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Evaluating ‘Best Interests’ as a Threshold for Judicial Intervention in Medical Decision-Making on Behalf of Children

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1. Introduction

In a series of high-profile cases over the past few years, the English courts have been asked to grapple with a question that had seemed well settled in English law: who should have the final say over a child’s medical treatment?[1] Such disputes can arise where parents cannot agree with one another, or where the medical treating team and parents cannot agree. This volume focuses on the latter kind of dispute, which featured in the cases of Charlie Gard, Alfie Evans and Isaiah Haastrup.[2] For the most part, when cases concerning treatment disputes come to court, the question for the court is which course of action is in the child’s best interests. This has been the focus of much of the case-law over the past few decades, and the courts have developed a nuanced, considered approach to this question. The question of *when* the courts have the authority to make such a determination has not, however, been regarded as one in need of answer. The threshold for judicial intervention until recently was seemingly uncontroversial, with the court considering itself permitted to take a decision in such matters at the point where the child’s welfare is engaged. In *Great Ormond St Hospital v Yates and Gard* (*Gard*),[3] however, this threshold was challenged, and it was argued that in at least some cases the threshold should be such that parents are the final arbiter in decisions about the medical treatment of a child unless there is a serious risk that their decision will

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[1] *Great Ormond Street Hospital v Yates and Gard* [2017] EWHC 972 (Fam) (*Gard)*; *Great Ormond Street Hospital for Children NHS Foundation Trust v Yates Court of Appeal (Civil Division)* [2017] EWCA Civ 410 (*Gard 2*)*; 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) (*Evans*), [2018] 2 FLR 1223; *Kings College Hospital NHS Foundation Trust v Ms Thomas, Haastrup and Haastrup* [2018] EWHC 127 (Fam), [2018] 2 FLR 1028 (*Haastrup*).

[2] ibid.

[3] *Gard* (n 1).

result in significant harm to the child. Such a position, echoed in much of the public discourse around the case (and that of *Alder Hey Children's NHS Foundation Trust v Evans*[4] (*Evans*)) as well as the ethics literature, is considered by some as a means to afford greater weight to parental decisions. In particular, Charlie Gard's parents are now pressing for a change in the law to ensure that rather than evaluating best interests, the court should not override parental wishes unless they pose a risk of significant harm to the child.[5]

The debate, then, centres around whether we should retain the low threshold of best interests or engagement with the child's welfare (the orthodoxy), or move to some form of harm threshold. Other chapters in this collection address this debate head on, such as those offered by Giles Birchley[6] and Dominic Wilkinson.[7] I have taken a position on this question elsewhere,[8] and hence in this chapter instead offer some thoughts on how we should approach the question of whether the threshold ought to shift. Rather than arguing for a particular stance, this chapter explains the current threshold's operation and then outlines the various considerations of which we should take account when considering whether to make a change.

The chapter begins by offering a brief background to the orthodox position that remains in place following *Gard* and *Evans.* It then outlines the various reasons for making a change that have been offered, both in *Gard* and also in some of the literature, both legal and ethical. It gives a brief account of the ethical position in favour of an alternative threshold based on risk of harm, before concluding with a number of concerns raised about the implications of such a shift in practice.

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[4] *Evans* (n 1).

[5] C Burns, 'Charlie Gard's Parents Want "Charlie's Law"' (*BBC News*, June 2018) https://www.bbc.co.uk/news/health-44334306 (accessed 11 June 2019).

[6] 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, forthcoming).

[7] D Wilkinson, 'In Defence of a Conditional Harm Threshold for Paediatric Decision-Making', in Goold et al (eds) (n 6)

[8] C Auckland and I Goold, 'Defining the Limits of Parental Authority: Charlie Gard, Best Interests and the Risk of Significant Harm Threshold (casenote)' (2018) *Law Quarterly Review* 37; C Auckland and I Goold, 'Parental Rights, Best Interests and Significant Harms' (2019) 11(2) *Cambridge Law Journal* 287–323.

The point at which the state may involve itself in our lives necessarily raises fundamental questions about the legitimate bounds of state involvement in citizens' private lives. This is particularly the case in decisions made within families about children, which are often considered private or the purview of parents alone. Certainly, this is the sentiment that animated much of the public discourse. [9]

The Gard family and those who support them are in part taking the position that parental decisions ought to have priority over the views of other interested parties except to the point where a parent's decision puts the child at risk of significant harm. This is, effectively, a demand to push back against state involvement and protect the privacy and authority of parental decisions. When we consider such questions, we cannot frame these merely as questions of parental rights versus the state, however, as they necessarily affect the vulnerable child at the centre of the situation. Therefore, in evaluating the current threshold, this chapter teases out the complexities of how we respect plurality of values in a democratic society while still taking communal responsibility for the protection of the vulnerable amongst us. Before moving on to this analysis, I will briefly explain why the recent cases raise a live question that invites academic attention.

Why It Is a Live Question?

