

# Resolving Disagreements about the Care of Critically Ill Children: Evaluating Existing Processes and Setting the Research Agenda\*

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## 1. Introduction

In the mid-2000s, the English courts adjudicated on the high-profile case of Charlotte Wyatt, a critically ill child. Charlotte’s parents wanted their daughter to receive potentially life-sustaining treatment (including ventilation), but her doctors believed that such treatment was not in the child’s best interests.<sup>1</sup> This intractable dispute came before the courts on no fewer than 11 occasions.<sup>2</sup> Commenting on the dispute, Margaret Brazier noted: ‘There is no right answer to the dilemma in *Re Wyatt*. Resolution in the courts may indeed exacerbate a tragedy nature created. But is there any alternative?’<sup>3</sup>

Brazier’s question has become particularly pressing in recent years, with the courts confronting more difficult cases of this sort, such as *Gard*, and the attendant dilemmas playing out across the world’s (social) media.<sup>4</sup> In this chapter, we survey and assess the main processes and mechanisms available for seeking to prevent, reduce or resolve disputes about the treatment (and non-treatment) of critically ill children. Our focus is on the UK (and England in

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<sup>1</sup> *Portsmouth Hospital Trust v Wyatt* [2004] EWHC 2247 (Fam).

<sup>2</sup> J Bridgeman, ‘Editorial: Critically Ill Children and Best Interests’ (2010) 5 *Clinical Ethics*, 184, 187.

<sup>3</sup> M Brazier, ‘An Intractable Dispute: When Parents and Professionals Disagree’ (2005) 13 *Medical Law Review* 412, 418.

<sup>4</sup> N Bhatia, ‘Disagreements in the Care of Critically Ill Children: Emerging Issues in a Changing Landscape’ (2018) *Nuffield Council on Bioethics* 7, [nuffieldbioethics.org/wp-content/uploads/Bhatia-N-2018-Disagreements-in-care-of-critically-ill-children-emerging-issues.pdf](https://nuffieldbioethics.org/wp-content/uploads/Bhatia-N-2018-Disagreements-in-care-of-critically-ill-children-emerging-issues.pdf).

particular<sup>5</sup>) and our analysis was informed by a ‘rapid review’ of available sources,<sup>6</sup> which was undertaken for the Nuffield Council on Bioethics.<sup>7</sup>

The review revealed five key processes for resolving disagreements about the care of critically ill children: discussions between families and clinicians; second-opinion experts; clinical ethics committees; mediation; and court proceedings. We found that the majority of these disputes appear to be addressed and resolved through discussion between the main stakeholders, primarily the parents and the healthcare team, with second opinions sometimes also being sought. Alternative processes – and the courts in particular – appeared to be viewed by stakeholders as options of last resort. Court proceedings had (at least) the benefit of securing resolution, but such resolution came at a cost, since it could exacerbate the damage already caused to the relationship of trust between these protagonists. Alternative processes such as mediation and clinical ethics consultation showed some promise, but data about these processes and their respective pros and cons appear to be lacking.

Our findings therefore indicate various areas in which further research is warranted. First, further research is needed into what the current situation actually *is*, which would usefully explore when, why, how and the extent to which these different mechanisms are used, and how they serve to secure resolution. Second, research is also needed into what the situation *should be*: how (if at all) should existing mechanisms be amended and, ultimately, which process (or processes) should be used in these cases of conflict?

## 2. Critically Ill Infants in (and Beyond) the Courts

Although cases of conflict have become particularly prominent in recent years, the treatment/non-treatment of critically ill children has long generated dilemmas and disagreement. As these dilemmas typically involve life-or-death questions, legal questions inevitably arise, and English law has a long history of seeking to resolve these sorts of disputes.

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<sup>5</sup> Different legal systems operate within the United Kingdom.

<sup>6</sup> Rapid reviews involve ‘a type of knowledge synthesis in which components of the systematic review process are simplified or omitted to produce information in a short period of time’: AC Tricco, J Antony, W Zarin, L Strifler, M Ghassemi, J Ivory, L Perrier, B Hutton, D Moher, and SE Straus, ‘A Scoping Review of Rapid Review Methods’ (2015) 13 *BioMed Central Medicine* 224.

<sup>7</sup> L Austin, ‘UK Processes for the Resolution of Disagreements About the Care of Critically Ill Children’ (2018) *Nuffield Council on Bioethics*, [nuffieldbioethics.org/wp-content/uploads/Austin-L-2018-UK-processes-for-resolution-of-disagreements-in-care-of-critically-ill-children.pdf](https://nuffieldbioethics.org/wp-content/uploads/Austin-L-2018-UK-processes-for-resolution-of-disagreements-in-care-of-critically-ill-children.pdf).

The law in this jurisdiction has generally viewed these sorts of cases through three sets of lenses, which derive from criminal law, civil (family) law and human rights law.<sup>8</sup>

In terms of priority and chronology, the *criminal* law comes first in this selective retrospective (or, to borrow a phrase that has fallen into desuetude, ‘selective non-treatment’ retrospective).<sup>9</sup> Failing to meet a duty to care for a dependent, which results in that dependent’s death, can amount to murder or manslaughter, depending on the accused’s intention or knowledge.<sup>10,11</sup> The last such trial involving a doctor occurred in 1981, when Dr Arthur, a paediatrician, was acquitted of attempting to murder John Pearson. After the parents rejected the new-born, who had Down’s syndrome, Dr Arthur prescribed a painkiller and ordered ‘nursing care only’. The child died 69 hours later.<sup>12</sup> In his direction to the jury, Farquharson J noted there was no ‘special law’ protecting doctors,<sup>13</sup> but he also pointed to the lawfulness of some omissions and of symptom relief, plus the good character and motives of the defendant, who had allegedly been following accepted practice.

Farquharson J’s direction indicated his discomfort with examining Arthur’s behaviour through the criminal law lens – indeed, the defendant was described in respectful terms, while the child was referred to as ‘it’.<sup>14</sup> A different legal lens was already available, based in the civil – and specifically *family* – law, and it had been deployed in a ruling passed down only weeks before Farquharson J’s direction, although he did not cite it. Contrary to the decision in *Arthur*, in *Re B*, the Court of Appeal authorised the provision of life-saving surgery in the ‘best interests’ of another new-born with Down’s syndrome, as the court found it was not the case that ‘the life of this child is demonstrably going to be so awful that in effect the child must be condemned to die’.<sup>15</sup> Like *Arthur*, that decision also had unfortunate aspects, since the appellate judges referred to the possibility that the child might be a ‘cabbage’.<sup>16</sup>

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<sup>8</sup> This section expands on points first made in R Huxtable, ‘Clinic, Courtroom or (Specialist) Committee: In the Best of Interests of the Critically Ill Child?’ (2017) 44 *Journal of Medical Ethics* 471.

<sup>9</sup> *ibid*, 471.

<sup>10</sup> *Gibbins v Proctor* [1918] 12 Cr App Rep 134.

<sup>11</sup> *R v Stone and Dobinson* [1977] QB 354.

<sup>12</sup> *R v Arthur* [1981] 12 BMLR 1.

