if rights are in their gift, can they not also assess the claims, and potentially withhold support for certain cases or versions relating to each Article?

UNCRC Article 12 asserts: “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” (UN, 1989, Article 12). To form and express views is more than a right that others can assure to children, it is an integral part of being human. From birth, children vividly and freely form and express their views of anxiety, hunger, fatigue, pain, pleasure, trust or fear, no one can stop them. Effective healthcare involves sensitively learning their “views” even from the youngest babies (AIs, 1999). It is often said that “children do not have the right to refuse” beneficial healthcare, but of course they frequently refuse and protest, about injections for example. Not only is this “freedom of expression” part of being human, and vital for self-preservation, it is

essential for informing other people about the child's needs and adequate care. The child's "right to refuse" concerns the refusal being respected by adults, or else being overridden when this is believed to be in the child's best interests.

Another way in which Article 12 makes children's rights seem provisional is when "the right to express those views freely" is confined to "the child who is capable of forming his or her own views". This opens up adults' discretion to decide who is capable, and potentially closes down and silences the views of children deemed not capable. Pre-verbal children, and even those aged 8-, 12-, 14-years or older are indeed commonly excluded as incapable, when the Article 12 concept can become a silencer instead of a liberator of children.

Article 12 may be interpreted and limited to include only children who are able to put their views into acceptable words for adults to hear. Six-year-old Samantha willingly underwent two liver transplants. As she said, she longed to be fit and well, and to look pink not yellow. But after these transplants both failed and her doctors and parents wanted to try a third transplant "with a two percent chance of success", as her mother recorded (Irwin, 1996, with Alderson 1996) she became so sad and withdrawn, refusing to speak or to eat, that her parents and then her doctors accepted her wish to go home to die.

Extremely ill young children think about dying (Alderson et al., 2006) and understand what it means (Clunies-Ross and Lansdown, 1988). Official views about this most serious of all decisions, potentially to end life, are radically changing, from the decriminalising of suicide (in the UK in 1961) to legally allowing assisted suicide. Although suicide assisted by doctors is not permitted in Britain, it is in a growing number of countries. A few countries respect that, very rarely, terminally ill children want to be relieved from their suffering. Assisted suicide has been "not punishable" in Holland since 2002 for children from the age of 12-years (Buiting, et al., 2009) in accordance with strict criteria. These criteria concern the patient's request, the patient's suffering (unbearable and hopeless), the information provided to the patient, the absence of reasonable alternatives, consultation with another physician, the applied method of ending life, and a full report to a review committee. Assisted suicide is very controversial, especially in cases of children, and is not mentioned here with the intention of advocating it. Many experts will continue to say that children cannot possibly understand, or really wish to die, and that such law scandalously fails to protect the most ill and vulnerable children of all. However, Dutch law illustrates how medical and legal experts, and parents, do respect and trust some children to make extremely complex, distressing, fatal decisions, and help them to carry out their decisions.

Many sick children strive to hide their suffering and reassure their parents (Alderson, 1993; Bluebond-Langner 1978), and they are likely to have great difficulty in beginning to form and express a wish to die. Like Samantha, they have to rely on very sensitive and respectful responses from adults. The UN Committee gives much practical advice on this communication in *General Comment No. 12*, mentioning the extra needs of disabled and other disadvantaged children and it counters assumptions that the child's views have to be justified in great detail, provided there is profound core understanding (UN, 2009: 20-21).

It is not necessary that the child has comprehensive knowledge of all aspects of the matter affecting her or him, but that she or he has sufficient understanding to be capable of appropriately forming her or his own views on the matter.

Paragraphs 20-21 also counter assumptions that only older children can form valid views, stating that the child's capability to form and express views begins "in early childhood".

This phrase [on capability] should not be seen as a limitation, but rather as an obligation for States parties to assess the capacity of the child to form an autonomous opinion to the greatest extent possible. This means that States parties cannot begin with the assumption that a child is incapable of expressing her or his own views. On the contrary, States parties should presume that a child has the capacity to form her or his own views and recognize that she or he has the right to express them; it is not up to the child to first prove her or his capacity.