In a series of high-profile recent cases, the orthodox approach to judicial intervention in disputes between parents and medical teams treating very ill children has come under fire. The cases of Charlie Gard, Alfie Evans and Isaiah Haastrup all involved an application by the treating hospital for life-sustaining treatment to be withdrawn from a seriously ill child. In each, the parents strongly resisted the withdrawal of care. The facts of these cases have been outlined elsewhere in this collection, but a key distinction

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[9] See, eg: 'Charlie Gard's Parents Refused Permission to Spend His Last Night at Home Before His Life Support Machine Is Switched Off on Friday' (*The Telegraph*, 27 June 2017) www.telegraph.co.uk/news/2017/06/29/charlie-gards-parents-refused-permission-spend-last-night-home (accessed 11 June 2019). Chris Gard, Charlie's father, has himself argued that 'our parental rights have been stripped away' by the court decisions, See M Robinson et al., 'Devastated Parents of Charlie Gard Spend their Last Night With their baby and Blast "Heartless" Doctors for Refusing to Let them Take Him Home to Die Before they Turn Off His Life Support Later Today' (*The Daily Mail*, 30 June 2017) www.dailymail.co.uk/news/article-4653894/Outpouring-grief-worldwide-Baby-Charlie-Gard.html (accessed 11 June 2019).

needs to be drawn out for the purposes of this chapter. In the cases of Alfie Evans and Isaiah Haastrup, the parents wanted a tracheotomy to be performed on the children and for artificial ventilation to be continued. Their hope was to extend their child's lives a little further. Certainly, in *Evans*, there was little expectation of anything but life extension. The relevant question, then, was whether prolonging the life of a heavily brain-damaged and physically disabled child who was likely to die relatively soon was in that child's best interests. Were the potential harms associated with these invasive treatments worth it for that those extra days or weeks of life.

By contrast, in *Gard*, Charlie's parents wanted him to be given an experimental treatment being offered by a physician in the United States. Their hope was that this might both extend his life and improve his condition to some degree. Charlie's treating hospital, Great Ormond Street, argued that it was not in Charlie's best interests to travel to the United States to receive the treatment as there was no real hope of success, and travelling (and the care he would need to do so) was potentially harming.

In all three cases, the court refused to accede to the wishes of the parents, holding that it was not in each child's best interests that they continue to receive life-sustaining care, nor to travel to be given an experimental treatment. Consequently, withdrawal of treatment was authorised in each case as being in the child's best interests. Such cases are far from unique; the courts deal with such requests on a regular basis. Yet, *Gard* (and to a lesser extent *Evans*) have precipitated a highly charged debate over whether the courts were right to intervene and take a decision about each child's care. This derived in part from the media attention the cases attracted, but there is more to it than this. Much of the public concern around *Gard* centred around the rights of parents to make decisions for their children, with many objecting to the role of the state in what some consider to be private, familial decisions. For example, one commenter wrote on social media:

> No matter how skilled the doctors, this was NOT their decision to make, they should have recommended a course of action, of course, but NEVER ever should have they felt they had the right to impose their wishes over those of the parents.[10]

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[10] Online comment on 'Charlie Gard's Parents Refused Permission to Spend His Last Night at Home Before His Life Support Machine Is Switched Off on Friday' (*Telegraph*, 27 June 2017). Chris Gard, Charlie's father, has himself argued that 'our parental rights have been stripped away' by the court decisions, see: Robinson et al, 'Devastated parents of Charlie Gard' (2017).

In response to their experience, both Charlie and Alfie's parents are now taking steps to change the law, and their efforts have received a degree of public support. Steven Woolfe MEP announced 'Alfie's Law', aimed at securing legal change to 'restore the rights of parents in such decisions'; while the parents of Charlie Gard have launched a similar initiative, 'Charlie's Law', arguing for a greater voice for parents in such decisions.[11] The latter proposes three core changes to the current system:

1. Ensuring all parties have access to mediation and the input of clinical ethics committees;
2. The provision of independent second opinions to families (and also legal aid); and
3. A shift to 'significant harm threshold', meaning that courts cannot intervene to make decisions on behalf of a child unless the parents' decision poses a serious risk that the child will suffer significant harm as a result.[12]

Thus far, these efforts have been unsuccessful, but as of October 2018, the Parliamentary Under-Secretary of State for the Department of Health and Social Security had agreed to work on possible future steps.[13]

This agitation for change is not itself a sufficient reason to consider changing the law, but the strength of opposition among some members of the community is an indicator that the law may need critical re-evaluation. One of the key reasons we should consider a change in the law, however, is that *Gard* has revealed the full extent of the courts' powers (or its view of its powers) under the inherent jurisdiction, and there are reasons to consider this authority as too wide.[14] Further, the justifications given for the courts' expansive power to intervene in those cases highlighted the lack of robust normative justification for the current legal position.[15] Given the cogent and widespread critique of the current position in the ethical and philosophical literature, there is good reason at least to pose the question of whether the orthodox approach is sufficiently justified.

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[11] 'MEP Launching Campaign for "Alfie's Law" to Give Parents More Say' (*ITV News*, 26 April 2018) www.itv.com/news/granada/2018-04-26/mep-launching-campaign-for-alfies-law-to-give-parents-more-say (11 June 2019); The Charlie Gard Foundation, 'Charlie's Law' (2018) www.thecharliegardfoundation.org/charlies-law (11 June 2019).

[12] The Charlie Gard Foundation, 'Charlie's Law' (2018) .

[13] HL Deb 15 October 2018 vol 793 col 387.

[14] R George, 'The Legal Basis of the Court's Jurisdiction to Authorise Medical Treatment of Children' in Goold et al (eds) (n 6).

[15] These justifications are outlined below, as is the novel basis of the challenge in the *Gard* case.

We might particularly wonder whether it is justifiable to have a low threshold in the context of medical decisions, when the threshold is higher in the context of family life and care proceedings. There may be good reasons for taking a different approach in different contexts,[16] but this needs greater exploration and discussion. If the current threshold is not sufficiently well justified, we should turn to the secondary question of whether a change should be made. In doing so, we must engage with the deeper concern on which these recent challenges to orthodoxy rest – where should the line be drawn to protect private, parental decisions about children from state intervention (if one should be drawn at all)?