<sup>13</sup> *ibid*, [5].

<sup>14</sup> *ibid*.

<sup>15</sup> *Re B (a minor) (wardship: medical treatment)* [1990] 3 All ER 927, 929 (*Re B*).

<sup>16</sup> *ibid*, 1423.

Hopefully the more troubling features of these two decisions can be consigned to legal history,<sup>17</sup> but *Re B*'s central focus on the 'best interests' or – following the Children Act 1989 – the 'welfare' of the child otherwise continues to lead the way in these decisions. Using these tests, which are to be considered synonymous,<sup>18</sup> the courts have decided on numerous occasions that life-sustaining treatment is not indicated.<sup>19</sup> Neither concept has been defined but five key elements of the legal position emerge from the 1989 Act and subsequent rulings.<sup>20</sup> First, as the 1989 Act states, 'the child's welfare shall be the court's paramount consideration'.<sup>21</sup> This remains the test and, in the aforementioned *Wyatt*, the Court of Appeal took pains to emphasise that references to an 'intolerably' poor quality of life,<sup>22</sup> which might be considered – in *Re B*'s words – 'demonstrably ... awful',<sup>23</sup> are not to be treated as supplementary tests.<sup>24</sup> Second, 'the judge must look at the question from the assumed point of view of the patient'.<sup>25</sup> Third, there is a strong presumption in favour of prolonging life, but this presumption can be rebutted.<sup>26</sup> Fourth, 'best interests' is a broad, pluralistic concept, which 'encompasses medical, emotional, and all other welfare issues'.<sup>27</sup> Rather than offering a definition, the Act only provides a checklist of factors to consider, which includes the needs

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<sup>17</sup> However, the troubling term 'vegetative state' continues to be used, although there are calls for its abandonment, eg: S Laureys, GG Celesia, F Cohado, J Lavrijsen, J León-Carrión, G Sannita, L Sazbon, E Schmutzhard, KR von Wild, A Zeman, G Dolce and the European Task Force on Disorders of Consciousness, 'Unresponsive Wakefulness Syndrome: A New Name for the Vegetative State or Apallic Syndrome' (2010) 8 *BioMed Central Medicine* 68.

<sup>18</sup> *Re B (a minor) (wardship: sterilisation)* [1987] 2 WLR 1213, 1217.

<sup>19</sup> See, eg, *Re C (a minor) (wardship: medical treatment)* [1990] Fam 26; *Re J (a minor) (wardship: medical treatment)* [1991] 1 FLR 366; *Re J (a minor) (wardship: medical treatment)* [1992] 2 FLR 165; *Re C (a baby)* [1996] 2 FLR 43; *Re T (a minor) (wardship: medical treatment)* [1997] 1 All ER 966; *Re C (medical treatment)* [1998] 1 FLR 384; *Royal Wolverhampton Hospitals NHS Trust v B* [2000] 2 FCR 76; *A National Health Service Trust v D* [2000] 2 FLR 677; *Re L (a child) (medical treatment: benefit)* [2004] EWHC 2713; *NHS Trust v A (a child)* [2007] EWHC 1696; *Re K (a child) (withdrawal of treatment)* [2006] EWHC 1007; *Re B (a child) (medical treatment)* [2008] EWHC 1996; *Re OT* [2009] EWHC 633. For a full discussion of these cases, see R Huxtable, *Law, Ethics and Compromise at the Limits of Life: To Treat or Not to Treat?* (London, Routledge, 2012), 39-49.

<sup>20</sup> See especially *Portsmouth Hospitals NHS Trust v Wyatt* [2005] EWCA Civ 1181 (*Wyatt*).

<sup>21</sup> Children Act 1989 s 1(1).

<sup>22</sup> *Wyatt* (n 20), [91].

<sup>23</sup> *Re B* (n 15), 929.

<sup>24</sup> *ibid.*, [91]. Foster, however, has argued that in *Re A (male sterilisation)* [2000] 1 FLR 549, 'intolerability' returned through the 'balance sheet' approach advocated in *Wyatt* (n 30). Foster notes that in *Re A* it was held that the detriments of continuing life would have to significantly outweigh its benefits in order for the presumption in favour of continuing life to be overturned. Foster describes this as 'intolerability by another name': C Foster, *Choosing Life, Choosing Death: The Tyranny of Autonomy in Medical Ethics and Law* (Oxford, Hart Publishing, 2009) 160.

<sup>25</sup> *Wyatt* (n 20), [87].

<sup>26</sup> *ibid.*

<sup>27</sup> *ibid.*

and ‘ascertainable wishes and feelings of the child’, and any harm he or she might suffer.<sup>28</sup> Finally, according to the Court of Appeal, ‘The court must conduct a balancing exercise in which all the relevant factors are weighed and a helpful way of undertaking this exercise is to draw up a balance sheet.’<sup>29</sup>

By the time of *Wyatt*, the family law lens had been supplemented by a third, *human rights*, lens, which was provided by the Human Rights Act 1998. That Act, which came into force in 2000, essentially brought the European Convention on Human Rights directly into English law. There were soon challenges to the rulings in this area, based (inter alia) on Article 2, the right to life.<sup>30</sup> The English courts nevertheless confirmed that there would be no violation of the 1998 Act if a decision not to offer life-supporting treatment was made in the best interests of the child.<sup>31</sup> The European Court of Human Rights did, however, find against doctors, following the complaint in *Glass* in 2004, in which the relationship between the child’s family and his doctors had deteriorated significantly, leading to fistfights on the ward.<sup>32</sup> The European Court found there to be a violation of Article 8, the right to respect for private and family life, since the mother’s right to consent to treatment had not been respected. The court further emphasised the importance of resolving disputes promptly.<sup>33</sup>

Against the backdrop of cases such as *Wyatt* and *Glass*, professional organisations sought to issue guidance on how future cases should be addressed. Generic guidance – applying to patients young and old – was available from the General Medical Council and British Medical Association.<sup>34</sup> However, more specific guidance was issued by the Royal College of Paediatrics and Child Health, first in 1997,<sup>35</sup> which was updated in 2004,<sup>36</sup> and then again in 2015.<sup>37</sup> The latest guidance refers to the permissibility of withdrawing or withholding life-sustaining

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<sup>28</sup> Children Act 1989 s 1(3).

<sup>29</sup> *Wyatt* (n 20), 87.

<sup>30</sup> *A National Health Service Trust v D* [2000] 2 FLR 677.

<sup>31</sup> *ibid.*

<sup>32</sup> *Glass v UK* [2004] 1 FCR 553.

<sup>33</sup> *ibid.*, [79]–[81].

<sup>34</sup> General Medical Council, ‘Withholding and Withdrawing – Guidance for Doctors’ (2002) [www.gmc-uk.org/-/media/documents/withholding-or-withdrawing-life-prolonging-treatments-2002---2010-55677704.pdf](http://www.gmc-uk.org/-/media/documents/withholding-or-withdrawing-life-prolonging-treatments-2002---2010-55677704.pdf); British Medical Association, *Withholding and Withdrawing Life-Prolonging Medical Treatment* (BMA, 1999).

