CHAPTER 10

Children, Age Discrimination Law, and Consent to Surgery

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Abstract

A central human right, most highly valued by adults, is respect for each person's autonomy and bodily integrity. In English law – and also in many other jurisdictions – the body may be touched only after the person concerned has given explicit or at least tacit informed consent; touching should cease if the person objects except in specific cases such as the duties of police and prison officers. Numerous court cases around the world confirm the importance of this legal protection, many involving healthcare. The major exception to this protection is legal minors. For them, parents' or guardians' consent is required but not their own consent.

This chapter considers reasons for discrimination against minors that allows touching without their consent and regardless of their resistance, with the benefits, risks and harms of this exception in relation to medical treatment, specifically surgery. Standards in international law and in bioethics are considered, with reasons and supporting pressures behind the long-held ageist views that undermine respect for children's consent. Examples of recent rethinking of this discrimination are reported, with hopes for future progress.

1 Introduction: Non-discrimination

The aspiring UN human rights Declarations and Conventions, and the 1989 UN Convention on the Rights of the Child (CRC), particularly Article 2, prohibit discrimination or 'distinction of any kind'. Yet age discrimination is notably missing. However, this affects nearly one third of humanity aged under 18-years, and countless older people too. Minority age is the prototype for all discrimination, which is to treat the other as inferior, ignorant, inexperienced, unreliable, immature, foolish, weak or untrustworthy – like a child.

The CRC has been criticised for its limitations, especially Article 12 for the power invested in adults to determine the 'weight' of a child's views.[1] This paper is about how all children's views should be respected unless there is significant risk of harm. Autonomy is so highly valued (by and for adults) in liberal democracies because we are "rational beings, deserving of dignity and control over our own destinies" and wellbeing. It is therefore "extraordinary that there has been so little progress in negotiating…the adult/child legal dichotomy [which] denies children any legal control over their own persons."[2]

Calls to reduce age discrimination and to equalise rights, opportunities and responsibilities between all age-groups risk placing undue burdens, responsibilities and, potentially, unfair blame on the very young. This can expose them to harms from which they have the right to be protected. Obviously young children cannot give detailed informed and legally valid consent, for example to surgery, in ways the average adult can. Yet there is a danger when over-emphasising adult-centric, over-legalised, informed consent, of neglecting respect for the two other vital aspects of consent, in which children can be deeply involved: physical bodily interactions, and moral emotions.

The active physical expression of consent or refusal involves the child's willing cooperation or frightened resistance, with the accompanying need for force, from which a major purpose of human rights and consent is to protect patients. It is contradictory to ignore and override this embodied aspect of consent when caring for the most vulnerable patients.

Consent to surgery is unusual in that the individual child's needs and rights are much more central than in most other experiences throughout life. In other services – education, social care, urban planning, care of asylum seekers – every individual child matters but they also have to be considered much more as part of a group, a family, a school, a community, than when they have surgery. In healthcare, the needs of other patients and fair use of time and resources are always also vital but the central concern is the patient.

The purpose of this chapter is not to advocate a form of rights as selfish individualism but to show how deeper understanding of the individual child during treatment for surgery can help to illuminate ways to respect children's

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[1] A. Daly, 'No Weight for "Due Weight"? A Children's Autonomy Principle in 'Best Interest Proceedings', 26:1 *International Journal of Children's Rights* (2018) pp. 61–92; P. Alderson, 'Weight for children's views in medical law', 26:1 *International Journal of Children's Rights* (2018) pp.16–37, doi:10.1163/15718182-02601001.

[2] A. Daly, Children, *Autonomy and the Courts: Beyond the Right to be Heard* (Brill, Leiden, 2018) pp. 189–190.

rights in all other contexts. All children can benefit when there is respect for individuals. My research explores consent as an emotional journey, which is relevant to many kinds of interactions and shared decision-making between children and adults.[3] The emotional aspects of voluntary consent develop when patients have time to overcome initial natural fears of painful frightening interventions. With adults' help, young children can move on from instinctive fear and rejection of proposed interventions, through doubt, towards trust in the practitioners, hope that interventions will help to heal their illness or injury, and courage to undergo any harms in order to gain the benefits. Very young children have strong life-preserving instincts and intuitions of fear and trust, of feeling harmed or helped, and healthcare professionals increasingly respect these emotions as an integral, practical part of therapeutic rights-respecting paediatrics.

A review of 56 journal papers about children's participation rights published over 30 years found "a remarkably consistent narrative…[with] far more written about challenges than solutions". The authors recommend expanding the "geographic and intellectual boundaries" and the use of "powerful concepts like agency, competency and autonomy with greater precision" with further exploration of "fresh ideas like child protagonism, activism and children as human rights defenders".[4] With surgery, challenges for the caring adults still include informing children as clearly as possible about the surgical options and hoped-for outcomes, and also offering advice and support while helping children to share in making decisions as much as they are willing and able to do so.

