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Re-evaluating 'best interests' in the wake of *Raqeeb* v *Barts NHS Foundation Trust & Anors*

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In *Raqeeb* v *Barts NHS Foundation Trust*, the latest of a number of cases concerning whether a child can travel abroad for treatment that doctors in the UK do not consider to be in their best interests, the High Court held that the hospital had acted unlawfully by failing to consider the child's rights under EU law when refusing to allow her to travel. Although this derogation could be justified on public policy grounds, as such treatment was, on the facts, in her best interests, no further interference with her rights was justified. In making this finding, the court recognised the 'stress' that such a case placed on the best interests test, lending weight to the argument for moving instead to a risk of significant harm threshold for judicial intervention in parental decisions, which better accounts for legitimate differences of value and strikes a better balance under Article 8 ECHR.

INTRODUCTION

Raqeeb v *Barts NHS Foundation Trust & Anors*[1] (*Raqeeb*) is the latest in a line of cases in which parents and a hospital have disagreed over whether or not a child ought to be permitted to travel abroad for treatment that doctors in the United Kingdom do not consider to be in the child's best interests. In both of the preceding cases, *Yates* v *Great Ormond Street Hospital For Children NHS Foundation Trust & Anor*[2] (*Gard*) and *Alder Hey Children's NHS Foundation Trust* v *Evans & Anors*[3] (*Evans*), the courts refused the parents' request, declaring the withdrawal of life-sustaining treatment lawful, and making it clear that, if necessary, they would be prepared to issue an injunction to prevent the parents from taking the child abroad. Yet despite the lack of precedent for such a move, neither judgment discussed the source of legal authority that would permit them to do so, nor whether such power resides exclusively in the court, or can be exercised by a hospital in the absence of a court order.

It is perhaps unsurprising, therefore, that only one year on, this issue has once more come squarely before the High Court in the case of *Raqeeb*, in which yet another set of parents sought to remove their child from the hospital where her life was being supported to another country where she would receive

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1 [2019] EWHC 2531 (Admin).
2 *Yates & Anor* v *Great Ormond Street Hospital For Children NHS Foundation Trust & Anor* [2017] EWCA Civ 410.
3 *Alder Hey Children's NHS Foundation Trust* v *Evans & Anors* [2018] EWCA 984 (Civ).

ongoing care. In this case, the child's parents sought judicial review of the hospital's decision to prevent them from taking their child abroad for treatment arguing that it was incompatible with her free movement rights under EU law. The court did find the actions of the hospital to be unlawful in failing to have had regard to her EU law rights when making the decision to prevent her from being transferred. However, it nonetheless concluded that even had the hospital done so, it would have found such a derogation from her rights to be justified, and so no remedy was necessary. Having dealt with this aspect of the case, MacDonald J went on to conclude that, on the facts, further treatment (in the form of a tracheotomy and continued ventilation) would be in Tafida's best interests and accordingly he authorised her transfer to Italy. In doing so, he recognised the 'stress' that cases such as this placed on the best interests test, particularly in the absence of the child experiencing pain or suffering. We agree that such cases challenge the current best interests approach, revealing its limitations, and argue that they demonstrate the need to move away from a best interests threshold for judicial intervention in parental decisions, and to adopt instead a risk of significant harm test. As well as better accounting for legitimate differences of value in disputes of this kind, and striking a better balance under Article 8 of the European Convention on Human Rights (ECHR), this would also better reflect the fact that in this case, as in *Gard*[4] and *Evans*,[5] it was the potential harm to the child that ultimately dominated the assessment of whether further treatment was in their best interests.

BACKGROUND TO THE *RAQEEB* CASE

In February 2019, Tafida suffered a bleed on the brain as a result of a rare condition, arteriovenous malformation. This caused severe, irreversible damage to her brain, leaving her in a minimally conscious state with little or no awareness. She is unable to see, move or feel, and is likely to suffer incontinence, spinal curvature and possibly epilepsy in the future. Her medical team at the Royal London Hospital concluded that she has no prospect of recovery, and that treatment was futile and no longer in her best interests. This was strongly opposed by her parents who wished, in accordance with their Muslim beliefs, to do everything possible to sustain her life. In July, the Gaslini Children's Hospital in Italy offered to provide Tafida with ongoing life-sustaining treatment, in the form of a tracheotomy and continued ventilation. The Italian hospital did not suggest that it could improve or treat her condition, but in line with the position under Italian law, it would not withdraw life-sustaining treatment from her until she suffered brain stem death. Despite the parents having the funds to move Tafida, the hospital refused to permit her to be transferred to Gaslini, on the grounds that it would not be in her best interests to continue care. It applied

4 *Yates & Anor* v *Great Ormond Street Hospital For Children NHS Foundation Trust & Anor* [2017] EWHC 972 (Fam).