<sup>35</sup> Royal College of Paediatrics and Child Health, *Withholding or Withdrawing Life-Saving Treatment in Children: A Framework for Practice* (RCPCH, 1997).

<sup>36</sup> Royal College of Paediatrics and Child Health, *Withholding or Withdrawing Life-Sustaining Treatment in Children: A Framework for Practice* [1997] (RCPCH, 2004).

<sup>37</sup> Royal College of Paediatrics and Child Health, *Making Decisions to Limit Treatment in Life-Limiting and Life-Threatening Conditions in Children: A Framework for Practice* [1997] (RCPCH, 2014).

treatment where the child's life is limited in *quantity* (since the child is brain-stem dead, imminently dying, or his or her death is inevitable and treatment confers no overall benefit) or limited in *quality* (with reference to the burdens of treatment or the child's underlying condition, or the child's inability to benefit).<sup>38</sup> Like its predecessors, the 2015 guidance recommends that efforts be taken to resolve disputes.<sup>39</sup> Dispute resolution was also considered by a working party of the Nuffield Council on Bioethics, which issued its report in 2006.<sup>40</sup> The report found (inter alia) that existing 'legal principles centred on seeking agreement between parents and professionals as to the best interests of the baby are, in principle, appropriate and sufficient',<sup>41</sup> although it did recommend that 'all neonatal intensive care units have rapid access to a clinical ethics committee for advice'<sup>42</sup> and that further research be undertaken into 'the possible merits' of mediation in this context.<sup>43</sup>

Despite these various efforts to prevent or address disputes, the latter part of the 2010s brought a series of high-profile legal cases, of which we will briefly mention four. The first, in 2014, involved five-year-old Ashya King, who had undergone surgical removal of a brain tumour. His doctors thereafter proposed chemotherapy and radiotherapy, but his parents favoured proton beam therapy (PBT). NHS funding for PBT was refused but Ashya's parents had identified a willing centre in Prague and had the requisite funding available. Believing the hospital would seek a Child Protection Order to prevent this (which the hospital denied), Ashya's parents removed him from the hospital and took him to Spain. Ashya was subsequently made a ward of court and a court hearing convened to determine whether he was at risk of significant harm from the plan to take him to Prague for PBT. Drawing on the medical evidence, Baker J concluded that the proposed treatment was reasonable, in Ashya's best interests and Ashya was not at risk of harm, so he could be transferred to the unit in Prague, at which point he would no longer be a ward of court.<sup>44</sup>

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<sup>38</sup> *ibid*, 4–5.

<sup>39</sup> *ibid*, 12.

<sup>40</sup> Nuffield Council on Bioethics, *Critical Care Decisions in Foetal and Neonatal Medicine: Ethical Issues* (2006), [nuffieldbioethics.org/wp-content/uploads/2014/07/CCD-web-version-22-June-07-updated.pdf](http://nuffieldbioethics.org/wp-content/uploads/2014/07/CCD-web-version-22-June-07-updated.pdf).

<sup>41</sup> *ibid*, [37].

<sup>42</sup> *ibid*, [40].

<sup>43</sup> *ibid*, [41].

<sup>44</sup> *Portsmouth City Council v Nagmeh King, Brett King, Southampton Hospital Trust, Ashya King (by his Children's Guardian)* [2014] EWHC 2964 (Fam).

Although Ashya's case generated headlines, the second, involving Charlie Gard in 2017, appeared to have even wider, international reach. Charlie, who was eight months old, had a form of mitochondrial DNA depletion syndrome and was being treated in Great Ormond Street Hospital (GOSH). His treating clinicians judged his quality of life to be poor, with no hope of recovery, such that continued ventilation would be futile. His parents opposed withdrawal of ventilation on the basis that an experimental treatment was available in the United States, which might help their son. The hospital was initially prepared to consider such treatment but, following Charlie's deterioration, his treating clinicians concluded that this too would be futile. Charlie's parents maintained that he should be transferred to the United States.<sup>45</sup>

In the first substantive ruling, Francis J looked particularly to the (UK) medical evidence, deciding that mechanical ventilation was not in Charlie's best interests.<sup>46</sup> The Court of Appeal permitted an appeal on certain grounds,<sup>47</sup> but the Supreme Court refused permission to appeal, finding there was no arguable point of law.<sup>48</sup> The European Court of Human Rights also declared inadmissible the parents' attempt to have the case heard in Strasbourg.<sup>49</sup> The case did, however, return to the High Court, on the basis (inter alia) of new evidence from a US clinician. However, during this hearing, the US clinician met with the treating clinicians and reviewed up-to-date scans, which led him to conclude that there was no possibility of the nucleoside therapy having any effect. Charlie's parents thereafter withdrew their opposition to the proposal to withdraw ventilation and Francis J confirmed his earlier declaration, adding that Charlie would continue to be treated at GOSH, before being transferred to an agreed hospice.<sup>50</sup>

Two prominent cases were then brought in 2018. The first, involving 11-month-old Isaiah Haastrup, concerned whether ventilation should be withdrawn on the grounds of 'futility'.<sup>51</sup> Isaiah had been born by emergency caesarean section due to uterus rupture, which led to him sustaining severe hypoxic ischaemic brain injury. The circumstances of his birth reportedly led

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<sup>45</sup> *Great Ormond Street Hospital v Constance Yates, Chris Gard, Charles Gard (a Child by his Guardian Ad Litem)* [2017] EWHC 972 (Fam).

<sup>46</sup> *ibid.*

<sup>47</sup> *Constance Yates, Christopher Gard v Great Ormond Street Hospital for Children NHS Foundation Trust Charles Gard (a Child, by his Guardian)* [2017] EWCA Civ 410.

<sup>48</sup> *In the matter of Charlie Gard* (8 June 2017), [www.supremecourt.uk/news/permission-to-appeal-hearing-in-the-matter-of-charlie-gard.html](http://www.supremecourt.uk/news/permission-to-appeal-hearing-in-the-matter-of-charlie-gard.html).

<sup>49</sup> *Gard and Others v UK* (app no 39793-17) [2017] ECHR.

<sup>50</sup> *Great Ormond Street Hospital for Children NHS Foundation Trust v Yates and Others* [2017] EWHC 1909.

<sup>51</sup> *King's College Hospital NHS Foundation Trust v Thomas, Haastrup and Haastrup* [2018] EWHC 127 (Fam) (*Haastrup*).

to a breakdown in trust between the parents and the hospital, which worsened when, shortly after his birth, Isaiah's parents were advised he was unlikely to recover and the possibility of palliative care was raised, following which Isaiah appeared to become more responsive. Various other doctors – including from other units – reviewed Isaiah, but they all concluded that further treatment was futile and ventilation should be withdrawn. Given the breakdown in trust, the treating hospital had sought to move Isaiah to another unit, but no willing unit could be found, given the perceived futility of further treatment. The court granted Isaiah's parents permission to obtain independent expert evidence from two further experts, but they too concurred with the treating clinicians; MacDonald J authorised the withdrawal of treatment from Isaiah.