This chapter considers benefits but also problems of increasing over-legalising of consent, how this affects discrimination against children and what it means to be 'treated like a child'. By over-legalising, I am not criticising any measures to legalise consent – to make it more legal, respected and powerful. I am also not criticising further legalisation, when this means the process of removing a legal prohibition against something which is currently not legal. I am concerned with the exaggerated legalising that involves adding unnecessarily complicated and often intimidating quasi-legal procedures and requirements. Then children's rights relating to discrimination are reviewed, the physical reality of rights, nonverbal thought and communication, and ways to increase respect for children's consent to surgery. The dangers of

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[3] P. Alderson, *Children's Consent to Surgery* (Open University Press, Buckingham, 1993).

[4] C. McMellon and E.K.M. Tisdall, 'Children and Young People's Participation Rights: Looking Backwards and Moving Forwards', 28:1 *International Journal of Children's Rights* (2020) pp.157–182, doi:10.1163/15718182-02801002.

overriding children's consent to surgery and the benefits of respecting their consent and reducing differences between the treatment of child and adult patients all highlight the importance of two terms that recur through this book: negative adultism and positive childism.[5]

The chapter is informed by my research, 1984–2021, about parents' consent to children's heart surgery,[6] children's consent to orthopaedic surgery,[7] and a recent study with Rosa Mendizabal and Katy Sutcliffe of parents' and children's consent to heart surgery.[8] All these projects involved years of observing[9] and interviewing children, parents and hospital staff. I will not attempt to give details about theses complex projects here but instead will draw on them to illustrate ideas in this chapter and I refer inquiring readers to the reports cited. The conclusion presents hopes for the future.

2 Over-Legalising of Consent

Human rights law tends to be discussed in quite abstract cerebral terms. Rights related to medical ethics mainly concern informed consent. Consent involves whether the patient or parent/guardian has been informed about all the relevant details of the nature, methods and purpose of the treatment, the risks and hoped-for benefits and outcomes, any alternative treatments, and the right to refuse or withdraw from treatment. The person who will

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[5] M. Liebel, 'Working children: Children without childhood or opponents against age-based discrimination?', This volume (2025); S. Morales and G. Magistris. 'Reinventing politics from a child perspective', In G. Magistris and S. Morales (eds.), *Reinventing the World with Children. From Adultcentrism to Child Perspectives* (Chirimbote and Ternura Revelde, Buenos Aires, 2023) pp. 13–42; M. Bourdillon and R. Carothers. 'Policy on Children's Work and Labour', 33 *Children & Society* (2019) pp. 387–395; M. Marcondes Smith and W. Vandenhole, '"Handle with Care": Addressing Disadvantage based on Childhood through a Non-discrimination Frame', This volume (2025).

[6] P. Alderson, *Choosing for Children: Parents' Consent to Surgery* (Oxford University Press, Oxford, 1990).

[7] P. Alderson, *Children's Consent to Surgery* (Open University Press, Buckingham, 1993).

[8] Children's Consent to Heart Surgery Website (2024) <https://www.ucl.ac.uk/ioe/departments-and-centres/centres/social-science-research-unit/consent-and-shared-decision-making-healthcare/heart-surgery>, visited on 24 January 2024. Open access papers reporting this research are listed on the website.

[9] During the 2018–2021 research, the COVID-19 pandemic ended observations in 2020, but interviews and other data collecting continued by 'phone and online group meetings and surveys.

give consent is expected to recall and understand the information, weigh the related risks and benefits, and make a competent rational decision to give or withhold consent.[10]

Children are often assumed to be unable to manage this intellectual process until around 12-years of age. In medical law, the legal status of the person, in being competent to give or withhold consent, is crucial. The need to avoid uncertainties that would not satisfy the court in cases of litigation leads many doctors to be cautious about minors' consent, and to rely mainly on parents' or guardians' consent. This paper is mainly about UK and US law and practices and their global influence, though under-estimation of children is not universal. For example, many indigenous social groups in Brazil believe children live ambiguously in-between this world and the world of spirits, and so children help societies to achieve their shared objectives. Children are respected as most able to mediate with the non-indigenous, the gods, or even, the enemies.[11] Western societies have much to learn from other cultures.

While legal standards of consent to surgery are vital protections for both patients and practitioners, over-legalising or over-concentration on the law of informed consent and the necessary intellectual interactions can divert attention from other crucial elements of consent. These include patients' embodied experiences in their active cooperation or resistance, as well as the emotions within voluntary consent. When these elements are recognised, the discriminatory adultism assumed in human rights law of consent can be more fully questioned. Children's capacities and the routines that 'treat them like a child' can then be reconsidered.

Numerous court cases around the world attest to the importance of legal protection from the tort of battery (or assault) or of negligence (neglecting to request consent). A tort is an act or omission that gives rise to injury or harm to another and amounts to a civil wrong for which courts impose liability. Many of these cases involve healthcare. Yet the major exception to this protection in law is legal minors. Their parents'/guardians' consent is required for healthcare interventions that would otherwise be assaults, and children's own

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[10] Consent was first defined in detail in relation to medical research in *Nuremberg Code.* (1947) https://media.tghn.org/medialibrary/2011/04/BMJ_No_7070_Volume_313_The_Nuremberg_Code.pdf, visited on 24 November 2024; World Medical Association, Declaration of Helsinki (WMA, Fernay-Voltaire, 1964/2013) https://www.wma.net/policies-post/wma-declaration-of-helsinki/, visited on 24 November 2024.