5 *Alder Hey Children's NHS Foundation Trust* v *Mr Thomas Evans, Ms Kate James, Alfie Evans (A Child by his Guardian CAFCASS Legal)* [2018] EWHC 308 (Fam).

to the court for a declaration under the inherent jurisdiction and section 8 of the Children Act 1989 that it would be lawful to withdraw treatment. In response, Tafida's parents sought judicial review of the Trust's decision to prevent her being taken to Italy and, as a secondary issue, challenged the decision of the doctors that further treatment of the kind offered by Gaslini would not be in her best interests.

The issue of whether parents could be prevented from seeking treatment abroad has garnered substantial attention from both courts and the media in recent years. *Raqeeb* is the third such case to come before the courts in the last two years, with all three contributing to a highly-charged debate over whether and when the courts ought to be able to intervene in parental decisions about their child's medical care. The issue was first raised in *Gard*,[6] a case concerning a young child with mitochondrial DNA depletion syndrome (MDDS). The High Court ruled that taking the child to the United States for experimental treatment would not be in his best interests, and declared the withdrawal of treatment from him lawful. In the Court of Appeal and the Supreme Court, the appellants argued that Great Ormond Street Hospital's application could only relate to whether it was lawful to withdraw treatment — not to whether he could be treated by another medical practitioner at the parents' request. In making an order that prevented the child from being taken to America, the Court had thus gone beyond its jurisdiction:

> The declaration made by the judge has de facto injunctive effect in that it prevents Charlie's parents from removing him from GOSH to undergo treatment in the USA. The judge would have had no power to grant such an injunction, had one been sought.[7]

The Court of Appeal disagreed,[8] holding that it was the court's role to determine which course of action was in the best interests of the child, which could include declaring that treatment abroad was not in the child's best interests. Lord Justice McFarlane, made clear that 'if necessary, and one hopes it that the situation will not arise, such an order would be backed up by an injunction in due course'.[9] The source of authority for such an injunction was never elucidated, so it remained unclear post-*Gard* whether it derives from the inherent jurisdiction or the Children Act 1989, or what the practical impact of it would have been had the parents had attempted to leave with the child. However, in refusing permission to appeal, the Supreme Court appeared to implicitly agree on the injunction point, as it upheld the hospital's right to bring the claim and the judge's determination of it, asserting jurisdiction to determine all matters related to a child's welfare.

Although the American doctor offering treatment to Charlie Gard later decided it would be futile, rendering an injunction unnecessary, the issue arose again shortly afterwards in the case of Alfie Evans, whose parents wished him

6 n 4 above.
7 n 2 above at [54].
8 n 2 above.
9 *ibid* at [117].

to receive life-sustaining treatment in Italy. Although neither court spoke in terms of an injunction, the High Court held that it would not 'permit the child's immediate removal to Italy',[10] a decision upheld by the Court of Appeal.[11] In the Court of Appeal, the parents argued that such an injunction would derogate from the child's rights to free movement (under Article 3(2) Treaty of the European Union (TEU) and Article 21 Treaty for the Functioning of the European Union (TFEU)) and access to services (Article 56 TFEU). Whether such a derogation is proportionate was a question of EU law and therefore in deciding it, EU law would treat the child's interests as a *primary* consideration (rather than the *paramount* consideration as under English law).[12] McFarlane LJ cursorily rejected this argument:

> There can be no derogation from the mandatory requirement to apply the gold standard, namely the best interests of the young person concerned … To submit, as Mr Coppel does, that in some manner that legally entrenched principle should be eroded or adapted where it is possible to contemplate moving the child for treatment elsewhere is one to my mind which can have no merit at all.[13]

Notwithstanding this, David Lock QC raised a similar but more detailed argument in *Raqeeb*.[14] He argued that the NHS Trust (as a public body exercising statutory functions) was under a duty when making decisions about Tafida to consider the impact of such a decision on her rights under EU law, which they had failed to do. Preventing her from travelling would undoubtedly interfere with her rights to free movement and to receive services (Article 56 TFEU), which includes the treatment requested (Directive 2011/24/EU). The hospital ought to have considered this, and whether such a derogation could be justified as a matter of EU law. Where a child has a right to receive healthcare services in another Member State as a function of her EU rights, public authorities may not restrict that right unless there is a proportionate public policy justification for doing so for the purposes of Article 52 TFEU. In this case, as there was a hospital in another Member State willing to provide treatment to Tafida, the transfer posed no risk to her, and there had been no best interests determination by a domestic court, it could not be said that there was a proportionate public policy justification for restricting her rights. The decision was thus unlawful.[15]

THE JUDGMENT

MacDonald J broke down the judgment into the two distinct issues: the judicial review of the Trust's decision to prevent Tafida transferring to the Gaslini

10 *Alder Hey Children's NHS Foundation Trust* v *Evans & Anors* [2018] EWHC 953 (Fam) at [8].
11 n 3 above.
12 In accordance with Article 24 of the Charter of Fundamental Rights of the European Union (the Charter).
13 n 3 above at [32].
14 n 1 above.
15 *ibid* at [43]-[55].