Yet the Committee's later point on presuming competence is partly contradicted by the earlier one on the "obligation" that someone must "assess the capacity of the child". This transfers agency from children to adults, whereas if capacity were presumed, as with adults though many lack strong competence, assessment would not be the starting point.

The Committee's advice on how to involve children includes working in five stages: preparation, the hearing (or the doctor-patient discussion about consent to treatment), assessment of capacity, information about the weight given to the views of the child, and complaints, remedies and redress. Important and practical though the advice is, it is presented as the means of adults countering children's vulnerable immaturity. Yet the Committee's advice can be argued to apply to people of all ages, children and adults. For example, Clause 43 (UN, 2009) states:

A child cannot be heard effectively where the environment is intimidating, hostile, insensitive or inappropriate for her or his age. Proceedings must be both accessible and child-appropriate. Particular attention needs to be paid to the provision and delivery of child-friendly information, adequate support for self-advocacy, and appropriately trained staff.

Many adults are poorly educated, have language and learning difficulties or mental health problems, many have extreme and distracting anxieties, and the average adult reading age in the UK is 10-years. Everyone needs sensitive adequate services – these needs are not solely limited to children. However, on average, children endure three further limitations. They are generally less experienced than adults (though children with long-term illness or disability can have exceptional experience and knowledge of their own condition). Their views are less likely to be respected in terms of being given due weight than adults' views are. And their protests are less likely to be taken seriously or to be supported by advocates that children can know and appoint.

UDHR (UN, 1948, Article 19) states: "Everyone has the right to freedom of opinion and expression...to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers." This broad yet flexible article has stood the test of time. UNCRC is more qualified and conditional in Article 12 about the child's "right to express those views freely in all matters affecting the child". Why is it necessary to add the "all matters" clause? And who decides what these matters are or are not? How might the vague term be

misapplied and restricted? Too often the matters are turned into narrow personal questions about direct goods and services for the individual child, whereas they also expand into global, political and economic matters. Choices about nurses for sick children in London, for example, extend to social justice and the politics of shortages of nurses and training places in England, and recruitment of nurses who have been trained in very poor understaffed countries where they are desperately needed. In Africa and Asia there are not only very high levels of illness and disability, but also a very high proportion of people aged under 15, over 45 per cent in parts of Africa.<sup>1</sup> “All matters affecting the child” involve how their health is affected by global decisions, such as about providing clean, safe water to the billion people without access to it, or about health promotion that aims to prevent the obesity epidemics. These are debates and activities in which children need to be involved too, and their views to be given due weight. Individual medical decisions are ever more closely related to the global politics and economics of health, healthcare and prevention of illness, so that Article 12’s term “due weight” has personal and also broadly political meanings.

UDHR assumes that the “right to be heard” is too integral to freedom of expression to need to be stated explicitly. An advantage of UNCRC’s addition, that the child is “provided the opportunity to be heard”, recognises that so often children are ignored. However, once again this transfers agency from the relatively passive child to the adult agents, who provide the opportunity and do the hearing – or not. And once again the right is qualified by unhelpful extra phrases. The right is not left open for all occasions, but is specified only “in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law”. The “proceedings” can apply to formal consent to medical treatment, and as Samantha’s example showed, healthcare can involve the most complex decisions of all, and set standards for all other matters in which children might have views. However, Article 12 redefines children’s daily activities into conditional permissions when it neither accepts children’s views unconditionally, nor recognises children’s right to make decisions, as reviewed in the next two sections.

## **4. “Due weight”: conditional acceptance of children’s views**

Article 12 sets the conditions of “the views of the child being given due weight in accordance with the age and maturity of the child”. Who decides when a child is mature enough? When is maturity defined as complying with adults and immaturity with resisting their authority? Adults here are the agents, and the child is the relatively passive helpless subject of their views. “Weight” is presented not as intrinsic to the child’s views, but as “given”, bestowed or ascribed by the adults. When Article 12 is so hedged around and dependent on adults’ discretion does children’s freedom of expression become a privilege rather than a right?

All human rights are subject to “respect for the rights and freedoms of others and [to] meeting the just requirements of morality, public order and the general welfare in

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<sup>1</sup> World Population Review (2017) <http://worldpopulationreview.com/countries/uganda-population/>

a democratic society” (*Universal Declaration of Human Rights?*, 1948, Article 29). Apart from these limitations, UDHR treats freedom of expression as unweighted, in that views are not weighed, assessed or compared, but are respected in their own right.