[11] L. Rabello de Castro, 'Decolonizing discrimination against children: alternative generationing and generativities', This volume (2025).

views may be ignored or overridden so that doctors do not routinely inform them about imminent surgery.

Consent has increasingly been seen as a legal contract designed to reduce and prevent the mistreatment and the stress and costs of complaints and litigation. This is in everyone's interests. Yet the consent contract is not always effective. In England, the National Health Service (NHS) Payments on Clinical Negligence Scheme "claims increased by £152.8 million (seven per cent) to £2,213.9 million from 2020/21".[12]

One main problem is insufficient or inadequate information. Ankuda and colleagues found that one third of the adult patients they studied did not know "the procedure being performed or risks and benefits".[13] With other patients, their doctors had not "addressed patient values, preferences and goals", and patients who did not speak English or who had a lower educational level or lower health literacy were most likely to be affected.[14] Many patients tend to feel under pressure to show respect and trust for the surgeon and not to ask as many questions as they would like to.[15]

Another problem is excess information that may confuse and intimidate patients and distract them from checking even basic questions. Patient information leaflets and consent forms may run to pages of details about risks and side effects, particularly in the USA. In English law, doctors must explain all known risks of proposed surgery.[16] Rare or mild risks may not interest most people, but they become highly significant for a few patients. One example is if a professional singer's voice is slightly impaired. This is devastating for the singer, but it is a problem most people would hardly notice when they are grateful that the treatment has effectively cured their problem. Detailed reading of contracts is unusual. When requested to tick the box online to show we have read all the information and we consent to the terms and conditions of the company whose services we are using, how many people actually read the details?

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[12] NHS England (2023) <www.resolution.nhs.uk/2022/07/20/nhs-resolution-continues-to-drive-down-litigation-annual-report-and-accounts-published-for-2021-22/>, visited on 8 June 2024.

[13] M. Falagas et al., 'Informed Consent: How Much and What Do Patients Understand?', 198:3 *American Journal of Surgery* (2009) pp. 420–35.

[14] C. Ankuda et al., 'Measuring Critical Deficits in Shared Decision Making Before Elective Surgery', 94 *Patient Education & Counselling* (2014) pp. 328–33.

[15] L. Convie et al., 'The Patient and Clinician Experience of Informed Consent for Surgery: A Systematic Review of the Qualitative Evidence', 21:58 *BMC Med Ethics* (2020).

[16] *Montgomery* v. *Lanarkshire Health Board* [2015].

Research repeatedly shows that many adults forget or misremember information to which they have consented before surgery.[17] This can reduce their informed cooperation with post-surgical care and may adversely affect their recovery.[18] Many people misunderstand the information.[19] Adults' thinking and memory may be impaired before and for months after major surgery by "anxiety, depression, fatigue, sleep disturbance and other characteristics",[20] burdens that can also affect parents/guardians. Excess information about risks deters many adults from wanting to learn about the dangers, worried that this will increase their pre-surgical anxiety. "High pre-surgical anxiety is associated with a high incidence of post-surgical pain, decreasing the ability to resist infection, delaying wound healing, imposing adverse effects on patients' mood and hospital stay, and reducing patient satisfaction with their treatment".[21] The self-defence of positive thinking, of not attending to negative aspects of their condition, is associated with better recovery after surgery.[22] Yet many adult patients also worry about their unanswered questions.[23] There are further complications in that patients vary, individually and in different countries, in the kinds and amounts of detail they want to know, and in the methods by which they want to be informed. Many prefer spoken to written information, but surgical teams may not be trained, or encouraged, or given quiet space or time, to hold open discussions with patients.[24]

These problems can be still more serious for children than for adults. There is likely to be even greater concern to shield children from worrying complex knowledge, and to deny them information, than there is to protect adult patients. On average, young children are more likely than adults to be confused,

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[17] D. Hekmatpou et al., 'Pathology of Patient Education: A Qualitative Study', 20 *Iran Journal of Nursing* (2007) pp. 51–60.

[18] F. Kim et al., 'Current Issues in Patient Safety in Surgery: A Review', 9 *Patient Safety in Surgery* (2015), doi:10.1186/s13037-015-0067-4.

[19] G. De Oliveira et al., 'The Impact of Health Literacy in the Care of Surgical Patients: A Qualitative Systematic Review', 15:86 *BioMedical Central Surgery* (2015), doi:10.1186/s12893-015-0073-6.

[20] Y.-Y.Allemann-Su et al., 'Pre-Surgery Demographic, Clinical, and Symptom Characteristics Associated with Different Self-Reported Cognitive Processes in Patients with Breast Cancer', 14 *Cancers* (2022) p. 3281.

