

# The legal framework empowering children under 18 to make decisions in relation to their medical treatment examined through the prism of international human rights obligations.

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## Introduction

For a doctor to avoid committing an act of battery - an intentional assault in criminal law or a trespass to the person in tort - valid consent to treatment must be obtained<sup>1,2</sup>. When considering the application of the law of consent to children, there are three factors that demand initial investigation; firstly how to legally distinguish a child from an adult; secondly how capacity to consent to treatment is established in children; and thirdly how the law accommodates the expressed wishes of children in relation to their medical treatment.

The early part of this discussion will focus upon establishing the current law on consent in England and Wales, as applied to children, by reference to statute and case law. The interpretation and application of the law will be examined for its consistency and ability to protect the rights and best interests of children. The discussion will then be widened to determine the degree to which the international human rights of children are supported by UK law.

An evaluation of the right of children under 18 years of age to make decisions in relation to their medical treatment implies a degree of capacity. Consequently, this discussion will not be distracted by considering circumstances in which treatment decisions are made on behalf of children clearly lacking in capacity; *it is the interface between the emerging competence of the child and their legal rights as individuals to self-determination that concerns us here.*

## Ethical considerations in children

In the modern era of internet globalisation there has been profound societal shift in the common perception of what constitutes childhood. Children under 18 years of age are undoubtedly greatly advanced in matters 'adult' compared with the youth of their parents' generation and draw upon influences that simply did not exist twenty years ago, influences which remain, perhaps, inaccessible to today's law makers.

The law has evolved over the past 20 years, post *Sidaway*<sup>3</sup>, to a more patient-centred position in which the reasonable patient test, as applied in *Pearce*<sup>4</sup>, is the standard

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<sup>1</sup> *Chatterton v Gerson* [1980] 3 W.L.R. 1003.

<sup>2</sup> *Appleton v Garrett* [1997] 8 Med. L.R. 75.

now applied to disclosure of risk. For a child to remain competent to consent, therefore, their level of understanding must parallel the increasing volume of information in relation to risk that must be imparted to them.

A child who is deemed competent to consent to one treatment may not be competent, by virtue of its greater complexity, to consent to another<sup>5</sup>. The primacy of a child's autonomy in determining treatment decisions is, however, difficult to equate with competence, especially when competence to consent may seem to fluctuate depending upon the circumstances; it would be difficult to argue that they have 'fluctuating autonomy'.

In truth, a child's autonomy is gradually acquired, and from that autonomy flows by degrees a spectrum of competencies that mature, at least in the eyes of the law, at the age of 18 years. In the meantime, the gap between autonomy and competence is filled by the parents of the child in deciding where their best interests lie or by the court exercising its role of *parens patriae* in wardship proceedings<sup>6</sup>.

In the case of children, however, the point at which the potential for self-determination is acquired is likely to change with the times, and for the law to remain relevant and valid in the eyes of young people it must keep pace with the world in which they live<sup>7</sup>.

#### An overview of the current legislation in England and Wales concerning children and consent.

The Family Law Reform Act 1969 defines a child as any person of less than 18 years of age<sup>8</sup> but allows for children aged 16 or 17 years to provide consent to medical treatment<sup>9</sup>. Below the age of 16 years, where a child is deemed to be sufficiently mature, they may still provide independent consent to treatment although, paradoxically, they may not always be given leave to refuse it (see *Gillick Competence and the right to self-determination for children* - below). In Scotland, by comparison, the legal age of consent is more clearly defined as 16 years<sup>10</sup>.

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<sup>3</sup> *Sidaway v Board of Governors of the Bethlem Royal Hospital and the Maudsley Hospital* [1985] A.C. 871.

<sup>4</sup> *Pearce v United Bristol Healthcare NHS Trust* [1999] E.C.C. 167.

<sup>5</sup> *Re R* [1991] 4 All ER 177.

<sup>6</sup> Statutory Instrument 1991 No.1247 (L.20). The Family Proceedings Rules 1991.

<sup>7</sup> See *obiter* of Lord Denning MR in *Hewer v Bryant* [1970] 1 Q.B. 357: 'The common law can, and should, keep pace with the times. It should declare, in conformity with the recent Report of the Committee on the Age of Majority [Cmnd. 3342, 1967], that the legal right of a parent to the custody of a child ends at the 18th birthday: and even up till then, it is a dwindling right which the courts will hesitate to enforce against the wishes of the child, and the more so the older he is. It starts with a right of control and ends with little more than advice.'

<sup>8</sup> Family Law Reform Act 1969, s1.