Hospital; and the application by the Trust that further treatment would not be in Tafida's best interests.

Judicial review of the Trust's decision

On the facts, MacDonald J concluded that the hospital had made a decision to prevent Tafida from being transferred to the Gaslini Hospital, and that this decision was amenable to judiciable review as a public body exercising a statutory function under the National Health Service Act 2006.[16] Accordingly, they had a duty to comply with all administrative law standards usually enforced by judicial review, including 'to direct itself correctly as to the applicable EU law'.[17] As the Trust did not give 'any consideration' to whether the decision would interfere with Tafida's rights under Article 56 nor, if it did interfere, to whether that inference was justified on the grounds of public policy,[18] their actions were 'prima facie' unlawful. Notwithstanding this, MacDonald J held that *had* it followed the correct process and considered Tafida's EU law rights, it would have reached the same decision,[19] because while preventing her from leaving 'constituted a plain interference with her directly effective EU rights under Article 56 TFEU',[20] such an interference could be justified on public policy grounds and so would not have been contrary to EU law.[21]

The reasons for this were as follows.[22] Firstly, MacDonald J found that in the event of a dispute between a parent with parental responsibility and treating doctors over a child's medical treatment, the Trust is — as a matter of EU as well as domestic law — under a duty to apply to the court for determination of the issue.[23] He gave four reasons for this. Firstly, under Article 8 of the Council Regulation (EC) 2001/2003 (BIIa), EU law confers jurisdiction to determine 'matters of parental responsibility over a child' on the courts of the Member State in which the child is habitually resident.[24] Secondly, under section 11(2)(a) of the Children Act 2004, NHS Trusts are under a duty to discharge their functions having regard to the need to safeguard and promote the welfare of children, which may require them to apply to the court to determine any dispute over the child's welfare.[25] Thirdly, the EU recognises

16 *ibid* at [140]-[141].
17 *ibid* at [144].
18 *ibid* at [144].
19 *ibid*.
20 *ibid* at [145].
21 *ibid* at [146].
22 Although MacDonald J did not make reference to it, this position accords with the position of the Court of Justice of the European Union in Case C-244/06 *Dynamic Medien Vertriebs GmbH* v *Avides Media AG* ECLI:EU:C:2008:85 at [42] that 'the protection of the child is a legitimate interest which, in principle, justifies a restriction on a fundamental freedom guaranteed by the EC Treaty' but that 'such restrictions may be justified only if they are suitable for securing the attainment of the objective pursued and do not go beyond what is necessary in order to attain it'.
23 n 1 above at [107].
24 *ibid* at [108].
25 *ibid* at [109].

the importance of allowing a margin of appreciation for the courts of Member States in cases raising sensitive moral and ethical issues.[26] Finally, the need for Member States to have a mechanism for resolving such disputes according to law is reflected in Article 6(2) of the Council of Europe's Convention on Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine, which provides that an intervention on a child may only be carried out with the authorisation of either their representative, or a person or authority provided for by law.[27] Therefore, either the parents or the doctors are *required* to put any such dispute before a judge for determination,[28] which in this jurisdiction is achieved via an application under either the inherent jurisdiction or section 8 of the Children Act 1989. The Trust had, in this case, made such an application.[29]

The question for the court was therefore whether this established national procedure for determining disputes over the best interests of the child amounts to a justification on public policy grounds for derogating from the child's directly effective EU rights. Drawing on the extensive case law in support,[30] MacDonald J concluded that it was for the national courts to decide whether something constituted a public policy justification,[31] through a consideration of the following:

i. Is the measure equally applicable to all persons and undertakings operating in the Member State in question … ?
ii. Is the measure justified by some legitimate public interest objective that is consistent with, or not incompatible with, the aims laid down in the Treaty provisions?
iii. Is the measure suitable for securing the attainment of the objective that it pursues?
iv. Is the measure proportionate to the objective, i.e. does ensure the objective it pursues and not go beyond what is necessary to attain that objective?[32]