[21] E. Nasiri et al., 'Health Care Team Understanding of Patients' Desire for Information on Surgery and Anesthesia: A Cross-sectional Study', 21 *Perioperative Care and Operating Room Management* (2020) p. 100134.

[22] C. Schwartz et al., 'Cognitive Processes during Recovery: Moving toward Personalized Spine Surgery Outcomes', 12 *Journal of Personalized Medicine* (2022) p. 1545.

[23] Nasiri, *supra* note 21.

[24] Ibid.

to misunderstand medical information, and to need skilfully explained details. Practitioners may not expect children to understand, and doctors are then likely to assume any problems with communication lie with the child and not with the adults. They may believe that it is kinder not to confuse and worry children with information, or they may accept the parents saying that their child should not be told.

Children can be left very confused. Alice Miller's research found that if adults hurt and frighten them, children tend to assume they are to blame for anything shameful or hurtful that happens to them.[25] She found that many think they are being punished for some unknown wrong they have done but dare not ask about. Lonely guilt and anxiety can increase their pain. From their earliest years, children are meaning makers and attribute motives to others' actions.

Doctors are still less likely to talk about children's own values, preferences and goals with them, than they would with adult patients. Many doctors tend to see only the parents' values as sufficiently formulated to be relevant, or they rely on parents' beliefs about their child's views and needs rather than the child's.[26] These traditional views persist with many adults still believing that only they should decide children's best interests, that children are too ignorant and volatile to be trusted to make wise decisions, and that children's reports of abuse from adults are only phantasies. CRC Article 12 respects adults' assessments ('due weight') about children's views, not children's views directly.

These traditions, which sideline children's views, are based on convictions that children are entirely different from adults, that they need different standards of care, and need 'to be treated like a child'. This includes being excluded from the adult-centric over-legalising of consent that prioritises preventing complaints and litigation by obtaining the legally valid adult's signature on the consent form. Doctors are deterred from risking queries about the child's uncertain legal liability or status or understanding. Children are routinely tested on their abilities if their consent is to be considered, whereas adults are not, although many adults would fail tests of their understanding and recall of the medical information.[27] Clear appropriate information and sensitive support are vital for all age groups.

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[25] A. Miller, *Thou Shalt not Be Aware: Society's Betrayal of the Child* (Plume, London, 1998).

[26] J. Goldstein et al., *The Best Interests of the Child: The Least Detrimental Alternative* (Simon & Schuster, London, 1973/1986).

[27] Falagas, *supra* note 13.

3 Rights Related to Consent: Combatting Discrimination

An alternative approach to over-legalising is to relate respectfully to children as persons with inalienable rights during the consent process. Children, especially young, ill or disabled children, tend to be seen as not-yet persons, to the extent of the young child being called "a capacitous person who has not yet existed".[28] In this chapter, the rights to bodily integrity and autonomy of young surgery patients are seen to involve complex mental legal process and also physical realities: the child's impaired body and physical needs; actual corrective surgery; the staff who interact with the child and who handle the child's body; the child's active physical cooperation, or resistance. Understanding that human rights at all ages involve physical realities and nonverbal mental processes and interactions is more inclusive and respectful of the rights of all young and disabled children. This accords with the Preambles of all the UN Human Rights Conventions: that "recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world". 'Inalienable' means that rights cannot be taken away, surrendered or transferred. This implies they are innate, not gradually emergent after the first years. 'Innate' is taken to mean from the moment of birth when the child is independent of the mother's body.[29]

An alternative to the cerebral, institutionalised, over-legalising approach is also to recognise consent as part of the respectful, therapeutic, personal doctor-patient relationship. "A patient's right to autonomy and dignity should today be accorded the highest priority in English law."[30] Respect for each person's autonomy and bodily integrity means that the body should be touched only after the person concerned has given explicit or at least tacit informed consent; touching should cease if the person objects except in specific cases such as the duties of police and prison officers.[31]

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[28] J. Pugh, 'The Child's Right to Bodily Integrity and Autonomy: A Conceptual Analysis', *Clinical Ethics* (2023) <https://journals.sagepub.com/doi/pdf/10.1177/14777509231188817> visited on 24 January 2024.

[29] Nation states chose the age when rights begin when they ratified the CRC, and in UK law rights begin when the child is born, in order not to infringe on mothers' rights.

[30] Judgment in the law case [2004] *UK* v *HL 16* cited in M. Brazier and E. Cave. *Medicine, Patients and the Law* (University of Manchester, Manchester, 2016), p.123.

[31] P. Alderson, 'Bodily Integrity and Autonomy of the Youngest Children and Consent to their Healthcare', 18:4 *Clinical Ethics* (2023), doi:10.1177/14777509231188006.

