

Resolving Disagreement: A Multi-Jurisdictional Comparative Analysis of Disputes about Children's Medical Care

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Abstract

Recently, the English courts have had to make determinations in a number high-profile, emotive disputes over the care of very ill children, including Charlie Gard, Alfie Evans, and Tafida Raqeeb. It is perhaps fair to say such cases have become a regular feature of the courts in England. But is the situation similar in other jurisdictions? If not, are there lessons to be learned from these jurisdictions that do not seem to need to call on judges to resolve these otherwise intractable disputes? We argue that many of the differences we see between jurisdictions derive from cultural and social differences manifesting in both the legal rules in place, and how the various parties interact with, and defer to, one another. We further argue that while recourse to the courts is undesirable in many ways, it is also indicative of a society that permits difference of views and provides for these differences to be considered in an public manner following clear procedural and precedential rules. These are the hallmarks of a liberal democracy that allows for pluralism of values, while still remaining committed to protecting the most vulnerable parties in these disputes – children facing life-limiting conditions. While we may lament the painful playing out of a parent's worst nightmare in the courts, we should also see the value in enabling parents and hospitals this recourse because the alternative, we argue, is worse.

Keywords

- Best interests
- Children
- Decision-making
- Life-sustaining treatment
- Parental rights
- Comparative analysis

I. INTRODUCTION

Over the past few years, the English courts have been called upon to determine a number of high-profile and emotive cases involving disputes over what care should be given to a very ill child. The cases of Charlie Gard,¹ Alfie Evans,² Isaiah Haastrup³ and Tafida Raqeeb⁴ are well-known, having attracted considerable attention in the media and within the community generally, marked by acrimonious disagreement over who should have the final say in decisions about a child's medical treatment. Given that such cases have, it is perhaps fair to say, become a regular feature of the courts in England, we might imagine that other jurisdictions have had a similar experience, with disputes between parents and doctors likewise failing to find resolution without recourse to the legal system. We might think that this is simply a feature of such emotionally-charged and polarising disputes and that most if not all jurisdictions face similar challenges as our courts have in dealing with these situations. This, however, appears not to be the case. In fact, the English experience is arguably atypical, and for the most part, disputes of this kind in other jurisdictions do not give rise to the levels of complex, distressing litigation that we see in this country. Given this, we might wonder what other jurisdictions are doing in similar situations and whether there is anything we can learn to avoid such situations continuing to come before the courts in the future. This is the question we explore in this paper.

We came to this view of England and Wales as an outlier in the wake of producing (with Jonathan Herring), our edited volume, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective*.⁵ In that collection, we brought together reports on decision-making from a wide range of jurisdictions, looking at both the law and practice on parent/doctor disputes over the care of ill children. One clear difference that emerged from these reports was a difference in how often, if at all, disputes about the care of children end up being resolved in the courts. Across almost 30 jurisdictions covered in the collection, disagreements appeared to

¹ The case involving Charlie Gard is officially *Great Ormond Street Hospital v Yates and Gard* [2017] EWHC 972 (Fam), [2017] 4 W.L.U.K. 260 and so we refer to it as “*Gard*” when referring to the decision and the litigation.

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), [2018] 2 F.L.R. 1223.

³ *Kings College Hospital NHS Foundation Trust v Ms Thomas, Mr. Haastrup and Isaiah Haastrup* [2018] EWHC 127 (Fam), [2018] 2 F.L.R. 1028.

⁴ *Raqeeb v Barts NHS Foundation Trust & Anors* [2019] EWHC 2531 (Admin).

⁵ I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing).

end up being judicially resolved much more frequently in this country than in most other jurisdictions.⁶

In this paper, we therefore begin by explaining the background and findings of the collection, before going on to consider how, if at all, the English system might benefit from emulating the approach in other jurisdictions. To answer this, we must first understand *why* levels of litigation are lower in other countries, and we posit a number of possible explanations for this. We argue firstly that in many countries, one party (parents or medics), is afforded much more authority to make definitive decisions about a child's care. This has implications for how disputes are managed in practice, as well as being reflected in the legal frameworks in place (or, indeed, not in place). Second, and relatedly, we suggest that litigation levels may be explained by different approaches to conflict, which are partly culturally or socially determined. Third, drawing these points together, we demonstrate how they often result in jurisdictions employing different mechanisms for addressing disputes which do not require the involvement of the court.

With this analysis in place, we then explore whether we might benefit from emulating some aspects of the practice of other jurisdictions in England and Wales. We argue that while there are lessons we might learn, in many ways the differences in approach appear to arise because of different cultural perspectives on how disputes *should* be resolved, and that there are good reasons not to share those perspectives in this country. One reason for this is simply structural and procedural — it would be very difficult for the English system to reform itself to adopt that seen in a number of African jurisdictions, for example, where the goal is harmonious, communal decision-making. More importantly, however, the level of disagreement that has been seen in disputes of this kind is a reflection of the multicultural, multi-faith society that is modern England. If we accept (as we believe we should) that we should respect differences of value and belief, then it follows that we will not all always agree about what is 'best' in complex medical situations, where a balance might need to be struck between preserving life and ensuring a minimally acceptable quality of life, and where views about what risks are worth taking at what costs, may differ. When we do not agree, intractable disputes about care will arise. That we see these openly, if acrimoniously debated in this country, is precisely because ours is a society in which such open debate is permitted. The real question we need to focus on is how we can navigate those disputes to arrive at supportable decisions that adequately protect

⁶ The United States and Australia were also outliers.

children from harm while still leaving room for value difference. We briefly examine some alternative mechanisms for resolving disputes, such as clinical ethics committees and mediation, the latter being of particular interest given the Bill currently before Parliament which would require health authorities to attempt mediation before they could apply to the courts for resolution. We conclude, however, that courts remain the best final arbiters in difficult cases, albeit that to respect the value-plural nature of our society and its implications for the ‘best interests’ approach, the courts ought to be more overt about the values to which they are committed, to allow open debate about these.

II. CREATING THE COLLECTION: EXAMINING THE EXPERIENCES OF OTHER COUNTRIES

When we began writing about conflicts between parents and medical professionals, our focus was on the English law’s approach to such disputes. But as the international media’s interest in Charlie Gard and subsequent cases grew, one interesting dimension to their response was a widespread belief that the families would have had a different experience had they been in other countries.⁷ In the United States, for example, it was often felt that greater deference was accorded to parental choice for libertarian reasons, with the tragic case of Jahi McMath raised in support. The structure of the medical industry, especially when compared to the ‘despotic hospital system’ of England,⁸ also meant that if a patient has the insurance to pay for a treatment, it would generally be given. This prompted us to think about whether the approach in other jurisdictions was similar, and if not, whether these differences could be instructive about how the English approach might be improved, or perhaps vice versa. To explore this, we sought out scholars from Europe, North and South America, Africa, Asia and Australasia, to produce a collection covering nearly 30 jurisdictions from six continents, on which this paper draws.

⁷ See, for example, S. Scutti, ‘Could Charlie Gard’s case happen in the United States?’ *CNN* (6th July 2017) <https://edition.cnn.com/2017/07/06/health/charlie-gard-us-laws/index.html>; S. Scott and R. Armitage, ‘Charlie Gard: Could a personal and legal tragedy of a terminally ill baby happen in Australia?’ *ABC News* (24th July 2017) <https://www.abc.net.au/news/2017-07-24/could-a-charlie-gard-case-happen-in-australia/8735900>; W.J. Smith, ‘Charlie Gard Has Happened Here Too’ *National Review* (4th July 2017) <https://www.nationalreview.com/corner/charlie-gard-has-happened-here-too/>.

⁸ See, for example, S. Foley, ‘Could an Alfie Evans case happen in the US?’ *Relevant Radio* (26th April 2018), available at < <https://relevantradio.com/2018/04/could-an-alfie-evans-case-happen-in-the-united-states/>> accessed 10th August 2019.

In putting together that collection, we had a second goal: we wanted not just to elucidate and learn from the approaches in other jurisdictions, but to contextualise the differences (and similarities) against the cultural and social values of other jurisdictions that might inform (and partly explain) them. We theorized that even though in all jurisdictions subject to the United Nations Convention on the Rights of the Child (UNCRC), the fundamental principle remains the best interests of the child, the weight given to welfare varies from paramountcy to being ‘a’ primary consideration, and the responsibility of fulfilling the child’s best interests would often be distributed differently between parents, doctors and the courts. We therefore asked contributors to explain the normative foundations of their jurisdiction’s approach, and the values that inform both who has decision-making authority and how it is exercised. The results bear out our hypothesis, with the range of approaches evidencing that even when starting from very similar normative commitments, a legal system can, for numerous reasons, arrive at quite different ways of resolving conflicts. There is much we could say about the similarities and differences, but here we focus on one key point of comparison – the extent to which courts are called upon to resolve disputes.

III. DO OTHER COUNTRIES ALSO HAVE NUMEROUS CASES COMING TO THE COURTS?

Writing in a jurisdiction which has seen such regular, high-profile and highly fraught litigation on these issues, it was notable that in many of the jurisdictions examined in the collection, contributors reported a distinct *lack* of cases coming before the courts.⁹ While the *Gard*, *Evans* and *Raqeeb* cases are the most well-known disputes of this kind to arise recently in England, they are certainly not the only ones, and statistics published by the Children and Family Court Advisory and Support Service suggest that between 2015 and August 2019, at least 22 cases concerning the withdrawal of life-sustaining treatment were decided by the courts.¹⁰ This is, of course, something both parents and hospitals seek to avoid, and most similar situations are

⁹ Contributors from Greece, Hong Kong, Scotland, Botswana, Sweden and Ireland, amongst others, noted that is rare (in some cases almost to the point of no litigation at all) for such disputes to be taken before the courts.

¹⁰ Response to a Freedom of Information request made to Cafcass, 21st January 2020.

dealt with by hospitals without ever requiring court resolution.¹¹ It is clear however, that many, even if by no means the majority of such disputes, end up being resolved by the courts.

In stark contrast, contributors from many jurisdictions — Greece, Hong Kong, Scotland, Botswana, Sweden, Norway and Ireland, amongst others — reported there were no similar recorded court cases of this kind, or very few.¹² Some contributors suggested that disputes reaching the court was such a rare event that it was difficult to discern what would happen in a situation like that of Charlie Gard or Alfie Evans in their jurisdiction because the case law was so sparse (or non-existent), that there was no precedent on which to draw. Others suggested that given how infrequent such cases were, there were not even legal mechanisms for bringing such disputes before the court. For example, Admark Moyo reported that there are no legislative provisions that directly regulate parental consent to medical treatment of children in Botswana at all, which he suggests partly explains the scarcity of case law.¹³ Pernilla Leviner, writing on the Swedish approach, made similar observations, noting

The simple answer to these questions is that we really do not know much more than the little anecdotal information that health care providers relate. No similar cases have been tried in a Swedish court and as will become clear in this chapter, it is also unlikely that such cases would be brought to court due to the lack of such mechanisms in our legal system.¹⁴

While Sweden does have legal avenues by which at-risk children can be taken into care, Leviner reports that “this does not extend to a facility for medics to request intervention”. Doctors simply “do not have the opportunity to petition for the authority to decide on the medical care initiatives that are to be carried out or not”.¹⁵ Similarly in Thailand, even where doctors consider the parents’ decision does not serve the best interests of the child, “the doctor or the healthcare service provider does not have any legal standings to bring a case to the court

¹¹ See, for example, the results of Joe Brierley *et al*’s study, at n155.

¹² These views are supported in the wider literature, such as Norway: M. K. Bahu and R. Føerde, ‘Parents As Decision-Makers — Do the Attitudes of Norwegian Doctors Conform to Law?’ (2011) *European Journal of Health Law* 18 531-547.

¹³ A Moyo, ‘Parental Responsibility and Medical Decision-Making in Southern Africa: A Comparative Analysis of the Laws Governing Parental Consent to Children’s Medical Treatment and Surgical Operations in South Africa and Botswana’ in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing).