All four of these questions could, in MacDonald J's view, be answered in the affirmative. The procedure is equally applicable to all children in the jurisdiction. It is justified by a legitimate public interest objective, consistent with the aims of EU Treaty provisions, namely the protection of a child's best interests; the interest in courts (rather than doctors) determining the outcome of such disputes and the importance of ensuring that the child has an independent voice in such disputes.[33] The procedure was suitable for attaining these objectives

26 *ibid* at [110].
27 *ibid* at [111].
28 *ibid* at [114] and reiterated at [147].
29 *ibid* at [114] and reiterated at [147].
30 Case 41/74 *Van Duyn* ECLI:EU:C:1974:133; Case C-33/07 *Ministerul Administraţiei Şi Internelor – Direcţia Generala De Paşapoarte Bucureşti* v *Jipa* ECLI:EU:C:2008:396; Case C-159-90 *Society for Protection of Unborn Children Ireland Limited* v *Grogan and others* ECLI:EU:C:1991:249; C55/94 *Gebhard* v *Consiglio dell'Ordine degli Avvocati e Procuratori di Milano* ECLI:EU:C:1995:411; Case C-19/92 *Kraus v Land Baden-Württemberg* ECLI:EU:C:1993:125.
31 n 1 above at [148].
32 *ibid*.
33 *ibid* at [152].

(the evidence is put before an independent judge, who evaluates all the available evidence by reference to a framework that places the child's best interests at the centre and gives the child an independent voice), and no other procedure would attain these objectives in a way less restrictive of rights.[34] Finally, the procedure is proportionate to the objective, as it goes no further than the jurisdiction conferred by EU law under Article 8 BIIa.[35] Moreover, EU rights were only interfered with where a transfer was not held to be in the child's best interests, and EU law would not require the implementation of an EU right in a way that was 'antithetic' to a child's best interests.[36] He concluded that the derogation from Article 56

> is accordingly temporary and lasts only as long as necessary to determine the issue in dispute in accordance with the jurisdictional provisions of EU law. Within this context, I am satisfied that the national requirement to bring before the court a dispute between treating doctors and parents on an issue as fundamental as whether life sustaining treatment should continue of be withdrawn does not have an effect beyond that which is necessary and complies with the principle of proportionality.[37]

As the result would have been the same had the Trust not acted unlawfully, the court exercised its discretion at common law to withhold a remedy where it would serve no practical purpose.[38]

Tafida's best interests

The second part of MacDonald J's judgment considered whether further treatment would be in Tafida's best interests. When determining this, MacDonald J held that her wishes (in so far as they could be ascertained) were one factor to be considered by the court, but they should not be given preeminent weight. Although he accepted evidence that she 'had a growing understanding of the practices of Islam, had developed a concept of the importance of life and an accepting and non-judgmental approach to those with disability',[39] given her age and level of understanding, this was an insufficient basis on which to extrapolate that she would wish to continue to live in her current situation, though she would be unlikely to 'reject out of hand' such a situation.[40]

MacDonald J recognised the inherent value of Tafida's life, which was 'precious to her parents, sibling and family.'[41] However the sanctity of life was not a trump card, and could be outweighed by countervailing reasons. He acknowledged that the treatment may not benefit Tafida in the sense that her current medical condition is 'substantially irreversible' and so would not be improved

34 *ibid* at [153].
35 *ibid* at [154].
36 *ibid*.
37 *ibid* at [154].
38 *ibid* at [156]-[158].
39 *ibid* at [166].
40 *ibid* at [168].
41 *ibid* at [169].

or ameliorated to any great extent. While some minimal neurological progress might be made in the future, she will remain profoundly neurologically disabled for the rest of her life.[42] Nonetheless he noted that benefit has meaning beyond merely its medical sense. For Tafida, possible benefits included:

> being at home, being in the care of her loving and dedicated family, and, insofar as she is minimally aware, gaining from such awareness as she has of those matters … [and also] that it permits Tafida to remain alive in accordance with the tenets of the religion in which she was being raised and for which she had begun to demonstrate a basic affinity.[43]

The burdens on her, by contrast, were not so great. Although it was accepted that with treatment she might potentially live for a further 10 to 20 years, and would likely suffer from a number of comorbidities, it was considered that Tafida does not experience pain,[44] and MacDonald J would not accept the argument that her continued life would 'burden her with indignity'. Moreover there was a responsible body of medical opinion who disagreed over her best interests: the doctors in Gaslini Children's Hospital had drawn a different conclusion, and the treatment that had been proposed was an accepted course of action for other children in the UK. Accordingly MacDonald J concluded that:

> in circumstances where Tafida is not in pain, where the burden of the treatment is low, where there is a responsible body of medical opinion that considers that she can and should be maintained on life support with a view to her being cared for at home on ventilation by her family in the same manner in which a number of children in a similar situation to Tafida are treated in this jurisdiction, where there is a funded care plan to this end, where Tafida can be safely transported to Italy, where the continuation of life-sustaining treatment is consistent with the religious and cultural tenets by which Tafida was being raised and having regard to the sanctity of Tafida's life, this case *does* in my judgment lie towards the end of the scale where the court should give weight to the reflection that in the last analysis the best interests of every child include an expectation that difficult decisions affecting the length and quality of the child's life will be taken for the child by a parent in the exercise of their parental responsibility.[45]

As treatment in Italy was in Tafida's best interests, there could be no justification for any further interference with her EU rights to receive services.

COMMENTARY

MacDonald J's conclusion that derogations from a child's rights under EU law can be justified where necessary to protect their best interests is not surprising.

42 *ibid* at [163].
43 *ibid* at [173].
44 *ibid* at [162].
45 *ibid* at [182] (emphasis in original).

Were EU law to have trumped the court's determination of the child's best interests, this would render the court entirely impotent wherever a dispute arises in which an alternative clinician can be found elsewhere in the EU who is willing to treat the child, leaving the court powerless to prevent a child being taken abroad in a situation where their best interests are, even on the broadest view, not being served by this action. The effect of the decision is nonetheless to render the child's ability to exercise their EU rights contingent on the prior determination of their best interests by a domestic court, even where the courts of another Member State, applying the same legal test, would reasonably disagree. MacDonald J's contention that 'this jurisdiction does not hold the monopoly on legal and ethical matters'[46] is true then, only in so far as the decision-maker accords the legal and ethical frameworks of other countries weight in the best interests calculus.

This proved uncontroversial on the facts of *Raqeeb*, as Tafida's parents wished for her to travel to a leading centre for paediatric excellence to undergo a course of treatment that was an established treatment for other children in a similar condition to Tafida. In these circumstances, MacDonald J was willing to accept that there might be a legitimate difference of opinion between the English and Italian approaches over what course of action was best for Tafida, which he accounted for by placing substantial weight on the Italian doctor's perspective when determining her best interests. In effect therefore, while the English court's view of best interests would 'trump' that of the Italian courts, the fact that there was a respectable body of medical opinion who disagreed, albeit 'in the context of the particular legal and ethical framework applicable in Italy',[47] could be taken account of within an expansive best interests assessment.

However this may not always be the case. Firstly, it is worth noting that the breadth and sensitivity of MacDonald J's best interests assessment may not be reflective of all such cases that come before the courts. In *Evans* for example,[48] where the parents similarly wished for their child to be transferred to a respected children's hospital in Italy to undergo a tracheotomy and continued ventilation (in line with their Catholic beliefs), Hayden J found that:

> The continued provision of ventilation, *in* circumstances which I am persuaded is futile, now compromises Alfie's future dignity and fails to respect his autonomy.[49]

Unlike in *Raqeeb,* there was little discussion of the need to encompass different value systems within the best interests assessment, nor direct engagement with the fact that there might be space for reasonable disagreement over whether it is better to live a longer life in a profoundly disabled condition or to end one's life 'prematurely'. In fact, by describing the parents position as 'irreconcilable with Alfie's best interests',[50] Hayden J seemed to imply there is a single, objective answer to what is 'best', a position that has been widely criticised in the

46 *ibid* at [178].
47 *ibid* at [178].
48 n 5 above.
49 *ibid* at [66].
50 *ibid* at [64].

biomedical ethics literature and which cannot account for cultural and religious differences, particularly in questions concerning what makes a good life.

The decision in *Raqeeb* thus places substantial weight on the way in which the decision-maker applies the 'objective' best interests test, and the extent to which they accept (and attempt to capture within it) the validity of different medical, ethical and legal systems. The difficulties in doing so were recognised by MacDonald J, who concluded his judgment by noting that within a context such as this, the 'objective best interests test' can be put 'under some stress':

> Absent the fact of pain or the awareness of suffering, the answer to the objective best interests tests must be looked for in subjective or highly value laden ethical, moral or religious factors extrinsic to the child, such as futility (in its nontechnical sense), dignity, the meaning of life and the principle of the sanctity of life, which factors mean different things to different people in a diverse, multicultural, multifaith society.[51]