2. Orthodoxy

The courts have made it clear that they have the authority to make medical decisions on behalf of children and affirmed the orthodox position that the threshold for judicial intervention is the welfare of the child, often referred to as the 'best-interests' approach (referring to both the threshold and the test applied). In this chapter, I am concerned only with the *threshold* for judicial intervention, that is, what must be the case for the court to have authority to decide on behalf of a child (in lieu of either parents or the treating team). The courts in both *Gard* and *Evans* considered that they had authority to intervene whenever a child's welfare is engaged such that it is possible their best interests may not be met.[17]

The courts' authority to intervene in decisions about a child's medical care has a fairly long history, but despite some minor technical dimensions, the position has remained essentially the same for at least a century. Indeed, Graeme Laurie argues that the courts' inherent jurisdiction to intervene can be seen as grounded in the feudal notion of *parens patriae*, whereby 'the monarch as the ultimate superior' has 'jurisdiction over the very "person" of those who inhabited the land'. As such, he explains, 'the monarch was *parens patriae* – parent of the country' which afforded the monarch 'the right and

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[16] A point that Rachel Taylor explores in her chapter, explaining that there are reasons not to take the same approach across different contexts: R Taylor, 'Parental Decisions and Court Jurisdiction: Best Interests or Significant Harm?' in Goold et al (eds) (n 6).

[17] *In the matter of Charlie Gard (Permission to Appeal Hearing)*, Thursday 8 June 2017; *Judgment of the UK Supreme Court in the Case of Charlie Gard*, 19 June 2017, [13].

duty to care for those not able to care for themselves'.[18] The origins of the jurisdiction lie, then, in both the monarch's authority and the vulnerability of those over whom the monarch had power. Like the modern variation (and also like parental authority and responsibility), the monarch has both power and responsibility.

By the mid-19th century, it was made clear in *Re Flynn* that the court had the power to protect children from their parents' decisions where this was 'essential to their safety or to their welfare, in some very serious and important respect'.[19] Although early on this jurisdiction did reflect a sense that parents knew best and so ought to be afforded a substantial degree of leeway, this began to recede. By 1886, the Guardianship of Children Act 1886 had equalised parental rights and made the 'welfare of the child' a statutory factor. A few years later the court's power to intervene was enshrined in the Custody of Children Act 1891 sections 1 and 2, which gave the court the power to interfere with parental rights in the interests of the child. The welfare of the child was considered of paramount importance and was to be understood in its widest sense, according to the court in *In re McGrath (Infants)* in 1893.[20]

This position did not change in any great sense over the following century, and from the 1970s onwards a string of decisions confirmed the ambit and effect of the court's jurisdiction. Lord Justice Waite stated in *Re T* that the Court has the authority to intervene whenever the child's best interests will otherwise not be promoted, and confirmed the welfare basis of this approach.[21]

This does not mean that parents have not been considered to have authority. Far from it. The courts have been at pains to ensure that parents retain power to make decisions for their children in relation to medical care. For example, Lord Scarman said in *Gillick v West Norfolk and Wisbech Area Health Authority* that:

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[18] GT Laurie, 'Parens Patriae Jurisdiction in the Medico-Legal Context: The Vagaries of Judicial Activism' (1999) 3 *Edinburgh Law Review* 95, 95.

[19] *In re Flynn* (1848) 2 De G & Sm 457, 474.

[20] *In re McGrath (Infants)* [1893] 1 Ch 143, 148.

[21] *Re T (A Minor) (Wardship: Medical Treatment)* [1997] 1 WLR 242.

> It is abundantly plain that the law recognises that there is a right and a duty of parents to determine whether or not to seek medical advice in respect of their child, and, having received advice, to give or withhold consent to medical treatment.[22]

Rachel Taylor explains elsewhere in this volume that in a free and diverse society, it is important that courts do not impose 'a particular view as to what is best for children without good reason and clear evidence to support that view', and she outlines how the courts do allow for parental discretion and demonstrate respect for parental decision-making in the approach they take. For example, she cites comments by Baroness Hale in *Williamson* to this effect:

> Children have the right to be properly cared for and brought up so that they can fulfil their potential and play their part in society. Their parents have both the primary responsibility and the primary right to do this. The state steps in to regulate the exercise of that responsibility in the interests of children and society as a whole. But 'the child is not the child of the state' and it is important in a free society that parents should be allowed a large measure of autonomy in the way in which they discharge their parental responsibilities.[23]

That said, Lord Scarman also made clear that 'the common law has never treated such rights as sovereign or beyond review and control',[24] for as Ward LJ explained in *Re A*, this parental authority 'exist[s] for the performance of their duties and responsibilities to the child' and hence 'must be exercised in the best interests of the child'. Therefore, 'overriding control is vested in the court'.[25] It is therefore clear, and has been for some time, that parents have authority to make medical decisions, subject to that authority being overridden by the courts at the point that welfare concerns are engaged. Fundamentally, however, the orthodox position was made abundantly clear by Lady Hale in *Gard* when she stated: '[P]arents are not entitled to insist upon treatment by anyone which is not in their child's best interests.'[26] Therefore, when in the *Gard*, Justice Francis considered he had jurisdiction to intervene, he was therefore taking very much the orthodox approach to such questions. In supporting his stance, the Court of

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[22] *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] AC 112, 184 (Scarman LJ) (*Gillick*).

[23] *R (on the application of Williamson and others) v. Secretary of State for Education and Employment and others* [2005] UKHL 15; [2005] 2 All ER 1, [72]; further discussed below.

[24] *Gillick* (n22), 184 (Scarman LJ).

[25] *Re A (Children)* [2001] 1 Fam 147 (HL); [2001] 2 WLR 480, 178 (Ward LJ).

[26] 'Lady Hale's explanation of the Supreme Court's decision', as delivered in Court (8 June 2017) www.supremecourt.uk/news/permission-to-appeal-hearing-in-the-matter-of-charlie-gard.html (accessed 11 June 2019).