¹⁴ P Leviner, ‘Who Has the Final Word? On Trust and Legal Uncertainty Within the Swedish Healthcare System’ in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing).

¹⁵ P Leviner, ‘Who Has the Final Word? On Trust and Legal Uncertainty Within the Swedish Healthcare System’ in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing).

for judicial intervention of parental decisions”.¹⁶ In China meanwhile, Ding Chunyan explains that within Chinese procedural law, “a proper procedure is lacking that enables either doctors or other relevant parties to file an action to challenge the parents’ medical decision on behalf of children.”¹⁷ Nor is there the concept of ‘inherent jurisdiction’ and ‘wardship’, and so the courts there do not have jurisdiction to intervene in parental decisions regarding the medical care of children. It emerges, then, that not only is there a lack of case law on this issue in some countries, but a number of jurisdictions do not even have mechanisms in place for bringing such disputes before the courts. This is, of course, markedly different from the English system, which offers a clear pathway through which doctors can request judicial determination of whether a treatment is in the best interests of the child, whether under the inherent jurisdiction or via section 8 of the Children Act 1989. In fact, of the jurisdictions covered, only Australia and the United States appeared to have similar levels of judicial treatment of such conflicts;¹⁸ a finding supported by a comparative analysis of the United States and English approaches to such cases by John Paris *et al.*¹⁹

This raises the question of whether we could learn anything from the approaches of those jurisdictions where matters are rarely taken to court. Certainly there may be reason to think that avoiding the lengthy and highly-fraught litigation seen in England in recent years would be desirable. As Mike Linney *et al* describe in the Royal College of Child and Paediatric Health guidance, going to court is ‘time consuming and protracted with a profound psychological

¹⁶ T Tenguamunaay, ‘Parental Authoritarianism and Medical Decision-Making in Thailand: The Need to Limit Parental Authority’ in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing).

¹⁷ D Chunyan, ‘Medical Decision-Making on Behalf of Children in China: A Multidimensional Analysis of Parental Authoritarianism’ in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing).

¹⁸ See C. Stewart, ‘Children and Medical Decision-Making in Australia Post-Gard: A Possible Reformulation’ in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing); L. Francis, J. Botkin and D. Diekema, ‘Decision-Making on Behalf of Children in the Research and Clinical Context: A US Perspective’ in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing). See further on the United States approach: J J Paris, J Ahluwalia, B M Cummings, M P Moreland, and D J Wilkinson, ‘The Charlie Gard case: British and American approaches to court resolution of disputes over medical decisions’ *J Perinatol.* 2017 Dec; 37(12): 1268–1271.

¹⁹ J J Paris, J Ahluwalia, B M Cummings, M P Moreland, and D J Wilkinson, ‘The Charlie Gard case: British and American approaches to court resolution of disputes over medical decisions’ *J Perinatol.* 2017 Dec; 37(12): 1268–1271. The Paris paper did not distinguish between the English and Welsh system and the Scottish courts as they ought to have done. By United Kingdom, they seem to mean the English and Welsh system as none of the cases cited are Scottish. We have also, in paraphrasing, assumed they mean common community in England as it seems problematic to elide Wales and England as a single, homogenous community.

impact on families and staff'.²⁰ The English and Welsh court system is inherently adversarial, which necessarily means that one party must win, and the other lose. By agreeing with one party's assessment of the child's best interests over the others, judges implicitly send a message that one was right and the other wrong, which as Louise Austin and Richard Huxtable explain, 'is not necessarily an appropriate framing' for an issue which is not black and white, but 'replete with ethical shades of grey'.²¹ Although attempts can be made to mitigate this, the losing party may, as Margaret Brazier observes, feel they have been offered little more than 'kind words' from the judge.²²

Taking a matter to court may also serve to exacerbate, rather than diffuse, conflict.²³ Simon Meller and Sarah Barclay for example, have suggested that it 'tends to result in entrenchment and further escalation of already strongly held opinions'.²⁴ Thomas Fassier and Elie Azoulay meanwhile, found that staff in ICU generally regarded litigation as an 'inefficient' means of resolving disputes which 'may impair the grief process in the family members and amplify frustration among the ICU staff.'²⁵

There are also substantial costs involved in going to court — both financial and emotional. In the absence of legal aid, this financial burden may make applying to the courts prohibitively expensive for parents and in *Gard*, Mr Justice Frances made reference to the many parents around the country who 'have had to struggle to represent themselves' in such proceedings.²⁶ Absent a lawyer willing to work pro bono (or with a view to encouraging one to do so), some parents may turn to crowd funding to finance litigations, drawing even greater public attention to the dispute. This may have its own downsides, making it difficult for parents to change their position, even if circumstances change. The strength of feeling among some parts of Charlie and Alfie's 'Armies' that the parents should not 'back down' or 'stop fighting' despite multiple

²⁰ M Linney, RDW Hain, D Wilkinson et al, 'Achieving consensus advice for paediatricians and other health professionals: on prevention, recognition and management of conflict in paediatric practice' (2019) *Arch Dis Child* 104:413-16.

²¹ L. Austin and R. Huxtable, 'Resolving Disagreements about the Care of Critically Ill Children' in I. Goold, J. Herring and C. Auckland, *Parental Rights, Best Interests and Significant Harms* (Hart Publishing, 2019), 225.

²² M Brazier, 'An Intractable Dispute: When Parents and Professionals Disagree' (2005) 13 *Med L Rev* 412, 417.

²³ G. Birchley and R. Huxtable, 'Critical decisions for critically ill infants: principles, processes, problems' in C. Stanton et al (eds), *Pioneering Healthcare Law: Essays in honour of Margaret Brazier* (2016), p122.

²⁴ S. Meller and S. Barclay 'Mediation: an approach to intractable disputes between parents and paediatricians' (2011) *Arch Dis Child* 96:619-21

²⁵ T Fassier and E Azoulay, 'Conflicts and Communication Gaps in the Intensive Care Unit' (2010) 16 *Current Opinion in Critical Care* 654, 662.

²⁶ *Great Ormond Street Hospital v Yates & anors* [2017] EWHC 1909 (Fam), 17.

defeats in court is perhaps an illustration of this. Even for NHS Trusts who can afford the litigation meanwhile, long and complex court cases will inevitably take their toll on their budgets, taking resources away from primary care.

The emotional cost to the parties may be even greater, with parents forced to watch their personal tragedy played out on the world's stage, devoting considerable time and energy during the final moments of their child's life to an often fruitless legal battle. Nor are healthcare professionals left unscathed by the process. As Greenberg and Weingarten have noted, forcing them to participate in integrity-compromising situations, where they must act in a way that is inconsistent with what they believe to be the 'right or desired course of action' can cause them to suffer emotional distress, decreasing their job satisfaction and leading them to withdraw from patients.²⁷ Doctors may also fear the negative publicity that may result from a court battle. In the wake of *Gard* and *Evans*, which resulted in doctors being subject to abuse and even death threats,²⁸ one can hardly blame them.

Finally, these disputes are rarely short. As Jo Bridgeman explains, despite the *Gard* case being fast-tracked, it still lasted for five months²⁹ and the *Evans* litigation was similar. During this time, healthcare professionals must continue to treat the child even if they do not consider it in the child's best interests, and perhaps even harmful. This can have an affect not just on the child and the staff, but also on the care of other children. Despite reaching their fundraising target for Charlie's treatment the day before the first High Court hearing was due to begin, for example, Charlie remained in intensive care for a further four months before treatment was withdrawn.³⁰ The average stay in neonatal intensive care ordinarily is just seven days.³¹

Given this, there are clear reasons to avoid going to court where possible. It would therefore be valuable to understand how other jurisdictions manage to avoid this outcome. In the next

²⁷ RA Greenberg and K Weingarten, 'When health care professionals say "more" and parents say "enough"' *Paediatr Child Health* Vol 20 No 3 April 2015, 132-4, 133.

²⁸ See for example, the Open Letter written by Sir David Henshaw, Chairman and Chief Executive of Alder Hey Children's NHS Foundation Trust detailing the 'unprecedented personal abuse' sustained by staff <<https://alderhey.nhs.uk/contact-us/press-office/latest-news/open-letter-chairman-and-chief-executive-alder-hey-childrens-nhs-foundation-trust>>

²⁹ J Bridgeman, '*Gard v Yates v. GOSH*, the Guardian and the United Kingdom: Reflections on the Legal Process and the Legal Principles' (2017) 17 *Medical Law International* 285, 292.

³⁰ D. Wilkinson and J. Savulescu, *Ethics, conflict and medical treatment for children: from disagreement to dissensus* (Elsevier, 2018), chapter 4.

³¹ Neonatal Care Statistics: available at <https://www.bliss.org.uk/research-campaigns/research/neonatal-care-statistics/statistics-about-neonatal-care> accessed 1st March 2020.

section, we draw on the reports in our collection and other sources to try to shed some light on why many jurisdictions have such a different experience of these situations from England and Wales.

IV. DIFFERENT PERSPECTIVES ON WHO SHOULD DECIDE FOR A CHILD AND THEIR IMPLICATIONS FOR LEVELS OF LITIGATION

There are many ways in which countries differ in how they deal with disagreements over the medical care of ill children. We identify four key areas of difference that may help to explain the lower levels of litigation in other jurisdictions. Although some of these are inherently intertwined, we attempt to tease them apart here to elucidate as far as possible their distinct implications.

The first of these is different approaches to the *legal* threshold at which the court's authority to determine what should be done arises. Very strongly related to this is the second difference, namely that in many jurisdictions, one group is afforded a much stronger say about a child's care. In a sense, there is a 'dominant' voice to which other views tend to yield (be it the doctors or the parents), either in law or merely as a matter of practice. Underpinning these different approaches, but also shaping how disputes are managed more generally, are the social and cultural differences between jurisdictions. These naturally affect both legal frameworks and the practice of dispute resolution, and so play a part in whether a 'dominant' voice emerges, and when it is considered appropriate for the state to intervene. However, there are also wider implications of these differences, most clearly a tendency in some countries towards communal decision-making and consensus building. Finally, these differences crystallise into some countries adopting non-legal or quasi-legal mechanisms for resolving disputes. We focus on two: mediation and the use of ethics committees.

A. The Threshold Question: When Do Courts Have the Authority to Determine What May be Done?

In England and Wales, the threshold for the court having authority to make determinations about a child's medical care is low: the court may make a decision wherever the child's 'welfare' is at issue or their 'best interests' are not being met (used interchangeably in the case

law).³² A number of other jurisdictions mirror this position: Belgium, Spain, and Hong Kong amongst others also use ‘best interests’ as a threshold; and given the likelihood that the Scottish courts may follow the English example, a similar threshold probably operates under Scots law.³³ This position has come under fire in recent years in England, after counsel for the parents in *Gard* explicitly challenged the state’s authority (exercised via the court) to intervene in what were argued to be private, family decisions. Although the Court of Appeal was not swayed by arguments to adopt a harm-based threshold for judicial intervention,³⁴ the case prompted a highly-charged debate about who should have the final say about a child’s treatment.³⁵

However, despite the controversy in this country, our collection demonstrates that numerous other jurisdictions already appear to adopt some form of ‘harm threshold’. In Chile, for example, the threshold is one of risk of serious harm or death,³⁶ while the Mexican Supreme Court has held that parental authority is only limited when the rights of the child are put at risk, or their health threatened. In Ireland, the court will make a determination only in exceptional cases where the parents’ failure in their responsibilities is likely to prejudicially affect the safety

³² See *Portsmouth Hospitals NHS Trust v Wyatt* [2005] EWCA Civ 1181. This was confirmed by the Court of Appeal (and, in refusing permission to appeal, the Supreme Court) in *Yates & Anor. v Great Ormond Street Hospital for Children NHS Foundation Trust & Anor* [2017] EWCA Civ 410.

