# PARENTS AND MEDICAL **PROFESSIONALS: CONFLICT,** COOPERATION, AND **BEST INTERESTS**

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# ABSTRACT

This paper seeks to engage with the ideas expressed by Professor Brazier in her commentary on the Charlotte Wyatt case and to develop contemporary analysis around parental rights, notions of best interests, and shared decision-making between parents and professionals. The article begins by setting the scene in relation to parental/professional conflict and frames the discussion in the context of medical decision-making. Parental rights are then explored before the analysis progresses to how the concept of best interests has recently developed. Finally, the article investigates the benefits of compromise, cooperation, and shared decision-making as the most effective method for resolving disputes concerning children.

Keywords: Consent, Children, Best Interests, Conflict, Parents

#### I. INTRODUCTION

Conflict between parents and healthcare professionals is not an infrequent occurrence.<sup>1</sup> In a medical context, the potential for dispute between clinicians and parents over treatment for children is both apparent and real, arising whenever questions are raised about the welfare of a child and what may or may not be in that child's best interests.<sup>2</sup> The majority of

<sup>\*</sup> Thanks are due to my colleague Dr Brigitte Clark and Dr Kevin Williams for their useful comments on an earlier draft of this paper. Thanks are also due to the journal's anonymous referees for their helpful suggestions.

<sup>&</sup>lt;sup>1</sup> See JB Moore and MF Kordick, 'Sources of Conflict Between Families and Health Care Professionals' (2006) 23 Journal of Paediatric Oncology Nursing 82. <sup>2</sup> *Re B (A Minor)* [1981] 1 WLR 1421.

the time parents and professionals agree about the best course of action, but sometimes they do not. If no agreement can be reached, the courts will be asked to settle the dispute. Interesting questions then surface about how the courts should make their decision and what factors should be taken into account when determining what is in a child's best interests.

This paper seeks to engage with the ideas expressed by Professor Brazier in her commentary on the Charlotte Wyatt case, in which she developed analysis around parental rights, notions of best interests, and shared-decision making between parents and professionals.<sup>3</sup> The article begins by setting the scene in relation to parental/professional conflict and frames the discussion in the context of medical decisionmaking. Parental rights are then explored before the analysis progresses to how the concept of best interests has recently developed. Finally, the article investigates the benefits of compromise, cooperation, and shared-decision making as the most effective method for resolving disputes concerning children.

#### II. PARENTAL/PROFESSIONAL CONFLICT

Medical disputes between parents and doctors are regularly brought into the public eve, mainly because they often concern matters of life and death; medical professionals wishing to take steps which would effectively end a child's life where the parents feel that more of an effort should be made to sustain that life and, vice versa, parents wishing to refuse treatment that may result in a child's life expectancy being diminished where the doctors feel there is a reasonable chance that it could be extended. The first of these scenarios is especially difficult to deal with and raises issues different from the second. It involves parents insisting that doctors act contrary to their professional judgement, something which the law has said quite firmly they may not do.<sup>4</sup> Yet, judicial endorsement of professional judgement is perhaps not that clear-cut. It was said by Lord Woolf MR in R v Portsmouth Hospitals NHS Trust, ex parte Glass that the refusal of the courts to dictate appropriate treatment to a medical practitioner is subject to the power which courts always have to take decisions in relation to a child's best interests.<sup>5</sup> It could be that the courts may decide to opt for a second opinion or perhaps even order the transfer of care. Either way, what is clear is

M Brazier, 'An Intractable Dispute: When Parents and Professionals Disagree' (2005) 13 Med L Rev 412.

A doctor cannot be compelled to provide treatment that he believes is not in a patient's best interests. R (on the application of Burke) v GMC [2005] EWCA Civ 1003 at [31], [50–52]. 5 [1999] 3 FCR 145, CA at 148.

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that the courts will not order an unwilling doctor to perform treatment against her wishes, which is a major obstacle for parents. Equally, where parents are demanding treatment, the often unspoken issue of resource allocation needs to be considered. Where there is convincing evidence that a child will not only fail to get better, but also that the treatment being provided is conferring no benefit, then no matter how disturbing it may seem there is at least an argument that the resources being used to sustain a life in this state could be better utilised elsewhere, in patients where there is a realistic chance of improvement. Judges and scholars alike tread carefully around this issue, but it is undoubtedly considered, even if not overtly, by the courts in their decision-making process.<sup>6</sup> Finally, in cases where parents are attempting to compel doctors to administer treatment, quality of life arguments are more likely to be raised. These are never easily resolved. Coverage at the time of the cases of the conjoined twins Mary and Jodie,7 Charlotte Wyatt,8 Hannah Jones,9 and Baby OT<sup>10</sup> illustrates that once cases such as these enter the headlines, public support is gathered for the plight of the parents, but seldom are facts reported in their entirety and very little consideration is given to the difficult position that health care professionals find themselves in and also the problems faced by the courts.<sup>11</sup>