That the view of Tafida's parents coincided with that of a reputable team of medical practitioners (and indeed, the legal position of another Member State of the EU) gave their position substantial legitimacy. It brought it within what we would argue should be considered a zone of discretion, in which there might be legitimate difference of opinion over what is best depending on the ethical framework adopted and the value ascribed to the inherent good of the continuance of life. We might wonder, however, whether the views of either the parents or the receiving medical team would have been given the same weight in the best interests evaluation had their position been more unorthodox. There is a good case to be made for the English courts being reluctant to release children into the care of medical professionals whose reputability is in question, which might well be at issue where a team offers a very unusual or experimental treatment. Indeed MacDonald J acknowledged himself that:

> in this case the court has a contrary view from a centre of paediatric excellence obtained with full co-operation of the applicant Trust rather than, as in some recent and unfortunate examples, the clandestine involvement of inappropriately qualified foreign medical practitioners.[52]

But the very flexibility of the best interests approach to managing situations of this kind may also lead parents with differing value perspectives to be unreasonably restricted in making choices for their children. One concern therefore, is that the best interests approach fails to give sufficient protection for those parents whose views fall outside of the 'norm'. While extreme examples exist (a parent preferring crystal healing to chemotherapy), arguably, *Gard* might also be an instance of this,[53] as the parents sought to take their child to the USA to undergo an extremely experimental treatment which had not even been trialled on a mouse model with his condition. It is doubtful whether the same weight

51 n 1 sbove at [191].
52 *ibid* at [178].
53 n 2 above.

would be ascribed to the parents view in that case, notwithstanding that the decision in that case was fundamentally about which chances are worth taking and at what cost, about which there cannot be a 'right' or 'wrong' answer. Yet in contexts such as this, where there is no objective right answer, and room for reasonable disagreement between parties over the 'best' course of action for the child, it might be questioned why, in a libertarian society committed to respecting plurality of values, the courts assessment of this cost-benefit analysis ought to take precedence above that of the parents (and the position of other doctors). As Joseph Goldstein contends:

> It is precisely in those cases in which reasonable and responsible persons can and do disagree about whether the 'life' after treatment would be 'worth living' or 'normal', and thus about what is 'right,' that parents must remain free of coercive state intervention in deciding whether to consent to or reject the medical program proffered for their child.[54]

It is this inability of the best interests approach to properly protect parents whose value systems fall outside of the norm which leads us to argue elsewhere for the need to consider moving to a 'significant harm' test for judicial intervention, which offers a more legitimate basis for the state to intervene in such disputes.[55] Lynn Gillam rightly describes 'best interests' as a 'notoriously subjective and grey concept', even 'when used in legal context by a judge'.[56] Given that 'there may be multiple legitimate, sufficient or reasonable answers' to the question of what is in a child's best interests, it is, in our view, important that the law leave space for reasonable disagreement between doctors and parents,[57] by creating a 'zone of parental discretion' free from interference, where parents may make decisions for their child providing that in doing so, they do not expose the child to significant harm.

This idea is widely supported in the ethics literature.[58] However, it would also better accord with public expectations, providing a clearer justification for intervening in parental decisions (that the child would otherwise suffer harm) which would be consistent with the threshold for the intervention of local authorities in care proceedings.[59] Douglas Diekema has also made the point that 'harm' is better understood by clinicians (and, we would argue, judges and parents), than 'best interests',[60] and therefore it is a much less opaque threshold point for parental decisions to yield to court authority. Given the level of public

54 J. Goldstein, 'Medical Care for the Child at Risk on State Supervision of Parental Autonomy' (1977) 86 *Yale Law Journal* 645, 654.

55 C. Auckland and I. Goold, 'Parental Rights, Best Interests and Significant Harms' (2019) 78 *Cambridge Law Journal* 287.

56 L. Gillam, 'The Zone of Parental Discretion: An Ethical Tool for Dealing with Disagreement between Parents and Doctors about Medical Treatment for a Child' (2016) 11 *Clinical Ethics* 1.

57 Auckland and Goold, n 55 above, 308.

58 See the systematic review reported in R.J. McDougall and L. Notini, 'Overriding Parents' Medical Decisions for their Children: A Systematic Review of Normative Literature' (2014) 40 *Journal of Medical Ethics* 448, 452.

59 Children Act 1989, s 31.

60 D. Diekema, 'Parental Refusals of Medical Treatment: The Harm Principle as Threshold for State Intervention' (2004) 25 *Philosophy of Medical Research and Practice* 243.

discontent with the current law, as seen in the support for measures such as *Charlie's Law*,[61] a threshold that is more easily intelligible might generate greater consensus and public support.