<sup>9</sup> Family Law Reform Act 1969, s8(1): 'The consent of a minor who has attained the age of sixteen years to any surgical, medical or dental treatment which, in the absence of consent, would constitute a trespass to his person, shall be as effective as it would be if he were of full age; and where a minor has by virtue of this section given an effective consent to any treatment it shall not be necessary to obtain any consent for it from his parent or guardian.'

<sup>10</sup> Age of Legal Capacity (Scotland) Act 1991 s2(4).

Where this degree of maturity is absent the child is considered incapable to consent to treatment under the criteria established by the Mental Capacity Act 2005 which identifies a person as lacking capacity if they are unable to understand the information provided to them, to retain it, to assimilate it and communicate their decision effectively<sup>11</sup>. Where these conditions are not satisfied, as is often, although not inevitably, the case in children (and not simply *because* they are children<sup>12</sup>), then treatment decisions are delegated to a person with parental responsibility, as defined by the Children Act 1989<sup>13</sup>. Under the Children Act, consent is valid when obtained from one person with parental responsibility even if the other parent disagrees<sup>14</sup>. Occasionally *both* parents must agree<sup>15,16</sup> and certain treatments, such as female sterilisation, are permitted only under the direction of the court<sup>17,18,19</sup>. If the parent(s) is under 18 years of age they can only provide consent to treatment on behalf of a child if they themselves are *Gillick*-competent (see below).

Emergency treatment may be provided where parental consent cannot be obtained by doctors who seek to act in the best interests of the child<sup>20</sup>. Where the wishes of parents and doctors are opposed, in deciding, the '*child's welfare shall be the court's paramount consideration*'<sup>21</sup>.

A person's ability to provide valid consent to treatment is defined slightly differently under the Mental Health Act 2007<sup>22</sup>, which relates to treatment provided during detention under that Act. Here, the patient (rarely a child) must have a reasonable understanding of '*the nature, purpose and likely effects of the treatment*'<sup>23</sup>, but in practice they quickly lose their autonomy to participate in treatment decisions if treated in accordance with the 1983 act under section 63<sup>24</sup>.

Importantly, in common law it is for the *doctor* to decide whether or not a minor has the capacity to consent. Research shows, however, that the point at which children consider themselves capable of consenting to medical treatment (14 years on average) is similar to the opinion of parents (13.9 years), while medical professionals would allow children the autonomy to consent to treatment from a much younger age (10.3 years)<sup>25</sup>.

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<sup>11</sup> Mental Capacity Act 2005, s2.

<sup>12</sup> Mental Capacity Act 2005, s2 (3a).

<sup>13</sup> Children Act 1989, s3.

<sup>14</sup> Children Act 1989, s2(7); 'Where more than one person has parental responsibility for a child, each of them may act alone and without the other (or others) in meeting that responsibility; but nothing in this Part shall be taken to affect the operation of any enactment which requires the consent of more than one person in a matter affecting the child.'

<sup>15</sup> *Re J (A Minor) (Prohibited Steps Order: Circumcision)* [2000] 1 FLR 571.

<sup>16</sup> *Re C (Welfare of Child: Immunisation)* [2003] EWCA Civ 1148.

<sup>17</sup> *Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1.

<sup>18</sup> *Re D (A Minor) (Wardship: Sterilisation)* [1976] 1 All E.R. 326.

<sup>19</sup> *Re B (A Minor) (Wardship: Sterilisation)* [1988] A.C. 199.

<sup>20</sup> Mental Capacity Act 2005, s4.

<sup>21</sup> Children Act 2009, s1(1).

<sup>22</sup> Mental Health Act 2007.

<sup>23</sup> Mental Health Act 2007, s27(3).

<sup>24</sup> Mental Health Act 1983, s63.

<sup>25</sup> Children's Consent to Treatment. Shield JPH, Baum JD. British Medical Journal 1994; 308: 1182-83.

## Gillick Competence and the right to self-determination for children

The case of *Gillick v West Norfolk and Wisbech AHA*<sup>26</sup> effectively reduced the age of consent to medical treatment for children established by the Family Law Reform Act 1969. A *Gillick*-competent child or young person may provide independent consent to treatment providing that they understand its nature and consequences and providing that consent is given voluntarily without coercion or undue influence from others<sup>27</sup>.