Appeal and the Supreme Court merely confirmed the status quo, as was also the case in *Evans*.[27]

3. The Challenge

With the law in such a settled state, it would take an unusual fact situation to provide the opportunity for a challenge to be made to the orthodox threshold for intervention. Such facts arose in the *Gard* case, as they offered a situation in which two parents were in agreement, but disagreed with the medical team treating their child. However, unlike other cases, this did not present the kind of impasse that generally gives the courts a basis on which to intervene, as parents cannot demand that an unwilling doctor treat their child, nor may a doctor undertake treatment on the child in the absence of consent from either the parents or the courts. Therefore, disputes come to the courts because the doctors will not or indeed feel they cannot, in good conscience, accede to parental wishes.[28] As a consequence, the court is needed to find a way through the impasse and in such instances, the 'best-interests' understanding of the *threshold* makes sense, because someone needs to take a decision on behalf of that child as those involved cannot. This was the situation in almost every case prior to *Gard*, and in these situations an application was made to the court which had to 'arbitrate' between the positions of the two parties and determine what should happen.

The facts of *Gard*, however, did not present such an impasse, and hence raised a novel question about the basis on which (and the point at which) the court could legitimately intervene. Connie Yates and Chris Gard were in disagreement with Great Ormond Street (GOSH) about whether Charlie should receive experimental treatment. GOSH maintained that he should not be given the treatment and was not prepared to do so despite the request made by Charlie's parents. Normally, this would prevent parents from being able to access the treatment, but in *Gard* this was not so because an alternative treating team based in the United States *was* willing to provide the

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[27] *Great Ormond Street Hospital v Yates and Gard* [2017] EWHC 972 (Fam), [47] – [50].

[28] Jo Bridgeman has rightly demonstrated that many of these cases can be seen as instances of professional conscience: J Bridgeman, 'Parental Responsibility, Professional Conscience and the Protection of the Court?' in Goold et al (eds) (n 6).

experimental ‘nucleoside therapy’. The parents were not trying to force GOSH to treat Charlie; they were merely asking for him to be allowed to be transferred to a different hospital in the United States.

Therefore, there was no need for the court to step in and provide its consent (or a declaration of unlawfulness): treatment had been offered to Charlie, and his parents had consented to him receiving it. Gard and Yates did not need the court to facilitate their wishes being fulfilled.[29] The fundamental question was instead whether GOSH could withdraw treatment from Charlie. This would effectively have prevented him from being taken to the United States. GOSH’s application requested that the court make a determination on, amongst other things, whether it was ‘lawful, and in Charlie’s best interests, for his treating clinicians to provide him with palliative care only’ and whether it was ‘lawful, and in Charlie’s best interests, not to undergo nucleoside therapy provided always that the measures and treatments adopted are the most compatible with maintaining Charlie’s dignity’.[30]

As the hospital could not be required to treat Charlie, there was no need to request a determination of whether refusing to treat Charlie was in his best interests. They could legally refuse.[31] This request, however, suggests that they were sufficiently concerned about the impact of the experimental treatment on Charlie’s welfare that they felt it necessary to seek a determination that to give it would not have been in Charlie’s best interests. This was likely also motivated by a desire to be sure that in withdrawing treatment they were acting appropriately in relation to Charlie. But as we can assume GOSH would not have involved itself in trying to prevent another hospital taking a different approach to a child not in GOSH’s care, it was hence also wanting to be sure that it was not required in any sense to *facilitate* Charlie receiving a treatment it felt was not in his best interests. This would in part have been motivated by the duties it, as his treating team, had towards him both in tort and via its human rights obligations to

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[29] But GOSH could have made an application to seek court confirmation that it would be lawful to facilitate his removal had they wished to, as it is likely that the hospital would have needed to take steps to enable this. I am grateful to Jonathan Herring for this point.

[30] *Great Ormond Street Hospital for Children NHS Foundation Trust v Yates* [2017] EWHC 972 (Fam), [5].

[31] See: *A Hospital Trust v GM, DK, HK* [2017] EWHC 1710, [23] (Baker J); *King’s College Hospital NHS Foundation Trust v MH* [2015] EWHC 1920, [34] (Francis J); *Re J (A Minor) (Child in Care: Medical Treatment)* [1992] 3 WLR 507, 516 (Donaldson MR).

him. In asking for a determination on this matter, it was essentially inviting the court to take a view on this. But in doing so, it opened up the question of whether the court could step into a situation and prevent parents from taking up an offer of treatment from a medical professional.

The question therefore became whether there ought to be a threshold that must be met before the court could interfere in the medical decisions of parents, and if so, what that threshold was. In the Court of Appeal, counsel argued that one could discern, by reading across from the Children Act 1989, and also the Ashya King case, in cases of this kind (what counsel referred to as 'Category 2 cases') the existence of a 'risk of significant harm' threshold.[32] Such a threshold would prevent a court from intervening in a parent's decision about a child's medical care unless that decision exposed the child to a risk of significant harm.

Usually, parents' decisions about *choice* of medical team or hospital are not policed, and they are free to choose between those options available to them. Such choices could, as was the conclusion in *Gard*, mean that a child receives a treatment that is not in his or her best interests. But for the most part, there is the implicit assumption that medical professionals offer treatments that are in a child's interests and if they treat in a way that falls below the *Bolam* standard, they will be negligent.[33] However, the question here was not about the treatment itself, but the parents' liberty to choose it amongst the range of options before them. The decision in *Gard* at all levels was to the effect that they could not choose the option of nucleoside therapy because it was not in Charlie's best interests that he receive it, and therefore the court could legitimately step in to prevent him having the treatment.