Article 12’s phrase “due weight”, however, implies that the content and validity of children’s views can actually be weighed and measured reasonably accurately with objective fairness and precision. Weight invokes gravity and gravitas and implies precision in attempts to estimate, calculate, compare and measure facts, risks and benefits. Weight has many meanings: force and significance; a burden to bear; a balancing of pressures for and against certain arguments; a measuring and ascertaining of exact heaviness or the exact importance and value of each view; allocating and counterpoising portions to different agents. This final meaning introduces zero-sum concepts of weight. The less weight given to the child’s view, the greater the weight of the adults’ view if there is disagreement.

Yet views held by children or adults are often partly immeasurable, messy, complicated, and unpredictable. They may be little understood, mistaken, partly subconscious, subjective and contested. Views may be incompatible, such as in conflicts between children’s and adults’ preferences, or between children’s seeming present and future best interests. Weight in Article 12 implies power: the inherent power of meaning and relevance in the child’s view, or the bestowed power that adults either ascribe to the child’s view or withhold from it. The routine balancing of power between clinical expertise and the patient’s preference, in the dyad of doctor and adult patient, is further complicated by the doctor-child-parent triad, and by children’s presumed immaturity. Children and also adults differ greatly in their ability to form and express views, in their knowledge and experience as either new emergency cases, or patients who have lived with a serious condition and been treated for months or years. The latter have unique embodied knowledge of how their condition continually affects their identity and daily life. An example I often cite is of two dynamic girls with very short stature (achondroplasia). Amy aged 10-years wanted surgical leg-lengthening treatment so that she would no longer be treated by strangers as if she was 4-years-old. Tina aged 12-years wanted to refuse treatment and insisted that her rights as a disabled person be respected (Alderson, 2003). Amy’s mother, a physiotherapist, supported her, saying that the treatment was so lengthy and painful that only the child concerned could decide. Years later, both girls firmly held the same views. They challenge notions that children are too immature, ignorant and volatile to form weighty and lasting decisions.<sup>2</sup>

With very young children, those with serious learning difficulties, and in emergency cases when there is not time to inform children adequately and negotiate decisions with them then adults may have to accept UNCRC Article 3, “the best interests of the child shall be a primary consideration”, and overrule children’s views and possibly enforce treatment. The numerous complex questions that balancing Articles 3 and 12 can raise for health care have been reviewed in great detail (for instance, Hagger, 2009). For example, four-year-olds refusing vaccination injections are often cited as evidence of young children’s inability to form sensible views, but this is when they

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<sup>2</sup> Tina and Amy both spoke at a conference four years after their interviews, reported in Alderson, P. (ed) (1992) *Consent to Health Treatment and Research: Differing Perspectives*. London: Institute of Education. Amy also repeated her views at the book launch for Michael Freeman’s *A ‘Magna Carta’ for Children: Rethinking Children’s Rights*, in London, 12 June 2017.

are unprepared and unused to injections. Four-year-olds with diabetes accept daily insulin injections and may administer these themselves when they have been informed, prepared and supported (Alderson et al., 2006). Yet even if children express clear sensible views, their words may not penetrate the fog of adult prejudice that children can have nothing useful to say. Incompetence may then be seen as an inevitable trait in the child, instead of an effect that can be constructed within unhelpful adult-child relationships.

Many authorities assume conflict between Articles 3 and 12 if they see children as too foolish and ignorant to understand their best interests and most likely to form self-destructive views, to fear and refuse beneficial treatments. Some commentators believe that only parents' views count, in order to maintain harmony in intimate families (Ross, 1998), or they assume parents' discretion sets aside the rights of all children up to age 18 (Gillam, 2016; McDougall et al., 2016).