Yet children are still often constrained and forcibly 'held' during clinical procedures, in the belief that there is not time to inform, prepare and support them to gain their cooperation, or that they are incapable of rational understanding. Increasingly, these views are challenged. Nurse researchers report the moral distress to practitioners and children during such interactions.[32] Research shows that young children can understand and cooperate, when they are carefully informed, far more than used to be believed possible.[33] Practitioners contend that treating young children respectfully, such as when administering anaesthesia before surgery, can prevent suffering including PTSD.[34] Time spent informing and supporting children, especially those with serious long-term conditions, is cost-effective when it can avoid much time being wasted later if they become more scared and resistant during repeated treatment as they grow older. Paediatric cardiology teams are deeply concerned that enforced interventions can cause children to lose mutual trust and respect with their clinical team. When aged about 16, they become responsible for booking their own regular clinic appointments. Some young people have such painful memories that they opt out of the life-long care on which their health and survival depend.[35]

Respectfully listening to children and negotiating with them involves many of the inter-related, indivisible CRC rights. The CRC Preamble recognises that many children need extra protections: "the child, by reason of his or her physical and mental immaturity, needs special safeguards and care, including appropriate legal protection". Yet many adults also have extra needs, and for plenty of mature young people 'special safeguards' can be unnecessary and unwanted oppressions. However, the wording 'special safeguards and care' and 'protection' can suggest flexibility that adapts to each child's needs and avoids coercive control. This involves checking with each child how much they want and need to know before and during their investigations and treatment.

CRC Article 2 states that every child shall be respected

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[32] L. Bray et al., 'A Qualitative Study of Health Professionals' Views on the Holding of Children for Clinical Procedures: Constructing a Balanced Approach', 23:1 *Journal of Child Health Care* (2019) pp. 160–171.

[33] I. Coyne. 'Children Should be Seen and Heard' 6:2 *Children's Research Digest* (2020) pp. 4–8; P. Alderson et al., 'Children's Consent to Medical Treatment', 36 *Hastings Centre Report* (2006) pp. 25–34.

[34] H. Wellesley et al., 'When children refuse their anaesthetic - restrain, deceive, or postpone?' 31:9 *Pediatric Anesthesia* (2021) pp. 1016–17.

[35] P. Alderson et al., 'Children's Ages of Consent to Non-urgent Heart Surgery: The Views of Two Paediatric Cardiology Teams' 38 *Children & Society* (2023) pp. 487–504.

> without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status [or] on the basis of the status, activities, expressed opinions, or beliefs of the child's parents, legal guardians, or family members.
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> Article 2

Age discrimination, the main concern of this chapter, is notably missing. However, Article 2 is vitally important on equal rights to healthy living and to healthcare among all children. This involves extra care and services for all disadvantaged children to bring these up to standards enjoyed by children in secure prosperous families and in wealthier countries, to counteract racism, classism and all other unjust discriminations. Many of these are detailed in the following paragraphs.

Article 3 continues: "The best interests of the child shall be a primary consideration [with] such protection and care as is necessary for his or her well-being, taking into account the rights and duties of his or her parents" or other legally responsible adults. There should also be respect for "the responsibilities, rights and duties of parents to direct and guide the child" (Article 5). During our research interviews about children's consent to heart surgery, a play specialist recounted working respectfully with parents but also persuading some parents, who insisted their child should not be informed before heart surgery, to see how greatly their child needed some explanations and preparation. She described parents' relief and growing confidence when she helped them to find ways to inform and prepare their child.[36] Eileen McPartland, among many authors, shows how the child's best interests are respected through listening to children's own views.[37]

The CRC positions 'states parties' as the key agents that observe and protect human rights, meaning governments, politicians and public servants who legislate and implement state policies and services. "States Parties shall ensure to the maximum extent possible the survival and development of the child" (Article 6). "Survival and development" involve not only the best outcomes for any healthcare intervention for children but also the best processes, through which children are respectfully involved and helped to learn and gain knowl-

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[36] P. Alderson et al., 'Children's understanding and consent to heart surgery: Multidisciplinary teamwork and moral experiences' 27:2 *Journal of Child Health Care* (2023) pp. 197–211, doi:10.1177/13674935221100419.

[37] E. McPartland, *The Best Interests of the Child* (Gill Education, Dublin, 2013/2020).

edge and confidence. The CRC's broad international standards can be interpreted and implemented in numerous local, detailed ways, for example by the whole range of healthcare professionals who care for children from surgeons to chaplains, psychologists to physiotherapists.

> States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.
>
> Article 12

Article 12 continues with the child's right to "be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child". Protection rights to keep children safe have traditionally been contrasted with so-called participation or freedom rights (mainly articles 12–17) as if, when allowed to make choices about their best interests, children will make foolish, ignorant, risky decisions, and are their own worst enemies. Yet although "to respect the rights and duties of the parents and…guardians, to provide direction to the child in the exercise of his or her right in a manner consistent with the evolving capacities of the child" (Article 14.2, repeating Article 5) can be interpreted oppressively to overrule young patients, it can also involve informing, respecting and supporting children's choices. Respect for autonomy therefore involves mutual respect for everyone's dignity and protection and support when needed.