In coming to this conclusion, both the Court of Appeal and the Supreme Court (in rejecting the application for leave to appeal) *effectively* dealt with the application as a question of whether they could make a determination on parental *choice* of treatment. They did not do so explicitly, but in being asked to determine whether a treatment that GOSH did not want to administer (and could not be compelled to administer) was not in Charlie's best interests, and then implying that they would prevent his parents

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[32] See references to *Re Ashya King* [2014] EWHC 2964 (Fam) in *Gard (CA)*, [54]–[82], [96]–[111]. See generally: Taylor (n 16); George (n 14).

[33] *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 583.

moving Charlie to obtain it, they effectively took the view that they could block Gard and Yates from making this choice of treatment. They were able to do so via the orthodox best-interests threshold approach, but did not directly engage with the question of whether a threshold currently exists, or with what that threshold might be. Lady Hale instead simply made clear that parents cannot demand treatment that is not in their child's best interests.[34]

The decisions in *Gard* and *Evans* also made clear how *broadly* the court understands its authority to make decisions once the best interests threshold has been met. Both cases involved questions about whether a child might be taken elsewhere for treatment, raising the issue of whether the court's powers under the inherent jurisdiction extended to issuing an injunction to prevent parents travelling abroad to seek alternative treatment. In *Gard*, McFarlane LJ stated: '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; but, if so, it would be an injunction made by the court.'[35] This situation did not arise in the end in *Gard,* but it was a more pressing question in the end in *Evans*. In that case, Alfie's parents wished to take him to Italy for treatment or at least ongoing life support. In response, Mr Justice Hayden made it was clear that he was refusing the parents' application to 'permit the child's immediate removal to Italy'.[36] The Court of Appeal upheld this decision, and this included rejecting the argument that this breached EU free-movement law. In both decisions, then, the courts were of the view that they had the power to restrain parents from removing children elsewhere for treatment that was not in their best interests. In *Gard,* Lord Justice McFarlane, implied that he would impose an injunction if needed to prevent Charlie's parents moving him to the United States. In doing so, he effectively not only agreed with the application by GOSH that the treatment was not in Charlie's best interests, but also that as a consequence they could legitimately be prevented from accepting an offer of that treatment from another doctor. The limits on parental decisions go beyond merely the court having the power to choose between parent and doctor, and instead prevent parents from accessing the

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[34] 'Lady Hale's explanation' (n 26).

[35] *Yates & Anor v Great Ormond Street Hospital for Children NHS Foundation Trust & Anor* [2017] EWCA Civ 410, [2017] WLR(D) 391, [117].

[36] *Evans* (n 1), [8].

treatment offered by other doctors. The courts also apparently would be prepared to issue injunctions and control the movement of children if need be, even though they did not always explicitly talk in such terms

The necessary logic of these determinations is that the best interests approach is understood as the court having the authority to intervene *wherever* a parent makes a decision that the court considers is not in the best interests of the child if an application that enables them to do so is made. Read in this way, as the decisions in *Gard* and *Evans* support, the threshold in medical decision-making for children under the inherent jurisdiction is potentially very low indeed, yet this is an entirely legitimate interpretation of the best interests threshold, and this is precisely why the *Gard* case is so important – because it reveals the extent of the court's authority to intervene in parental decision-making.

If, as the court suggested in *Gard* and *Evans*, judges can decide upon *any* matter relating to a child's welfare, and intervene wherever they disagree with the parents' assessment of the child's best interests, this would be an exceptionally large intrusion by the state into the private decisions of parents. As counsel for Charlie Gard's parents put it before the Supreme Court:

> [I]f the State can, without the highest of justification, intrude into so private an area of human life as a joint parental decision made about one's child's upbringing, the scope for protection against state interference afforded by our most basic constitutional values, as well as by Article 8 ECHR, is considerably eroded.[37]

These cases have rightly sparked both public and academic interest because they make apparent just how low the threshold for judicial intervention is, and how broad the court's power is once it is involved. I have argued elsewhere that the low threshold requires greater justification,[38] and that the law should move to a 'risk of significant harm' threshold before the courts may intervene. In this chapter, I will give an overview of the arguments on both sides of this debate, some of which are explored in more depth by Giles Birchley and Dominic Wilkinson later in this volume. In my view, these arguments fall on the side of moving to a harm threshold, but there is no question that that the issue is a very finely balanced one, with multiple dimensions to it.

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[37] *In the matter of Charlie Gard* (n 17).

[38] Auckland and Goold (2019) (n 8).

4. Objections to a Harm Threshold

A. The Orthodox Approach: Sufficient and Appropriate

There are two strands to this general point. First, one argument for retaining the current approach is that the orthodox approach does already sufficiently account for parental views. The other is that court also already exclude vexatious claims.

On the first argument, as Rachel Taylor points out, while the law read strictly 'appears to allow the court to impose the values of the "reasonable person" to restrict the lawful decisions of parents, simply because a stranger to the decision has raised a question that the court is willing to consider', in fact this kind of 'draconian interference in parental discretion' is already avoided by the attitude the court takes, and in particular the respect it expresses for the importance of parental decisions. She argues that this, rather than a harm threshold, is a better way to permit discretion and scope in parenting while protecting vulnerable children from harmful decisions.[39]

We might also note that clinicians do already take account of parental views well before the court is involved. Giles Birchley makes this point in his chapter, demonstrating from his empirical research as well as that of others that clinicians generally attempt to balance parental autonomy, parental needs and the best interests of the child when deciding how to treat.[40]

Katie Gollop and Sarah Pope, both of whom appeared in the recent case of *Re R*, which also involved a dispute over a child's care, describe the process of decision-making as one in which 'everyone at the hospital including the lawyers … try hard to facilitate consensus building',[41] rather than one that is adversarial and against the parents.