These approaches overlook five vital matters that combine Articles 3 and 12: ignoring and overriding individuals' deeply-held views can be very harmful and counter to their best interests, the main object of rights is to prevent such harm; a crucial part of therapy is to spend time helping patients to understand the need for treatment, respecting their views and anxieties, negotiating, and encouraging their willing with agreed cooperation; children are not inevitably self-destructive, many form views that further their best interests, especially in matters where they are knowledgeable and experienced; children have great capacities to understand if they are informed and respected. Besides common misunderstandings of children and their capacities, there is misunderstanding about decision-making and consent, if it is assumed that someone's initial view equals their final view. Decision-making is a process of developing and perhaps radically altering initial views while gradually forming the eventual view.

When children and adults agree, there is less need to assess children's actual understanding and to try to give weight to their views, but when they disagree, UNCRC could seem to complicate rather than clarify uncertainties between Articles 3 and 12. UNCRC Article 41 and the opportunities it opens are therefore relevant, as considered in the next section.

## 5. Beyond Article 12: national laws

UNCRC Article 41 respects "any provisions which are more conducive to the realization of the rights of the child" in the national law of the state party. Whereas UNCRC recognises children's right to be informed (Article 13) and to form and express views, and influence decisions (Article 12) it does not recognise the right of legal minors to make decisions. English statute law states that most 16- and 17-year olds can give valid consent.<sup>3</sup> In English common law, which influences 53 British Commonwealth countries inhabited by over a billion people, the *Gillick* case [1985]<sup>4</sup> ruled that minors aged under-16 have the legal right to consent provided they are competent to do so. Lord Scarman defined a competent child as one who

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<sup>3</sup> Family Law Reform Act 1967.

<sup>4</sup> *Gillick v West Norfolk & Wisbech AHA* [1985] 3 ALL 423.

achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed [and] has sufficient discretion to enable him or her to make a wise choice in his or her own best interests...As a matter of law, the parental right to determine whether or not their minor children below the age of 16 will have medical treatment terminates if and when the child achieves a sufficient understanding and intelligence to understand fully what was proposed.

This echoes Lord Denning's ruling on the "dwindling" parental right, which "starts with a right of control and ends with little more than advice".<sup>5</sup> Scarman's ruling asserts that children can be not only clever, but also have mature discretion and wisdom.

The notion of "*Gillick* competent" minors became widely respected (for example, Kennedy, 1988; Freeman, 2006). *Gillick* concerns minors aged under-16, but may be mistakenly assumed to apply only to minors aged over 16, such as by the US bioethicist Weisleder (2007). The series of *Children Acts for England and Wales* also have influence around the Commonwealth. The 1989 *Children Act* repeatedly emphasises that authorities should have regard to "a) the ascertainable wishes and feelings of the child concerned (considered in the light of his age and understanding); (b) his physical, emotional and educational needs; c) the likely effect on him of any change in his circumstances". Although not specifically about medical treatment, the *Children Act* is taken to be generally applicable in law relating to children included medical law.

The *Children (Scotland) Act* 1995 more explicitly recognises adults' duty to have regard for the children's views. It presumes that children aged 12-years and older have sufficient age and maturity, although the duty does not apply to all children. The *Age of Legal Capacity Act Scotland* 1991 (S 2.4) clarifies Lord Scarman's ruling by stating that the child may be deemed legally competent in the view of the treating doctor. This protects doctors from litigation by parents or other authorities if they treat competent children who do not wish their parents to be involved. Tisdall (2015) explains how Scottish law leads the world in respect for children's views in theory if not always in practice.

The respectful laws, however, often seem to be forgotten. Later English case law has provided examples of minors up to age 17 being overruled, so the present law is that if parents give consent, doctors are allowed to ignore the child's refusal, although if the child gives consent, parents' refusal can be overruled.<sup>6</sup> Montgomery (1992) discussed how consent was perceived to be the key that unlocks permission for medical treatment, and which can be turned by anyone with the relevant legal authority, child or adults with parental responsibility.

There is also growing international influence from the USA via pharmaceutical companies (ABPI, 2004) concerned to standardise and streamline consent to medical research, in order to increase recruitment, and to reduce the costs of lengthy negotiations with potential participants and the risks of litigation. One means of doing so is to rely solely on parents' consent to all research with minors. European law on

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<sup>5</sup> *Hewer v Bryant* [1970] 1 QB 357 at 369.