The *Gillick* case concerned the prescription of the oral contraceptive pill to a minor. Mrs Gillick contested the lawfulness of the treatment of her daughter without her consent in the House of Lords which held that where a child is of ‘*sufficient understanding and intelligence to enable him or her to understand fully what is proposed*’<sup>28</sup> the parental rights and duties outlined in the Children Act are displaced by the overriding autonomy of child to decide. Lord Scarman summarised the position in law as:

*‘It is that parental right yields to the child's right to make his own decisions when he reaches a sufficient understanding and intelligence to be capable of making up his own mind on the matter requiring decision.’*

An important caveat here, however, was that while the child should have a full understanding of the treatment proposed and its consequences, a concept retained by the Mental Capacity Act 2005, they should also appreciate the consequences of failing to treat as was considered in the case of *Re R*<sup>29</sup>. Here a child, detained under the Mental Health Act 1983, refused to receive antipsychotic medication for a mental illness which, due to its intermittent nature, resulted in seemingly intermittent (*Gillick*) competence upon which she relied to assert that refusal.

The Court of Appeal, however, was reluctant to apply the *Gillick* test to a patient with a mental illness whose capacity to consent was deemed to fluctuate in this way<sup>30</sup> and ordered treatment in accordance with its best interests obligations under the Children Act 1989.

The ruling in *Re R* was followed in *Re W*<sup>31</sup> in which the refusal of a sixteen year old girl, suffering the effects of anorexia nervosa, to consent to her admission to a specialist treatment unit was overridden by the Court of Appeal. In his summary, however, Lord Donaldson’s *dictum* cautioned against ignoring the importance of the child’s autonomy to make treatment decisions, an autonomy that strengthens with age and maturity:

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<sup>26</sup> *Gillick v West Norfolk and Wisbech AHA* [1985] 3 All ER 402.

<sup>27</sup> Reference guide to consent for examination or treatment. 2<sup>nd</sup> Ed. Department of Health 2009.

<sup>28</sup> Lord Scarman, *Gillick v West Norfolk and Wisbech AHA* [1985] 3 All ER 402.

<sup>29</sup> *Re R (A Minor) (Wardship: Consent to Treatment)* [1991] 3 W.L.R. 592. Lord Donaldson: ‘...what is involved is not merely an ability to understand the nature of the proposed treatment - in this case compulsory medication - but a full understanding and appreciation of the consequences both of the treatment in terms of intended and possible side effects and, equally important, the anticipated consequences of a failure to treat.’

<sup>30</sup> Farquharson LJ: ‘The *Gillick* test is not apt to a situation where the understanding and capacity of the child varies from day to day according to the effect of her illness.’

<sup>31</sup> *Re W (A Minor) (Medical Treatment: Court's Jurisdiction)* [1993] Fam. 64.

*'No minor of whatever age has power by refusing consent to treatment to override a consent to treatment by someone who has parental responsibility for the minor and a fortiori a consent by the court. Nevertheless such a refusal is a very important consideration in making clinical judgments and for parents and the court in deciding whether themselves to give consent. Its importance increases with the age and maturity of the minor.'*

The courts encounter special difficulty when a minor refuses to accept life saving treatment; in these cases the child's right to self determination that flows from the notion of *Gillick* competence must be carefully balanced against the court's duty to make welfare decisions on their behalf. In some cases, such as *Re M (A Child) (Refusal of Medical Treatment)*<sup>32</sup>, the court's decision to order a life-preserving heart transplant was one, *prima facie*, of best interests (contrast this with the decision in *Re T*<sup>33</sup> in which the court chose to respect the parents' decision to decline a liver transplant on behalf of their baby son), while in cases involving Jehova's Witnesses additional cultural and religious dilemmas are encountered.

In *Re E (A Minor) (Wardship: Medical Treatment)*<sup>34</sup>, a *Gillick*-competent 15 year old boy refused to consent to the blood transfusions required to treat his leukaemia on account of his Jehova's Witness faith, and the parents similarly withheld consent. Ward J applied the paramountcy principle contained within the Family Law Reform Act 1969 in ordering a transfusion to go ahead, refusing to allow the child to 'martyr' himself before the court<sup>35</sup>.

A similar scenario was encountered subsequently in *Re L*<sup>36</sup>, where a critically injured fourteen year old Jehova's Witness child was considered lacking in understanding (and therefore incapable) of the true nature of her likely death unless a blood transfusion were administered. Notwithstanding the fact that the medical staff had a duty to *ensure* the required level of understanding<sup>37,38</sup>, this conveniently enabled the court to avoid overriding valid *Gillick*-competent refusal of the transfusion which it almost certainly would have done.

The result of these various child refusal cases has been viewed as a 'retreat from *Gillick*'<sup>39</sup>, re-establishing control over the autonomy of the child.