³³ Alan Brown examines the question of whether the Scots courts will follow the English in A Brown, ‘Parental Rights’, ‘Best Interests’ and the Withdrawal of Life-Sustaining Medical Treatment of Children in Scotland: A Lack of Authority’ in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing); I Goold, C. Auckland and J. Herring, ‘Medical Decision-Making on Behalf of Children in English and Welsh Law: A Child-Centred Best Interests Approach’ in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing). This is particularly likely as the English dicta align fairly easily with ‘welfare test’, set out in section 11 (7) (a) of the Children (Scotland) Act 1995, which covers disputes regarding all aspects of ‘parental responsibilities’ and ‘parental rights’. s.11 of the Children (Scotland) Act 1995 sets out the court’s powers in relation to parental responsibilities and rights; in particular s.11 (2) provides that, ‘[t]he court may make such order...as it thinks fit’.

³⁴ See, however, the ongoing campaign to introduce changes via what is known as ‘Charlie’s Law’: <https://www.thecharliegardfoundation.org/charlies-law/>. We will discuss this later in this piece.

³⁵ See for example, C. Auckland and I. Goold, ‘Parental rights, best interests and significant harms: who should have the final say over a child’s medical care?’ (2019) *The Cambridge Law Journal* 1-37; D. Archard, ‘My child, my choice’: parents, doctors and the ethical standards for resolving their disagreement.’ (2019) *Northern Ireland Legal Quarterly* 70(1): 93-109; S. Shar, A. Rosenberg and D. Diekema, ‘Charlie Gard and the Limits of Best Interests’ (2017) *JAMA* 171(10): 937-938; 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/.

³⁶ F Lathrop Gómez, ‘Decisions About Their Body: Children’s Rights and Parental Responsibility in Chile’ in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing).

or welfare of any of their children³⁷ — a parental refusal for their child to receive a heel prick test to screen for disorders at birth was not, for example, sufficient.³⁸ Swiss law meanwhile, requires that the parents’ wishes pose serious endangerment to the child’s health, although if the doctors treating the child consider that this poses a significant risk to the child’s welfare, they can involve the child protection authority.³⁹ Calvin Ho and Sharon Kau, too, note that the threshold in Singapore is effectively a significant harm threshold and the courts have consistently reflected the view in their judgments that judicial intervention “should be an avenue of last resort”.⁴⁰

Even in countries where the legal threshold is best interests, it may be that in practice the courts apply something closer to a harm threshold. This could explain the outcomes in English cases: while in both *Gard* and *Evans*, the court supported applications by hospitals to withdraw life-sustaining treatment against the wishes of the parents, as the recent *Raqeeb* decision suggests, where the child is unlikely to suffer harm, life-sustaining treatment may be permitted to continue, even though doctors do not consider it in the child’s best interests.⁴¹ Similarly in *Director Clinical Services, Child & Adolescent Services v Kiszko*⁴² in Australia, Thackray CJ was clear that the court ‘should not interfere in the exercise of parental responsibility unless there is some clear justification for doing so’,⁴³ a statement which Cameron Stewart regards as “very close in flavour to the principle of ‘risk of significant harm’”, suggesting as it does “primacy for parental decision-making and a preference for the court not exercising power in cases when the parental decision is clearly not incorrect or badly made.”⁴⁴ Leslie Francis et al

³⁷ L. Bracken and J. Lombard, ‘Medical Decision-Making on Behalf of Children in Ireland’ in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing).

³⁸ L. Bracken and J. Lombard, ‘Medical Decision-Making on Behalf of Children in Ireland’ in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing).

³⁹ A. Buechler, ‘Parental Decisions on their Children’s Medical Treatment’ in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing).

⁴⁰ C. Ho and S. Kaur, ‘Parental Rights, Best Interests and Significant Harms: Singapore and Malaysia Perspectives on Medical Decision-Making on Behalf of Children’ in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing).

⁴¹ *Raqeeb v Barts NHS Foundation Trust & Anors* [2019] EWHC 2531 (Admin).

⁴² [2016] FCWA 34.

⁴³ *Ibid*, [67]-[68]. This was later reiterated by O’Brien J in *Director Clinical Services, Child & Adolescent Services v Kiszko* [2016] FCWA 75 (*Kiszko* 3) at [72].

⁴⁴ C. Stewart, ‘Children and Medical Decision-Making in Australia Post-*Gard*: A Possible Reformulation’ in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing).

meanwhile, argue that the approach in the United States, in some states at least, is similar.⁴⁵ They suggest that ‘the state generally respects parental decisions except when they place a child’s health, well-being, or life in jeopardy’,⁴⁶ although Paris et al have noted that this may be shifting more towards a best interests approach.⁴⁷ What emerges from this is that the legal threshold for intervention is only a very small part of the story, with the mechanisms available for bringing disputes before the courts, and differing cultural attitudes on who ought to have decisive say being far more important in practice to the outcome of cases. This is perhaps clearest in China, where although Article 35 of the *General Provisions of Civil Law 2017* (‘GPCL’) requires guardians to exercise their responsibilities in accordance with the child’s best interest, in practice:

the best interests of the child principle laid down in article 35(1) of the GPCL has hardly restricted how guardians make proxy medical decisions for children. Hospitals and medical practitioners always follow the guardian’s proxy medical decision even though it appears prejudicial to the child where the guardian refuses a treatment proposed by the treating doctor.⁴⁸

This is unsurprising given the high level of deference to familial decisions (explored below), and the lack of procedural rules for dealing with conflicts where the child’s best interests are clearly not being met. Nonetheless it suggests that when attempting to learn from the approach of other jurisdictions, one must look beyond merely the legal structures in place.

B. Culture, Society, Family: Who Decides for a Child?

Alongside these legal thresholds, we can also discern practices, as opposed to legal frameworks, that afford one voice *de facto* authority over others where there would otherwise be dispute. In order to understand these, we will consider them in conjunction with the wider social and cultural forces that shape how a jurisdiction approaches these situations.

⁴⁵ L. Francis, J. Botkin and D. Diekema, ‘Decision-Making on Behalf of Children in the Research and Clinical Context: A US Perspective’ in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing).

⁴⁶ L. Francis, J. Botkin and D. Diekema, ‘Decision-Making on Behalf of Children in the Research and Clinical Context: A US Perspective’ in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing).

⁴⁷ J J Paris, J Ahluwalia, B M Cummings, M P Moreland, and D J Wilkinson, ‘The Charlie Gard case: British and American approaches to court resolution of disputes over medical decisions’ *J Perinatol.* 2017 Dec; 37(12): 1268–1271

⁴⁸ D Chunyan, ‘ Medical Decision-Making on Behalf of Children in China: A Multidimensional Analysis of Parental Authoritarianism’ in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing).

In English law, parents' authority to consent to or refuse treatment on behalf of their child must be exercised in a manner that promotes the child's welfare.⁴⁹ As Lady Hale explained, "parents are not entitled to insist upon treatment by anyone which is not in their child's best interests".⁵⁰ While the medical team are therefore entitled to apply to the court in the event that they disagree with the parents over the best course of action for the child, in practice, Dominic Wilkinson explains that medical teams generally defer to parental wishes unless the child is likely to be harmed:

Paediatricians and general practitioners spend a good deal of time counselling parents and encouraging them to make healthcare 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.⁵¹

While no jurisdiction conceived parental 'rights' as absolute, other countries took very different approaches to the question of when parents' authority to decide for their child ought to yield, notwithstanding the fact that all jurisdictions considered (barring the United States) had ratified the UNCRC⁵² and the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the application of Biology and Medicine. These legal differences in parental authority appeared to be underpinned by social and cultural differences, in particular over the centrality of the family unit in society. While we are conscious about not wishing to make sweeping or unsubstantiated generalisations about other cultures, it was notable that some jurisdictions reported that parental and familial views held much greater authority than they do in England and Wales. For example, Daisy Cheung explained that Confucianism continues to guide behaviour in Chinese societies, such as China, Hong Kong and Taiwan,⁵³ according to

⁴⁹ *Wyatt v. Portsmouth NHS Trust* [2005] EWHC 117 (Fam); *Great Ormond Street Hospital v Yates and Gard* [2017] EWHC 972 (Fam) (Gard); *Great Ormond Street Hospital for Children NHS Foundation Trust v Yates* [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 AFCASS 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). *Raqeeb v Barts NHS Foundation Trust & Anors* [2019] EWHC 2531 (Admin).

⁵⁰ "Lady Hale's Explanation of the Supreme Court's Decision", as delivered in court on 8 June 2017, available at <<https://www.supremecourt.uk/news/permission-to-appeal-hearing-in-the-matter-of-charlie-gard.html>> (accessed on 20 March 2019).

⁵¹ D. Wilkinson, 'In defence of a conditional harm threshold for paediatric decision-making' in I. Goold, J. Herring and C. Auckland (eds) *Parental Rights, Best Interests and Significant Harms*, 92-93.

⁵² UN-CRC of 20 November 1989.

⁵³ D. Cheung, 'Medical Decision-Making on Behalf of Minors: The Hong Kong Context' in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing).

which the key unit for decision-making is the family, and not the individual. Edwin Hui has similarly argued that:

Most modern people in the West adopt an ‘individualist worldview’, i.e. they regard personal values held by individuals as more valid than the collective values held by a given social entity such as the family. In contrast, East Asian people have a ‘familist worldview’: individuals take their values from the collective values of the family. Traditionally, a Chinese person’s existence is entirely ‘family-centred’. He depends on his family for his identity and for all his financial, physical, emotional and spiritual needs. Without a family he has nowhere to go and no one to trust. For China and many of her neighbouring countries, familism has been traditionally attributed to Confucianism.⁵⁴

The centrality afforded to the family in Chinese societies means that, as Cheung explains, ‘medical decisions are to be made by the family as a whole, with the emphasis being on ‘harmonious interdependence’’.⁵⁵ Hui further explains that it is the family who have ‘authority as interpreters of the patient’s best interests’;⁵⁶ in particular, the father is ‘responsible for maintaining family integrity and harmony’⁵⁷ and so his authority ‘is supreme and final’.⁵⁸ The result is that ‘physicians in Chinese societies may be less willing to contradict family decisions because this can be seen as disruptive of family harmony and integrity’,⁵⁹ which may help to explain why there are ‘very few examples of such decisions’ in the case law.⁶⁰ Ding Chunyan, writing in China, similarly observed that medics largely defer to parental decisions, although she attributed this in part to “strained relationships” between families and doctors. This deference, she suggests, enables parents to make decisions in the interests of the family as a whole (rather than just the child), taking into account “financial burdens of the family, the interests of other children in the family, the impact on the career of adult family members, the

⁵⁴ E. Hui, ‘Parental Refusal of Life-Saving treatments for adolescents: chinese familism in medical decision-making re-visited’ (2008) *Bioethics* Vol 22(5): 286–295, 286-7.

⁵⁵ D. Cheung, ‘Medical Decision-Making on Behalf of Minors: The Hong Kong Context’ in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing).

⁵⁶ E. Hui, ‘Parental Refusal of Life-Saving treatments for adolescents: chinese familism in medical decision-making re-visited’ (2008) *Bioethics* Vol 22(5): 286–295; citing R. Fan & B. Li. ‘Truth Telling in Medicine: The Confucian View’ (2004) *J Med Philos* 29: 179–193.

⁵⁷ E. Hui, ‘Parental Refusal of Life-Saving treatments for adolescents: chinese familism in medical decision-making re-visited’ (2008) *Bioethics* Vol 22(5): 286–295, 286-7.

⁵⁸ *Ibid.*

⁵⁹ D. Cheung, ‘Medical Decision-Making on Behalf of Minors: The Hong Kong Context’ in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing).

⁶⁰ D. Cheung, ‘Medical Decision-Making on Behalf of Minors: The Hong Kong Context’ in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing).

implications for family life etc.”⁶¹ The result is that she reports that the courts in China “have never intervened in a guardian’s medical decision for a child”,⁶² even in cases of parental refusal of treatment for conditions that are curable.