The second case also concerned the withdrawal of ventilation.<sup>52</sup> Alfie Evans, who was nearly two at the time of the hearing, had been found (at six months) to have developmental delay and had been admitted to Alder Hey Hospital with seizures. The seizures persisted and Alfie was noted to have little response to different types of stimulation. No one was able to provide a definitive diagnosis of Alfie's underlying neurological condition but his condition had caused such significant brain damage that there was judged to be no prospect of recovery, so the hospital wished to withdraw ventilation. Alfie's parents contested this and wanted their son transferred to a hospital in Italy for further investigations and the continuation of life support. In light of the medical consensus as to the futility of further treatment, Hayden J concluded that treatment was not in Alfie's best interests. The parents unsuccessfully appealed,<sup>53</sup> and subsequently brought further proceedings, seeking the same outcome on different legal grounds,<sup>54</sup> including a failed attempt to initiate a murder prosecution against some of the clinicians.<sup>55</sup> None of the appeals succeeded.

Each of these cases appeared to involve intractable disputes, which suggests that they inevitably and understandably ended up before the courts. However, prior to that point, each had involved recourse to a variety of methods by which the dispute might have been resolved.

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<sup>52</sup> *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)

<sup>53</sup> *E (a child)* [2018] EWCA Civ 550; *Evans v UK* 14238/18 [2018] ECHR 297.

<sup>54</sup> *Alder Hey Children's NHS Foundation Trust v Evans* [2018] EWHC 818; *Evans v Alder Hey Children's NHS Foundation Trust* [2018] EWCA Civ 805; *Evans v UK* (app no 18770/18) [2018] ECHR 357; *Alder Hey Children's NHS Foundation Trust v Evans* [2018] EWHC 953; *Evans v Alder Hey Children's NHS Foundation Trust* [2018] EWCA Civ 984.

<sup>55</sup> *Alder Hey Children's NHS Foundation Trust v Evans* [2018] EWHC 953, [14].



In the following sections, we review and assess some of the main methods, starting with discussions between families and clinicians.

### 3. Discussions between Families and Clinicians

As the aforementioned cases indicate, it is typical for clinicians and families (in particular, parents) to meet to discuss the child's condition, prognosis and treatment/non-treatment options. The process appears initially to involve discussions between the treating team, before a discussion (or discussions) is then held with the family.

The aim of such discussions is apparently to achieve consensus through 'shared decision-making'.<sup>56</sup> There is, however, no fixed definition of the latter concept,<sup>57</sup> nor agreement on whether it is entirely suited to paediatric decision-making.<sup>58</sup> Drawing on qualitative research with key participants in such decisions, 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.<sup>59</sup> 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,<sup>60</sup> thus cultivating a fear of bad faith.<sup>61</sup>

Other research nevertheless suggests that a positive consensus can be reached through appropriate discussions. In a study of their unit at GOSH over three years, Brierley et al found that, following initial discussions, 186 out of 203 cases resulted in parents agreeing with

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<sup>56</sup> G Birchley and R Huxtable, 'Critical Decisions for Critically Ill Infants', in C Stanton, S Devaney, A-M Farrell and A Mullock (eds), *Pioneering Healthcare Law: Essays in Honour of Margaret Brazier* (London, Routledge, 2016) 120.

<sup>57</sup> C Charles, A Gafni and T Whelan, 'Shared Decision-Making in the Medical Encounter: What Does it Mean? (or it Takes at Least Two to Tango)' (1997) 44 *Social Science and Medicine* 681; C Munthe, L Sandman and D Cutas, 'Person Centred Care and Shared Decision-Making: Implications for Ethics, Public Health and Research' (2012) 20 *Health Care Analysis* 231.

<sup>58</sup> G Birchley, 'Deciding Together? Best Interests and Shared Decision-Making in Paediatric Intensive Care' (2014) 22 *Health Care Analysis* 203.

<sup>59</sup> Birchley and Huxtable (n 56), 121.

<sup>60</sup> G Birchley, R Gooberman-Hill, Z Deans, J Fraser and R Huxtable, "'Best Interests" in Paediatric Intensive Care: An Empirical Ethics Study' (2017) 102 *Archives of Disease in Childhood* 930, 932.

<sup>61</sup> C Shaw, E Stokoe, K Gallagher, N Aladangady and N Marlow, 'Parental Involvement in Neonatal Critical Care Decision-Making' (2016) 38 *Sociology of Health & Illness* 1217.

clinicians that continued treatment was not in the child's best interests.<sup>62</sup> Six of the remaining 17 cases were resolved following further discussions with the families. In this study, discussions between the team and the family therefore generated consensus about treatment withdrawal in 94.58% of the cases.

*Gard* demonstrates that discussions in GOSH do not always lead to consensus, but its reputation as a world-renowned specialist hospital and the expertise of its staff might explain its success in achieving consensus in many cases. The literature further reveals the importance of good communication to reaching resolution. Communication, of course, is a two-way process, and Richards suggests that a key component of good communication is that clinicians not only talk, but also *listen to* families and explore their views, including those about alternative treatment options.<sup>63</sup> As for what clinicians *say to* families, Birchley et al's study reveals that clinicians will sometimes need to reframe conversations in terms more acceptable to families,<sup>64</sup> with Waldman and Frader cautioning that words like 'futile', 'harm' and 'suffering' might cause parents to feel they are being accused of not doing what is best for their child.<sup>65</sup>

Communication evidently matters and Forbat et al have found communication breakdown to be the most common cause of conflict between families and healthcare professionals in children's healthcare.<sup>66</sup> Amongst the reasons for such breakdown are, first, *pejorative labelling* by clinicians of those parents who disagree with them. Forbat et al refer to this as a factor in the escalation of conflict in paediatric healthcare disputes.<sup>67</sup> In this vein, one might refer to a clinician's email, which described the parents in *Gard* as a 'spanner in the works'.<sup>68</sup>

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<sup>62</sup> J Brierley, J Linthicum and A Petros, 'Should Religious Beliefs Be Allowed to Stonewall a Secular Approach to Withdrawing and Withholding Treatment in Children?' (2013) 39 *Journal of Medical Ethics* 573, 573.

<sup>63</sup> T Richards, 'When Doctors and Patients Disagree' (2014) *British Medical Journal Online*, [www-bmj-com.bris.idm.oclc.org/content/bmj/349/bmj.g5567.full.pdf](http://www.bmj-com.bris.idm.oclc.org/content/bmj/349/bmj.g5567.full.pdf).

<sup>64</sup> Birchley et al (n 60), 932.

<sup>65</sup> E Waldman and J Frader, 'Charlie Gard: How Did Things Go Wrong?' (2018) 6 *Current Paediatric Reports* 173, 174; See also: R Taylor, 'Parental Decisions and Court Jurisdiction: Best Interests or Significant Harm?', chapter 3 above. One reason Taylor gives for rejecting the application of the 'significant harm' test to such disputes 'is that it would be unnecessarily cruel and combative to require loving and sincere parents to defend themselves against a test based on harm' (XXX).