Although the parents in these cases who have not been allowed to choose for their child as they wish certainly feel disempowered, that in and of itself is not enough to

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[39] Taylor (n 16).

[40] Birchley (n 6).

[41] K Gollop and S Pope, 'Charlie Gard, Alfie Evans and R (A Child): Why A Medical Treatment Significant Harm Test Would Hinder Not Help' (*The Transparency Project*, 2018) www.transparencyproject.org.uk/charlie-gard-alfie-evans-and-r-a-child-why-a-medical-treatment-significant-harm-test-would-hinder-not-help (11 June 2019).

demonstrate that the law as it stands and the processes within hospitals *actually* prevent parents having a sufficient say in the treatment of their children. There is substantial evidence to suggest that parental views are respected to a very great extent in the law and in practice, and so this concern alone is insufficient to support a move to a harm threshold.[42]

On the second point, on vexatious claims, Rachel Taylor argues in this volume that there is no need to import a harm threshold into medical decision-making because the courts already have the mechanism in place to avoid hearing applications with no merit. This is so because an application may only be made where the applicant can demonstrate a genuine interest in the child, regardless of whether the applicant is an individual or a state institution such as an NHS Trust. The courts, she argues, can use this to 'filter out vexatious or unwarranted applications' but it provides 'no substantial hurdle to the applicant with genuine welfare concerns'.[43]

B. Change will be Counter-Productive

In proposing change on the basis of principle, it is right to consider whether that change will produce adverse effects in practice. A number of ways in which a move to a harm threshold might do so have been raised. One concern is that moving to a harm threshold will entail shifting away from an approach that emphasises deciding what is *best for* a child, towards one that explicitly requires the court to demonstrate that is has authority because a parental decision will place that child at risk of harm. Giles Birchley suggests that this involves greater 'evaluative overtones',[44] directing the judge to evaluate the impact of a parent's decision and then determine whether that decision is likely to harm the child. It would, he rightly suggests, demand that their decision be explicitly characterised as 'harmful', and this could consequently have 'pejorative connotations'.[45] Rather than the court's intervention being framed as a mediation in a

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[42] See further on steps that might be made to improve current processes: L Austin and R Huxtable, 'Resolving Disagreements about the Care of Critically Ill Children: Evaluating Existing Processes and Setting the Research Agenda' in Goold et al (eds) (n 6).

[43] Taylor (n 16).

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

[45] ibid.

conflict between parents and medical practitioners, where the court takes the authoritative view on what is best for the child, the process would necessarily become one in which the court must determine whether the quality of the parents' decision means they can be overridden. The entire process changes by establishing parents as prima facie decision-makers who can then be overridden if they take a decision that is problematic. They have strong initial control but that control is contingent on how it is exercised, and that contingency is determined by the court's view on the risks posed by their decisions. Where parents are, in their own minds, doing everything they can to protect a loved child, such a determination might be particularly harmful. It is clear from Connie Yates' statement when they agreed to withdraw support from Charlie that the way her actions had been characterised by the media and courts had hurt her, and we should be rightly wary of harming parents who are already experiencing such a desperately sad situation. As Gollop and Pope write: 'It's bad enough to have a court finding that what you wanted for your child was not in your child's best interests. It's worse to have a court finding that you have caused your child significant harm.'[46]

Although it may be that in some cases parents will feel this evaluation of their position as a hurtful criticism, it is not clear that parents would necessarily find it any more distressing. However it is framed, a decision to prevent parents having the ultimate say over the treatment of their very ill child is likely to be devastating regardless. The harm derives from the thwarting of their desires, the belief that the alternative decision is one that will harm their child, or fail to save him when he or she could have been saved. This was clearly Connie Yates' view of what happened to Charlie.[47] But if this is so, then the framing of the basis on which the court can intervene will make little real difference, because, however, one phrases it, the essential position is the same – the court's view trumps the parents' view because the court's view (and therefore that of the doctors) is deemed more likely to be what is best for the child (or, conversely, less likely to be harming to the child). Therefore, this argument does not appear sufficient in itself to outweigh the benefits to parents in terms of their enhanced decision-making powers.

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[46] Gollop and Pope (n 41).

[47] ibid.

C. Change Will Make No Practical Difference

An alternative objection is that changing to a harm threshold will make no difference to how these situations play out – in hospitals and in the courts. If this is the case, then it might be suggested that there is no point in pressing for change. There are two senses in which this might be the case.

First, this is likely to be so because in fact cases rarely, if at all, come to court when there is *not* some risk of harm to the child. In this volume, Birchley and Wilkinson, both of whom work in the medical system and interact with parents in exactly the sorts of situations that arise in these cases, note that medical practitioners do not generally pursue court intervention until they are worried that the child will be harmed by acceding to the parents' wishes.[48] This, in fact, is the very thrust of Jo Bridgeman's analysis of these cases – that they are instances where medics cannot agree to give parents what they want for reasons of professional conscience. They are being asked to do something that is not simply not in the child's best interests, but is in fact something they consider they cannot, morally, do.[49] As Wilkinson comments:

> Paediatricians and general practitioners spend a good deal of time counselling parents and encouraging them to make health care decisions for their children that are likely to promote the child's interests. However, if parents make suboptimal decisions, professionals will usually only seek to override parents if what parents have decided poses a real risk of harming the child.[50]

That harm is generally a key issue is evident, too, from the considerations that the judges examine in their determinations.[51] For example, in *Gard*, the Court of Appeal noted in its conclusion on best interests that: 'It must follow from that unanimous professional and expert evidence, that to move Charlie to America and expose him to treatment over there would be likely to expose him to continued pain, suffering and distress.'[52]

Harm is at issue in most, if not all, of these cases, which given how clinicians tell us they approach these situations, is to be expected. Therefore, it is fair to say that in

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[48] Birchley (n 7); Wilkinson (n 7).