Within the boundaries of the law, a competent child's right to refuse treatment would thus appear to be limited to non-life threatening conditions, a right which might be reasonably expected to be upheld upon reaching the age of 16 years in accordance with the Family Law Reform Act 1969. However, as is the case for *Gillick*-competence in younger children, the right to consent to treatment between 16 and 17 years of age does not necessarily imply the converse right to refuse treatment, as

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<sup>32</sup> *Re M (A Child) (Refusal of Medical Treatment)* [1999] 2 F.L.R. 1097.

<sup>33</sup> *Re T (A Minor) (Wardship: Medical Treatment)* [1997] 1 W.L.R. 242.

<sup>34</sup> *Re E (A Minor) (Wardship: Medical Treatment)* [1993] 1 F.L.R. 386.

<sup>35</sup> Ward J: 'There is compelling and overwhelming force in the submission of the Official Solicitor that this court, exercising its prerogative of protection, should be very slow to allow an infant to martyr himself.'

<sup>36</sup> *Re L (Medical Treatment: Gillick Competence)* [1998] 2 F.L.R. 810.

<sup>37</sup> *Deriche v Ealing Hospital NHS Trust* [2003] EWHC 3104.

<sup>38</sup> *Cooper v Royal United Hospital Bath NHS Trust* [2005] EWHC 3381.

<sup>39</sup> G. Douglas, 'The Retreat from *Gillick*' (1992) 55 MLR 569.

illustrated by *Re P (Medical Treatment: Best Interests)*<sup>40</sup>. Here Johnson J struggled with the competing best interests argument and the clearly-stated views of the patient and his relatives, deciding eventually in favour of the patients best interests ‘...in the widest possible sense — medical, religious, social, whatever they be’.

The BMA’s consent toolkit summaries the current legal position in England and Wales succinctly<sup>41</sup>:

*‘Where a competent young person refuses treatment, the harm caused by violating a young person’s choice must be balanced against the harm caused by failing to treat. In these cases the courts have said that children and young people have a right to consent to what is being proposed, but not to refuse it if this would put their health in serious jeopardy.’*

### The NHS Constitution

The NHS Constitution<sup>42</sup> clearly upholds the right of children not to be discriminated against in terms of access to healthcare on the basis of age:

*‘You have the right not to be unlawfully discriminated against in the provision of NHS services including on grounds of gender, race, religion or belief, sexual orientation, disability (including learning disability or mental illness) or age.’*

Furthermore, in terms of consent to treatment, the Constitution does not distinguish between an adult and a child, so long as the patient is capable, in the right to refuse treatment:

*‘You have the right to accept or refuse treatment that is offered to you, and not to be given any physical examination or treatment unless you have given valid consent. If you do not have the capacity to do so, consent must be obtained from a person legally able to act on your behalf, or the treatment must be in your best interests.’*

This raises an interesting contradiction to the common law since, if a child is considered *Gillick* competent, there appears to be a provision in the constitution, afforded legal protection by statute<sup>43</sup>, for them to refuse treatment.

### Children, consent to treatment and the European Convention on Human Rights

Subsequent to *Gillick* there have been challenges to a child’s right to receive advice or treatment on matters related to sexual health without their parents’ knowledge or

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<sup>40</sup> *Re P (Medical Treatment: Best Interests)* [2003] EWHC 2327 (Fam).

<sup>41</sup> Consent Toolkit. British Medical Association. 5<sup>th</sup> Ed. 2009. Available at [www.bma.org.uk](http://www.bma.org.uk)

<sup>42</sup> The NHS Constitution for England. January 2009. Available at:

[www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_093419](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093419)

<sup>43</sup> The Health Act 2009 (c.21)

consent, based upon Article 8 of the European Convention on Human Rights<sup>44</sup>, to which UK law must give effect under the Human Rights Act 1998<sup>45</sup>.

In *R (on the application of Axon) v Secretary of State for Health*<sup>46</sup>, a case with the confidential nature of the doctor-patient relationship at its centre, a parent's Article 8 'parental' rights, in this context to be included in discussions concerning sexual matters, including abortion, relating to minors for whom they have parental responsibility, were measured against the child's autonomous right to make such decisions for themselves. Silber J, upholding *Gillick*, concluded that:

*'...a parental right yields to the young person's right to make his own decisions when the young person reaches a sufficient understanding and intelligence to be capable of making up his or her own mind in relation to a matter requiring decision, and this autonomy of a young person must undermine any article 8 rights of a parent to family life.'*

Consequently, according to Silber J, there is no primacy afforded to the Article 8 rights of a parent; it is, instead, the Article 8 right of the child to confidentiality that succeeds.