Confronted with opposing views from both parties to the dispute, the court must engage in a delicate balancing act, weighing the respective strengths and weaknesses of the conflicting opinions to reach its own conclusion as to the best way to promote the welfare of the child. Judges in England have usually favoured an interventionist approach in circumstances where parents have refused treatment that is deemed necessary to save the life of a minor. To this end, erring on the side of preservation of life, certainly where children are involved, is justified.<sup>12</sup>

See A Pedain, 'Doctors, Parents, and the Courts: Legitimising Restrictions on the Continued Provision of Lifespan Maximising Treatment for Severely Handicapped, Non-Dying Babies' (2005) CFLQ 535.

Re A (Children) (Conjoined Twins: Surgical Separation) [2001] Fam 147.

<sup>&</sup>lt;sup>8</sup> Re Wyatt (A Child) (Medical Treatment: Parent's Consent) [2004] EWHC

 <sup>&</sup>lt;sup>10</sup> Re OT [2009] EWHC 633 (Fam); [2009] EWHC 633 (Fam).
 <sup>10</sup> Re OT [2009] EWHC 633 (Fam); [2009] EWCA Civ 409.

<sup>&</sup>lt;sup>11</sup> The GMC advises clinicians 'complex and emotionally demanding decisions may have to be made' and that 'it can be very difficult to judge when the burdens and risks, including the degree of suffering caused by treatment, outweigh the benefits of the treatment to the patient'. See GMC, 'Treatment and Care Towards the End of Life: Good Practice in Decision-Making' (2010) at 45–47. <sup>12</sup> See Re S (A Minor) (Medical Treatment) [1993] 1 FLR 377; Re O (A Minor)

<sup>(</sup>Medical Treatment) [1993] 2 FLR 149; Camden LBC v R (A Minor) (Blood Transfusion) [1993] 2 FLR 757.

Nonetheless, this is not the only consideration. There is also the question of quality of life, which to some is equally, if not more, important, An added layer of complexity is immediately added to the courts' job as it is sometimes difficult to draw a finite line between preservation and quality. In some cases, it will be relatively easy for the courts to identify the two arguments as being distinct. For example, in the case of Re T, in which the parents of a young boy refused to consent to a liver transplant on his behalf, it was clear that the main concern of his parents was with his quality of life. The court accepted this argument and in doing so recognised that even if preservation of life was perceived to be the dominating principle, pain and discomfort may be caused to the child in the future which would not be in his best interests.<sup>13</sup> This case represents a rare example of the courts siding with parents over medical professionals, but this may have had more to do with its particular facts than anything else. T's parents were both health care professionals who were experienced in caring for sick children, and the child had also undergone earlier unsuccessful surgery which had caused him pain and distress. Also, pragmatically, at the time of the hearing, the family had moved to another country and so not only would the court have had to grant an order authorising the transplant, it would also have had to grant an order requiring the family to return to England in order for the operation to go ahead. In other cases, however, the ostensibly competing positions of quality versus preservation will not be as clear-cut; there may sometimes be an overlap when attempting to reconcile the opposing arguments. Thus, in Re A,<sup>14</sup> the parents tried to argue that the quality of Jodie's life would be compromised if the separation was allowed to go ahead; the operation would render her disabled, in pain, unable to walk, and possibly incontinent. The Court of Appeal disagreed and said that Iodie had a reasonable prospect of a decent quality of life and therefore took the view that allowing the separation to go ahead was lawful as it was in her best interests.<sup>15</sup> In adopting this line of reasoning, the Court of Appeal's initial focus on quality of life led to the conclusion that preservation of life was necessary.

It is clear that the courts are faced with a difficult task. When a dispute over a child's medical care reaches them, they have to examine with great care and sensitivity the arguments from both sides, for if they are too quick to displace parental views with those of their own, or of the medical professionals, any belief that the law provides

Re T (A Minor) (Wardship: Medical Treatment) [1997] 1 WLR 242. See A Bainham, 'Do Babies Have Rights?' (1997) 56 CLJ 48.

<sup>&</sup>lt;sup>14</sup> *Re A*, above, n 7. <sup>15</sup> *Re A*, above, n 7, at 182–3.

adequate protection for parental rights to make decisions about their children's healthcare becomes instantly questionable.