Other countries also reported parents having extensive authority when it comes to making medical decisions for their child. According to Thitinant Tengaumnay for example, in Thailand this offers an explanation for the lack of judicial intervention in the parents’ decision-making, and the lack of “legal provisions setting particular checks or reviews on parental decisions concerning their children’s medical treatment”.⁶³ She argues that Thai doctors often remain passive in the face of parental decisions with which they do not agree, asserting that doctors “would not provide health treatment that opposes the parents’ decision”. In Peru meanwhile, Paula Siverino Bavio likewise states that doctors tend to avoid conflict and defer to parental desires to continue treatment for fear of being regarded as having illegally failed to treat.⁶⁴ She noted that

If the *Gard* case had happened in Peru, and the parents had been able to afford the treatment, their will would have been fulfilled. It is unlikely that the medical team would oppose, let alone legally fight to achieve the withdrawal of life support.⁶⁵

In these countries, the low levels of litigation seem to be explained in part by medical teams deferring to the parents wishes, even where they might disagree, rather than taking matters to court. This was also borne out in a study in Norway, where there are similarly few cases.⁶⁶ Researchers presented doctors with a hypothetical case concerning a critically ill child, whose parents are insisting on life-prolonging treatment that, on medical opinion, is futile. The study found that doctors would defer to parents ‘to a greater extent than justified by the law,

⁶¹ D Chunyan, ‘Medical Decision-Making on Behalf of Children in China: A Multidimensional Analysis of Parental Authoritarianism’ in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing).

⁶² *ibid.*

⁶³ T Tengaumnay, ‘Parental Authoritarianism and Medical Decision-Making in Thailand: The Need to Limit Parental Authority’ in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing).

⁶⁴ P Siverino Bavio, ‘Who Decides the Best Interests of the Child in the End-of-Life Process? A Look at the Peruvian and Argentine Reality’ in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing).

⁶⁵ *Ibid.*

⁶⁶ K. Sovig, ‘Reviewing Medical Decisions Concerning Infants Within the Norwegian Health Care System – A public Law approach’ in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing).

sometimes in contravention of the child's best interests'⁶⁷ and a majority would give intensive treatment to a child, despite it not being medically indicated and notwithstanding the Norwegian Patients Rights Act being clear that doctors are permitted to make their own evaluation of best interests and need not follow parental requests.⁶⁸ Most would have attempted to influence parents to change their minds first, but 5% would said they would not have even tried to dissuade parents. In their explanations for this, doctors tended to focus on the parents' authority and responsibility for the child. One said 'treating a child in conflict with the wishes of the parents is almost equivalent to treating a patient against his or her own will', while another suggested that 'if the parents insist, it seems unreasonable to refuse.'⁶⁹

In some jurisdictions, however, deference appeared to be paid to the medical professionals rather than to families, again potentially resulting in much lower levels of dispute and recourse to the courts. In relation to Malaysia for example, Ho and Kau observed that:

The fact that the courts have never been asked to intervene in a situation where parents and healthcare providers disagree about a child's treatment options is instructive. Malaysian parents may be reluctant to challenge decisions made by healthcare providers. There is some evidence that parents in most instances defer to recommendations of doctors.⁷⁰

In Sweden, Leviner explains that there is a "high degree of trust" of individuals for one another and for public institutions, particularly the medical profession, who have traditionally enjoyed substantial respect as a profession.⁷¹ In her view, this may have led to a greater degree of deference to the view of the medical professionals, with families more likely to acquiesce rather than continue to voice their disagreement and resist. Similar observations were made by Monica Navarro-Michel writing about the experiences of Spain, who suggested that the fact that parents had *never* challenged doctors in the courts could be explained by the fact that

⁶⁷ M. K. Bahus and R. Føerde, 'Parents As Decision-Makers — Do the Attitudes of Norwegian Doctors Conform to Law?' *European Journal of Health Law* 18 (2011) 531-547. The results were based on over 400 respondents with relevant experience with critically ill children.

⁶⁸ Lov om pasientrettigheter [Act on Patient Rights] LOV-1999-07-02-63.

⁶⁹ M. K. Bahus and R. Føerde, 'Parents As Decision-Makers — Do the Attitudes of Norwegian Doctors Conform to Law?' *European Journal of Health Law* 18 (2011) 531-547, 538.

⁷⁰ C. Ho and S. Kaur, 'Parental Rights, Best Interests and Significant Harms: Singapore and Malaysia Perspectives on Medical Decision-Making on Behalf of Children' in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing).

⁷¹ P. Leviner, 'Who Has the Final Word? On Trust and Legal Uncertainty Within the Swedish Healthcare System' in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing).

physicians are highly respected in Spain, ranking top of the most trusted professionals.⁷² We would tentatively suggest that in these jurisdictions, one ‘voice’ tends to be dominant, and others yield to it, and that therefore disputes are less likely to arise. By contrast, in the much more litigious United States, a study of American paediatricians found that a majority would override parents with whom they disagreed (on a treatment refusal) if they felt treatment was in the child’s best interests.⁷³

Other jurisdictions meanwhile, reported taking a much more communitarian approach to decision-making, rather than allowing one voice to dominate, and this too appeared to be associated with lower levels of litigation. For example, both contributors from African countries⁷⁴ noted a communitarian approach to decision-making in the jurisdictions considered which, coupled with a commitment to resolving disputes by avoiding conflict, meant disputes rarely found their way into the courts. This was bolstered by the central position occupied by the family in some African countries. As Moyo comments, for example, both South Africa and Botswana

are largely inhabited by ethnic groups that are predominantly communitarian and therefore view children as an integral or inseparable part of the family. Communitarian cultures and societies pose a serious challenge to the individualistic nature of rights, particularly those of children. Children’s rights potentially clash with African cultural ideology because the latter emphasises collectivism, reciprocal duties of support and restraint on individual rights. Hence, the preservation of group identity is thought to be in the interests of the child and the interests of the family. There is an attempt to limit conflict at all costs, even though this may mean a violation of children’s rights to medical treatment and access to health care services.⁷⁵

Samuel Ujewe suggests that this communitarianism is a feature of the “African ethics outlook” wherein

communal responsibility takes centre stage and the moral frame of reference is underpinned by the network of communal relationships. The ethic of communal responsibility emphasises a preoccupation with the wellbeing of whole communities or societies; not simply of individuals constituting them. It motivates individual members to seek the good of the community or

⁷² M. Navarro-Michel, ‘Young children and healthcare decisions in Spain: Who decides?’ in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing).

⁷³ E. Talati, C. Lang, L. Friedman Ross, ‘Reactions of Pediatricians to Refusals of Medical Treatment for Minors’ *Journal of Adolescent Health* 47 (2010) 126-132.

⁷⁴ Who between them discussed Tanzania, Northern Nigeria, Uganda, South Africa, and Botswana,

⁷⁵ S. Ujewe, ‘Making Decisions for Children in Healthcare and Medical Research: African Communal Responsibility or Individual Rights?’ in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing).

society as a whole, in virtue of which they also seek their own good and build a firm basis for a sustained wellbeing.

Consequently, he explains, “[r]estoring the health of the family member, especially if they are a child: “...cannot be a matter for doctor and patient alone: it demands the participation of the entire community”.⁷⁶ Highly communitarian cultures may therefore also correlate more strongly with lower levels of litigation.

All of these approaches are fairly distinct from the English experience, where no voice (other than eventually that of the court) tends to dominate. This is illustrated by the very fact that so many cases end up in the courts, with neither party having been prepared to yield, but it was also evidenced in the deeply divided public discourse that followed the recent cases of *Gard* and *Evans*, which showed that far from there being a clear and dominant perspective in this country, significant differences of opinion exist about who is best placed to decide what is best for a child (and accordingly whether the parents should or should not have been allowed to take the child abroad for treatment in these cases). Not only is there no homogenous perspective in this country on whether it is doctors or parents who ought to have the decisive say in disputes of this kind, but England and Wales also clearly do not share the collectivist outlook seen across some African jurisdictions and there is rarely a wider communal response to such questions. Given this, we may ask what, if anything, we can learn from the way that other countries approach these disputes, informed as they are by social and cultural values which are not necessarily shared in England and Wales.

C. Can We Learn from these Perspectives?

In order to critically evaluate whether can achieve a reduction in litigation by making some changes inspired by this comparison (and whether this would be desirable), it is first necessary to consider why such disputes are arising, and what the nature of the disagreement is in these cases. Only then can we appraise how we might otherwise avoid or resolve such disputes.

Deciding whether to offer further treatment to a seriously ill child engages not just medical considerations, but a range of emotional, psychological, relational and spiritual interests of the child. When determining the child’s best interests, the decision-maker must then balance these

⁷⁶ Ibid, quoting from B. Bujo, *Foundations of an African Ethic: Beyond the Universal Claims of Western Morality* (New York, The Crossroad Publishing Company, 2001), 46-47.

different interests and factors against one another, to form a view about what, overall, is best for them. This necessarily involves a process of weighting, attaching greater importance to some interests or factors, and lesser importance to others. How one goes about this will inevitably be influenced to some extent by the decision-makers own values and beliefs, for example over the inherent value of life, what makes for a ‘good’ death, or what chances are worth taking and at what costs. As Alexander Kon observes, ‘deciding when the outcome of care will be a fate worse than death’ is a deeply personal matter: ‘there is no right or wrong answer.’⁷⁷ Perspectives may also change over time. In *Re B* in 1981 for example,⁷⁸ the English courts caused controversy when they authorised life-saving treatment for a child with downs syndrome against the wishes of her parents, yet it seems inconceivable now that a court would even contemplate refusing to authorise a straightforward operation to remove an intestinal blockage, where the child would otherwise die.

Different people, with different belief structures or values, or who ascribe different weights to medical considerations vis-à-vis other factors, might then reasonably weigh the interests differently, reaching a different assessment of the child’s best interests. As Ros McDougall explains:

a child’s well-being is made up of different elements, such as being free from pain, having a long lifespan, having meaningful relationships and being able to play. There is no straightforward way of calculating well-being and comparing it across treatment options to identify which would be best. And there are often several possible courses of action, each of which would benefit the child in different ways.⁷⁹

Disputes will therefore inevitably arise whenever doctors balance the child’s interests differently to parents. This may be as a result of differences in perspective, beliefs and values, which as Janine Winters explains, derive not merely from the person’s origin, but rather a person may be a part of different ‘cultures’: ‘their professional subculture, their culture of origin, and the prevailing societal culture’,⁸⁰ all of which will influence their values to some extent. Certainly there is some evidence that doctors may assess quality of life differently to parents. An empirical study by Paul Muirhead for example, found that while healthcare

⁷⁷ A. Kon, ‘When Parents Refuse Treatment for Their Child’ (2006) *JONA’S Healthcare Law, Ethics, and Regulation* Volume 8(1): 5-9, 7.

⁷⁸ *Re B (A Minor) (Wardship: Medical Treatment)* (1981) [1981] 1 W.L.R. 1421.

⁷⁹ R. McDougall, ‘When parents disagree with doctors on a child’s treatment, who should have the final say?’ *The Conversation* (7th September 2016).

⁸⁰ J.P. Winters, ‘When Parents Refuse: Resolving Entrenched Disagreements Between Parents and Clinicians in Situations of Uncertainty and Complexity’ *The American Journal of Bioethics*, 18(8): 20–31, 2018, 25.

professionals and parents ‘viewed the mild to moderately disabled states similarly’, ‘parents were more accepting of the severely disabled health state than health care professionals’.⁸¹

Douglas Diekema’s example of chemotherapy illustrates the scope for disagreement:

Although medical considerations are important, a child’s interests will also be affected by emotional and physical accompaniments of the chosen course. Best interests all too frequently may be reduced to objective medical interests alone. In discussing chemotherapy for a child with leukaemia, for example, medical professionals frequently focus on the fact that therapy will increase the child’s chance of survival while underestimating the negative aspects of cancer treatment. Some parents may place greater weight on the risks, side effects, discomforts, and disruptions that the child may endure in being treated, perhaps making the judgment that the increased chance of survival does not justify those burdens. Determining how these multiple factors ought to be weighed is no simple matter.⁸²

Best interests assessments then, especially when they relate to how and when it is best for a child’s life to end, are not solely medical decisions, nor are they susceptible to proof. Rather they are value-decisions, about what is important in life and what makes a life go well, over which people may — and do — legitimately disagree.