<sup>6</sup> *In re R (A Minor)* [1991] WLR 3 592; *In re W (A minor)* [1992] WLR 3 758-82.

medical research enacted in all EC countries<sup>7</sup> allows adults merely to “consider” but then override children’s views and wishes, and it assumes, implausibly, that parents always know and support their child’s “presumed will”. Although the EC law referred only to clinical trials, in English law it covers all medical research, as reviewed by Biggs (2009) who criticised the confusing legal inconsistencies with *Gillick*.

Besides the USA being the only country not to ratify the UNCRC, two USA concepts particularly undermine respect for children’s views. One is “assent”, which replaces any mention of consent by minors. Assent has neither the long history nor the definite meaning and detailed standards of consent set out in the *Nuremberg Code* (1947) and the *Declaration of Helsinki* criteria (WMA 1964/2013) that set international standards for medical research. (Unfortunately, in recent versions of *Helsinki*, minors’ consent has been replaced by assent.) Assent does not even require that the child be informed, and could mean the child either expressing agreement or not expressing active refusal, which children may be too uninformed, afraid, shy or embarrassed to do (reviewed in Alderson, 2012). The second USA concept, the “mature minor” (AAP, 1995), refers to teenagers who are living apart from their parents or who refuse to involve their parents when they need help with sexual, alcohol, drug or mental health problems. The youngest age when mature minor-hood begins is 12-years in Texas; the oldest age when it ends is 21-years in Mississippi. The “mature minor” legitimates professionals providing treatment when it is too complicated to involve the parents. However, the term does not include or respect the views of the (possibly more mature and law-abiding) majority: the young people who want to share decision-making with their parents. US law treats them all as immature, and assumes that whenever parents are involved they will always be the consent-givers.

Scarman’s ruling on *Gillick* competence respects all minors, whether accompanied by their parents and in accord with them or not, deviant or law-abiding. Yet in Britain, child protection agencies (for example, NSPCC, 2016) promote the narrower ruling by Lord Fraser in *Gillick*, which like the US “mature minors” concept can bypass parents. The Fraser ruling has the advantage that bereft minors can still receive medical treatment, but has the disadvantages that they are vulnerable to professionals’ and researchers’ agendas, especially social workers and NGOs concerned with child protection and minors may lack their own adult advocates and defenders (Wheeler, 2006). Fraser also ignores young people whose parents are involved, implying that whenever parents are involved they will be the consent-givers. Fraser’s five standards are mainly concerned with advice for contraception, so would seem to be less broadly useful than Scarman’s far more general guidance. Fraser’s five standards are that:

the girl (although under the age of 16 years of age) will understand his (the doctor’s) advice;  
he (the doctor) cannot persuade her to inform her parents or to allow him to inform the parents that she is seeking contraceptive advice;  
she is very likely to continue having sexual intercourse with or without contraceptive treatment;

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<sup>7</sup> European Regulation. *Medicinal Products for Paediatric Use* (1901/2006) came into binding force in all EC countries in January 2007.

unless she receives contraceptive advice or treatment her physical or mental health or both are likely to suffer;

her best interests require him to give her contraceptive advice, treatment or both without the parental consent."<sup>8</sup>

The appeal of Fraser over Scarman to child protectionists would appear to be the seeming exclusion of parents, granting greater power and influence to professionals.

Despite the many activities, guidelines and laws, and the long history of oppressions and of progress on rights, which all concern reasons to respect and give weight to children's views, and their consent to or refusal of medical treatment and research interventions, children's views are still too often ignored in theory and practice. This is reviewed in the next section.

## 6. Overlooking and overriding children's views

The literature and research observations suggest that, paradoxically, children's views and consent are most highly respected by surgeons performing the most high-risk surgery. The likely reasons (reviewed in Alderson 1990, 1993) are surgeons' aims to avoid complaints and possible litigation from patients who believe they were not informed adequately. There is the surgeons' need to gain their patients' informed, willing and active cooperation with treatment, and not to force treatment onto resisting patients. Surgery is performed on single individuals not groups, and it can dramatically and immediately benefit or harm the child. All these considerations concentrate attention on the individual child's views and viewpoint.

