

Voices, choices and law: weighing children's views in justice proceedings

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Weight for children's views in medical law

Priscilla Alderson, UCL

Abstract 3/12/15

Although Article 12 is seen as the jewel in the crown of the UNCRC, would any adult want to be blessed or cursed with this right? The Article 12 concept, to weight children's views, is fraught with splits, contradictions and paradox. Contradictions include: being guided by principles or by calculated utility; developmental stage theory versus 'respect for...the equal and inalienable rights of all members of the human family'; redefining children's daily activities (expressing wishes and feelings, refusing, protesting) as conditional permissions; reducing richly experienced knowledge into stark risk-benefit calculation; medical and legal expertise versus respect for patients' choices.

Article 12 treats adults as the agents. They inform, assess and possibly 'provide opportunities' for children to be involved, and they 'weight' children's views. Powerful 'negative' rights of freedom of expression and non-interference are turned into weak, highly conditional 'positive' rights (using Isaiah Berlin's concepts). Whereas adults' views are 'weightless' (not assessed or compared) children's views appear to have some weight in surgical decisions, less in medical decisions, and none in the reported court cases. Might children benefit if UNCRC and the children's rights industry were replaced by explicitly including children in all the 'adult' human rights conventions, and requiring that any move to apply different standards to children is strongly justified?

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To weight children's views is a challenge fraught with splits, contradictions and paradox. Contradictions include: being guided either by principles or by calculated utility; hierarchy in developmental stage theory versus 'respect for the inherent dignity and the equal and inalienable rights of all members of the human family'; redefining children's daily activities as conditional permissions; at times reducing knowledge, which is also social and experiential, into stark risk-benefit calculation; expert clinical decision-making versus doctors' legal obligation to ensure patients/parents give real consent/refusal; individual versus collective interests; personal free choice within coercive constraints and Scarman's versus Fraser's guidance.

The UN Committee on the Rights of the Child (2009) described UNCRC Article 12 with its concept of 'due weight' 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.

Principles or utility; freedom and need

Law, philosophy and medical ethics have strong and partly conflicting traditions. There is the weighty but immeasurable respect for human dignity and adult-centric Kantian self-determination versus calculated utilitarian practicality. The latter weighs and calculates how the ends can justify the means, such as in decisions about high-risk medical treatment.

Rights originated in age-old 'bottom-up' struggles for freedom from tyranny and injustice, which came to be refined by philosophers into intellectual 'top-down' concepts. Another partial contradiction is when rights as independent freedoms interact with dependent needs to be freed from want and illness. Modern international human rights emerged from the Holocaust, the medical experiments and abuse of bodies. That history highlights tensions between intellectual and somewhat disembodied notions of autonomous rights and the daily reality that rights are enacted in and through bodies. These tensions are especially apparent in dilemmas about medical treatment for children and in the rare and exceptional cases referred (in England and Wales) to the high court.

Developmental stage theory versus ‘respect for the inherent dignity and the equal and inalienable rights of all members of the human family’ (UN 1948, 1989)

Developmental assumptions about children’s vulnerable, non-competent dependence may assess children’s views as weightless in comparison with adults’ views. For example, this autumn the High Court ruled to allow NHS surgeons to perform life-saving surgery on a child with an aggressive form of bone cancer, despite the objection of the child’s Polish parents who favour traditional Chinese remedies. The child, ‘J’, has a four inch-long tumour on his right jawbone which is likely to spread if not surgically removed. The operation has a 55-65 percent chance of survival for five years with a 35-45 percent risk of the cancer re-emerging within that period. The court ruled that it was in J’s best interests to receive surgery, to save him from what his doctor described as ‘a brutal and agonising death’.¹ Surgery can legally be enforced on a child but not on an adult. We do not know the child’s view. Some minors hold strong religious beliefs, such as the young Jehovah’s Witness who chose to end his enforced treatment when he became 18 and chose to die. The courts allow but do not enforce treatments, as reviewed later.

The UN Committee’s *General Comment on Article 12* illustrates the tensions within debates about children’s rights and interests, by listing topics and areas where states parties should respect Article 12 more, while inevitably also pointing to its limitations. Self-expression is integral to adults’ right of self-determination, apart from rare exceptions (such as when free speech is deemed racist). It suggests an image of a huge area with a few boundaries, whereas Article 12 suggests efforts to extend a little island of children’s freedoms. Adult rights assume and reinforce trust in the competent independent person; child rights documents are shot through with anxiety about how to respect but also protect the vulnerable, developing child.