#### III. CIRCUMVENTING PARENTAL RIGHTS

Parents are under a duty in law to provide proper medical care for their children.<sup>16</sup> The corollary of this is that they have the right to consent to certain forms of medical treatment on their children's behalf. Yet, what at first glimpse appears to be a wide-range of decision-making powers bestowed upon parents by the law is, in fact, rather limited.<sup>17</sup> Parents can only consent to treatment that is in the best interests of their child and may not ordinarily refuse treatment that may jeopardise their child's long-term welfare. So, when it comes to medical decision-making, the law allows parents to make certain decisions, provided those decisions accord with the courts' conception of best interests.<sup>18</sup> If a decision does not meet with this approval, the courts will step in and substitute their own judgment for that of the parent. In this sense, a partial right is provided with a protective paternalistic undercoat.19

It has been suggested that no one knows a child better than its parents and, when viewed this way, the argument that it is they who are best placed to make a decision about what is truly in their child's best interests is not implausible.<sup>20</sup> Similarly, if the law is to take seriously views about freedom of religion, expression, and the right to respect for private and family life, it must attach genuine significance to medical decisions which are underpinned by those values, values which the English courts have only ever tipped their hats to in the evolving case law.<sup>21</sup> Despite this, judges have recognised that the danger in characterising parental views as being sacrosanct is that

<sup>&</sup>lt;sup>16</sup> Children and Young Persons Act 1933, s 1 (1), s 1 (2) (a).

It is generally accepted in English law that parental rights exist only insofar as they are necessary for the parent to fulfil their duty to care for the child. See Gillick v West Norfolk and Wisbech Health Authority [1986] AC 112 at 184–5. <sup>18</sup> For discussion of the scope and limits of parental rights see A Bainham, *Chil*-

dren: The Modern Law (3rd edn Jordans, Bristol 2005); M Freeman, 'The Right to Responsible Parents' in J Bridgeman, H Keating and C Lind (eds),

<sup>Right to Responsible Parents' in J Bridgeman, H Keating and C Lind (eds),</sup> Responsibility, Law and the Family (Ashgate, London 2008).
<sup>19</sup> For critique see A Bainham, 'Is Anything Now Left of Parental Rights?' in R Probert, S Gilmore and J Herring (eds), Responsible Parents and Parental Responsibility (Hart, Oxford 2009).
<sup>20</sup> Hedley J acknowledged this in Re Wyatt (A Child) (Medical Treatment: Parent's Consent) [2004] EWHC 2247 at [34].
<sup>21</sup> See, for example, the ease with which the courts overruled the refusal of blood transferiors in the Johowh's Witnessen access above a 12 See above.

blood transfusions in the Jehovah's Witnesses cases, above, n 12. See also the cases cited below in n 41.

those views may be projected onto their children at a point in their lives when they are not in a position to make their own mind up about what is best for them. It is important, then, for the law to retain the power to override certain parental decisions where the welfare of a child is compromised.<sup>22</sup> The important point though, is that intervention from the courts ought only to be regarded as the exception rather than the rule, and there should be a genuine reluctance to interfere with the reasonably held views of the parents. To this end, there are safeguards in place to limit the powers of the court. Where a court is considering whether or not to make one or more orders under the Children Act 1989 with respect to a child, it cannot make the order or any of the orders unless it considers that doing so would be better for the child than making no order at all.<sup>23</sup> Consequently, in practice, the majority of parental views about medical treatment are actually respected and only on rare occasions are they challenged and overturned. If, however, an exceptional case does reach court, it becomes crucial, in order for the law to maintain its integrity, that intervention is justified on the correct basis-that of the best interests of the child. This strikes at the very heart of the legal debate: the tension is not so much whether the courts can override parental views, because it is clear they can, and will; rather the key legal question focuses on what is meant by best interests as a justification for agreeing with, or rejecting, the views of parents or clinicians. Amid a difference of opinion between the two, if the courts are too quick to view best interests from a narrow medical perspective, it may give the impression that they are doing nothing more than providing unquestioning support for medical paternalism. It is this criticism that led Professor Brazier to query whether best interests is little more than an 'empty mantra'.<sup>24</sup>

# IV. BEST INTERESTS: SOMETHING OLD, SOMETHING NEW

Traditionally, best interests was dictated by the medical profession. The Bolam test, lifted from the law of negligence,<sup>25</sup> was also used by the courts to resolve disagreements about appropriate medical treatment where adult patients were unable to consent or refuse for themselves;

<sup>&</sup>lt;sup>22</sup> It should be noted that it is the courts who have the authority to override decisions of parents, not the doctors. Glass v United Kingdom (61827/00) [2004] 1 FLR 1019.

<sup>&</sup>lt;sup>23</sup> Children Act 1989, s 1 (5). Where proceedings are initiated outside the Children Act 1989, for instance if the inherent jurisdiction of the court is invoked, this does not apply. <sup>24</sup> Brazier, above, n 3 at 415.