In contrast, we have found that physicians are much less concerned about requesting consent, and they seldom use consent forms except in extreme cases such as intensive chemo-therapy. Paediatricians may see diabetes treatment, for example, as too low-key and routine, yet also too obviously essential for the child's survival to merit formal consent. However, this ignores the major part that children play in their diabetes care, managing their diet, exercise and insulin injections, monitoring their blood sugar levels, and other complex tasks (Alderson et al., 2006). Their informed willing cooperation, their active consent, is central.

Non-clinical professionals, such as teachers, social workers and police, are allowed by law to ignore consent and to override parents' and children's views. They can all justify their dealings with children on grounds of their view of the child's best interests or more general societal interests without the child's or parents' consent. In cases of disagreement, these professionals can legally claim, even in court if necessary, that families are too ignorant or misguided to know what is best for the child (reviewed in Alderson, 2006). When professionals claim that children and parents are incapable, in law power and weight transfer to professionals' decisions. Medical practitioners uniquely may not do so and cannot bypass the law on patient's/parents' informed consent to treatment. If they are sued, in court they are required to provide evidence that they requested informed, voluntary consent to any intervention. There is a paradox that doctors who are far more highly trained than most other professionals have the least power or weight to enforce their own decisions on to their

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<sup>8</sup> [Gillick v West Norfolk, 1985](#)

patients/clients. The doctor's responsibility is to increase the power and weight of the patient's autonomous choice as far as possible, to give sufficient information and to request consent. Patients and parents are often unaware of their rights, or are unwilling to protest if they feel forced to accept treatment, or if it is withheld against their wishes. Yet if families actively refuse to accept doctors' decisions either to give or withhold treatment, in the UK, doctors can only carry out their own decisions by obtaining approval from the law courts. Although social workers also work through the courts, they do not have to negotiate the question of the informed consent of their clients. Children's views and status can also carry greater weight with doctors, who treat them as individuals, whereas teachers are responsible for whole classes, social workers for siblings and families, and the police protect the whole community, when group concerns override individuals' needs. School students and social work clients are treated primarily as children, but child patients in medical law share most routines, the status and the long history, such as of medical ethics, and the legal respect for consent with adult patients.

Archard and Skivenes (2009) compared medical court cases in England with family welfare court cases in Norway. The Norwegian courts appear to take children's views more seriously, but proper comparison would have to compare similar cases, not high-risk medical cases concerned with survival, against usually lower-risk family cases concerned with wellbeing. It is actually likely that the English medical court cases could be shown to be more respectful of children or at least parents than Norwegian systems are, for two reasons. First, the authors may have been unable to compare medical cases because in Norway there are none. At least until recently, most European countries have not had consent forms for tests or treatment, but only for medical research, because it is assumed that if a patient comes into the hospital or clinic that signifies consent to anything the doctor deems necessary. Formal consent to medical treatment is an Anglo-American legal concept, so that there is less formal respect for children's and adults' consent in Norwegian healthcare settings and courts.

Courts in the UK hear unusual medical cases, rather than broadly typical ones from which generalisations can easily be drawn. Key cases that might seem to clarify *Gillick* standards have confused young people's mental illness with age-related (im)maturity. The courts rely on expert medical witnesses, and they always rule in the doctors' favour, whether doctors wish to provide or withhold treatment, with one exception (as far as I know). In the very unusual case of *Re T* where the court ruled in favour of the parents, the child's mother was an intensive care nurse, so her view might have been counted as an expert professional one. She believed a liver transplant would do her baby more harm than good, and though the court refused to authorise the treatment, months later she did consent to a liver transplant.<sup>9</sup>

The weight or validity of children's and adults' views can develop as they learn and experience more about their own case. It is vital to recognise this process, rather than dismissing people's initial thoughts as incompetent and not capable of developing. For example, judges tend to refer to minors' confused overwhelming feelings, and their need for adults to make rational decisions for them. When a 15½-year-old refused a heart transplant, the hearing, as often happens, was treated as an emergency, with no time to consult her properly. She was seen as "overtaken and overwhelmed by events...not able to come to terms with her situation", and the court

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<sup>9</sup> *Re T (a minor) Liver Transplant: Consent* [1996].

authorised the transplant, which was performed (Dyer, 1999).<sup>10</sup> In 2008, Hannah Jones aged 13 refused a heart transplant, after her heart was damaged by ten years of leukaemia treatment. She gave media interviews and thanked her parents for respecting her view about her best interests (Jones, 2008). Her mother was an intensive care nurse who has worked in transplant units. Child protection services decided not to apply to the courts to authorise treatment. Hannah consented to a transplant the following year, and recorded her joy that she has survived.