In law and theory, doctors must request informed and voluntary consent, but in practice this does not appear to happen in many children’s treatments. Although surgeons are alert to the risks of litigation if they overlook consent, and they seek support from the courts, physicians when prescribing drugs seem less concerned and even seem surprised that consent has any relevance in the treatment, for example, of type I diabetes or hyperactivity.

Children’s services are still dominated by child development theory and its Piagetian origins. At a recent national meeting of university lecturers in education psychology, who run PhD and Ed Psych courses, not one person said they had any training in children’s rights,² despite UNCRC Article 42 on states’ duties to publicise the Convention widely. Disabled children from five years of age have little or no say in medically informed decisions to send them to special day or boarding schools. Some schools are over 100 miles away from the children’s homes. Each boarding place costs over £200,000 per annum. If parents and children were offered the total cost of the schooling, over £3million in some cases, and if they were asked how they would choose to spend those funds, Article 12 and *Gillick* standards of informed consent could play an invaluable part in their lives. Yet in the eighth centenary year of Magna Carta, families no longer have legal aid to help them to appeal against decisions, complaints, referrals or exclusions related to special schooling.

The Committee tried to repair some of the damage done by the Article 12 phrase ‘capable of forming his or her own views’. This is so commonly taken to exclude pre-verbal children, and even those aged under 8, 12, 14 or older as incapable, when Article 12 becomes a silencer instead of a liberator for many children. The Committee stated:

‘This phrase 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

¹ England and Wales High Court (Family Division) *JM (A Child), Re* [2015] EWHC 2832 (Fam) (07 October 2015) <http://www.bailii.org/ew/cases/EWHC/Fam/2015/2832.html>

² UCL Institute of Education London, National Educational Psychology Tutors’ Training Day, 2nd October 2015

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.'

However, the later points on presuming competence are 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, and if capacity were presumed, assessment would not be the starting point. The paragraph weakens the Committee's later point that the child's ability to form and express views begins 'from early childhood'.

The Committee's advice on how to involve children includes working in five stages (preparation, the hearing, assessment of capacity, information about the weight given to the views of the child (the 'feedback'), and complaints, remedies and redress. Important and practical though the advice is, it is presented as means of countering children's vulnerable immaturity. Another approach would show how this advice is valuable for people of all ages, children and adults. For example:

'34. 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.'

This advice on clear, age-appropriate support could apply at all ages, when many adults are poorly educated, have learning difficulties or mental health problems, have extreme and distracting anxieties such as debt,³ and the *average* adult reading age in the UK is ten years.

Redefining children's daily activities into conditional permissions

'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). To form and express views is not a right but an integral part of being human. From birth, children vividly and freely express their views and experiences of anxiety, hunger, fatigue, pain, pleasure and human interaction. It is said that 'children do not have the right to refuse', but of course they frequently refuse and protest, such as refusing unwanted food. 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 UN Committee (2009, clause 20-21) counters assumptions that expression can only be verbal, to include non-verbal body language. One example is 6-year-old Samantha who willingly underwent two liver transplants. But after these both failed and her doctors and parents wanted to try a third transplant 'with a 2 percent chance of success', she became so sad and withdrawn, refusing to speak or to eat, that her parents accepted her wish to go home to die (Alderson 1996). Extremely ill young children understand what dying means (Alderson et al. 2006). The UN Committee (2009, 20) usefully states:

'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'.

Profound core understanding can outweigh detailed information.

Forming and expressing views is integral to self-determination and self-defence against being used as a means to other people's ends. Kantian self-determination is so much assumed and taken-for-granted as the basis of all adult rights and freedoms that it is not explicitly mentioned in rights

³ People in the UK had personal debts totalling £1,447 trillion August 2015, <http://themoneycharity.org.uk/money-statistics/>

treaties. It is most powerfully expressed in the legal prohibition on unlawful touching, and in the negative right to non-interference, such as:

‘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 Council of Europe 1950, Article 8).

As Isaiah Berlin (2004) analysed, negative rights to non-interference are far more powerful than positive rights, such as to goods and services. Article 12 however, turns children’s negative freedom of self-expression into a positive right to be heard by others, to *‘be provided the opportunity to be heard’* although this 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.’* Article 12 is a limited right (*‘in all matters affecting the child’*: what does this mean? how might the vague term be misapplied and restricted? Who decides what is relevant?). It is a highly conditional right (*‘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? Does maturity relate to complying with adults and immaturity to resisting their authority?). Adults are the agents (they ‘give’ due weight; the child is the relatively passive or helpless recipient). ‘Weight’ is presented not as intrinsic to the child’s views, but as bestowed or ascribed by the adults. Article 12 is so hedged around and dependent on adults’ discretion, is it a privilege rather than a right?