This was exemplified in the recent case of *Raqeeb*,⁸³ which concerned a young girl with severe and irreversible brain damage, who was in a minimally conscious state with little or no awareness. Her medical team concluded that she had no prospect of recovery, and that further treatment was therefore futile and not 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. Unlike in *Gard* and *Evans*, MacDonald J concluded that further treatment would be in her best interests. In doing so however, he noted that the answer to what was in her best interests rested on “subjective” and “highly value laden ethical, moral or religious factors” which “mean different things to different people in a diverse, multicultural, multifait society”.⁸⁴ In particular, he recognised that the inherent value or ‘benefit’ of continued existence was a question of value. Given ‘the religious and cultural tradition in which Tafida was being raised’, she *would* derive some benefit from continued life precisely because it would

⁸¹ Paul Muirhead, ‘When parents and physicians disagree: What is the ethical pathway?’ *Paediatr Child Health* Vol 9 No 2 February 2004 , 85-86, 85

⁸² D. Diekema, ‘Parental Refusals of Medical Treatment: The Harm Principle as Threshold for State Intervention’ (2004) *Philosophy of Medical Research and Practice* 25(4) 243, 248.

⁸³ *Raqeeb v Barts NHS Foundation Trust & Anors* [2019] EWHC 2531 (Admin).

⁸⁴ *Ibid*, [191].

enable her to live according to the tenets of the religion in which she was raised and ‘for which she had begun to demonstrate a basic affinity.’⁸⁵

In disputes of this kind, where the treating team and parents fundamentally disagreed over whether there was any inherent value to being kept alive in a heavily disabled and brain damaged state, it is difficult to see how consensus could ever have been reached. As Kon rightly observes, when parents objections derive from ‘religious, cultural, or personal beliefs, there may be no common ground on which the team and the parents can agree.’⁸⁶ This is further exemplified in the cases of Alfie Evans (whose parents were Roman Catholics) and Isaiah Haastrup (whose parents were Pentecostal Christians), both of which concerned whether further treatment ought to be given to severely brain damaged children. In the latter case Macdonald J noted the ‘strong religious component to the mother’s view of what should happen in this case’, according to which ‘it is not her right, or indeed anybody’s right, to say who should live and who should die.’⁸⁷ This is not to suggest that disputes are all over questions of values, and not matters of fact. In the case of Isaiah Haastrup for example,⁸⁸ the dispute was compounded by the parents’ refusal to accept medical facts about his prognosis put forward by both his treating team, and the independent experts appointed by them.⁸⁹ However it does demonstrate that differences of values have been a crucial component of many of the disputes that have come before the courts in recent years, as acknowledged by the Nuffield Council on Bioethics, who regarded value-differences as a key reason for disputes arising in this context.⁹⁰

Given this, there may be reason to think that it would be hard to extrapolate the cultural tendency towards consensus-building and avoidance of conflict seen in some countries, to a country such as England, which is less homogenous in values. Certainly a number of contributors to the collection suggested that consensus was feasible in their jurisdictions because of the substantial levels of shared values and cultural homogeneity. Moyo observes of

⁸⁵ Ibid, [173].

⁸⁶ A. Kon, ‘When Parents Refuse Treatment for Their Child’ (2006) *JONA’S Healthcare Law, Ethics, and Regulation* Volume 8(1): 5-9, 7.

⁸⁷ *Kings College Hospital NHS Foundation Trust v Ms Thomas, Mr. Haastrup and Isaiah Haastrup* [2018] EWHC 127 (Fam), [2018] 2 F.L.R. 1028, [54].

⁸⁸ Ibid.

⁸⁹ For a more extensive discussion of this case, and the difference between fact and value-based disputes, see C. Auckland and I. Goold, ‘Parental Rights, Best Interests and Significant Harms’ *Cambridge Law Journal* (2019) 78(2) 287-323, 303-310.

⁹⁰ Nuffield Council on Bioethics, *Disagreements in the care of critically ill children* (April, 2019), 4. In support of this, they cite: *Central Manchester University Hospitals NHS Foundation Trust v A & Others* [2015] EWHC 2828 (Fam); *Re A (A Child)* [2015] EWHC 443 (Fam).

Botswana for example, that the presence of only one major ethnic group (the Tswana), combines with “the socialisation of citizens along communitarian lines” to leave only “limited room for the clash of diverse values”. Hence he suggests, “it could be that the prevailing uniform value system limits the possibility of conflicts between parents themselves”.⁹¹ The opposite may be true of England, and we might speculate that in a multi-cultural and multi-faith country such as this, with greater value-pluralism and fewer shared cultural perspectives, disagreements over values may be both more likely to arise, and, when they do arise, harder (albeit not impossible) to resolve without court intervention.

Within this context, there is also a concern that attempts to achieve consensus might in fact result in undue deference to one party, with the voice of the other being effectively silenced. Leviner suggests that this might be an explanation for the lack of case law in Sweden, positing that what looks like consensus building might be better characterised as ‘conflict-burying’ rather than conflict-solving.⁹² There is a risk, in her view, that the consensus paradigm in fact conceals coercion that ‘should be dealt with legally.’⁹³ Drawing on empirical research from the domestic context, Austin and Huxtable have raised similar concerns that where ‘shared decision-making’ is attempted between doctors and parents,

some researchers have suggested that, in practice, these discussions might amount to no more than a *consultation* of the parents’ views, with the true aim being to secure their *acquiescence* to the care plan proposed by the clinical team. Efforts at persuasion appeared to feature in the cases just outlined. There is a risk, however, that such efforts will cause parents to feel they have no real choice in decision-making, thus cultivating a fear of bad faith.⁹⁴

A culture of deference to doctors which results in parents feeling unable to voice discontent at the way their child is being treated would clearly be undesirable, especially when it comes to something as fundamental as the manner of their child’s death. The parents’ perspective on what is best for their child is clearly crucial to making good decisions for them, given their

⁹¹ S. Ujewe, ‘Making Decisions for Children in Healthcare and Medical Research: African Communal Responsibility or Individual Rights?’ in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing).

⁹² P Leviner, ‘Who Has the Final Word? On Trust and Legal Uncertainty Within the Swedish Healthcare System’ in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing).

⁹³ P Leviner, ‘Who Has the Final Word? On Trust and Legal Uncertainty Within the Swedish Healthcare System’ in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing).

⁹⁴ L. Austin and R. Huxtable, ‘Resolving Disagreements about the Care of Critically Ill Children’ in I. Goold, J. Herring and C. Auckland, *Parental Rights, Best Interests and Significant Harms* (Hart Publishing, 2019).

special knowledge of the child's preferences,⁹⁵ and unique interest in their well-being. As Angela Alessandri explains,

in most cases, parents are the people most able to identify their child's best interests. They are embedded in the same cultural, racial, religious and financial context and have personal experience of their child's developmental progress, personality and capacity.⁹⁶

It is also they who will ultimately bear the consequences of that decision, and who will take on the primary care burden for that child. More fundamentally, however, where disagreements concern questions of value, it is not the case that doctors necessarily know the answers to them any better, nor that they are the most legitimate final arbiter on them. In this case then, parents ought to be able to make these value-judgments for themselves, and not merely acquiesce to the doctors, providing that in doing so they do not expose their child to harm.

But while it is important that parents feel able to participate fully in decisions about their child's care, and have their voice listened to by the doctors, the opposite scenario — undue deference on the part of doctors to parental decisions — may be equally, if not more harmful. In the examples given above of China, Hong Kong, Thailand and Peru, a desire to avoid conflict when disagreements arose was thought by contributors to result in doctors failing to challenge parental decisions or escalate disputes, even where they believed them to be contrary to the child's best interests, or worse, harmful to them. Hui describes two cases from Hong Kong in which fathers rejected limb amputations for their children. One persisted, and the child died, yet neither made it to court.⁹⁷ Discussing the position in China meanwhile, Chunyan gives two further examples. In one widely-publicised case, a father refused treatment for his baby's imperforate anus, yet judicial intervention was not sought notwithstanding others offering to pay for and arrange the surgery, and instead the decision was made to give the child palliative care.⁹⁸ In another, the father of a new-born baby girl suffering from congenital oesophageal atresia refused to consent to an operation proposed by the doctor and the baby eventually died

⁹⁵ 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.

⁹⁶ A. Alessandri, 'Parents know best: Or do they? Treatment refusals in paediatric oncology' (2011) *Journal of Paediatrics and Child Health* 47: 628–631, 629

⁹⁷ E. Hui, 'Parental Refusal of Life-Saving treatments for adolescents: Chinese familism in medical decision-making re-visited' (2008) *Bioethics* Vol 22(5): 286–295, 287-8.

⁹⁸ 'The Father Discontinued Treatments of a Baby Girl with Imperforated Anus' (肛闭女婴父亲放弃治疗) *Guangzhou Daily* (5 February 2010). Available at <gongyi.ifeng.com/news/detail_2010_02/05/443433_0.shtml>

without medical care.⁹⁹ Chunyan also speculated that although no such cases have been reported in China thus far, if the parents were to request a life-prolonging treatment for their child (as in *Gard* or *Evans*), doctors would likely provide it as long as they are able to afford it. Similar observations were made by Siverino Bavio when reporting on the approach in Peru. These are, of course, only a handful of examples which may sit within complex factual matrices, and it is important to not make too sweeping generalisations on the basis of them. Nonetheless they raise a concern that undue deference on the part of doctors, operating without court oversight, may result in decisions which expose children to harm, even death, being accepted without challenge.

Refusal of treatment is not unusual in some countries, and indeed partly explains lower survival rates in low and middle income countries compared to developed countries. There are a range of reasons for this. In the case of the child with an imperforate anus for example, the father reportedly felt that the treatment was causing the child pain and did not wish her to suffer.¹⁰⁰ One study of treatment refusal for acute lymphoblastic leukemia (ALL) in China meanwhile, found cost to be an important factor, as well as a belief in the incurability of ALL, despite the five-year survival rate following appropriate treatment being 80%.¹⁰¹ Indonesian and Indian studies on treatment refusals by parents similarly found monetary concerns to be a cause, as well as concerns about side effects, a belief that the condition was incurable (when it was not), transport difficulties, and distrust of healthcare professionals.¹⁰² Some parents also seek alternative treatments to avoid the side effects of standard treatments.¹⁰³ While some of these

⁹⁹ ‘The Newborn Baby Has Serious Disease, the Parents Decide to Discontinue Treatments’ (新生儿身患重病 父母要放弃治疗) *Today’s Morning Post* (17 October 2009). Available at <news.sina.com.cn/c/2009-10-17/052416451799s.shtml>.

¹⁰⁰ ‘Abandoned child receiving treatment in Beijing’, *China.org.cn* (8 February 2010). Available at <http://www.china.org.cn/china/2010-02/08/content_19384381.htm>.

¹⁰¹ Y Wanga, R Jinb, J Xub, Z Zhang, ‘A report about treatment refusal and abandonment in children with acute lymphoblastic leukemia in China, 1997–2007’ (2011) *Leukemia Research* 35:1628–1631.

¹⁰² MN Sitaesmi et al, ‘Treatment refusal and abandonment in childhood acute lymphoblastic leukemia in Indonesia: an analysis of causes and consequences’ (2010) *Psychooncology* 19(4):361–7. See also: R Moulik et al ‘Tracking children with acute lymphoblastic leukemia who abandoned therapy: Experience, challenges, parental perspectives, and impact of treatment subsidies and intensified counselling’ (2016) *Pediatric Hematology And Oncology* Vol 33(5): 327–337.