While strongly supporting Article 12, researchers have shown problems associated with the concept of 'due weight', as assessed by adults. It can be an obstacle, allowing adults to dismiss children's views that seem to have insufficient 'weight', to silence and exclude them from discussions. Aoife Daly contends that when the child's best interests are the primary consideration, the child's involvement in decision-making and the child's choices should be supported unless there is risk of significant harm.[38] Kay Tisdall has analysed concepts of competence and capacity to show they have uncertain meanings, interpretations and applications. Too often they are seen as integral to the child's development, whereas poor communication often arises from adults' own limited competencies and capacities. The concepts need to be more precisely and critically defined and the 2006 UN Convention on the Rights of Persons with Disabilities offers fresh ideas on recognising and supporting peo-

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[38] Daly, *supra* note 1.

ple's legal capacities.[39] Centuries of prejudice in philosophy, law and psychology can confuse today's analyses and need to be unravelled.[40] Long-standing research evidence of young children's capacity for profound understanding needs to be much more widely known, such as their realistic knowledge about death.[41] Children should not be tested for their general knowledge but for their understanding of the specific matter, especially ill and disabled children. Their daily lives may be limited but their understanding of their condition may be profound. The UN Committee on the Rights of the Child has also emphasised that children do not need "comprehensive knowledge of all aspects of the matter…but sufficient understanding" to enable them to form their own views on the matter.[42] This begins "in early childhood" and therefore adults should not assume incapacity but "should presume that a child has the capacity" to form and express views; "it is not up to the child to first prove his or her capacity". The Committee offered much useful advice on the stages of consulting with children, avoiding an environment that "is intimidating, hostile, insensitive" or age-inappropriate, and instead providing "child-friendly information, adequate support for self-advocacy, and appropriately trained staff".[43] This firmly puts responsibility on the adults, not the child, to ensure the encounter is effective. There is a slowly growing literature on the benefits of respectfully consulting with children who have serious conditions.[44]

English and Scottish law exceed CRC standards, that the legal right to consent or refuse begins at a fixed age, 16- or 18-years and before then only pa-

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[39] E.K.M. Tisdall, 'Challenging Concepts of Competence and Capacity?', 26 I*nternational Journal of Children's Rights* (2018) pp. 59–82.

[40] R. McDougall et al., *When Doctors and Parents Disagree: Ethics, Paediatrics and the Zone of Parental Discretion* (Federation Press, Sydney, 2016).

[41] M. Bluebond-Langner, *The Private Worlds of Dying Children* (Princeton University Press, New Jersey, 1978); C. Clunies-Ross and R. Lansdown, 'Concepts of Death, Illness and Isolation Found in Children with Leukaemia' 14 *Child: Health, Care and Development* (1998) pp. 373–86; Alderson, *supra* note 8.

[42] UN Committee on the Rights of the Child, General Comment no. 12 The Right of the Child to be Heard (United Nations, Geneva, 2009) pp. 20–21.

[43] Ibid.

[44] I. Coyne et al., 'Children's Participation in Shared Decision-Making: Children, Adolescents, Parents and Healthcare Professionals' Perspectives and Experiences' 18:3 *European Journal of Oncology Nursing* (2014) pp. 273–280; E. Beecham et al., 'Children's and Parents' Conceptualization of Quality of Life in Children With Brain Tumors: A Meta-Ethnographic Exploration' 29:1 *Qualitative Health Research* (2019) pp. 55–68, doi: 10.1177/1049732318786484; P. Alderson et al., 'Children as Partners with Adults in their Medical Care', 91 *Archives of Diseases in Childhood* (2006) pp. 300–303; Alderson, *supra* note 8; Children's Consent to Heart Surgery Website, *supra* note 7.

rents/guardians may give consent. Instead, doctors assess and determine the child's Gillick competency and right to consent.[45] They

> take into account the child's age, mental capacity and maturity, their understanding of the issue, the risks, implications and consequences that may arise from their decision, how well they understand any advice or information they have been given, their understanding of any alternative options, and their ability to explain a rationale around their reasoning and decision making.[46]

Some hospitals move on from the legal tradition that only one person may sign the consent form. They provide two spaces and families can choose whether the child's or a parent' signature is written on the first line to show who was the 'main decider'. In the USA, the 'mature minor' is respected on similar terms to the UK, though in the definition there is more emphasis on a lack of supportive involved adults than on the child's capacity.[47] The USA is the only state in the world not to have ratified the CRC. The British NHS respects healthcare as a right, a view that is undermined in countries where healthcare is a profitable commodity mainly on offer to those who can afford it.

CRC Article 12 is valuable in setting out children's rights to be involved and listened to in decision-making that affects them. Yet as noted earlier, the right is qualified by concerns about capacity, and too often depends on adults who, it is assumed, will make the actual decision. The CRC is both more advanced than other Conventions in having an Article that relates to the right to make personal decisions, but less advanced in qualifying this right in mainly adult-centric terms. In other Conventions, such as the Universal Declaration of Human Rights (UDHR) 1948, it is implied this right is too obvious and basic to all other rights, such as privacy or noninterference, even to be worth mentioning. It is referred to most nearly in UDHR Article 19, "Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers." Yet everyone's human rights are qualified: by "due recognition and respect for the rights and

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[45] *Gillick* vs *West Norfolk & Wisbech AHA* [1984] Age of Legal Capacity Scotland Act [1991].