[49] Bridgeman (n 28).

[50] Wilkinson (n 7).

[51] See, eg: *Gard* (HC), [16-22]; *Gard* (CA), [49] [97] [114].

[52] *Gard* (CA), 114.

combination with the discretion already afforded to parents by the courts and the application of a ‘reasonable-parent’ approach to difference, that a de facto harm threshold is already being applied. A move to an overt one would make no difference in practice. Whether this is a reason to make a shift, however, is therefore necessarily dependent on other considerations.

It may mean that a change in the law is unwarranted. On this analysis, it is more likely to mean that the harm threshold is more in keeping with the actual threshold being applied, both by medical professionals when they refrain from requesting judicial intervention, and by courts when they refuse to override a parent’s wishes. Therefore, a move in favour of a harm threshold will not have a *problematic* impact, but it will carry the signalling power of bolstering parental confidence that their wishes will be respected, while offering a clearer line for clinicians to engage with about when to request judicial input. Alternatively, as Gollop, Pope and Taylor suggest, being explicit in response to parents that their decisions are considered harmful may itself be an unnecessarily harsh response for no practical gain (or, as Gollop and Pope argue, with unhelpful impacts). These considerations are examined below.

D. A Harm Threshold Will Privilege Parental Views

A core tenet of child law is that the child’s welfare takes precedence above other concerns, including parental ‘rights’. As Taylor writes: ‘[T]he law regards the upbringing of children not as a matter of exclusive parental rights, to be defended unless forfeited, but as a collaborative responsibility in which parents take the leading role.’

The move to harm threshold is based on a desire to make parents the primary arbiters of a child’s welfare by constraining the courts’ power to intervene. This was the view put in *Gard*, and is the justification behind ‘Charlie’s Law’ – that parents should have substantially stronger decisional rights in relation to their children. As Taylor notes, those who support this position can raise ‘understandable concerns’ that the rejection of this approach in *Gard* ‘undermines parental freedom’. But, she argues, the law already recognises the value of parents taking the primary role in determining their child’s welfare. This view is borne out in many judicial statements on the nature of the court’s jurisdiction and its role in disputes. A harm threshold, Taylor suggests, would effectively carve out a space for parental decisions to be ‘immune from challenge’.

One response to this is that the only decisions that would become immune to challenge are precisely those decisions that already are essentially treated in that way. Where parents' decisions fall within what the court considers the range of reasonable parenting, the court does not concern itself, nor do hospitals tend to dispute these decisions. As we saw above, clinicians tend to accede to decisions that fall within this sphere, unless there are reasons to resist doing so.[53] Therefore, currently they are in effect immune, and if the threshold is changed, they will just be more overtly protected. We might also say that a shift would at least make the threshold parents face clearer and more intelligible.

5. In Favour of a Harm Threshold

A. Parents as Prima Facie Decision-Makers

One of the key arguments made in favour of a move to a harm threshold is that it better reflects the parents as the appropriate decision-makers on behalf of their children. This was the basis for much of the anger around the *Gard* and *Evans* cases, and is certainly the position taken by the parents in those cases. Many good reasons for treating parents as prima facie decision-makers for their children can be identified, and this is recognised by the courts as noted above. There are, of course, also many instances where we do not believe this to be the case and the law restricts parents (and children) with this in mind.[54]

One reason is that parents must make a great many choices for their children, and if the state were to police these, it would entail regular invasive monitoring. This would undermine our commitment to respecting privacy and family life in liberal democratic

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[53] For example, Jonathan Herring suggests that clinicians might care about a parents' *motives*, such that a slightly harmful procedure might be tolerated if the parent thinks it will help and the doctor is less confident of this, but might be resisted by the doctor if the parent wants it purely to make money by selling the child's story, or because the parent is affected by a condition such as Munchausen syndrome by proxy.

[54] Compulsory education, film classifications, smacking and alcohol consumption are all examples. I am grateful to Jonathan Herring for this point.

society, and practically, would require vast resources to administer, implement and police.[55]

Another is that in fact many everyday decisions made on behalf of children do not require special skills: most adults can make these decisions relatively well and there is no reason to think that anyone else would likely do better. Therefore, there is little reason to suspect that they need to be policed, or that another party could make these decisions better. Further, the majority of these are trivial decisions that do not, individually, have very large impacts on the child. That some less-optimal choices are made is tolerable, and also allows for differences in parental resources and capacity. These are also best balanced and navigated by parents within the context of the particular family.

Both of these reasons are less likely to hold, however, in the context of medical decisions. In such contexts, the courts *do* have the resources to supervise some of these decisions. Also, the consequences for a child of having or not having treatment may well also be grave. This does not mean parents should immediately yield, because there are other reasons that mean parents ought to retain a degree of authority. One is that parents may be best placed to know what is in their child's interests based on their knowledge of the child's preferences.[56] The parent is also very likely to be motivated largely by care and love for the child, and hence be making a decision aimed at promoting the child's interests. As such, a parent's decision may be more likely to lead to the option that does, in actuality, benefit the child most where that is a decision of *value* (that is, a decision about how to live one's life and what will make it go well).[57]

Allowing parents a fair degree of latitude in decision-making may also benefit the children in other ways. For example, Goldstein suggests that 'the right of parents to raise their children as they think best, free of coercive intervention, comports as well

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[55] J Goldstein, 'Medical Care for the Child at Risk on State Supervision of Parental Autonomy' (1977) 86 *Yale Law Journal* 645, 650.