<sup>&</sup>lt;sup>25</sup> Bolam v Friern Hospital Management Committee [1957] 1 WLR 582.

this effectively translated into something which said that if a responsible body of medical opinion thought the treatment to be in the patient's best interests, the law would agree.<sup>26</sup> Bolam's wings have since been clipped across a range of areas in medical law, and best interests has been taken to mean something more than a simple medical assessment. Insofar as children are concerned, a more holistic view of best interests was introduced by the Children Act 1989, which includes a range of nonexhaustive factors that must be taken into account when determining the welfare of a child.<sup>27</sup> The courts themselves have also recognised that best interests is not one-dimensional and encompasses 'medical, emotional and all other welfare issues'.<sup>28</sup> More recently, the legislature has had the final word in respect of adults who lack capacity (and, where relevant, young people over the age of sixteen). The Mental Capacity Act 2005 now sets out a range of factors which must be considered by the decision maker when assessing best interests.<sup>29</sup> These statutory criteria in the Mental Capacity Act 2005, whilst not directly applicable to children under the age of sixteen, may have some influence on how the courts look at cases involving younger children.<sup>30</sup> Yet, there is still doubt about the extent to which the courts are truly prepared to look

<sup>&</sup>lt;sup>26</sup> F v West Berkshire Health Authority [1990] 1 AC 1.

<sup>&</sup>lt;sup>27</sup> Children Act 1989, s 1 (3). The court must consider (a) the ascertainable wishes and feelings of the child concerned (considered in the light of his age and understanding); (b) his physical, emotional, and educational needs; (c) the likely effect on him of any change in his circumstances; (d) his age, sex, background, and any characteristics of his which the court considers relevant; (e) any harm which he has suffered or is at risk of suffering; (f) how capable each of his parents, and any other person in relation to whom the court considers the question to be relevant, is of meeting his needs; (g) the range of powers available to the court under this Act in the proceedings in question. It should be noted that this checklist is only mandatory in the circumstances set out in s 1 (4) of the Act. It is not mandatory where there is a specific issue for the court to decide but which is not contested by the parents. Furthermore, the checklist is not mandatory where the inherent jurisdiction is invoked. For critique of this welfare test, see M Woolf, 'Coming of Age? - The Principle of 'The Best Interests of the Child' (2003) 2 EHRLR 205. 28

<sup>&</sup>lt;sup>28</sup> Re A (Mental Patient: Sterilisation) [2000] 1 FLR 549 at 555.

<sup>&</sup>lt;sup>29</sup> Mental Capacity Act 2005. S 4 (4) states that the decision maker must permit and encourage participation in the decision-making process. S 4 (6) places an obligation on the decision maker to consider, so far is as reasonably ascertainable, (a) the person's past and present wishes and feelings, (b) the beliefs and values that would be likely to influence the decision if the person had capacity, and (c) the other factors that the person would be likely to consider if he were able to do so. S 4 (7) (c) also states that the views of anyone engaged in caring for the person or interested in his welfare must be taken into account. For discussion, see M Donnelly, 'Best Interests, Patient Participation and the Mental Capacity Act 2005' (2009) 17 Med L Rev 1.
<sup>30</sup> Precisely how much influence the Mental Capacity Act 2005 will have on the

<sup>&</sup>lt;sup>30</sup> Precisely how much influence the Mental Capacity Act 2005 will have on the courts when it comes to cases involving children is unclear. However, it is arguable how relevant the factors are to a child who has never had capacity and is incapable of expressing a view.

beyond the medical evidence in assessing best interests. Returning to the conjoined twins, the legitimate reservations held by the parents about whether the proposed separation was in fact in Jodie's best interests were perhaps not given the attention they deserved.<sup>31</sup> Are parents not entitled to be concerned about agreeing to a medical procedure which may cause their child to become incontinent, possibly condemn them to an existence dependent upon medical care and potentially leave them psychologically damaged in the knowledge that their survival caused the inevitable demise of their sibling? The exceptional circumstances of the case may have rendered these concerns ill-founded to some, but they were not wholly unreasonable. The social and emotional factors were of significance in the quality of life assessment, but the courts allowed Jodie's medical outlook to dominate their reasoning. This poses the question: are the non-medical factors merely a smokescreen for what is fundamentally still a judgment grounded in medical tenets?32

The attraction of best interests is that it is a flexible mechanism that can be used by the courts in a variety of different ways to justify a decision. The courts enjoy a wide margin of appreciation where, on the one hand, they can view the concept in a narrow sense to justify a particular outcome and, on the other, they can view it from a much wider perspective in order to support a different result. This discretion is not necessarilv a bad thing, but it does make it difficult to predict which view will prevail in a given case. A further criticism is that it sets the threshold for intervention at too low a level, allowing the courts too much freedom to circumvent parental opinion. For this reason, other tests have been mooted, such as that of 'intolerability', which would give greater credence to parents' views with the courts only being allowed to interject where the 'parents' wishes militate against the interests of the child.'33 In Wyatt, if the intolerability approach had been used, the courts would only have been allowed to override the parents' wishes if their decision would have made continuing Charlotte's existence intolerable. This is a different and higher threshold for legitimising court action than currently operates under best interests, but it is not without problems. The question that remains is what might intolerability actually mean where the infant has little or no capacity to appreciate the quality of its existence? The ability of a child to experience pain does not, per se, equate to an ability to judge what is intolerable, because the

<sup>&</sup>lt;sup>31</sup> *Re A*, above, n 7 at 172.