The ruling in *Axon* represented a significant departure from the previously held European position established in *Nielsen v Denmark*<sup>47</sup> where a 12 year old boy was detained without foundation in a psychiatric unit at the behest of his mother through the exercise of her Article 8 'parental rights'. An action based upon an alleged breach of the child's Article 5 rights<sup>48</sup> was dismissed in the European Court of Human Rights (ECHR) largely on account of the broad definition attributed to parental rights under Article 8, and one which might well have supported Mrs Gillick in her earlier representations to the House of Lords:

*'Family life in the Contracting States encompasses a broad range of parental rights and responsibilities with regard to the care and custody of minor children. The care and upbringing of children normally and necessarily require that the parents or a single parent decide where the child must reside and also impose, or authorise others to impose, various restrictions on the child's liberty. Family life and especially the rights of parents to exercise parental authority over their children, having due regard to their corresponding parental responsibilities, is recognised and protected by Article 8 of the Convention.'*

The *Axon* case has attracted much legal commentary. With regards to the juxtaposition of the law in England and Wales and international human rights, Rachel Taylor eloquently observes that:

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<sup>44</sup> Convention for the Protection of Human Rights and Fundamental Freedoms. Council of Europe 1950. Article 8(1): 'Everyone has the right to respect for his private and family life, his home and his correspondence.'

<sup>45</sup> Human Rights Act 1998.

<sup>46</sup> *R (on the application of Axon) v Secretary of State for Health* [2006] EWHC 37 (Admin).

<sup>47</sup> *Nielsen v Denmark* [1989] 11 E.H.R.R. 175.

<sup>48</sup> Convention for the Protection of Human Rights and Fundamental Freedoms. Council of Europe 1950. Article 5: 'Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law.'

*'The decision in Axon is important both as an affirmation of Gillick principles after the HRA and as a confirmation of the duty of confidentiality owed to mature minors. Nevertheless, it is in its broader implications that the case is most likely to be influential. Silber J's analysis of the rights of parents over their children, following the HRA, is novel yet appealing. A 'dwindling' Article 8 parental right of parental authority is capable of allowing for the growing autonomy of children and of harmonising domestic and human rights law in this area.'*<sup>49</sup>

As an aside, in *Glass v United Kingdom*<sup>50</sup>, a case which was also heard in Strasbourg, the court upheld the Article 8 rights of the child to the physical integrity afforded by non-treatment without consent (in this case the consent of the mother). The treating Trust could, however, have sought the permission of the High Court to provide treatment and thus could have prevented an escalation of the action to the ECHR.

Article 8 framed similar legal argument in *Storck v Germany*<sup>51</sup> in which Article 5 rights were also engaged by the non-consensual detention and treatment of a 15 year old girl in a psychiatric facility. Both her detention and treatment were consented to by her father while the claimant was a minor and subsequently. The ECHR determined that the patient *did* have capacity to make her own treatment decisions and upheld her claim of unlawful detention in breach of Article 5 and unlawful treatment in breach of her right to physical integrity under Article 8. The State was unable to defend its actions based upon any overriding national interest<sup>52</sup>.

### United Nations Convention on the Rights of the child (UNCRC)<sup>53</sup>

The UNCRC entered into international law in September 2009, replacing and updating the Declaration of the Rights of the Child 1923<sup>54</sup>. It has been ratified by every member State of the United Nations, with the exceptions of Somalia and the United States; both countries have expressed an intention to become signatories to the Convention with the additional commitment of the US to optional protocols concerning the rights of children in relation to armed conflict<sup>55</sup> and child trafficking<sup>56</sup>.

The UNCRC is implemented under the auspices of the United Nations Committee on the Rights of the Child, and places a duty upon States to protect the best interests of

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<sup>49</sup> Rachel Taylor. Reversing the retreat from Gillick? *R (Axon) v Secretary of State for Health*. [2007] CFLQ 81.

<sup>50</sup> *Glass v United Kingdom* [2004] 1 F.L.R. 1019.

<sup>51</sup> *Storck v Germany* [2006] 43 E.H.R.R. 6.

<sup>52</sup> Convention for the Protection of Human Rights and Fundamental Freedoms. Council of Europe 1950. Article 8(2): 'There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.'

<sup>53</sup> Convention on the Rights of the Child. General Assembly of the Council of Europe 1989.

<sup>54</sup> Declaration on the Rights of the Child. International Save the Children Union. Geneva, 1923.