The preoccupation of judges with the minors' confused overwhelming feelings ignores two realities. One is that, when facing the need for very high risk surgery, adults too feel overwhelmed by emotions at first, and they need time to think through their feelings and come to terms with them, as my research on parents' consent to children's heart surgery showed (Alderson, 1990). The other, as mentioned earlier, is that consent is not an instant or purely mental choice. It involves an emotional journey, richly informed by moral emotions from fear and rejection, sadness, shock and perhaps horror at the prospect of surgery, towards trust and confidence in the clinical team, belief that the untreated condition can be worse than the treatment, and courage to consent. This process takes time at any age, and respect for consent involves allowing the time needed whenever possible.

Healthcare practitioners, lawyers and ethicists are still dominated by Kantian theories of rational decisions and by Piagetian child development theory. These frame children's competence within slow developmental age-stages, and they contrast the incompetent child against the competent adult. Pre-adult youth has recently been extended by neuroscientists up to 25-years or more, when the synaptic balance in the brain becomes more inhibitory than excitatory and reason is believed to predominate over natural passion and risk-taking (Weinberger et al. 2005). These theories deny, for instance, routine risk-taking among the adults who run the world in finance, the military and politics, and how imaginative risks are central to the creative arts. The theories also ignore the reality that the competence of many children develops largely through their experience far more than by age. Developmental assumptions and neuro-theories assess children's views as weightless, when they assume children are ignorant and irrational in comparison with experts' views, and when they overlook the profound insights that children with long-term illness or disability can have (Alderson et al., 2006).

Kantian reasoning that avoids emotions and contingencies (Kant, 1984, p. 84) dismisses the social, experiential, emotional knowledge that informs and gives weight to families' views. Yet children and parents have to take account of contingencies when they consider how surgery might change, or indeed end, their lives and aspirations. Children have unique and essential knowledge to contribute to decisions about their care. Such complex involvement transcends the detached objective expert medical and legal view, especially when children have long-term illness or disability and have been deeply informed by their experiences. Rethinking Kantian and Piagetian traditions also involves respecting children and parents who are very anxious, shocked and agitated *because* they understand the risks.

Expert risk-benefit calculations are important in decision-making, when mathematical computations of risk give weight or gravitas to reasoned conclusions. Yet great inherent complexity is too often over-looked in scientific efforts to simplify decision-making. Bhaskar (2008) noted this complexity. "A fact or event is the convergence of multiple facets of reality each with its own history and geography,

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<sup>10</sup> Re M Medical Treatment Consent [1999] 2 FLR 1097.

trajectories and processes that come together at a given moment [in] the convergence of multiple domains of reality at empirical, structural and ontological levels". D'Souza (2013, p. 520) extended this view to contend that the present "thin" calculating thinking is confined into Enlightenment assumptions, which "transform the merchant's world view into the [whole] human world view". Facts and events are atomised, and nothing counts as relevant except the specific transaction, reduced into abstracted figures as in merchants' ledgers, extracted from their social context. The transactions include legal contracts, such as consent informed by risk-benefit calculations. Then, D'Souza continues, only the fact is seen as authentic; events seem arbitrary and accidental; values, justice, absences, alternatives and all the rest are extraneous or simply dubious assumptions. And these assumptions are taken to "reify the already entrenched merchantile ontology and the forgetting of history and place, time and space". So when children talk of their hopes and fears about how surgery might affect their daily present and future life, their identity, friendships, and appearance (scars), such weighty matters for them might be dismissed as trivial – "all that matters is to save your life, the operation has a 30% mortality risk".