<sup>66</sup> L Forbat, C Sayer, P McNamee, E Menson and S Barclay, 'Conflict in a Paediatric Hospital: A Prospective Mixed Method Study' (2016) 101 *Archives of Disease in Childhood* 23, 25.

<sup>67</sup> L Forbat, B Teuten and S Barclay, 'Conflict Escalation in Paediatric Services: Findings from a Qualitative Study' (2015) *Archives of Disease in Childhood* 1, 3.

<sup>68</sup> *Gard* (n 45), [84].

Second, clinicians and parents will sometimes have *different understandings* of key terms or information. Forbat et al refer to divergent interpretations of terms such as ‘futility’ or prognostic information.<sup>69</sup> Such differences can arise, suggest Fassier and Azoulay, because families weigh the clinician’s prognostic information against factors such as their own perception of the patient’s strength of character and will to live, and the patient’s history of illness and survival.<sup>70</sup> *Evans* exemplifies this, with the trial judge noting that the parents, having been told early on in their son’s treatment to prepare for ‘the real possibility that [he] might not recover’,<sup>71</sup> viewed his initial recovery as ‘indicative of his potential for more general recovery’.<sup>72</sup> *Haastrup* is another example of parents rejecting medical views in favour of their own. The judge recorded that ‘neither parent is able to accept the consensus medical view’ that Isaiah’s condition was caused by his severe brain injury. Instead, the parents believed the inability to wean their son from the ventilator was due to the medication he was receiving.<sup>73</sup>

Third, clinicians and families will sometimes differ in their views about *decisional authority*. According to Forbat et al, many families believe that decisions about withdrawal or withholding of treatment should be made jointly between themselves and the clinical team, but a minority believe this should be a matter for the parents alone to decide.<sup>74</sup> Other studies support the latter point: essentially, some parents maintain that life-or-death decisions about their offspring are theirs to make.<sup>75</sup>

Even where the parties disagree about these (or other) matters, it is not necessarily the case that disagreement will develop into an intractable conflict.<sup>76</sup> Such escalation might even be avoided – and consensus potentially achieved – if discussions can enable the parties to identify areas of disagreement and clinicians are trained to recognise and manage conflict at an early stage.<sup>77</sup>

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<sup>69</sup> Forbat et al (n 66), 24.

<sup>70</sup> T Fassier and E Azoulay, ‘Conflicts and Communication Gaps in the Intensive Care Unit’ (2010) 16 *Current Opinion in Critical Care* 654, 661.

<sup>71</sup> *Evans* (n 52), [10].

<sup>72</sup> *ibid.*

<sup>73</sup> *Haastrup* (n 51), [59]

<sup>74</sup> Forbat et al (n 66), 23.

<sup>75</sup> L Gillam and J Sullivan, ‘Ethics at the End of Life: Who Should Make Decisions about Treatment Limitation for Young Children with Life-Threatening or Life-Limiting Conditions?’ (2011) 47 *Journal of Paediatrics and Child Health* 594; Birchley et al (n 61), 932.

<sup>76</sup> D Wilkinson, S Barclay and J Savulescu, ‘Disagreement, Mediation, Arbitration: Resolving Disputes about Medical Treatment’ (2018) 391 *Lancet* 2302, 2304.

<sup>77</sup> Fassier and Azoulay (n 70), 661; Forbat et al (n 68), 4; S Barclay, ‘Recognising and Managing Conflict Between Patients, Parents and Health Professionals’ (2016) 26 *Paediatrics and Child Health* 314, 314.

But ongoing discussion can also impose costs, and not only on the parents and clinicians. First, ongoing discussion can exacerbate, rather than resolve, a dispute. If there is a breakdown in communication and trust that is not resolved, this can lead to both sides becoming entrenched in their positions,<sup>78</sup> rendering third-party intervention necessary.<sup>79</sup> However, as we will see, clinicians can be reluctant to seek such intervention, and particularly court proceedings, for fear of costs, negative publicity, inconsistent decisions or being seen as a failure by colleagues.<sup>80</sup> Such reluctance might incline clinicians to continue a discursive process, which is nevertheless failing to progress towards resolution. But quite *when* discussions should be deemed to have failed, and third-party intervention sought, is (as yet) unclear.<sup>81</sup> Second, ongoing discussion might be contrary to the interests of the child. In the absence of agreement about non-treatment/treatment, the status quo is likely to be maintained, meaning the child will continue to receive the contested treatment. This may not be in the child's best interests – and might even be harmful.<sup>82</sup> In addition to the child, there are also the interests of the disputants to consider. Research suggests, for example, that healthcare professionals can experience moral distress as a consequence of being asked to treat a child contrary to what they feel is in the child's best interests.<sup>83</sup>

These observations suggest that communication and ongoing discussions between the stakeholders are important, but they also reveal at least two questions, which future research might usefully explore. First, at what point should clinicians (or, indeed, other parties) recognise that discussion is no longer effective and third-party intervention should be sought? Second, which form(s) of third-party intervention are indicated, and in which circumstances? We will start to explore the latter question in the following sections, beginning with the use of second medical opinions.

## 4. Second Opinion Experts

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<sup>78</sup> Forbat et al (n 67), 3.

<sup>79</sup> *ibid*; RD William Hain, 'Voices of Moral Authority: Parents, Doctors and What Will Actually Help' (2018) 44 *Journal of Medical Ethics* 458, 460; Wilkinson et al (n 75), 2304.

<sup>80</sup> Brierley et al (n 62), 576; Birchley et al (n 60), 932.

<sup>81</sup> Birchley and Huxtable (n 56), 121.

<sup>82</sup> Brierley et al (n 62), 576.

<sup>83</sup> *ibid*; G Morley, C Bradbury-Jones and J Ives, 'Moral Distress in End-of-Life Care' forthcoming, 6.

If discussions between the team and family have not resulted in agreement, then further clinical opinions might be sought. This, however, appears to be an under-researched phenomenon in this context. It is apparent that second (or third or more) opinions will sometimes be sought by clinicians and sometimes by families.<sup>84</sup> Such consultation might occur within or without the context of court proceedings, and, indeed, might even be ordered by a court. Those consulted can come from within the institution or from elsewhere, including from overseas; indeed, in all of the recent legal cases, both UK and non-UK experts were instructed.

Beyond these indications, however, there appears to be a lack of research into when and how second opinions are sought, who determines which expert is instructed, and any role they might play in addressing or resolving conflict. Some suspect that such additional opinions can prove useful, for example if the family's interpretation of the medical facts differs from those of the treating clinicians.<sup>85</sup> Families will also sometimes disagree with the clinicians about the treatment to be given, with Forbat et al noting that this is the second most common cause of conflict.<sup>86</sup> In such cases, an independent view might prove helpful.

The utility of such opinions is not, however, established in the literature. In their study, Brierley et al noted that second opinions were sought in six of the 203 cases in which withdrawal of treatment was recommended. However, in none of those six cases did resolution result from the provision of the additional opinion. The authors suggested that this was due to the intractable religious views held by the parents in those cases,<sup>87</sup> and the study does not provide evidence that second opinions, in general, are ineffective.