<sup>55</sup> Optional Protocol to the Convention on the Rights of the Child on the involvement of children in armed conflict. New York, 25 May 2000.

<sup>56</sup> Optional Protocol to the Convention on the Rights of the Child on the sale of children, child prostitution and child pornography. New York, 25 May 2000.



children across wide ranging socio-political issues. With respect to the rights of children undergoing medical treatment, decisions made on their behalf must be with their best interests in mind<sup>57</sup>:

*'In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.'*

Article 5 of the UNCRC speaks of the evolving capacities of the child to which the parents should have regard in the exercise of their duties in accordance with the Convention<sup>58</sup>. Here UK common law may be seen to be in contravention of a child's Article 5 rights but has yet to be tested in the post-*Gillick* era, possibly on account of the primacy of Article 2 of the European Convention<sup>59</sup>.

More recently, the proceedings of the Oviedo Convention<sup>60</sup> addressed the rights children to participate in treatment decisions in terms that are broadly commensurate with *Gillick* case law while again appearing to distinguish UK law from international human rights obligations to respect valid refusal of treatment:

*'Where, according to law, a minor does not have the capacity to consent to an intervention, the intervention may only be carried out with the authorisation of his or her representative or an authority or a person or body provided for by law. The opinion of the minor shall be taken into consideration as an increasingly determining factor in proportion to his or her age and degree of maturity.'*

In *Mabon v Mabon*<sup>61</sup> it was the child's UNCRC Article 12 right<sup>62</sup> to express their own opinions on matters that affect them, along with Article 8 of the European Convention that were engaged. Although not concerning medical *treatment*, the emerging importance of autonomous decision-making was illustrated, in this case in the context

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<sup>57</sup> Convention on the Rights of the Child. General Assembly of the Council of Europe 1989. Article 3(1).

<sup>58</sup> Convention on the Rights of the Child. General Assembly of the Council of Europe 1989. Article 5: 'States Parties shall respect the responsibilities, rights and duties of parents or, where applicable, the members of the extended family or community as provided for by local custom, legal guardians or other persons legally responsible for the child, to provide, in a manner consistent with the evolving capacities of the child, appropriate direction and guidance in the exercise by the child of the rights recognized in the present Convention.'

<sup>59</sup> Convention for the Protection of Human Rights and Fundamental Freedoms. Council of Europe 1950: Article 2 (1) 'Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.'

<sup>60</sup> Chapter II (Consent) Article 6(2). Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine. Council of Europe, Oviedo 1997.

<sup>61</sup> *Mabon v Mabon* [2005] EWCA Civ 634.

<sup>62</sup> Convention on the Rights of the Child. General Assembly of the Council of Europe 1989. Article 12(1): '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.'

of child custodial arrangements, by the Court of Appeal's decision to allow independent representation in the proceedings on behalf of the three older children.

Thorpe LJ defended the children's right to self determination *beyond* the intervention of the courts, declaring:

*'Unless we in this jurisdiction are to fall out of step with similar societies as they safeguard article 12 rights, we must, in the case of articulate teenagers, accept that the right to freedom of expression and participation outweighs the paternalistic judgment of welfare.'*

This case demonstrated good concordance between international human rights obligations and the directions contained in the Family Proceedings Rules 1991<sup>63</sup> that establish the right of children to:

*'...prosecute or defend, as the case may be, such proceedings without a next friend or guardian ad litem-*  
*(a) where he has obtained the leave of the court for that purpose; or*  
*(b) where a solicitor-*  
*(i) considers that the minor is able, having regard to his understanding, to give instructions in relation to the proceedings'*

### A Bill of Rights for the United Kingdom

In August 2008 the Joint Committee on Human rights published draft proposals for a Bill of Rights for the United Kingdom<sup>64</sup> to build upon the Human Rights Act 1998 while protecting rights under the European Convention. The new coalition government draws support for these proposals from both Conservative<sup>65</sup> and Liberal Democrat<sup>66</sup> members, although the Bill itself was not mentioned directly in the Queen's speech of 2010<sup>67</sup>.

Nevertheless, the committee stated its belief *'that there is a strong case for a Bill of Rights and Freedoms having detailed rights for children'* which, according to Carolyne Willow of the Children's Rights Alliance for England, unlike the Human Rights Act, looks set to give effect to the full ambit of children's rights as detailed in the UNCRC<sup>68</sup>:

*'We will remain vigilant and strongly resist any dilution of the Human Rights Act, which has brought essential protection for children in a variety of*

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<sup>63</sup> Family Proceedings Rules 1991 (SI 1991/1247), r 9.2A.