Children's competence is sometimes assessed using general knowledge or maths or literacy tests, as if wisdom to make a personal decision equates to IQ or academic performance. Standardised tests of competence are unhelpful when what really matters is each child's specific understandings of the unique case learned through deep experience. Some young children and those with learning difficulties are able to make wise decisions (Alderson, 1993), and standardised tests on irrelevant questions risk misjudging them as generally ignorant. Yet their views carry weight by virtue of their complex experiences. On average, children in the consent to surgery study had had four to five operations already, including ones that had wholly or partly failed. The children therefore tended to know deeply about the risks and pain they were agreeing to undergo for the sake of the hoped-for but not guaranteed benefits. Instead it is more fair and efficient to assess their competence on the *Nuremberg* and *Helsinki* criteria (WMA, 1964/2013): that consent is based on understanding the nature and purpose of the intervention, methods and timing, risks and hoped-for benefits, and alternatives. These criteria not only help the caring adults to give and discuss the relevant details, they also can relate to many aspects of the child's life and hopes.

## 7. Conclusion

In theory in the UK, UNCRC Articles 12 and 13 along with the UK Family Law Reform Act 1967, and *Gillick* competence can invest almost equal weight in the rights of competent children as in adults' rights to self-determination, and they recognise that children aged under-16 can have understanding, discretion and wisdom. Many children, young people and adults need and want the protection of others to decide for them about painful risky medical treatment. However, many other children, young people and adults need and want to decide for themselves independently, and most children and adults want to decide in shared partnerships (Alderson, 1993, 1996a).

Article 12's phrase "due weight" involves an unresolved contradiction between concepts of adults objectively "weighing" children's views as if these have an independent value or weight, and adults subjectively "weighting" children's views,

investing them with a nominal weight that might or might not be accurate or fair. This can give great power to adults, and could veil their subjective and possibly mistaken evaluations in a semblance of just and scientific accuracy.

In an extensive review of how parental responsibility erodes children's rights under English law, Erlings (2016, p. 640) is disappointed to see in medical law:

a strong signal that the judiciary continues to see the [child's] right to consent principally as a corollary to the responsibilities of parents, which take priority over the rights of children, who do not carry any particular responsibility with regard to their medical treatment and therefore hold a weaker claim to the exercise of rights.

In practice, children carry great responsibility, not only for the effectiveness of their medical treatment, but also for their daily healthcare. Speaking of the lifelong follow-up medication of immuno-suppressants after transplant surgery, a senior nurse believed that children's lives lie in their own hands, because they will only survive if they actively take daily medication (Alderson, 1993). Yet to authorities in the UK today, children's views appear to have some weight in surgical decisions, less in medical decisions, little in all other aspects of their lives, and none in the few reported medical-legal court cases. More research evidence is urgently needed to address the current confusions (Brierley and Larcher, 2016).

The legal cases may give a misleading picture, however. Almost all doctors and families reach some agreement and do not take their conflicts to court. And after months or years of treatment, when families and healthcare staff have developed mutual trust and respect, if hope is failing and the risks of treatment outweigh the hoped-for benefits as for Samantha, unknown numbers of children may share in decisions to refuse further attempts at cure, and they may accept such help as high levels of pain relief that shorten agonising lives.

The reason for reviewing such extreme examples is to raise the question: if adults can give due weight to some children's views about the most challenging decisions of all, why can they not give more weight to children's views in all other aspects of their lives that involve easier decisions? After all, most decisions are about relative life styles, not about ultimate survival. More public knowledge of these quite rare medical examples would offer very helpful information for children and parents and for all the professions that work with them, as well as for the mass media and the general public. For such knowledge to be accepted and applied, barriers need to be reduced and removed to make way for greater respect for children's competent views.

A major barrier is children's and adults' unawareness of their rights and how to claim them. Another barrier is the limited recognition that children's views are informed by their everyday lives and routines, their emotions and embodied experiences, the serious problems that many of them encounter, their relationships, the information, respect and support they receive from adults and peers, besides constant pressures from the social, political and economic contexts. A third barrier is child development theory, which assumes that clever advantaged children are the most competent, whereas children who experience adversity and disadvantage can be highly informed and wise. In order to understand children's views, adults may first have to overcome their own prejudices and to be alert to children's subtle cues and unexpected responses. A helpful beginning is Lord Scarman's ruling which combines

Articles 3 and 12 in the belief that children's views can have the weight of "sufficient discretion to enable [them] to make a wise choice in [their] own best interests".<sup>2</sup>

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