But other authors do express concerns about the gathering of such opinions. First, the second opinion might lack – or be perceived to lack – the requisite *independence*. Meller and Barclay note this as a risk when the treating team, rather than the family, select the expert. To avoid that risk, they propose that families select the expert.<sup>88</sup> However, the family's satisfaction will also depend on what the expert *says*: in *Haastrup*, the father instructed his own expert, but he viewed that expert as colluding with the NHS when the expert took the same view as the treating clinicians.<sup>89</sup> Meller and Barclay also raise the concern that allowing families to select

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<sup>84</sup> Brierley et al (n 62), 576; S Meller and S Barclay, 'Mediation: An Approach to Intractable Disputes Between Parents and Paediatricians' (2011) 96 *Archives of Disease in Childhood* 619, 619.

<sup>85</sup> Wilkinson et al (n 76), 2304.

<sup>86</sup> Forbat et al (n 66), 25.

<sup>87</sup> Brierley et al (n 62), 574.

<sup>88</sup> Meller and Barclay (n 84), 619.

<sup>89</sup> *Haastrup* (n 51), [46].

the expert will lead to families ‘doctor-shopping’ for those experts likely to share their view.<sup>90</sup> For example, in *Gard*, the mother’s Internet research revealed the possibility of an experimental treatment, which led to the instruction of an expert from the United States.<sup>91</sup> Such cherry-picking can then lead to a second potential area of difficulty, if the expert departs from the view of the treating clinicians and this *exacerbates the conflict*.<sup>92</sup> This appears to be what happened in *Gard*, as the expert’s views did indeed differ from those of the responsible team.<sup>93</sup>

These are, however, only indications and further research appears to be needed. Such research could, in particular, explore how often second opinions are sought, how the process works, and its effectiveness, or otherwise, in resolving disputes.

## 5. Clinical Ethics Consultation

Clinical ethics support services are another source of external input to the clinicians (and, occasionally, patients and their families). Such services take different forms internationally but, in the UK, a clinical ethics committee (CEC) model dominates. Unlike their research-facing counterparts, CECs are not legally mandatory or even regulated as such. During the passage of the Mental Capacity (Amendment) Bill through the House of Lords, an amendment was tabled that would have required all NHS bodies to have access to CECs.<sup>94</sup> However, the proposed amendment was subsequently withdrawn in favour of discussions with the minister instead.<sup>95</sup> Pending any such change in the law, the UK Clinical Ethics Network (UKCEN) provides leadership, by seeking to promote clinical ethics support and facilitate communication between UK CECs.<sup>96</sup> It describes CECs as ‘multidisciplinary groups, including health professionals and lay members that aim to provide support for decision-making on ethical issues arising from the

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<sup>90</sup> Meller and Barclay (n 84), 619.

<sup>91</sup> *Gard* (n 45), [71]–[72].

<sup>92</sup> C Wallis, ‘When Paediatricians and Families Can’t Agree’ (2018) 103 *Archives of Disease in Childhood* 413, 413.

<sup>93</sup> In the court hearings, the US expert acknowledged that the treatment was unlikely to work, although he felt, if the parents wanted to try it, then it should be provided, given the lack of other treatment options: *Gard* (n 45), [18]–[19].

<sup>94</sup> The proposed amendment also included provision for regulations to be made as to their membership, funding and constitution. See [publications.parliament.uk/pa/bills/lbill/2017-2019/0117/18117-I\(a\).pdf](https://publications.parliament.uk/pa/bills/lbill/2017-2019/0117/18117-I(a).pdf). Parental access to CECs in the case of disagreements about the care of critically ill children is being sought by Charlie Gard’s parents as part of the proposed ‘Charlie’s Law’, Charlie Gard Foundation, ‘Charlie’s Law’, [www.thecharliegardfoundation.org/charlies-law/](http://www.thecharliegardfoundation.org/charlies-law/).

<sup>95</sup> Hansard HL vol 793 cols 387–88 (15 October 2018).

<sup>96</sup> UK Clinical Ethics Network, ‘About the Network’, [www.ukcen.net/main/about](http://www.ukcen.net/main/about).

provision of patient care within NHS Trusts and other health care institutions’.<sup>97</sup> Committees therefore tend to include health professionals, lay members, legal members and ‘ethicists’, but they have no fixed structure, function or membership criteria, and their constitution varies between settings.<sup>98</sup> The number of UK committees (voluntarily) registered with UKCEN waxes and wanes, from 20 in 2000, to 85 in 2009,<sup>99</sup> to 77 in 2018.<sup>100</sup> Where they exist, CECs tend to be involved in education and policy, as well as – of most relevance here – case consultation.

CECs tend to have an *advisory* remit: they issue advice on request, rather than making decisions about (for example) ethically contentious cases. There are, however, many questions surrounding UK committees, including about the extent to which their advice is sought. The literature suggests that CECs are infrequently utilised as a mechanism for dispute resolution,<sup>101</sup> with most UK committees advising on 1–10 cases a year.<sup>102</sup> As many CECs are based in large NHS Trusts, the referrals they receive will span a variety of patients and specialties. However, even in paediatric settings, referrals appear to be low, with Brierley et al noting that only six of the 186 contested cases in their study were referred for ethical review.<sup>103</sup> The relative scarcity of ethical review also appears to be borne out in the recent legal cases: only in *Gard* is reference made to CEC input.<sup>104</sup>

They may appear to be relatively under-utilised, but commentators nevertheless believe that CECs have the potential to contribute positively to the resolution of difficult cases. Three groups of reasons tend to be given. First, ‘CECs seek to provide practical advice, thus neither amounting to a mere “talking shop”, nor posing a threat to clinical autonomy’.<sup>105</sup> Second, 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

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<sup>97</sup> UK Clinical Ethics Network, ‘Clinical Ethics Committees’ [www.ukcen.net/committees/introduction](http://www.ukcen.net/committees/introduction).

<sup>98</sup> Birchley and Huxtable (n 56), 123; UK Clinical Ethics Network (n 97).

<sup>99</sup> V Larcher, ‘The Development and Function of Clinical Ethics Committees (CECs) in the United Kingdom’ (2009) 22 *Diametros* 47, 48.

<sup>100</sup> UK Clinical Ethics Network, ‘CEC Member List’, [www.ukcen.net/committees/member\\_list](http://www.ukcen.net/committees/member_list).

<sup>101</sup> A Fiester, ‘The Failure of the Consult Model: Why “Mediation” Should Replace “Consultation”’ (2007) 7 *American Journal of Bioethics* 31, 32.

<sup>102</sup> AM Slowther, L McClimans and C Price, ‘Development of Clinical Ethics Services in the UK: A National Survey’ (2012) 38 *Journal of Medical Ethics* 210, 212–13.

<sup>103</sup> Brierley et al (n 62), 574. The CEC’s advice did not lead to resolution in those six cases, which the authors attribute to the parents’ decisions being driven by fundamentalist religious beliefs that they were not prepared to discuss.

<sup>104</sup> *Gard* (n 45), [17] and [59]. It should be noted, however, that some CECs do not offer formal advice and will only act to help the clinical team work through the presenting problem.