¹⁰³ R Singh Arora, T Eden, B Pizer, ‘The problem of treatment abandonment in children from developing countries with cancer’ (2007) *Paediatric and Blood Cancer* Vol 49(7): 941–946.

reasons are understandable, acquiescence by doctors may nonetheless result in unnecessary loss of life in some cases.¹⁰⁴

Avoidance of conflict may therefore sometimes be coming at the expense of protecting the most vulnerable members of society. While consensus-building may be a good goal to pursue, this should not result in voices being hushed for the sake of avoiding a fight. For all that the protracted court cases in England were intensely distressing for those involved, they did ensure that neither doctor nor parent's voice was presumptively silenced and that both perspectives were rigorously debated and scrutinised, before the court, acting as arbiter, made a final determination on best interests. Some degree of independent oversight and scrutiny is therefore essential to ensure that the child's interests are protected and all those with a legitimate interest in their fate have a space to be heard.

V. ALTERNATIVE DISPUTE RESOLUTION MECHANISMS

Although there are reasons to think that England is in some senses culturally and socially likely to be home to disputes, and may not be able to emulate other countries entirely, it does not follow that we cannot learn anything from other jurisdictions, and in particular, from the mechanisms they employ to resolve disagreement without requiring court intervention. In this section we explore two alternative forms of dispute resolution observed in other jurisdictions and consider their efficacy in the English context: mediation and hospital ethics committees.

Before we do so, we should make clear that we are not intending to suggest that hospitals do not currently attempt to achieve consensus, or that they generally fail in doing so. In the Paediatric and Neonatal Intensive Care Unit at Great Ormond Street Hospital for example, Joe Brierley *et al* found that between 2010 and 2013, only 17 of 203 cases involving the withdrawal or limitation of invasive therapy could not be resolved through extensive discussion,¹⁰⁵ suggesting that hospitals are often successful in reaching an outcome that is amenable to parents. This has been bolstered by a number of recent attempts by professional bodies to avoid

¹⁰⁴ There is, indeed, a substantial literature on what medical professionals can do to address the problem of treatment refusal or abandonment, particularly cancer treatment in developing countries. This focuses on providing financial support, education, psychosocial support for parents and locally adapting protocols: R Singh Arora, T Eden, B Pizer, 'The problem of treatment abandonment in children from developing countries with cancer' (2007) *Paediatric and Blood Cancer* Volume 49, Issue 7L 941-946.

¹⁰⁵ J. Brierley et al 'Should Religious Beliefs be Allowed to Stonewall a Secular Approach to Withdrawing and Withholding Treatment in Children?' (2013) 39(9) *Journal of Medical Ethics* 573–7.

conflict, drawing on practice in other countries for inspiration. The new Royal College of Child and Paediatric Health guidance¹⁰⁶ offers a series of practical steps, as does the 2019 Briefing Paper produced by the Nuffield Council on Bioethics,¹⁰⁷ which recommends that NHS trusts should be supported to develop processes for ‘recognising and managing disagreements...such as introducing conflict management frameworks’, which have proved successful in Australia.¹⁰⁸ As the Nuffield Council rightly points out, ‘there is scope for policy makers and others to do more to support the creation of healthcare environments that foster good, collaborative relationships between parents and healthcare staff’, through better communication with, and involvement of, parents in decisions about their children.¹⁰⁹ This would of course welcome, and we share the hope that they will reduce recourse to other mechanisms. However our focus here is the steps that can be taken to resolve conflicts when consensus-building has failed at this stage.

A. Mediation

One suggestion that has recently gained traction is mediation. This is defined as ‘a flexible, confidential process which involves a neutral third party helping the parties in dispute towards a negotiated resolution, where the parties have the final say as to whether agreement is reached and, if so, on what terms’.¹¹⁰ It is hoped, as Austin and Huxtable explain, that it might help the parties to work through any stalemate, so as to reach agreement without having to rely on court intervention.¹¹¹ Certainly Mr Justice Francis appeared to recognise its potential to do so in *Gard*, when he suggested that

it would, in all cases like this, be helpful for there to be some form of Issues Resolution Hearing or other form of mediation where the parties can have confidential conversations to see what common ground can be reached between them.¹¹²

¹⁰⁶ Citation

¹⁰⁷ Nuffield Council on Bioethics, *Disagreements in the care of critically ill children* (April, 2019).

¹⁰⁸ The Nuffield Council (ibid) noted: ‘Early trials of a conflict management framework in an Australian hospital, that provided healthcare staff with training and a plan for recognising, managing and reporting disagreements, led to a substantial reduction in the number of conflict incidents.’ See also L. Forbat and S. Barclay, ‘Reducing healthcare conflict: outcomes from using the conflict management framework’ (2018) *Arch Dis Child* 0: 1–5.

¹⁰⁹ Nuffield Council on Bioethics, *Disagreements in the care of critically ill children* (April, 2019), 1

¹¹⁰ L. Austin and R. Huxtable, ‘Resolving Disagreements about the Care of Critically Ill Children’ in I. Goold, J. Herring and C. Auckland, *Parental Rights, Best Interests and Significant Harms* (Hart Publishing, 2019), quoting from the Centre for Effective Dispute Resolution, ‘Glossary of Terms.’

¹¹¹ Ibid, 220.

¹¹² *Great Ormond Hospital v Yates, Gard and Gard* [2017] EWHC 972 (Fam), [130].

As Dominic Wilkinson et al argue, conflict can sometimes cause the focus to shift away from the welfare of the child, and mediation can help parents and professionals to acknowledge that, and facilitate a ‘less confrontational conversation’ between parties;¹¹³ as well as correcting any misunderstandings and ensuring that all relevant information is before each party. It also has the advantage of being flexible, as it can be invoked at any time, and involve anyone in the process, including, for example, religious leaders.¹¹⁴ Certainly other jurisdictions have found mediation to be helpful, with Ko and Haur commenting that in Singapore and to a more limited extent Malaysia, a combination of mediation and ethics committees ‘appear to have been effective in preventing a disagreement from escalating into a full-scale legal battle’.¹¹⁵

Accordingly, the Royal College of Paediatric and Child Health now recommends the early involvement of mediation services as a strategy for helping to achieve consensus.¹¹⁶ To facilitate this, a Bill is currently before Parliament to mandate its wider use, which has passed its second reading in the House of Lords and is currently at Committee Stage. According to the Access to Palliative Care and Treatment of Children Bill (the campaign for which has colloquially been termed ‘Charlie’s Law’), an application could not be made to the High Court under the Children Act 1989 or inherent jurisdiction *unless*:

(a) the health service body has followed a process of mediation with an independent mediator in an attempt to resolve any differences between the health service body and any person who has parental responsibility for the child or is recognised by the health service body to have an interest in the welfare of the child, and

(b) that process has been unsuccessful in reaching substantial agreement about the medical treatment to be given or not to be given to the child.

The only exception would be where the issue is urgent and it is in the best interests of the child to proceed to a court hearing, or where the parents fail to engage in the mediation process.

¹¹³ D. Wilkinson, S. Barclay, J. Savulescu, ‘Disagreement, mediation, arbitration: resolving disputes about medical treatment’ (2018) *The Lancet* 391, 2302-2305.

¹¹⁴ C. Auckland and I. Goold, ‘Parental Rights, Best Interests and Significant Harms’ *Cambridge Law Journal* (2019) 78(2) 287-323, 223.

¹¹⁵ C. Ho and S. Kaur, ‘Parental Rights, Best Interests and Significant Harms: Singapore and Malaysia Perspectives on Medical Decision-Making on Behalf of Children’ in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing).

¹¹⁶ M. Linney, RDW Hain, D Wilkinson et al, ‘Achieving consensus advice for paediatricians and other health professionals: on prevention, recognition and management of conflict in paediatric practice.’ (2019) *Arch Dis Child* 104:413-16. They also emphasise the importance of careful listening and understanding, and honest and open communication.

While mediation certainly has the potential to resolve disputes before court intervention, and ought to be available to parents who wish to access it, it is unlikely in itself to prove a panacea. Often the contexts in which it proves to be most effective — the dissolution of marriages or commercial disputes — are those in which the issue is amenable to some ‘give-and-take’ or compromise. Mediation is then directed at reaching an outcome that is broadly agreeable to both parties. It is more difficult to see how it will help in decisions which are inherently more binary, such as over whether to offer treatment to a child at the end of life, where there is not obvious ‘middle ground’ between positions. In *Gard, Evans* and *Raqeeb* for example, either the child was allowed to go abroad for further treatment, or treatment would be withdrawn and they would die. Achieving compromise in this context is hard: for the parent who regard’s their child’s life as inherently valuable, anything short of further treatment would be unacceptable. For the doctor meanwhile, agreeing to act in a way that they strongly believe to be contrary to the child’s interests (and potentially harmful), would require them to compromise on their core ethical duty to do good for their patient, or as Jo Bridgman puts it, to act contrary to their professional conscience.¹¹⁷ Anticipating this, one or other party may fail to engage fully in the process, which will further undermine its likelihood of success.

Mediation in these cases may then have done little more than to delay access to court proceedings and entrench the parties’ positions further. Even absent mandatory mediation, Joe Brierley et al have raised concerns that the process of seeking second opinions and ethical reviews before applying to court

can be protracted and arguably damaging to parents, to healthcare workers looking after the child and of course most importantly to the child itself. Such situations should result in rapid intervention... Instead, usually after many weeks or months of protracted unsuccessful discussions, with both sides trying to get the other to see their point of view, a request is made to the courts for a declaration on how to proceed.¹¹⁸

This led them to conclude that ‘protracted dialogue was often unable to resolve these differences’ (meanwhile ‘the child was subject to pain and discomfort from invasive

¹¹⁷ J. Bridgeman, ‘Beyond Best Interests: A Question of Professional Conscience?’ 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 Yates* (Hart Publishing 2019).

¹¹⁸ Joe Brierley, Jim Linthicum, Andy Petros, ‘Should religious beliefs be allowed to stonewall a secular approach to withdrawing and withholding treatment in children?’, *J Med Ethics* 2013;39:573–577, 576.

ventilation, suctioning and multiple injections’) and we should instead facilitate rapid access to the courts.¹¹⁹

In addition to concerns about delays, mediation may also prove to be very expensive for the NHS. It is also essential that there is clarity over what question is being mediated (is it the possibility of further treatment, the current treatment, or palliative care?); and over who selects the mediator. Given Janine Winters’ concerns that mediators may be subject to ‘inadvertent bias, particularly cultural bias toward medical culture and medical values’,¹²⁰ parents must have faith in their independence if they are to be successful in building trust between parties.

But mediation is also unlikely to prove effective in the absence of court determination of at least *some* cases. While we clearly support allowing space for different perspectives, an entirely unstructured or open-ended debate on what should be done can be unproductive. Judicial declarations on disputes therefore create a legal framework within which subsequent discussions can be had, which as Robert Mnookin and Lewis Kornhauser observe, can aid resolution in mediation.¹²¹ They make this point in the context of divorce, but the point arguably applies in this context as well. As they put it:

Divorcing parents do not bargain over the division of family wealth and custodial prerogatives in a vacuum; they bargain in the shadow of the law. The legal rules governing alimony, child support, marital property, and custody give each parent certain claims based on what each would get if the case went to trial. In other words, the outcome that the law will impose if no agreement is reached gives each parent certain bargaining chips—an endowment of sorts.¹²²

They suggest that this helps facilitate parties reaching agreement because it reduces the range of possible options in mediation to only those that leave the parties better off than if they failed to agree and had to resort to the courts.¹²³ In the treatment context, this might translate into removing some options from the table if the courts have consistently deemed them not to be in the best interests of a child in the past (such as heavily experimental treatment which might result in pain to the child). For mediation to be successful therefore, some judicial determination remains essential.

¹¹⁹ Ibid.

¹²⁰ J.P. Winters, ‘When Parents Refuse: Resolving Entrenched Disagreements Between Parents and Clinicians in Situations of Uncertainty and Complexity’ *The American Journal of Bioethics*, 18(8): 20–31, 2018, 23.

¹²¹ Robert H. Mnookin and Lewis Kornhauser, ‘Bargaining in the Shadow of the Law: The Case of Divorce’ (1979) 88 *Yale Law Journal* 950.