Further, such an approach would more accurately reflect the reasoning of the judges in cases such as this. In *Raqeeb* for example, much of the judgment focussed on the lack of harm to Tafida, who would not experience pain or have any awareness of her situation. It was on this basis that MacDonald J concluded that the potential benefits to her outweighed the burdens. This can be contrasted with the children in *Gard*[62] and *Evans*,[63] both of whom may have been able to experience pain and discomfort, which was crucial in the court's determining that being kept alive in this condition was not in their best interests. In *Gard*, for example, Francis J was clear that 'the only course now in Charlie's best interests is to let him slip away peacefully and not put him through more pain and suffering'.[64]

MacDonald J also rightly noted that in a case such as this, where Tafida is not harmed in any meaningful sense by ongoing treatment, there is

> a cogent argument that the making of orders the effect of which would be to override the choice made by the parents in the exercise of their parental responsibility would not constitute a necessary and proportionate justification for the interference in their Art 8 rights that would thereby occur.[65]

In our view this is not only correct, but represents an important additional reason for the law to shift to a risk of significant harm threshold before courts can make declarations about the medical treatment of children. Article 8 ECHR protects a person's right to respect for 'private and family life', and the European Court of Human Rights has been clear that a medical intervention on a child without the parent's consent constitutes a violation of Article 8 ECHR, subject to some qualifications.[66] The right is qualified, and subject to restrictions made 'in accordance with law' where 'necessary in a democratic society' for 'the protection of health or morals, or for the protection of the rights and freedoms of others'.[67] However, it is questionable whether intervening on the basis that the decision is not in the child's best interests can be said to be 'necessary' for the protection of the child's health according to Article 8. 'Necessary' has been taken to imply '"the existence of a pressing social need" for the interference'[68] in the Strasbourg jurisprudence. In *Dudgeon* v *United Kingdom*, the Court was clear that

> According to the Court's case-law, a restriction on a Convention right cannot be regarded as 'necessary in a democratic society' — two hallmarks of which are

61 https://www.thecharliegardfoundation.org/charlies-law/ (last accessed 10 February 2020).
62 n 4 above.
63 n 5 above.
64 n 4 above, 128.
65 n 1 above, 182.
66 *MAK and RK* v *United Kingdom* (2010) 51 EHRR 14. See also the protection of parental rights in United Nations Convention on the Rights of Children, Arts 3(2) and 5.
67 ECHR, Art 8(2).
68 *Dudgeon* v *United Kingdom* (1983) 5 EHRR 573 at [51].

> tolerance and broadmindedness — unless, amongst other things, it is proportionate to the legitimate aim pursued.[69]

Given that best interests determinations involve (in the words of MacDonald J), the weighing of 'subjective or highly value-laden' factors which mean 'different things to different people', it follows that room should be made for reasonable disagreement between the parents and the Court about how these factors or interests ought to be weighed. Yet under the current law, as *Gard*,[70] *Evans*[71] and *Haastrup*[72] demonstrate, parental decisions may be overridden wherever the Court disagrees with the parents weighing of these factors, even where the child is not likely to suffer any harm as a consequence. Arguably, if the aim of the interference is to protect the child's health and welfare, then intervening in the absence of harm goes beyond what is necessary to secure this, especially when considered in light of the importance attached to 'tolerance and broadmindedness' in a democratic society. As counsel for the appellants in *Gard* observed:

> If best interests were to be relevant touchstone, the distinction between legitimate state action and the discharge of parental responsibility would disappear since any action by parents with which court disagreed could be overruled.[73]

Moving to a significant harm threshold might therefore strike a better balance under Article 8 than the current best interests approach; and in a similar vein, show greater respect for the parent's right to freedom of thought, conscience and religion under Article 9 ECHR. Such a shift does not conflict with the Charter requirement for the child's best interests to be 'a primary consideration'. Under our proposed approach, the court will still evaluate what is in the child's best interests; our approach merely increases the threshold test for *when* the court has the authority to consider what is in the child's interests, which is when the decision of the parents is likely to cause the child harm. Considering whether there is a sufficient risk of harm such that it may make a declaration does not preclude the court considering the child's best interests, as this necessarily entails thinking about whether the parents' decision poses a risk to the child. It merely gives emphasis to the parents' conception of best interests, one which yields to the court's when it poses a risk of harm.