Social, experiential, emotional knowledge reduced into stark risk-benefit calculation

Kantian reasoning that avoids emotions and contingencies (Kant 1984, p. 84) hovers behind definitions of the competent person. My research with parents who were asked to consent to heart surgery on their child found, however, that their reasoned decisions about very high-risk life-threatening surgery were richly informed by their moral emotions (Alderson 1990). Research about children’s consent found that they too were deeply and emotionally engaged and had to take account of contingencies when they considered how surgery might change, or indeed end, their lives and aspirations (Alderson, 1993). Such complex involvement transcends the clinical quasi-mathematical computation of risk that is supposed to give weight or gravitas to reasoning. To give due weight to children’s views, especially those with long-term illness or disability who have been deeply informed by their experiences, involves rethinking Kantian Millian traditions and respecting children and parents who are very anxious and agitated *because* they understand the risks.

Hannah Jones rejected a heart transplant in 2008 when she was aged 13 and newspapers celebrated her joy when she became 16 and 18 that in 2009 she changed her mind and consented to a transplant. Although the courts authorised the doctors to perform the transplant, they had to wait until Hannah agreed, because her life lay in her hands. Some children, with cystic fibrosis for example, who were not well-prepared for heart-lung transplants, refused after surgery to take their daily, life-long treatment of immuno-suppressants and they died (Alderson 1993). Although Hannah’s change of mind has often been attributed to her growing maturity, at 13 she went through the same process that adults endure when consenting to high-risk surgery, journeying from doubt, rejection and even horror about the proposed treatment, through growing confidence, towards hope and trust in the clinical team, coming to realise that the untreated condition can be worse than the treatment. Consent is not simply an event and a contract. It is also a process and a journey.

Weight in medical decisions involves great complexity, too often over-looked in scientific efforts to simplify decision-making. ‘A fact or event is the convergence of multiple facets of reality each with its own history and geography, trajectories and processes that come together at a given moment [in] the convergence of multiple domains of reality at empirical, structural and ontological levels’ (Bhaskar 2008). Radha D’Souza (2013, 520) extends this view to contend that the present ‘thin’

sociology 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. Then 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’. Children’s competence is sometimes assessed using maths and literacy tests, as if wisdom to decide equates to IQ or academic performance. Standardised tests of competence have been devised. Yet young children and those with learning difficulties are able to make wise decisions weighted by their complex experiences, and their competence may be assessed on the *Helsinki* criteria (WMA 1964/2013): nature and purpose of the intervention, methods and timing, risks and hoped-for benefits, alternatives, which may relate to many aspects of the child’s life and hopes.

Expert clinical decision making versus doctors’ legal obligation to ensure patients/parents give real consent/refusal

If they are sued for abuse or negligence, social workers and other professionals such as teachers or police who work with children can claim in court that they had to make decisions for children when the child and parents appeared to be unable to make decisions that the professionals could accept. When professionals claim that children and parents are incapable, power and weight transfer to professionals’ decisions.

In law and theory, doctors are in the opposite position of being accountable to the court to show that they offered choice and enabled the child and/or parents to make informed and unpressured decisions. 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 patients/clients (because their work involves touching the body and exposing it to danger). The doctor’s work is to increase the power/weight of the patient’s autonomous choice as far as possible, or else to apply to the high court to make the decision. The weighting then shifts away from the child. With only one exception (?) English courts have supported doctors’ preferences either to give or to withhold treatment. They work within an ancient medico-legal fraternity, with doctors acting as weighty ‘expert witnesses’ against the ignorant lay family. The courts permit doctors to act, or not, but do not enforce the legal ruling, thereby transferring the weight in decision making to medical power.

Personal free choice within coercive constraints; individual versus collective interests;

‘Freely made’ medical decisions occur within all the constraints of illness or disability, limited medical knowledge and skill, and finite resources and services. Freedom or voluntariness negatively involves absence of direct avoidable pressures, 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’ (Nuremberg 1947).

Medical decisions made by and for children are unusual in concerning treatment for individuals, instead groups such as the teachers’ concern with the class, the social workers with the siblings and family, or the police with the community. The child patient shares a status and long history, such as of medical ethics, with adult patients, and this too increases the weight of the child’s view and status.

However, national and international shortages of funding, skilled staff and essential clinical resources are increasingly being recognised. In Britain, we heavily rely on doctors and nurses who were trained in Africa and Asia and are desperately needed by those countries with their very high levels of illness and disability, and very high proportion of people aged under 19, up to 50 percent in parts of Africa. ‘All matters affecting the child’ stretch across the world; personal decisions such as about costly cancer care relate to, and are implicitly weighed against, global decisions about

providing clean water to the billion people without it, or preventing the obesity epidemics and their massive burden on health services. Individual medical decisions are ever more closely related to the global politics and 'matters affecting' children of health, healthcare and prevention of illness.