<sup>105</sup> Huxtable (n 8), 473.

*Haastrup*,<sup>106</sup> 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.<sup>107</sup> 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.<sup>108</sup> Moreover, CECs appear to have the experience (and perhaps even some form of expertise) in addressing dilemmas such as those considered here, since they notably tend to be consulted about such issues as withdrawing or withholding life-supporting treatment.<sup>109</sup> Indeed, some CECs exist in specialist settings – like GOSH’s committee<sup>110</sup> – which implies they will have a specialist body of experience (and, again, perhaps also specialist expertise).<sup>111</sup> Third, CECs are intended to be supportive and as such they may have advantages over their competitors. For example, relative to the courts, CECs are able to pool diverse, pertinent expertise and they are less formal and costly (in both financial and emotional terms).<sup>112</sup> Although data is lacking, not only about how often CECs are used, but also about whether their advice is accepted,<sup>113</sup> some parties do record high satisfaction rates.<sup>114</sup>

The news is not all good, however. Amongst the ‘unresolved issues’ noted by Weise and Daly are ‘questions about qualifications for clinical ethicists, required competencies, the appropriateness of formal certification or licensure, and metrics for evaluation’.<sup>115</sup> The main concerns can be gathered into three groups. First, there are problems of *orientation*. UK CECs are typically there to support clinicians, which raises questions about their availability and

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<sup>106</sup> *Haastrup* (n 51), [54].

<sup>107</sup> Brierley et al (n 52), 576.

<sup>108</sup> Wilkinson et al (n 76), 2304; Huxtable (n 19), 156–57.

<sup>109</sup> Slowther et al (n 102) 212; KM Swetz, ME Crowley, C Hook and PS Mueller, ‘Report of 255 Clinical Ethics Consultations and Review of the Literature’ (2007) 82 *Mayo Clinic Proceedings* 686, 686.

<sup>110</sup> Great Ormond Street Hospital, ‘About the Clinical Ethics Service’, [www.gosh.nhs.uk/wards-and-departments/departments/clinical-specialties/clinical-ethics-service-information-health-professionals/about-clinical-ethics-service](http://www.gosh.nhs.uk/wards-and-departments/departments/clinical-specialties/clinical-ethics-service-information-health-professionals/about-clinical-ethics-service).

<sup>111</sup> Huxtable (n 8), 474.

<sup>112</sup> *ibid*, 473.

<sup>113</sup> Fiester (n 101), 31.

<sup>114</sup> Fassier and Azoulay (n 70), 662.

<sup>115</sup> KL Weise and BJ Daly, ‘Exploring Accountability of Clinical Ethics Consultants: Practice and Training Implications’ (2014) 14 *American Journal of Bioethics* 34, 34.



commitment to patients and their families,<sup>116</sup> their accountability,<sup>117</sup> and their independence from the healthcare setting.<sup>118</sup> The parents and nurses interviewed by Birchley were supportive of CEC involvement in paediatric disputes, although those participants did not have direct experience of CECs.<sup>119</sup> Others' concerns about bias and the like might nevertheless be assuaged if, for example, parents and nurses are permitted to *bring* referrals;<sup>120</sup> indeed, as we noted, Charlie Gard's parents have proposed legislation that would ensure such access.<sup>121</sup> As for those *receiving* the referrals as members of the committee, it is also possible – as GOSH's CEC evinces – to include in the membership those who have direct ('lay') experience of care in the relevant setting.<sup>122</sup>

Second, there are questions of *operation and process*, which McLean pithily captures when she refers to CECs as a 'due process wasteland',<sup>123</sup> and asks: '[W]hat and who are clinical ethics committees for?'<sup>124</sup> The relative informality of CECs may appear to be a strength but, as Weise and Daly noted, there are concerns about the qualifications, certification and competencies of CEC members, and about the ethical deliberation frameworks that CECs use to reach their advice.<sup>125</sup> As things stand, there are no formal requirements for the expertise or training required to sit on such committees,<sup>126</sup> and Birchley's study noted that one of the criticisms paediatric clinicians had of CECs was their lack of paediatric experience.<sup>127</sup> Fiester has argued that lack of training and expertise may bring into question CECs' right to be

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<sup>116</sup> AJ Newson, 'The Role of Patients in Clinical Ethics Support: A Snapshot of Practices and Attitudes in the United Kingdom' (2009) 4 *Clinical Ethics* 139; V Fournier, E Rari, R Forde, G Neitzke, R Pegoraro, AJ Newson, 'Clinical Ethics Consultation in Europe: A Comparative and Ethical Review of the Role of Patients' (2009) 4 *Clinical Ethics* 131.

<sup>117</sup> Weise and Daly (n 115).

<sup>118</sup> M Magelssen, R Pedersen, R Førde, 'Sources of Bias in Clinical Ethics Case Deliberation' (2014) 40 *Journal of Medical Ethics* 678.

<sup>119</sup> Birchley and Huxtable (n 56), 124.

<sup>120</sup> Ibid, 124, 127; R Forde, T Linja, "'It Scares Me to Know that We Might Not Have Been There!': A Qualitative Study into the Experiences of Parents of Seriously Ill Children Participating in Ethical Case Discussions' (2015) 16 *BioMed Central Medical Ethics* 40.

<sup>121</sup> Charlie Gard Foundation (n 94).

<sup>122</sup> *Great Ormond Street Hospital* (n 110); E Updale, 'The Challenge of Lay Membership of Clinical Ethics Committees' (2006) 1 *Clinical Ethics* 60.

<sup>123</sup> S McLean, 'Clinical Ethics Committees: A Due Process Wasteland?' (2008) 3 *Clinical Ethics* 99.

<sup>124</sup> S McLean, 'What and Who Are Clinical Ethics Committees For?' (2007) 33 *Journal of Medical Ethics* 49.

<sup>125</sup> V Larcher, AM Slowther and AR Watson, 'Core Competencies for Clinical Ethics Committees' (2010) 10 *Clinical Medicine* 30; AM Slowther, L McClimans and C Price, 'Development of Clinical Ethics Services in the UK: A National Survey' (2012) 38 *Journal of Medical Ethics* 210.

<sup>126</sup> Huxtable (n 19), 159.

<sup>127</sup> Birchley and Huxtable (n 56), 125.

involved in decisions that affect the lives of others.<sup>128</sup> Having the ‘wrong’ sort of expertise or focus can be problematic: some of Birchley’s clinicians felt that CECs have too great a legal focus,<sup>129</sup> but legal scholars (eg McLean) have conversely queried whether CECs sufficiently attend to legal concerns, such as those associated with due process, transparency and consistency.<sup>130</sup> But quite what the requisite expertise should be remains an open – and vexed – question.<sup>131</sup>

Another vexed question is whether a CEC is even the best model for providing clinical ethics support. Other models exist, such as clinical ethics consultants, although these tend to be rare in the UK.<sup>132</sup> Of course, what counts as the ‘best’ (or even just an ‘appropriate’) model remains to be seen, and this leads onto a third area of difficulty, concerning the *impact and evaluation* of clinical ethics support. The impact of CECs is questionable, not least because they lack the ability formally to resolve disputes by determining the outcome: they only offer advice to clinicians, which the clinicians are free to reject.<sup>133</sup> But, again, quite what is to count as impact in this context, and how it is to be evaluated, merits further research.<sup>134</sup>

CECs therefore show promise but also appear to have their pitfalls. Amongst the many proposals for improving CECs are: ensuring that committees are pluralistically composed and that members have training in (for example) communication and conflict management;<sup>135</sup> having specialist committees with subject-specific expertise;<sup>136</sup> and formalising committees, including through the creation of an appeals process and auditing and evaluation of decision-making.<sup>137</sup> Further research is nevertheless needed into CECs and these proposals, including those for alternative types of clinical ethics services.