[46] R. Griffith, 'What is Gillick competence?', 12 *Human Vaccines Immunotherapeutics* (2016) pp. 244–247, doi:10.1080/21645515.2015.1091548.

[47] G. Sigman and C. O'Connor, 'Exploration for Physicians of the Mature Minor Doctrine', 19:4 *Journal of Pediatrics* (1991) pp. 520–5, doi:10.1016/s0022-3476(05)82398-4.

freedoms of others…meeting the just requirements of morality, public order and the general welfare in a democratic society", and in never being "exercised contrary to the purposes and principles of the United Nations".[48]

When doctors began to perform heart transplants for children in the late 1980s, they soon found that they had to listen to young children's views. Doctors were not only mending impaired bodies, they also encountered inquiring minds. A psychologist who worked with the first paediatric cardiac transplant team and is still in practice explained how she had to persuade the doctors to listen and respect the children's views. Children who did not want the transplant literally had their life in their hands. They had to take daily immunosuppressive medication for the rest of their lives. Some children refused to do this and they died.[49] There are too few small donated hearts for all the children who need them, and doctors have to choose their patients very carefully, treating those who have most hope of success. The psychologist explained how she discussed his transplant with a 3-year-old. She compared his heart transplant to a car that gets a new engine. This showed how his body and identity would be unchanged. She told him his new engine would need petrol and that was the daily medicine. She believed the little boy deeply understood what was involved, as he was so ill and in great need of the treatment. He knew what it was like when his 'engine' was not working well and 'might stop'.[50]

Also vital is "freedom to seek, receive and impart information and ideas of all kinds…orally, in writing or in print, in the form of art, or through any other media of the child's choice" (Article 13). This especially helps children who need more than verbal explanations, in images or play with medical equipment or with puppets.

"Freedom of thought, conscience and religion" (Article 14) extends Articles 12 and 13 to imply respect for children's decisions. Freedom of religion is most clearly debated when young Jehovah's Witness patients refuse life-saving blood transfusion and blood products, deeply believing this is vetoed in the Bible. Doctors rely on the courts to authorise treatment that overrules legal minors' choices. However, there is now greater concern to respect children's religious beliefs and to work with them as closely as possible, with early communication and multidisciplinary team planning.[51]

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[48] Universal Declaration of Human Rights (United Nations, New York, 1948) Article 29, 2,3.

[49] P. Alderson and M. Goodwin, 'Contradictions within Concepts of Children's Competence', 1:3 *International Journal of Children's Rights* (1993) pp. 303–313.

[50] Alderson, *Supra* note 35.

[51] E. Murphy and P. McConnell, 'The Perioperative Care of Jehovah's Witnesses', 23(8) *Anaesthesia & Intensive Care Medicine* (2022) pp. 472–476; A. Klein et al., 'Association

Article 16 states, the child's right to be protected by law from "arbitrary or unlawful interference with his or her privacy, family, or correspondence [and] unlawful attacks on his or her honour and reputation". Parents who wish to see their child's medical records should request permission from children aged from about 13,[52] and all healthcare staff should be extremely careful about spreading criticisms of children or parents.

While being protected from 'injurious' information, children have the right to access the mass media and "information and material from a diversity of national and international sources, especially those aimed at the promotion of his or her social, spiritual and moral well-being and physical and mental health" (Article 17). Clear information with images helps children and parents to become highly informed before surgery. A surgeon we interviewed recalled explaining planned heart surgery to a boy aged 7, "who was looking at his iPad and he was watching the operation I was going to do, he'd found it on YouTube, sitting there saying 'Is this what you're going to do?'"

Article 18 recognises that parents have "the primary responsibility for the upbringing and development of the child. The best interests of the child will be their basic concern". Article 19 concerns "measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation". 'Neglect' refers to millions of children around the world who do not have the surgery they need to cure problems from blindness to cancer. Avoiding abuse relates to careful planning and informed negotiation with children and parents, especially before high-risk or experimental surgery. CRC later states more forcefully, "States Parties shall protect the child against all other forms of exploitation prejudicial to any aspects of the child's welfare" (Article 36). "No child shall be subjected to torture or other cruel, inhuman or degrading treatment or punishment" (Article 37). By the uninformed child, surgery can be experienced as torture, another reason for ensuring that children are as fully informed and involved in decisions as possible.

States Parties recognise that "a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community". The aim is the child "achieving the fullest possible social integration and individual development" (Article 23). Surgery enables countless children to enjoy better health, mobility and a more 'normal' fulfilled childhood. Ensuring 'dignity'

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of Anaesthetists: Anaesthesia and Peri-operative Care for Jehovah's Witnesses and Patients Who Refuse Blood', 74 *Anaesthesia* (2019) pp. 74–82.