Nor does this shift conflict with the proposition of the European Court of Human Rights in *Sahin* v *Germany* that where the Article 8 rights of both a child and their parents are engaged, 'particular importance must be attached to the best interests of the child which, depending on their nature and seriousness, may override those of the parent.'[74] The fact that a parent is in dispute with

69 *ibid*.
70 n 2 above, 1.
71 n 3 above.
72 *Kings College Hospital NHS Foundation Trust* v *Ms Thomas, Mr Haastrup and Isaiah Haastrup* [2018] EWHC 127 (Fam), [2018] 2 FLR 1028.
73 Counsel's submissions in Permission to Appeal Hearing at https://www.supremecourt.uk/watch/charlie-gard/080617-pm.html (last accessed 20 March 2018).
74 *Sahin* v *Germany* [2003] ECHR 340 (8 July 2003) at [66].

doctors over what is best for the child does not in itself mean that the parents interests and those of their child are in conflict, such that one's interests must be prioritised over the others. In our view, such a tension arises only where the decisions or actions of the parents expose that child to a risk of harm. Indeed in the sentence immediately following that given above, the judge in *Sahin* notes in particular that under Article 8, parents are not entitled 'to have such measures taken as would harm the child's health and development',[75] lending further support for the idea that the child's best interests take priority over the parents' Article 8 rights where their actions are harmful.

It might be questioned whether such a move is necessary, given evidence that both clinicians,[76] and the courts,[77] do already attach importance to parental views when determining best interests. Indeed some suggest it may do more harm than good. Giles Birchley for example, is critical of the greater 'evaluative overtones'[78] and possible 'pejorative connotations'[79] of explicitly characterising a parents decisions as 'harmful'; while others have raised concerns about the potential indeterminacy of the concept of 'harm', and the difficulties deciding when this is 'significant'.

But as decisions such as *Gard* and *Evans* illustrate, not all judgments attach the same degree of importance to parental views. Even if it will not change much in practice, it is nonetheless important to be clear and transparent with parents about why someone other than them may decide their child's fate, and on what basis their decision is being overridden. Moreover a decision to prevent parents having the ultimate say over the treatment of their very ill child is likely to be devastating regardless of whether it is framed as 'harmful' or not in the child's 'best interests', and it is far from clear that notions of harm are any more indeterminate than 'best interests'. In fact, as Diekema argues (above), it may be that 'harm' generates greater consensus. The challenging facts of *Raqeeb* might therefore give greater impetus to arguments for reforming the law in a way that better respects the uniquely important relationship of a parent with their child.

Finally, MacDonald J was clear in *Raqeeb* that where a hospital refuses to release a child because it considers moving the child not to be in their best interests, such a dispute *must* now be referred to the High Court for resolution. While he regarded this as necessary to comply with EU law, with Brexit impending, it would be helpful for the courts to clarify what the hospital's obligations are as a matter of domestic law. This is especially important given that the international dimension to these cases is likely to become a feature of disputes more and more often, as the internet provides both information on alternative treatments and a means of raising funds to pursue them. Hospitals

75 *ibid*.

76 D. Wilkinson, 'In Defence of a Conditional Harm Threshold for Paediatric Decision-Making' and G. Birchley, 'The Harm Threshold: A View from the Clinic' in I. Goold, J. Herring and C. Auckland (eds), *Parental Rights, Best Interests and Significant Harms: Medical Decision-Making on Behalf of Children Post-Great Ormond Street Hospital v Gard* (Oxford: Hart Publishing, 2020).

77 See R. Taylor, 'Parental Decisions and Court Jurisdiction: Best Interests or Significant Harm?' in Goold, Herring and Auckland (eds), *ibid*. This is exemplified in the *Raqeeb* case.

78 G. Birchley, 'The Harm Threshold and Parents' Obligation to Benefit their Children' (2016) *Journal of Medical Ethics* 111, 113.

79 *ibid*.

may find themselves in this difficult situation again, and it will be particularly complex if parents press for the release of a child who cannot safely be moved. Conversely, hospitals also need clarity about what they *must* do (if anything) to sustain a child where the child is to be taken elsewhere, where they do not consider this in the child's best interests. Guidance is needed on what this might require of doctors and how that interacts with the law's position that doctors cannot be compelled to offer treatment.

CONCLUSION

In the wake of the *Gard*[80] and *Evans*[81] rulings, the decision in *Raqeeb* that it would not contravene EU law to prevent a child from travelling abroad for treatment was not entirely surprising, albeit that there remains some confusion over what powers the hospitals have in such cases, in the absence of a court order. Perhaps more importantly, however, this case illustrates the difficulties in applying the best interests test in cases involving a dispute over values: here, where parties disagreed over the inherent good of continuance of life. The limitations of the best interests approach, which ultimately fell to be determined by reference to the harm that Tafida would suffer, lends support for the claim that the law is in need of reform so as to permit judicial intervention only where the parent's decision exposes their child to a risk of significant harm. A true commitment to pluralism means tolerating decisions based on values and beliefs that we find problematic — even abhorrent — providing that they do not harm others.

80 n 2 above.
81 n 3 above.