¹²² *ibid*, 968.

¹²³ *ibid*, 969.

Even if agreement can be reached, there remains a more fundamental concern that finding a ‘middle ground’ that is broadly amenable to both parties, will not necessarily result in the best outcome for the child. While Wilkinson et al suggest that mediation must be directed ‘towards an ethical outcome’, not mere agreement,¹²⁴ it is difficult to see how this can be guaranteed.

B. Hospital Ethics Committees as Decision-Makers

Another suggestion that came out of the collection was the possibility of utilising clinical ethics committees (‘CECs’) in the place of the courts. Many countries have internal hospital mechanisms for managing disagreement, albeit these operate under different names and carry varying degrees of authority. While in most jurisdictions (including England) they do not carry legal authority, in some, for example Israel, Texas, Chile and Argentina, ethics committee can make best interest determinations.¹²⁵ In Israel for example, the institution’s committee is able to make binding determinations. A distinction is drawn there between children who are dying (defined as terminally ill with less than six months to live) and those who are not, but suffer from incurable conditions. In relation to the former, section 28 of the Dying Patient Act 2005 provides that in the event of a disagreement between the parents and treating clinicians, the matter will be brought before the institution’s ethics committee which has the authority to make decisions in these matters, including a decision to withhold treatment.¹²⁶ These committees comprise doctors, nurses, bioethicists, lawyer, social workers, psychologist, and relevant clergy. According to Roy Gilbar (with whom Carmel Shalev agrees¹²⁷), the goal of this system is to avoid conflicts being taken before the court, and to facilitate rapid decision-making that is “not subject to rigid legal procedures”,¹²⁸ and is less adversarial in approach.¹²⁹ Similarly in

¹²⁴ D. Wilkinson, S. Barclay, J. Savulescu, ‘Disagreement, mediation, arbitration: resolving disputes about medical treatment’ (2018) *The Lancet* 391, 2302-2305.

¹²⁵ Fabiola Lathrop Gómez, ‘Decisions About Their Body: Children's Rights and Parental Responsibility in Chile’ in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing).

¹²⁶ R. Gilbar in ‘Withholding and Withdrawal of Life-Prolonging Treatment from Young Children in Israel’ in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing).

¹²⁷ C Shalev, ‘End-of-Life Care in Israel—The Dying Patient Law, 2005’ vol 42, Issue 2 2009, pp. 279-305 *Israel Law Review*.

¹²⁸ R. Gilbar ‘Withholding and Withdrawal of Life-Prolonging Treatment from Young Children in Israel’ in I. Goold, C. Auckland and J. Herring, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (forthcoming, Hart Publishing). See also A. Steinberg and C. Sprung, ‘The Dying Patient Act, 2005: Israeli innovative legislation’ *The Israel Medical Association Journal* 9(7):550-2.

¹²⁹ Interestingly, where a disagreement arises over the case of children suffering from incurable (but not terminal) conditions by contrast, the Legal Capacity and Guardianship Act 1962 states that the matter is to be brought before the Family Court, rather than according jurisdiction to ethics committees.

Argentina, Fabiola Lathrop Gomez explains that under Article 17 of 'Regulations on the rights and responsibilities of people in the context of actions related to their health care',¹³⁰ any parental decision which puts a child at risk of serious harm must be referred to an ethics committee, who then determines the child's best interests. This can then be appealed to the Court of Appeal.

Clinical ethics committees enjoy even greater authority in Texas, United States. Under the Advance Directives Act (now Chapter 166 of the Texas Health and Safety Code), where doctors wish to refuse a request for treatment by a patient or their family, doctors may refer the case to a hospital ethics committee. If the committee agrees that further treatment would be 'medically inappropriate', the medical team are legally permitted to withdraw or withhold treatment after 10 days, unless the family can find another doctor who is willing to offer the treatment sought.¹³¹ In 2005, for example, ventilation was withdrawn from a baby dying from a form of dwarfism, against the wishes of his family, using this process.¹³² The family can appeal to a court to extend this period, but only if there is evidence that the patient is likely to be accepted at another unit if given more time. Otherwise they can only apply for judicial review of the committee's decision.

These examples prompt us to question whether clinical ethics committees ought to play a greater role in disputes of this kind, and in particular whether they ought to be able to make legally binding decisions, in the place of courts. Austin and Huxtable explain that

CECs explicitly focus on the ethical dimensions of the case before them, which suggests they might be well-equipped to advise on values-based disputes. For example, as was the case in *Haastrup*, a clinician might believe that treatment should stop, but a family with particular religious beliefs – such as in the sanctity of life – might want treatment to continue.¹³³ In such cases, a CEC could help to identify and elucidate the underlying ethical values, and point to areas of commonality or in which a compromise might be achieved, through which efforts resolution might then be reached.¹³⁴

¹³⁰ Law 20,584 (Argentina).

¹³¹ Available at <<https://codes.findlaw.com/tx/health-and-safety-code/health-safety-sect-166-046.html>>; [https://www.law.uh.edu/healthlaw/perspectives/2007/\(CM\)TXFutileCare.pdf](https://www.law.uh.edu/healthlaw/perspectives/2007/(CM)TXFutileCare.pdf).

¹³² 'Life Support stopped for 6-Month Old in Houston' (blog post). Available at <https://lawprofessors.typepad.com/healthlawprof_blog/2005/03/lifesupport_sto.html> In the case, the hospital also took the unnecessary step of getting court authorisation.

¹³³ J. Brierley et al 'Should Religious Beliefs be Allowed to Stonewall a Secular Approach to Withdrawing and Withholding Treatment in Children?' (2013) 39(9) *Journal of Medical Ethics* 573–7, 576.

¹³⁴ L. Austin and R. Huxtable, 'Resolving Disagreements about the Care of Critically Ill Children' in I. Goold, J. Herring and C. Auckland, *Parental Rights, Best Interests and Significant Harms* (Hart Publishing, 2019), 220.

They also observe that clinical ethics committees often have extensive experience considering issues such as the withdrawal of life-sustaining treatment; and that they are not intended to be adversarial, with the result that ‘relative to the courts, CECs are able to pool diverse, pertinent expertise and they are less formal and costly.’¹³⁵ Their diverse make-up may help in drawing out the exact nature of the disagreement in cases (is it over facts or values?) and identifying possible conflicting values, which is crucial to finding a solution which accommodates parental values while still protecting the interests of the child. It may also help to ensure that the decision isn’t influenced too heavily by the values of one individual (as it can be by a judge), and where the decision does involve committing to one set of values, that these are brought out into the open and scrutinised by other committee members.

Despite this, CECs in England are not currently directed towards resolving complex ethics disputes between doctors and parents, but at advising doctors and approving experimental treatments. To do this then, they would need to substantially re-orientate (and restructure) themselves, in a way that would enable parents to have confidence in their neutrality. Even then, Winter’s experiences on a CEC in Canada led her to conclude that:

Despite our intention to provide a balanced, family-centered approach, the “facts” as presented by one clinician and the accompanying arguments had a lot of weight. The members of the CEC generally knew, and had collegial regard and respect, for their medical peers. This influenced and medicalized our first impression of the cases. The members then tried to understand the family’s values, but these were often less clearly articulated as families speak from outside of the medical culture and vary in their skill to communicate. The focus of CEC discussions was primarily on medical interests and secondarily on the parental motivation in their disagreement with the recommended medical course. Even with sincere goals for family-centered care, the CEC was under an “umbrella” of a hospital system with professionals focused on medical values. In the setting of conflict between medical providers and parents, these medical goals often outweighed all other values, including social and psychological well-being.’¹³⁶

More fundamentally, while the varied composition and informal processes of committees may be useful for resolving disagreements without requiring recourse to the courts, this same informality militates against giving them any binding legal authority, given the lack of robust and transparent procedures for making decisions. The importance of such ‘formalities’ cannot be understated. When a case goes to court, procedural and evidential rules ensure that each party has the opportunity to put forward all important evidence in advance of the hearing and that both sides have an opportunity to present their case. The child has an independent Guardian

¹³⁵ Ibid.

¹³⁶ Janine Winters, *When Parents Refuse: Resolving Entrenched Disagreements Between Parents and Clinicians in Situations of Uncertainty and Complexity* The American Journal of Bioethics, 18(8): 20–31, 2018, 25.

appointed to represent their interests; and the judge must give reasons for the decision reached, in light of the evidence and legal precedent put before them, in a judgment that is ordinarily publicly available and thus open to scrutiny. It is then open to either party to apply to appeal the decision, which in *Gard*, went as high as the European Court of Human Rights. While this process may take time, this is an inevitable consequence of reviewing and evaluating a substantial body of evidence rigorously and thoughtfully. As Wilkinson et al have noted, the legal process provides ‘impartial assessment of the claims of professionals and parents, and rigorous evaluation of the evidence and the credibility of expert witnesses.’¹³⁷ This as Austin and Huxtable observe, affords the legal process credibility ‘as a means of decisively settling disputes’.¹³⁸

That legal procedure is essential to the courts legitimacy as a decision-maker is captured by Hazel Genn who argues that procedural rules are important because they ‘guarantee procedural fairness, and procedural fairness is important both in its own right and through its link with substantive justice’.¹³⁹ As Genn explains,

the system of procedure is designed to ensure that judges have all the appropriate evidence available so that they can find the material facts and apply the substantive law to those facts. In this way, procedural rules reflect a sense of justice. Procedure is the means by which substantive rights are enforced.¹⁴⁰

Genn’s point is a powerful one in our context: ‘if substantive justice lies in the correct application of legal principles to a factual situation, then procedures that increase the likelihood of a correct decision being reached are vital’.¹⁴¹

Legal processes may also be important for the parties involved and Genn notes a substantial body of research in support of this.¹⁴² According to this, the value of legal decision-making lies in the opportunity for parties to feel heard, the chance to present views and have them influence

¹³⁷ D. Wilkinson, S. Barclay, J. Savulescu, ‘Disagreement, mediation, arbitration: resolving disputes about medical treatment’ (2018) *The Lancet* 391, 2302-2305.

¹³⁸ L. Austin and R. Huxtable, ‘Resolving Disagreements about the Care of Critically Ill Children’ in I. Goold, J. Herring and C. Auckland, *Parental Rights, Best Interests and Significant Harms* (Hart Publishing, 2019), 225.

¹³⁹ Hazel Genn, *Judging Civil Justice*, (Cambridge University Press, 2009), 13.

¹⁴⁰ *Ibid.*

¹⁴¹ *Ibid.*, 14.

¹⁴² Eg, Genn cites E A Lind and TR Tyler *The Social Psychology of Procedural Justice*, (Plenum, 1988).

the outcome, the even-handed treatment of the issues by the court, and simply the courtesy and respect with which parties (and their views) are treated).¹⁴³

These processes are currently crucially absent from CECs, which Sheila McLean aptly describe as a ‘due process wasteland.’¹⁴⁴ As well as there being no established procedures in place for the submission of evidence and conducting of oral hearings, there is also no requirement to publish reasons for the decision, or a process for challenging or appealing their decisions (except recourse to the courts). This lack of transparency and absence of any precedent value for decisions removes the demand for robust development of principle, which could result in highly inconsistent decisions. Of course were the decisions of CECs to be legally binding, more rigorous procedures could be introduced. In Texas for example, the Act contains various procedural requirements that must be followed for the withdrawal of treatment to be legal, including that the family are given 48 hours’ notice about the ethics consultation process,¹⁴⁵ are invited to attend,¹⁴⁶ and are provided with a written report of the committee’s findings.¹⁴⁷ Clearly, however, these still fall short of the processes usually involved in bringing a case to trial. Indeed it may be something of a paradox that in order to supplant courts, committees would need to introduce a degree of formality that would in turn undermine the flexibility that makes them so effective at resolving disputes.