<sup>&</sup>lt;sup>32</sup> For further discussion, see M Brazier and E Cave, Medicine, Patients and the Law (Penguin, London 2011) at 428–34. <sup>33</sup> Brazier, above, n 3 at 415. The test of intolerability was raised in *Wyatt*,

above, n 8, and rejected.

ability to judge that demands a more extensive cognitive process and increased level of awareness, enabling one to consider a range of different factors. Intolerability, as both a concept and a legal test, is vague and unpredictable and in light of the factors which need to be considered under the Children Act 1989 (and the Mental Capacity Act 2005 if it is to have any influence), it would seem that intolerability is merely one aspect of a much broader assessment of a child's welfare or best interests.<sup>34</sup>

The courts have always made explicit reference to the balancing act that must be performed when determining best interests.<sup>35</sup> Hedley I, in Wvatt, stressed that whilst there was a presumption in favour of preserving life, this was not absolute and could be rebutted if there was sufficient evidence to indicate that life-sustaining treatment would actually work to the detriment of the child.<sup>36</sup> A similar balancing exercise was conducted with painstaking care by Parker I in the recent case of Baby OT.<sup>37</sup> Baby OT was diagnosed as suffering from a mitochondrial condition of genetic origin within three weeks of being born. The condition caused him to suffer severe and irreparable brain stem damage which left him incapable of breathing unaided. His hospital carers applied to the court for a declaration that it would be lawful to discontinue ventilation as the nature of the life-sustaining treatment was increasingly invasive, was causing him immense distress, and was not going to make him better. Parker J acknowledged that the law demanded of her a balancing exercise in which she set out clearly the burdens of continuing the treatment. These included, *inter alia*, the irreversible nature of Baby OT's brain damage and the negative effect that this would have on his continued existence, the fact that the treatment needed to sustain him was invasive, that Baby OT was clearly distressed and felt pain as a result of his condition and continued treatment, that his suffering outweighed his brief moments of pleasure, and, finally, that he had lived all bar three weeks of his life in a paediatric intensive care unit which was unnatural and which would continue in the future.<sup>38</sup> On the other side, Parker J took into account such things as the love that Baby OT's parent had for him, the likelihood that the baby experienced some comfort from his parents and carers, signs of response, emotion and happiness being sometimes displayed from the child, and that he would continue to receive superb medical treatment

<sup>&</sup>lt;sup>34</sup> See above nn 27 and 29.

<sup>&</sup>lt;sup>35</sup> See Re J (A Minor) (Wardship: Medical Treatment) [1991] Fam. 33; Re A, above n 28 at 560.

<sup>above n 28 at 560.</sup> *Re Wyatt (A Child) (Medical Treatment: Parent's Consent)* [2004] EWHC 2247 at [38]–[39]. *Re OT*, above, n 10. *Re OT* [2009] EWHC 633 (Fam) at [110]–[135].

which would extend his life, a life which was of incalculable value in itself.<sup>39</sup> After considering all of these points, she granted the declaration sought from the hospital.<sup>40</sup> This contemporary example of the process which the courts go through makes one thing abundantly clear: no matter how hard the courts try to give the impression that they are willing to consider a wider range of social and emotional factors in their best interests' assessment, they find it incredibly difficult to distance themselves from medical opinion. Furthermore, as meticulous as this balancing act may have been, legitimate questions still exist about what is truly meant when judges, doctors, or others talk about carefully 'balancing' the various factors that form part of the best interests assessment. The reality is that many of the factors are actually impossible to measure or compare. How can a child's pain be weighed in the same scale as their parents' wishes? Specific factors also seem to be given precedence. Thus, despite it being a concept open to multiple interpretations, in cases such as Wyatt and Baby OT, futility may well have been the true reasoning behind the courts' decision in the sense that the treatment would not have brought about any significant improvement in the patient's prospects or alleviate pain and discomfort. Some may disagree that this should be treated as the overriding consideration and there may be some merit in that argument, but the legal reality is that it is happening, at least insofar as life and death cases are concerned. That does not mean to say that it is only in life and death cases that best interests raises difficult questions. On the contrary, disputes which do not concern matters of life and death have challenged the courts and it is arguably in these cases that we begin to see whether or not we truly have moved away from a medical interpretation of best interests.<sup>41</sup>

Consider the example of a live organ transplant between siblings.<sup>42</sup> It is widely accepted that those responsible for overseeing transplants, as well as those who actually perform the surgery, have effectively rejected the possibility of such procedures involving minors as donors taking place, at least insofar as non-regenerative tissue is concerned.43

<sup>&</sup>lt;sup>39</sup> *Re* OT, above, n 38 at [136]–[145]. <sup>40</sup> *Re* OT, above, n 38 at [110]–[135].