<sup>64</sup> A Bill of Rights for the UK? Twenty-ninth Report of Session 2007–08. Joint Committee on Human Rights. HL Paper 165-I; HC 150-I 2008.

<sup>65</sup> Cameron promises UK bill of rights to replace Human Rights Act. The Guardian, Monday 26 June 2006.

<sup>66</sup> Liberal Democrat Policy Paper 83: 'For the People, by the People' August 2007, paragraph 4.2.4.

<sup>67</sup> Available at: <http://www.number10.gov.uk/news/speeches-and-transcripts/2010/05/queens-speech-2010-2-50580>.

<sup>68</sup> Bill of Rights could strengthen the rights of children (press release). Carolyne Willow, Children's Rights Alliance for England, 20 May 2010. Available at: <http://www.crae.org.uk/news-and-events/press/bill-of-rights-could-strengthen-the-rights-of-children.html>.

*situations. However, the Human Rights Act was never designed to deliver children the scope and strength of rights in the Convention on the Rights of the Child. This Convention sets the international benchmark of human rights protection for children and this is what British politicians must now aspire to.'*

The joint committee concur in this view and have even ventured to suggest that '*children and young people should be included in the consultation on a Bill of Rights*'. As the Bill gathers momentum during the lifetime of the current Parliament it seems likely that the UNCRC will become increasingly cited in support of a child's right to self determination where their medical treatment is at issue.

### Research and children

When recruiting to clinical trials, it may be difficult to assert that participation will be in the best interests of a child if, for example, they are randomised to the control (placebo) arm of a double blind prospectively randomised phase III trial. Yet without such research the momentum of medical advances would inevitably be slowed, an outcome that would clearly be contrary to the best interests of patients, including children.

Where a child is considered to lack capacity to consent to participation in a clinical trial, the duty of consent falls to a person with parental responsibility. The Medicines for Human Use (Clinical Trials) Regulations 2004<sup>69</sup> set out the guiding principles for the recruitment of children, defined in Regulation 2 as less than 16 years of age, to pharmaceutical trials. In common law we have seen how children appear to have rather discretionary rights to refuse medical treatment; where clinical trials are concerned, and the child would otherwise be considered to be *Gillick*-competent, that right looks equally vulnerable:

7. The explicit wish of a minor who is capable of forming an opinion and assessing the information referred to in the previous paragraph to refuse participation in, or to be withdrawn from, the clinical trial at any time is *considered* (my emphasis) by the investigator.

13. Informed consent given by a person with parental responsibility or a legal representative to a minor taking part in a clinical trial shall represent the minor's *presumed* (my emphasis) will.

In terms of the international standard, the lengthy document produced by the *ad hoc* group of the European Commission, tasked with making recommendations regarding the conduct of research involving children, '*Ethical Considerations for Clinical Trials on Medicinal Products Conducted with the Paediatric Population*'<sup>70</sup> begins with the pretext that:

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<sup>69</sup> The Medicines for Human Use (Clinical Trials) Regulations 2004 Schedule 1 part 4. Statutory instrument No. 1031.

<sup>70</sup> *Ethical Considerations for Clinical Trials on Medicinal Products Conducted with the Paediatric Population*. Recommendations of the Ad hoc group of the European Commission 2008. Available at: [http://ec.europa.eu/enterprise/sectors/pharmaceuticals/files/eudralex/vol-10/ethical\\_considerations\\_en.pdf](http://ec.europa.eu/enterprise/sectors/pharmaceuticals/files/eudralex/vol-10/ethical_considerations_en.pdf)

6.1 As the child (minor) is unable to provide legally binding consent, informed consent must be sought from the parents/ legal representative on the child's behalf.

Notwithstanding the failure to distinguish the meaning of 'assent' relating to minors from 'consent' relating to adults, there is some reassuring and persuasive authority in this document pointing towards a power of veto to participation in trials resulting from a child's emerging autonomy:

7. The Clinical Trials Directive only requires that the minor's will be 'considered', however, although not a legal requirement, this document recommends that the investigator obtains assent in addition to informed consent of the legal representative. If the child's assent is not obtained, it is recommended that this be documented with *justification* (my emphasis) in the consent form which is signed by the parents / legal representative and investigator.

7.2 Every effort should be made to understand and respect differences of opinion between the child and his/her parents or legal representative. *Strong and definitive objections from the child should be respected* (my emphasis).