This lack of due process and transparency is not just a structural problem. Rather it fundamentally militates against CECs ever having authority to make a legally-binding decision, since it goes to core of their legitimacy to make these kinds of decisions. We explained above that there is often no one, agreed view of what is ‘best’ for a child,¹⁴⁸ which will depend on the weight that one ascribes to different interests that a child has, in a way that will inevitably be influenced to some extent by the decision-makers own values, beliefs and priorities. However once it is accepted that this process can never be entirely value-neutral, then the forum in which such determinations are made is crucial. Given the gravity of these decisions — which go to

¹⁴³ Hazel Genn, *Judging Civil Justice*, (Cambridge University Press, 2009), 14.

¹⁴⁴ S. McLean, ‘Clinical ethics committees: A due process wasteland?’ (2008) 3 *Clinical Ethics* 99.

¹⁴⁵ Texas Health and Safety Code § 166.046 (b)(2).

¹⁴⁶ *Ibid*, § 166.046 (b)(4)(a).

¹⁴⁷ *Ibid*, § 166.046 (b)(4)(b).

¹⁴⁸ While fully recognising the limitations of our collection as a source and not intending this analysis as a form of empirical research, we would suggest that the reports from the various jurisdictions on how best interests is understood and applied suggest that ‘best interests’ is understood differently in different countries, with decision-making ranging from utilitarian and centred on the well-being of the family, to highly child-focused.

the heart of the value that we as a society place on human life, and when we will consider death preferable to continued life — it is essential that these decisions are susceptible to public scrutiny and challenge. The very fact that the *Gard* and *Evans* cases precipitated such intense public debate over who should have the ultimate say and whether the courts were right to deny parents the chance of prolonging their child's life, adds credence to the idea that these decisions ought to be made in open forums, with adequate reasons given for them. This is, of course, a feature of courts, which generally sit in public and issue judgments, but it is not a feature of clinical ethics committees.

This is not to suggest that CECs do not play a useful role in advising healthcare professionals faced with complex ethical decisions and for this, the absence of rigid legal procedures might be valuable. Nor is it to suggest that mediation may not be a pathway to achieving consensus that enables all involved to avoid the stress of going to court. But it does also suggest that the very processes which make litigation slow and cumbersome are also those which afford it the legitimacy to make binding legal decisions. While avoiding disagreements escalating has undoubted advantages, where an intractable dispute arises which cannot be resolved except by the use of an independent arbiter, courts, with their commitment to due process and robust reasoning, offer the most legitimate option, especially in the kinds of complex and highly contentious value-based disputes seen in *Gard*, *Evans* and *Raqeeb*. In particular, they possess three features that have been identified above as crucially lacking from other approaches to dispute resolution. Firstly, through ensuring that both parties have the opportunity to present their own case (and challenge each others), the court process avoids concerns that one voice may be presumptively silenced by the other, in a way that may not promote the child's welfare. Secondly, by appointing a Guardian to advocate for the child, the child's well-being remains at the centre of any dispute — a concern raised by Hui who noted that where disputes have been resolved outside of the court system in Hong Kong, there is no one to represent the child's interests. Finally the openness and transparency of courts (and judgments) enables the public to scrutinise the decision and the value judgments that underpin it; and, if they disagree with these, to challenge them through our democratic processes. This is exemplified by 'Charlie's Law' which is currently before Parliament, that arose as a direct consequence of the decisions in *Gard* and *Evans*.

Rather than seeking to avoid disputes coming before the courts therefore, we must instead work towards accommodating the value-differences that give rise to disagreements over treatment in a respectful and transparent way. As Wilkinson et al aptly capture,

disagreement is not, in itself, a bad thing. Ethically complex decisions—like those around a child's treatment towards the end of life—touch on deeply held questions of value on which there can be different reasonable views. Disagreement in medicine is inevitable but conflict should not be. What is crucial, then, is how we deal with disagreement.... Diverging views must be addressed in a way that is respectful, considered, ethically informed, and compassionate, without losing sight of the wellbeing of the child.¹⁴⁹

In our view value-difference *can* be accommodated within assessments of best interests providing judges are sensitive and transparent about the values that necessarily underpin them. This sensitivity was exemplified by the decision of the High Court in *Raqeeb*, in which MacDonald J conducted a detailed and balanced evaluation of the multiple factors and interests at play, engaging closely with both the religious and cultural perspective of her parents, and the arguments made by the hospital in favour of ceasing support and preventing her removal to Italy. However the clarity and transparency with which McDonald J detailed the values at play and how they (in his view) interacted, may be the exception rather than the rule. In *Evans* for example,¹⁵⁰ 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 accordance with their Catholic beliefs, yet Hayden J refused, stating that further treatment would compromise 'Alfie's future dignity.'¹⁵¹ While the cases might be distinguished on the basis that in *Evans*, unlike in *Raqeeb*, there was evidence that the child might have been able to experience pain,¹⁵² nonetheless Hayden J did not engage with the need to encompass different value systems within the best interests assessment, nor did he acknowledge 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',¹⁵³ Hayden J implied the opposite: that there is a

¹⁴⁹ D. Wilkinson, S. Barclay, J. Savulescu, 'Disagreement, mediation, arbitration: resolving disputes about medical treatment' (2018) *The Lancet* 391, 2302-2305.

¹⁵⁰ *Alder Hey Children's NHS Foundation Trust v Mr Thomas Evans, Ms Kate James, Alfie Evans (A Child by his Guardian AFCASS Legal)* [2018] EWHC 308 (Fam).

¹⁵¹ *Alder Hey Children's NHS Foundation Trust v Mr Thomas Evans, Ms Kate James, Alfie Evans (A Child by his Guardian AFCASS Legal)* [2018] EWHC 308 (Fam), [66].

¹⁵² Although we note that there is room for doubt, from a medical perspective, on whether there can be certainty on this both contemporaneously and as a prediction of future experience. We are grateful to Dr Emily Harrop for this point, which we have very much taken on board in our understanding of these cases.

¹⁵³ *Alder Hey Children's NHS Foundation Trust v Mr Thomas Evans, Ms Kate James, Alfie Evans (A Child by his Guardian AFCASS Legal)* [2018] EWHC 308 (Fam), [64].

single, objective answer to what is ‘best’ and the court, and not the parents, were able to discern that.

Even in *Raqeeb*, it may have been important to the outcome of the decision 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). This leaves open the question of whether their views would have been given the same weight if they had been less orthodox. Comments by MacDonald J suggests not:

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.¹⁵⁴

Joe Brierley et al have also questioned whether the same weight is ascribed to all religious beliefs, nothing that:

There is ethical tolerance to values that we are more accustomed to and an overt understanding and acceptance of the validity of religiously founded claims, which emanate from the tenets of older, more established religions. In our readiness to question minority religions we may not be giving them an equal voice and establishing a hierarchy of religions, some of which a secular system is prepared to accept and some to challenge.¹⁵⁵

However in a liberal democracy committed to religious freedom and tolerance, it is crucial that we leave space for people to disagree. Dominic Wilkinson and Julian Savulescu are right to suggest that ‘value-based disagreements are part of living in diverse progressive communities. So, in a sense, disagreement is a *good* thing – it is a sign of a pluralistic and tolerant society’.¹⁵⁶ However the issue goes deeper than this, raising fundamental questions about the nature of the citizen’s relationship with the state, and where the boundaries lie between private decisions and those the state can control. In the United States context, Joseph Goldstein refers to the state’s ‘fundamental constitutional commitment to individual freedom’, arguing that it is in just these sort of cases involving disagreements about value that it is right that the US Constitution ‘dictates abstention from imposing one group’s orthodoxy about health care or truth about the

¹⁵⁴ *Raqeeb v Barts NHS Foundation Trust & Anors* [2019] EWHC 2531 (Admin), [178].

¹⁵⁵ Joe Brierley, Jim Linthicum, Andy Petros, ‘Should religious beliefs be allowed to stonewall a secular approach to withdrawing and withholding treatment in children?’, *J Med Ethics* 2013;39:573–577, 575

¹⁵⁶ D. Wilkson and J. Savulescu, *Ethics, conflict and medical treatment for children: From disagreement to dissensus* (Elsevier, London, 2019) 146. Wilkinson and Savulescu offer some valuable insights into how we might draw a line between reasonable and not reasonable disagreements, and the important implications of this distinction: chapter 3.

meaning of life or, for that matter, death upon another'.¹⁵⁷ Before the UK Supreme Court, Richard Gordon QC similarly appealed to English constitutional principles in *Gard*, when arguing that value-differences ought to be accommodated in the law by allowing parents to retain decision-making capacity providing they did not expose their child to a risk of significant harm. As he put it,

if 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.¹⁵⁸

While the law should allow for value difference, as with many other areas of life, a balance must be struck. Just as freedom of speech does not mean the state should not be able to curtail *any* speech (and currently both hate speech and defamatory are examples of constrained speech), so too must there be limits on parental decisions. Given that these decisions are other-regarding (that is, they are made on behalf of vulnerable children), there is good reason to constrain them where they are potentially harming to that other. Lady Hale recognised this in her support of the best interests approach in *Gard*,¹⁵⁹ and we share her perspective, even though we do not agree on the appropriate point at which parental choice yields to the state's perspective. As we have argued elsewhere,¹⁶⁰ in our view a harm-threshold strikes a more legitimate balance between allowing for value difference and protecting those who cannot protect themselves. But regardless of where we draw that particular line, what we should agree on is that it is vitally important that we remain committed to allowing for differences of value to the greatest extent that we can if we are to remain true to the liberal democratic values on which our laws are built.

¹⁵⁷ J. Goldstein, 'Medical Care for the Child at Risk on State Supervision of Parental Autonomy' (1977) *Yale Law Journal* Vol 86: 645-670, 649.

¹⁵⁸ R. Gordon, Counsel's submissions in Permission to Appeal hearing before the UK Supreme Court, 8th June 2017. Available at < <https://www.supremecourt.uk/watch/charlie-gard/080617-pm.html>>.

¹⁵⁹ "Lady Hale's Explanation of the Supreme Court's Decision", as delivered in court on 8 June 2017, available at <<https://www.supremecourt.uk/news/permission-to-appeal-hearing-in-the-matter-of-charlie-gard.html>> (accessed on 30th March 2020).

¹⁶⁰ C. Auckland and I. Goold, 'Parental rights, best interests and significant harms: who should have the final say over a child's medical care?' (2019) *The Cambridge Law Journal* 1-37.

VI. CONCLUSION

When parents and medics disagree about a child's treatment, going to court is often regarded as a last, desperate option, to be avoided if at all possible. Requesting the court resolve such disputes is certainly time-consuming, draining and painful, and so when we see other jurisdictions experiencing very little recourse to the courts, there is good reason to ask whether we can learn from the experiences of these other countries. Are they doing something we are not? However, when one examines the approaches of other countries, it emerges that while they are doing things differently, this derives in part from different cultural perspectives on who ought to have the dominant voice in such disputes, which would not transpose easily to English society. While we can learn from some of the approaches to consensus-building elsewhere, where there are good reasons to resist placing the desirability of reaching consensus above other principles. Moreover while we may want to expand some use of alternative mechanisms for resolving disputes relied on in other countries, such as ethics committees and mediation, in the main these approaches ought not to be emulated in England and Wales.

More importantly, however, what emerges from our analysis is that in many jurisdictions the lack of judicial involvement in such cases is achieved by *avoiding* disputes, through deferring or acquiescing to one dominant voice (sometimes doctors, sometimes parents). In our view, this risks not only failing to protect the interests of the child, but failing to appreciate the importance of facilitating open and robust debate on questions as fundamental as when a child's life ought to be brought to an end. While litigation may be long, costly and adversarial, it does at least allow each party space for the refutation of the other's views on what is best for a child, and the wider public the opportunity to scrutinise the value-judgments that underpin these decisions. A commitment to a liberal democracy which promotes pluralism and tolerance of difference demands that we allow for disagreements on matters of value. This cannot be the whole of our approach and we must ensure the most vulnerable in our society are protected. But we can achieve this while accepting that there can be reasonable disagreement over questions of value and leaving space for these to be respected.