[52] British Medical Association, *Children and Young People Toolkit* (BMA, London, 2021).

involves respecting children's thoughts as well as their bodies when making decisions about surgery. "International cooperation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of disabled children" (Article 23) help to spread surgical research knowledge and technical expertise around the world. Medicine is the most internationally practised and shared profession (perhaps apart from music) and Articles 23 and 24 endorse "the spirit of international cooperation, the exchange of appropriate information" enabling practitioners "to improve their capabilities and skills and to widen their experience…Particular account shall be taken of the needs of developing countries".

All CRC rights contribute to supporting "the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health" (Article 24). There is no right to health because health cannot be willed or enforced. A dying child has no "right to heath", only to the "highest attainable standard of health". "The right of every child to a standard of living adequate for the child's physical, mental, spiritual, moral and social development" includes assistance for families in need "particularly with regard to nutrition, clothing and housing" (Article 27). This involves preventing illness and the need for medical treatment, and it complements education that is directed to "the development of the child's personality, talents and mental and physical abilities to their fullest potential" (Article 29). There are also health-related rights "to rest and leisure, to engage in play and recreational activities appropriate to the age of the child and to participate freely in cultural life and the arts" (Article 31).

Other vital health-related rights that involve children's minds and bodies and informed decision-making and partnership with adults include the rights to protection from: economic exploitation and from performing any work that is likely to be hazardous or to interfere with the child's education, or to be harmful to the child's health" (Article 32); illicit use of narcotic drugs and psychotropic substances (Article 33); "sexual exploitation and sexual abuse" (Article 34); "the abduction of, the sale of or traffic in children" (Article 35); "all other forms of exploitation prejudicial to any aspects of the child's welfare" (Article 36); arbitrary imprisonment and associated mistreatment (Article 37); recruitment into the armed forces (in the UK young people aged over 15 are not protected despite the serious known physical and mental health harms) (Article 38). Healthcare includes 'all appropriate measures to promote physical and psychological recovery and social reintegration' of a child victim recovering from a range of named abuses (Article 39). Article 40 lists health-related dangers of treating children like adult criminals.

"Nothing in the present Convention shall affect any provisions which are more conducive to the realization of the rights of the child and which may be contained in … the law of a State party" (Article 41). This supports USA mature minors law. English Gillick law also exceeds CRC standards in that it respects young children deemed to be competent to consent with no stated age barrier. There is much further valuable information in CRC, the General Comments, and the Committee's Concluding Observations.

4 Conclusion: Hope for Future Progress

As noted earlier, the UN human rights Conventions, especially CRC Article 2 prohibit discrimination or 'distinction of any kind' except for age discrimination. Perhaps the UN will reconsider this omission and declare retrospectively that anti-age discrimination is formally included in all its treaties, with reservations that respect each nation's age-related laws. If adultist, anti-child discrimination were challenged and prohibited more, that is likely to improve attitudes underlying discrimination against all other groups of people.

To replace the present weak "right to be heard" in CRC Article 12, and so to honour non-discrimination standards in Article 2, children need rights, embedded in good systems, to be encouraged and assisted to express themselves. Instead of dismissing children's (and adults') emotions as problems, adults need to understand and support the emotional moral journey that patients have to make from initial fear and possibly rejection of proposed surgery through doubt and trust towards resolve and courage to undergo the treatment hoping for the intended benefits. Very young children can be helped to achieve this. The following view of the future, in an analysis mainly of law on adults' rights, also affects children.

> The next stage in the development of health care law lies in spelling out the scope of our rights as citizens, not as patients awaiting the ministrations of professionals. I have suggested that this will leave the judicial protection of clinical freedom intact, but it will bring it out into the open, and place it in the context of the obligations of health services to give people worthwhile choices.[53]

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[53] J. Montgomery, 'Patient No Longer? What Next in Health Care Law?' (2017) https://discovery.ucl.ac.uk/id/eprint/1569251/1/Montgomery_Patient_No_Longer.pdf> visited on 23 November 2024.

To relate to children as present and future citizens with rights gives them greater equality with adults. Society depends on having healthy citizens and this involves 'the highest attainable standards' of healthcare. Working *with* children can increase their active cooperation with their treatment and reduce the risk of enforcing interventions that leave some children with long-term trauma. The heart surgery teams were observed to look ahead to the years when young people become responsible for their own care. Practitioners knew that, for children's present and future wellbeing, they must sustain mutual trust and strive to work with the child's informed willing consent.

Finally, this chapter and this book have advocated that children should not be 'treated like a child', which equals negative discrimination. But perhaps we are falling into adultist prejudices. Some great philosophers have imagined a positive world where we are all treated, and treat one another, like young children in preference to being like adults. Jesus said, "Allow [suffer] the little children to come unto me and forbid them not, for as such is the kingdom of heaven".[54] And he warned, "Unless you change and become like little children, you will never enter the kingdom of heaven. Therefore, whoever humbles himself like this child is the greatest in the kingdom of heaven."[55]

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[54] Matthew 19.14.

[55] Matthew 18.3.