<sup>&</sup>lt;sup>41</sup> See Re C (A Child) (Immunisation: Parental Rights) [2003] EWCA Civ 1148; Re J (A Minor) (Prohibited Steps Order: Circumcision) [2000] 1 FLR 571.

<sup>&</sup>lt;sup>42</sup> See for recent discussion B Lyons, 'Obliging Children' (2011) 19 Med L Rev 55. 43

Principle 4 of The World Health Organisation's Guiding Principles on Human Organ Transplantation (1994) states that there ought to be a complete ban on using minors as organ donors for non-regenerative tissue. Accordingly, many doctors would not even consider such a procedure. Yet, it is clear that the Human Tissue Authority (HTA) does not completely envisage non-regenerative transplants involving minors as being unlawful. Code 2 of the HTA states that 'children can be considered as living organ donors only

However, the following hypothetical scenario raises some interesting points. Imagine identical same-sex twins who have just reached the age of ten, one of whom has been diagnosed with a serious kidney condition and placed on the transplant list, the other who possesses two healthy kidneys. The latter child offers to be a live donor. For the purposes of this example, let us say that the twins are found not to be *Gillick* competent.<sup>44</sup> Parent one agrees that the transplant should go ahead, but parent two does not.<sup>45</sup> As unlikely as it would be in practice, both the doctors and the Human Tissue Authority support the view of parent one and they are also satisfied that the proposed treatment has not been a result of coercion and that no money has changed hands.<sup>46</sup> Notwithstanding the green light from the professionals, the parental disagreement causes the matter to be referred to court. How would the courts approach the balancing exercise in this situation? Would we see a more pragmatic assessment of best interests than we have seen before in cases involving regenerative tissue, or would the courts retreat to the safety of medical best interests?<sup>47</sup> If they were to adopt this approach, the balancing act would still not be easy. Medically, there is no benefit whatsoever to the donor child; in actual fact, the surgery would positively expose him to an increased risk of harm but, on the other hand, the donee would receive the benefit of a new kidney and therefore a much longer and healthier life. Medically, therefore, it is without doubt in the recipient's best interests, but the same cannot be said of the donor. It would be interesting to see which way the courts would go here.

Clearly the scenario raises a number of interesting points about how a court can apply a best interests test where two children are involved.<sup>48</sup> Would both children be the subjects of the court application in the

in extremely rare circumstances'. This will only be authorised after relevant parental consent has been obtained under the Human Tissue Act 2004, s 2 (3) and the case has been referred to, and approved by, an independent HTA panel. Court approval must now also be obtained before the procedure can go ahead (Code 2, para 47). <sup>44</sup> *Gillick*, above, n 17.

<sup>&</sup>lt;sup>45</sup> See above, n 43. Ordinarily consent would only be needed from one of the parents for medical treatment to go ahead. Where there is a disagreement between the two over a seriously invasive procedure, particularly where it is of no medical benefit to the child such as this, it seems the case must be referred to the court. See Re J, above, n 35. 46

In all probability, the major obstacle in this scenario would be that the doctors did not believe it to be in the donor twin's best interests and no one can require a doctor to provide treatment that he/or she does not feel is warranted. See above nn 4 and 5.

In England, see *Re Y (Mental Patient: Bone Marrow Donation)* [1997] Fam 110; in America, see *Strunk v Strunk* 445 SW 2d 145 (Ky, 1969).

<sup>&</sup>lt;sup>48</sup> Some of these questions have been raised before and were starkly illustrated in Jodie and Mary's case. Re A, above, n 7.

case, or just the donor? If it is the latter, it would surely have to be his best interests that took precedence in deciding whether or not to authorise the procedure. If, however, both children were the subjects of the application, it would not be that straightforward. Either way, this author tentatively suggests that the courts would be unlikely to authorise the procedure and this is mainly because two sets of competing interests are at stake. The court would have to resolve this by favouring one over the other and it would seem that the mere *potential* for extending and preserving one life does not outweigh the significant risk of harm that would be caused to the other. That being said, a completely different view may be taken which would certainly not be unreasonable. 'Emotional' and other 'welfare' issues may come to the fore, encompassing such things as how the donor may be affected psychologically if his brother dies as a result of him not being allowed to donate, how it may alter the relationship between him and his parents in the future and how, if indeed at all, the procedure will impact upon his current and future health, lifestyle and career. These considerations bear a striking resemblance to those which formed an integral part of the court's pragmatic assessment of best interests in Re Y in which a bone marrow transplant was allowed to go ahead where the donor was a suitable match.<sup>49</sup> Thus. despite a clear reticence from the courts to place great weight on 'wider' considerations, it is evident that they can, and will, if they feel it is warranted in the given circumstances of a particular case.