In *Simms v Simms*<sup>71</sup> the court considered whether to allow experimental treatment to proceed in two teenagers, one of whom was a minor and both lacking in capacity to consent, suffering from the incurable effects of Creutzfeldt Jacob disease. In the absence of any alternative treatment options, a best interests decision was made declaring treatment lawful since it posed little risk to the patients and, invoking *Bolam*<sup>72</sup>, was considered to be one which would be supported by a responsible body of medical opinion. In her *dictum*, however, Dame Butler-Sloss was careful not to rely too heavily on *Bolam* which she feared might impede the progress of clinical research:

*'The Bolam test ought not to be allowed to inhibit medical progress. And it is clear that if one waited for the Bolam test to be complied with to its fullest extent, no innovative work such as the use of penicillin or performing heart transplant surgery would ever be attempted'*

Dame Butler-Sloss justified her judgment by reference to European Convention rights under Article 2 and Article 8.

### Living organ donation

Ethically, it would be difficult to argue that organ donation from a living child would be in their best interests, save for the fact that they might derive some benefit either from the knowledge that they have saved the life of a parent or sib or the material advantages that might flow from that altruistic act.

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<sup>71</sup> *Simms v Simms* [2003] Fam 83.

<sup>72</sup> *Bolam v Friern Hospital Management Committee* [1957] 1 W.L.R. 582.

If it were left to the parents alone, providing consent to living organ donation on behalf of an incompetent minor would be likely to engage competing interests; imagine if the beneficiary of the organ were the same parent from whom consent was sought or the difficulties that might arise if a child refuses to donate an organ to the advantage of a sibling despite consent having been provided by a parent. The Human Tissue Act 2004<sup>73</sup> states that both the consent of the child, in so far as the child is competent to either consent or indeed refuse, and of a parent are required for living organ donation to go ahead:

(2) Subject to subsection (3), where the child concerned is alive, “appropriate consent” means his consent.

(3) Where—

(a) the child concerned is alive,

(b) neither a decision of his to consent to the activity, nor a decision of his not to consent to it, is in force, and

(c) either he is not competent to deal with the issue of consent in relation to the activity or, though he is competent to deal with that issue, he fails to do so,

“appropriate consent” means the consent of a person who has parental responsibility for him.

Furthermore, the Human Tissue Authority Code of Practice 2 demands that any decision on living organ donation from an incompetent minor must be made by a panel of the HTA<sup>74</sup> having sought court approval<sup>75</sup>.

## Conclusion

As ever, the law concerning consent to medical treatment in children continues to evolve, paralleling their accelerating maturity, and autonomy, in a changing world. In general, the law in England and Wales respects and upholds international human rights as defined by the European Convention and the UNCRC although conflicts occasionally arise between a child’s acknowledged right to self determination and the paternalistic welfare concerns of parents, or indeed the judiciary.

Children remain unable to refuse life saving treatment but what responsible State would casually allow children to forfeit life in the name of human rights? The new NHS constitution appears to be inconsistent with this position in law but awaits further examination in the courts. For the future, the proposed Bill of Rights for the United Kingdom promises to galvanise children’s rights in domestic law where, perhaps, the Human Rights Act has applied itself less diligently.

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<sup>73</sup> Human Tissue Act 2004 C.30

<sup>74</sup> Human Tissue Authority Code of Practice 2: Donation of solid organs for transplantation. Para 38(i): ‘A decision on a transplant must be made by an HTA panel if the donor is a child’. Available at: [http://www.hta.gov.uk/legislationpoliciesandcodesofpractice/codesofpractice/code2donationoforgans.cfm?FaArea1=customwidgets.content\\_view\\_1&cit\\_id=673&cit\\_parent\\_cit\\_id=669](http://www.hta.gov.uk/legislationpoliciesandcodesofpractice/codesofpractice/code2donationoforgans.cfm?FaArea1=customwidgets.content_view_1&cit_id=673&cit_parent_cit_id=669)

<sup>75</sup> Human Tissue Authority Code of Practice 2: Donation of solid organs for transplantation. Para 47: ‘Children can be considered as living organ donors only in extremely rare circumstances. In accordance with common law and the Children Act 1989 before the removal of a solid organ or part organ from a child for donation, court approval should be obtained.’ Available at: [http://www.hta.gov.uk/legislationpoliciesandcodesofpractice/codesofpractice/code2donationoforgans.cfm?FaArea1=customwidgets.content\\_view\\_1&cit\\_id=673&cit\\_parent\\_cit\\_id=669](http://www.hta.gov.uk/legislationpoliciesandcodesofpractice/codesofpractice/code2donationoforgans.cfm?FaArea1=customwidgets.content_view_1&cit_id=673&cit_parent_cit_id=669)

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