[56] D Diekema, 'Parental Refusals of Medical Treatment: The Harm Principle as Threshold for State Intervention' (2004) 25 *Philosophy of Medical Research and Practice* 243, 244.

[57] This is in contrast to decisions about medical treatment that are about which treatments are likely to work and so forth, as these rest on the application of specialist knowledge rather than a position about value and experience.

with each child's biological and psychological need for unthreatened and unbroken continuity of care by his parents'.[58]

Within the medical context, supporting parents as far as possible to be decision-makers is therefore likely to support the familial connections that may be vital to their well-being. Society values the family unit, and as Diekema argues, families *need* to be able to make decisions about themselves with some degree of autonomy and with 'sufficient space and freedom from intrusion from others' to flourish.[59]

There is also the fact that it is parents, along with the child, who will ultimately bear the burdens that flow from the decision. Where, as is almost invariably the case, parents want treatment to continue, it is they who will carry the care burdens that may result. This would seem to be quite a strong reason for them to have a considerable say over what treatment the child receives. As Erica Salter puts it: 'Parents, as the central leaders and bearers of responsibility and accountability for the family, are also generally the central bearers of these decisional consequences.'[60]

Douglas Diekema supports this view with the further point that decisions about a child often affect other family members, and require that parents 'weigh the competing interests … in making a final decision'.[61] Parents are best placed, often, to achieve this balance, and giving them the authority to do so is more likely to support the family unit remaining cohesive.

These reasons do not, of course, hold in all situations. There are parents who make unwise, irrational decisions. There are parents who are not motivated by love and care for their children. But these are the exceptional cases, and are not sufficient, therefore, to speak against a prima facie role for parents as decision-makers who can be displaced. A harm threshold much better reflects this trust, while retaining plenty of space for overriding the decisions of parents where these things are not true – where the parents do not appreciate their child's interests, or are not motivated by care for the child – as the court can still intervene if the consequences seem likely to be unacceptable.

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[58] *Bolam* (n 55), 649.

[59] ibid.

[60] E Salter, 'Deciding for a Child. a Comprehensive Analysis of the Best Interest Standard' (2012) 33 *Theoretical Medicine and Bioethics* 179, 181.

[61] 'Lady Hale's explanation' (n 56), 244.

B. Transparency and Reflecting Practice

Above we saw that in many ways, the law and clinicians already operate on the basis of a de facto harm threshold. We might then consider this is a reason not to change the system as it is already accords with the harm threshold, so there is no need to alter the law. To do so would be redundant. However, the fact that this is the practice already, but the law does not reflect actual practice, might also be a good reason to consider change. There may be situations in which it helps for parents to be given a clear message as to why their decision is being overridden. 'Best interests' leaves space for perhaps more dispute, while 'harm' is direct. This, of course, may be harming to the parents if, as noted above, the language is hurtful.

But if this is the threshold point at which clinicians bring in the courts, then we ought to be clear about why that is happening to enable both parties to have a clear, open, honest debate about why someone other than a parent may decide. If a real harm cannot be demonstrated, then it may be clear also that there is not a sufficient reason to override parents' wishes. A best-interests approach may obscure the basis for the court making the decision, while harm overtly engages with a parental failure to act in accordance with the welfare of the child. It more accurately reflects the actual position of parents in the law, that is as individuals with *authority* and *responsibilities*, but not rights.

C. Tolerance and Value Decisions

Perhaps the strongest reason, however, to prefer a harm threshold picks up where the clarity and directness point leaves off. There are many hard decisions about a child's care that need to be made, and some of these are on questions where there is space for reasonable disagreement. These will very often be questions of *value*, about what is important in life, about what makes a life go well. In the medical context, a good example is the question of whether length or quality of life is more important. Such a question is often one that challenges the courts in cases of this kind. Indeed, as I have argued elsewhere, the difficult cases that challenge the courts and put pressure on where the right line for intervention lies concern disputes not of fact, but of *value* or *belief*.[62] The courts find these difficult precisely because they test our commitment to respect

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[62] Auckland and Goold (n 8).

for plurality of values, pitting our commitment to respect for belief against the communal responsibility for the vulnerable in our society.

If we are really to respect difference and work towards a respectful, pluralistic society, we need to leave space to allow for people to make different decisions about important things. The care of a child is one of these. Some might value more time with their child. Some might think that there are vital features of a good life that others do not value, and these might be intellectual, physical or emotional. A best-interests approach does a poor job of cutting through these issues precisely because once we tolerate difference, we have to tolerate the view that there can be more than one 'best' for a person, dependent on what is considered valuable. Where that person cannot speak for themselves, as the children in these cases cannot, then best interests will not help in many cases to yield an answer. A harm threshold, by contrast, does a better (if still imperfect) job by leaving it first to parents to make these decisions of value within the context of their own family, their own values and their knowledge of their child. But it also retains a protective fallback in the form of limiting parental discretion at the point where harm arises. Harm of the vulnerable is the point at which others should step in to protect them; it is the point at which the value determination demands further voices to explore what should be done for the child. We can debate the nature of harm, and we might import notions of dignity and the like into it, but it at least offers a clearer, more effective point at which to override parents.

6. Conclusion

The debate over when the courts can intervene in the decisions made in relation to a child is by its nature highly emotive. Parents in such situations will almost invariably be distressed and fighting for their children. Hospital staff will also be fighting to save this child, but also fighting to do their best to ensure that child is not in needless distress. Courts must step into the middle when relations break down, and when they do so they step into a sphere of life that is otherwise private. We must, therefore, be very careful to ensure the line is clear and appropriate. The debate around where that line should lie is naturally complex, as the chapters in this volume demonstrate. But, on balance, the stronger case lies for the harm threshold.