There is also a further dimension to best interests which needs considering: the views of the child must be taken into account. This is easier said than done. Disputes will not always involve infants too young to have any (even imputed) views of their own. The courts may be faced with a slightly older, albeit not Gillick competent, child. The exact weight that the courts place on these views will understandably fluctuate and there may be a justifiable reluctance on the part of a judge to attach any great significance to the views of an older child who is found not to be able to sufficiently appreciate the nature and consequences of his or her actions. But regardless of that, it seems clear that both the past and present wishes of a child should be of some relevance.<sup>50</sup> This ought to be

Re Y, above, n 47. Here the courts sanctioned a bone marrow donation from a mentally incapacitated adult patient to her elder sister. The courts concluded that the transplant was in the mentally ill sister's best interests because if her other sister died, this would have a profound effect on her mother who would no longer be able to devote the same amount of care and attention to her in the future. This case needs to be treated with caution though. It was stressed that its value as a precedent was limited and that the outcome may not have been the same had the case involved more intrusive surgery. See D Feenan, 'A Good Harvest' (1997) 9 CFLQ 305.

particularly relevant in cases which do not involve matters of life and death and so, in the organ transplant scenario above, based on the factors listed in the Children Act 1989, the views of both children should be subject to careful scrutiny. If they were both in support of the procedure going ahead, that should be an important factor in favour of the courts authorising the operation. If one objects, that should also be significant. It is trite that children's views should not be determinative, but they must be heard, and be seen to be heard, in the decision-making process.<sup>51</sup>

Best interests will no doubt continue to evolve by building on the existing principles in domestic legislation and case law. It may well be that in the future parental perspective is given more weight, and certainly in some cases that would be desirable. On the other hand, the courts may adopt a more flexible approach to best interest, recognising that there are no hard and fast rules for determining where a child's best interests lie. One consequence of this, as noted previously, is unpredictability. This has implications for medical practitioners who, in their treatment decisions, will be left to second guess in which cases the courts will place greater emphasis on wider social and quality factors at the expense of medical considerations. This could be something that the courts are anxious to avoid and, as such, maintaining a preference for medical best interests, from a practical standpoint if nothing else, may be the preferable course of action.

### V. PARENTS AND PROFESSIONALS: A RELATIONSHIP OF MUTUAL COOPERATION

There will always be rare and exceptional cases which undoubtedly call for court involvement because the dispute cannot be settled in any other way, Re A being a classic example.<sup>52</sup> But the issues will not always be that stark and, with this in mind, it is important that, wherever possible, parents and medical professionals are encouraged to work together to sort out any differences before resorting to the law. Indeed, Brazier emphasises the importance of partnership of care between parents and professionals. Yet, she warns that where that partnership fails, it may well be that there is no alternative way to resolve a dispute other than in the formal setting of a court.<sup>53</sup> Thus, it is crucial that partnership of care is allowed to flourish in clinical practice.

 <sup>&</sup>lt;sup>51</sup> See M Donnelly and U Kilkelly, 'Child-Friendly Healthcare: Delivering on the Right to be Heard' (2011) 19 Med L Rev 27.
 <sup>52</sup> *Re A*, above, n 7 at 171.
 <sup>53</sup> Brazier, above, n 3, at 418.

In contemporary medicine, more and more emphasis is being placed on shared-decision making and partnership care. It is no longer acceptable for doctors to make decisions for patients without any consultation as to the available options and the risks and benefits attendant upon each. This practice naturally extends to involving parents in treatment decisions about their children. If there is a difference of opinion between doctors and parents, the majority of the time, as is the case in everyday life, a favourable solution can be reached by compromise and reason. If parents are shown respect, they will give respect and, more often than not, no matter how heart-wrenching the decision may be, will be prepared to listen to what the medical professionals have to say about the effectiveness of the various treatment options for their child.54