Scarman's versus Fraser's guidance

Child protection workers and social workers rely on Lord Fraser's standards in his *Gillick* ruling,⁴ although Lord Scarman provides more helpful general guidance when assessing the weight of children's and young people's views. Lord Fraser's second of five points is that the doctor should respect the minor child as competent when 'he (*sic* the doctor) cannot persuade her (*sic* the minor) to inform her parents or to allow him to inform the parents that she is seeking contraceptive advice'. However, most competent young people prefer to share their medical decision-making with their parents; some incompetent and 'deviant' young people do not. Sharing with parents does not correlate with competence or with the weight of young patients' views. The ruling illustrates the problems in *Gillick*, the US 'mature minors' law and Article 12 when assessments of weight or competence are unrelated to the ability of children and young people, but may be interpreted to serve the power or convenience of professionals.

⁴ *Gillick v Wisbech & W. Norfolk AHA* [1985]

Conclusion

'Weight' in Article 12 refers to 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, in the dyad of doctor and adult patient, between clinical expertise and the patient's preference is further complicated in the doctor-child-parent triad by children's presumed immaturity. Yet with children and adults, there is a great difference between new and emergency cases, and those who have lived with a serious condition for months or years and have unique embodied knowledge of how the conditions continually affect their identity and daily life.

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. 'Weight' invokes gravity and gravitas and implies precision in attempts to estimate, calculate, compare and measure facts, risks and benefits. Yet these are all partly immeasurable and often incompatible, such as in conflicts between children's and adults' preferences, or between children's seeming present and future best interests.

The children's heart surgeons' office at Great Ormond Street Children's Hospital (away from the patients) had a notice, 'we do precision guess work here'. That could equally apply to efforts to apply the contradictory Article 12 in medical cases with prudence, respect and justice.

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Contradictions and problems

Weighty immeasurable Kantian autonomy - Utilitarian calculation

Bottom up political practical protest and struggle for HR - intellectual philosophy of rational Man

Weight of adult autonomy non-interference with self determination - child in need of protection, override weightless views "feelings and wishes"

Article 12 jewel in UNCRC - but in no other treaties

Developmental stage theory hierarchy versus 'respect for the inherent dignity and the equal and inalienable rights of all members of the human family' (UN 1948, 1989)

Vulnerable child - all HR protect vulnerable person

Consent accepts risk, can be a £multimillion decision financial weight

Children not acknowledged as economic agents

Weight of child's views in court v. Medico-legal fraternity lawyers led by doctors' expert advice, authorise but do not enforce medical action
almost never rule in favour of child's and parents' views

weight of professional expert v lay family

2015 child 'J' jaw tumour can enforce surgery on child but not adult unless treatment part of psychiatric/neuro care

Yet young children with serious long term illness/disability can be informed and wise

Article 12 – UNCRC only convention to give 'right to form and express views'

But not a right it is part of being human - babies do it

'Children's can't refuse'

Adults' freedom of expression a huge area with few boundaries

Children's "seems a small island hedged round with reservations

Children have little weight in most medical (not surgical) decisions – diabetes Ritalin

Age-related stereotypes and prejudices compound the problems that other patients

Quasi medical decisions about schooling statements - special boarding schools

£3m –v informed choice

Withdraw legal aid

"capable of forming his or her own views" 8, 12, 14, +?

UN Committee's commentary (2009) begins by assuming competence but immediately start to assess capacity in 5 stages
Child as vulnerable emphasis ignores how adults can be very vulnerable and intimidated and incapable too

Adults as agents
assess ability,
child to be 'provided with the opportunity to be heard'
'give due weight'
'assure' the right to form and express views – not a right a human activity part of self-defence and expressing need
turns powerful negative right to privacy, non-interference in self-determination
the unexpressed centre of all HR
into weak positive right (Berlin) that adults bestow
+ highly conditional on adults' perceptions of relevance and sense

Kant no emotions contingencies
The cost benefit ledger deletes contexts atomises
But these inform
child's views, moral feelings,
complex experiences, hopes, fears
and inform consent (Hannah Jones)
and voluntariness – free from constraints or courage to take them on?
Difference new and experienced patients

Competence does not correlate with IQ or age

Pressures lack of time, skill, support for staff,
Dominance of development theory stereotypes

Scarman v Fraser involving parents and weight

D-P dyad D_P_Ch triad

Weight includes balancing, calculating risk-benefit, present and future interests
implies precision

Yet daily decisions messy, complicated, partly immeasurable
GOS 'we do precision guess work here'