This relationship of mutual trust and respect develops from honesty, transparency and good communication. If utilised correctly, these can be effective tools for reaching a desirable outcome in a range of cases that involve not only those disputes which concern younger children, but also older ones. Take, for example, the recent case of Hannah Iones.<sup>55</sup> Hannah was thirteen years old and said to be Gillick competent. She suffered from a critical heart condition and healthcare professionals initially proposed a heart transplant on the basis that it was in her best interests. Hannah refused. Rather than supporting the medical professionals, her parents took the unusual step of agreeing with her. This caused the medical professionals to consider invoking care proceedings, plans which they eventually abandoned. Had the medical professionals maintained an intransigent stance, and had Hannah been taken into care, it seems highly probable that the local authority could have applied to the court to exercise its inherent iurisdiction and authorise the transplant against Hannah's wishes.<sup>56</sup> The medical team opted to abandon this course of action, instead deciding to respect the wishes of Hannah and her parents. Did the medical professionals' pacifying approach lead to the tragic outcome which many anticipated? No-it was reported later in the year that Hannah had eventually changed her mind and agreed to be placed on the transplant

<sup>54</sup> For discussion, see GMC, '0-18 Years: Guidance for All Doctors' (2007) at [1]–[21]. <sup>55</sup> See Heywood, above, n 9.

<sup>&</sup>lt;sup>56</sup> See Re M (A Child) (Refusal of Medical Treatment) [1999] 2 FLR 1097. Whilst the procedure was authorised in Re M against the child's wishes, it is difficult to say with certainty that the same would have happened if the Hannah Jones case had made it as far as court. M was an emergency case with no history of the condition, whereas Hannah had been receiving care for her condition for some time. Equally, her objections were based not on religious beliefs, but on a quality of life assessment, so it may have been that her views were taken more seriously.

list.<sup>57</sup> Of course, it could have gone differently, and there is always a problem with the benefit of hindsight, but nonetheless there is still a lesson to be learned here; recourse to formal legal proceedings can sometimes be counterproductive. Asking the court to authorise treatment against the wishes of Hannah and her parents would only have created further tension in a situation that was already delicately poised. Rather than alienating the patient and her family, in opting to respect their perceptions about important quality of life arguments, the professionals would have instilled a greater feeling of trust and confidence between the parties. This is not to suggest that the medical professionals cannot work together with parents and children to gently persuade them that their advice is sensible, but it is clear that this is much more about shared-decision making than usurping. Persuasion was probably a tactic employed with great effect in Hannah's case because of the cooperation between carers and parents, but this might not necessarily have been the case had the original confrontational stance been sustained.

Resolving disputes requires that parents are heard and so too the care team. This is not just the immediate surgeons or physicians, but also the wider team, including the nursing staff and other carers, who spend considerable time with sick children. It is these people who often develop a rapport with infants and begin to get a feel for any pain and suffering that they may be going through and indeed any sense of enjoyment they get out of life.

### VI. CONCLUSIONS

The potential for disagreement between parents and medical professionals when it comes to healthcare decisions about children has been a perennial problem in the evolution of medico-legal jurisprudence and, given that there will always be grounds to question what is in a child's best interests, this threat continues to exist. Where parents see treatment being withheld from their sick child which in their eyes is necessary to save its life, they will understandably voice concern; conversely, where medical professionals think they can offer treatment that will save and prolong life, they are unlikely to allow parental objections to go unchallenged. However, court proceedings are unpleasant and financially and emotionally costly, so recourse to the law should be the last resort and reserved for the most serious of cases where the dispute is patently intractable.

<sup>&</sup>lt;sup>57</sup> M Weaver, 'Right-to-Die Teenager Hannah Jones Changes Mind About Heart Transplant' *The Guardian* (21 July 2009).

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Even though compromise is the best way to resolve disputes, sometimes it will not be possible and judicial input will be required. When this happens, perhaps one should not be too critical of any decision taken by the courts and recognise that they are faced with a thankless task of having to adjudicate in a forum which requires a more pragmatic than academic perspective. They can weigh up the advantages and disadvantages of each possible course of action, but in the end they have to make a decision. The best interests test is a flexible mechanism that has allowed them to do this, although it does not follow that the courts are immune from criticism for the manner in which they have approached the balancing exercise in the past. It is clear that, in the majority of cases, medical factors have taken precedence and the likelihood is that they will continue to do so. It may be that this approach is the most pragmatic, but that does not necessarily mean it is correct or, moreover, that it will be viewed as being correct in everyone's eves. In certain situations, the courts may place the emphasis incorrectly which, in some instances, will leave parents feeling aggrieved and medical professionals in others. For this reason, Brazier's conclusion that there is 'no right answer' to the dilemmas posed in cases where there is a dispute between parents and medical professionals about what is in a child's best interests is wholly accurate.<sup>58</sup> It is a matter of conjecture as to which direction the courts will head in the future, but it is essential that if they are unconvinced by wider social, emotional and quality of life considerations, they ensure that their approach to best interests can withstand careful scrutiny and remains justifiable.

<sup>&</sup>lt;sup>58</sup> Brazier, above, n 3, at 418.