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<sup>128</sup> Fiester (n 101), 31.

<sup>129</sup> Birchley and Huxtable (n 56), 125.

<sup>130</sup> McLean (n 123), 101–03; Huxtable (n 19), 166–72.

<sup>131</sup> Huxtable (n 19), 172–76.

<sup>132</sup> For a discussion of the benefits that clinical ethics consultations can offer clinical ethics support services, see: E DeRenzo, N Mokwunye and JJ Lynch, ‘Rounding: How Everyday Ethics Can Invigorate a Hospital’s Ethics Committee’ (2006) 18 *HEC Forum* 319; E DeRenzo, J Vinicky, B Redman, JJ Lynch, P Panzarella and S Rizk, ‘Rounding: A Model for Consultation and Training Whose Time Has Come’ (2006) 15 *Cambridge Quarterly of Healthcare Ethics* 207.

<sup>133</sup> Birchley and Huxtable (n 56), 126.

<sup>134</sup> E Fox and RM Arnold, ‘Evaluating Outcomes in Ethics Consultation Research’ (1996) 7 *Journal of Clinical Ethics* 127; J Schildmann, B Molewijk, L Benaroyo, R Forde and G Neitzke, ‘Evaluation of Clinical Ethics Support Services and its Normativity’ (2013) 39 *Journal of Medical Ethics* 681.

<sup>135</sup> Fassier and Azoulay (n 70), 662; Huxtable (n 19), 169.

<sup>136</sup> Birchley and Huxtable (n 56), 127; Huxtable (n 8), 473. This is arguably already the case with GOSH’s CEC.

<sup>137</sup> Huxtable (n 19), 160, 170, 171.

## 6. Mediation

One alternative to CECs, which is beginning to be explored in this context, is mediation. Mediation is 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.<sup>138</sup> Already familiar in some other contexts, there is growing interest in mediation as a method for resolving paediatric healthcare disputes, following the establishment of the Medical Mediation Foundation in 2010.<sup>139</sup>

The use of mediation in this context has attracted support including, in *Gard*, from Francis J.<sup>140</sup> Mediation is said to have various benefits. First, the method allows for – indeed, requires – open discussion, which might help to rebuild relationships and restore trust.<sup>141</sup> The method can therefore be contrasted with more adversarial mechanisms, such as recourse to law. Second, and again in contrast to court proceedings, the timing is flexible: Wilkinson et al note that mediation can be attempted at any stage of a dispute.<sup>142</sup> There is also, third, flexibility over who can be involved in the process – unlike, again, court proceedings.<sup>143</sup> Input beyond that of the disputing clinicians and parents can prove beneficial: Brierley et al, for example, found that involving religious leaders in discussions of end-of-life care aided resolution of disputes.<sup>144</sup>

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<sup>138</sup> Centre for Effective Dispute Resolution, ‘Glossary of Terms’, [https://www.cedr.com/about\\_us/library/glossary.php](https://www.cedr.com/about_us/library/glossary.php).

<sup>139</sup> Meller and Barclay (n 84), 620.

<sup>140</sup> *Gard* (n 45), [130]. The legislation Charlie Gard’s parents are seeking (n 95) also provides for access to medical mediation when disputes as to the care of critically ill children arise.

<sup>141</sup> T Allen, ‘A New Way to Settle Old Disputes: Mediation and Healthcare’ (2005) 73 *Medico-Legal Journal* 93, 98; Meller and Barclay (n 84), 620; Huxtable (n 8), 473.

<sup>142</sup> Wilkinson et al (n 76), 2304.

<sup>143</sup> Meller and Barclay (n 84), 620. Whilst third parties can intervene in court proceedings, this is restricted to the provision of written or oral submissions and only applies to third parties who have some ‘knowledge or particular point of view [that enables them to provide the court] with a more rounded picture than it would otherwise obtain’ (*Re E (A Child) (AP) (Appellant) (Northern Ireland)* [2008] UKHL 66, [3]).

<sup>144</sup> Brierley et al (n 62), 573. Whilst there is scope for others besides the parties to a dispute to intervene in proceedings (eg religious leaders), it is at the court’s discretion whether to accept such submissions and, if they do, the weight they will be given. In addition, whilst the intervention can support one of the parties, the interveners must raise issues of principle beyond those raised by the parties: A Samuels, ‘The Intervener Is Here to Stay’ (2017) *New Law Journal* 17.

Despite these advantages, mediation also has its drawbacks and uncertainties. First, the process requires voluntary engagement and a willingness on the part of the disputants to move beyond their initial positions.<sup>145</sup> Not every disputant will be so inclined. Indeed, according to the Trust's legal counsel, mediation failed in *Evans* because the family and their advisors did not genuinely engage with the process.<sup>146</sup> It is not only families who might fail to engage, however. Second, research by Forbat et al found that healthcare staff see mediation as a mechanism of last resort.<sup>147</sup> Yet, as *Evans* arguably illustrates, such a waiting game might doom mediation to fail because, by the time it is attempted, relationships have broken down and the parties have become entrenched in their positions.

Even if the parties do sincerely engage, third, there is the risk that important elements of the dispute might be missed. Disputes in this context appear often to rest on conflicting ethical positions, which mediation might fail to draw out or seek to resolve.<sup>148</sup> To address such a concern, scholars suggest that mediation should be underpinned by an ethical framework and be directed towards the goal of achieving an ethical outcome.<sup>149</sup> Proponents of mediation, such as Meller and Barclay, agree that effective mediation in this context requires mediators to be equipped with knowledge of medical law and medical ethics, an understanding of paediatric issues, and access to independent expert advice.<sup>150</sup>

These latter proposals suggest that CECs and mediation might usefully be brought together, since they apparently offer different ways of fulfilling the same, or at least similar, functions. CECs can provide the requisite ethical reflection, whilst mediation brings an impartiality and

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<sup>145</sup> Allen (n 141), 99.

<sup>146</sup> M Mylonas QC, 28 April 2018: '[1/2] In Alfie's case the first mediation in July 2017 with 2 trained mediators (one medical) was useless when family turned up very late allowing only 90 minutes rather than full day. Second was hijacked days before when Giuristi per La Vita said no to [2/2] mediation and family wanted only a "meeting". 3rd in Jan failed after start was delayed for 5 hours (with whole Alder Hey team waiting) while pro-life activist Broesamle argued with family's advisors. Mediation will not work unless families are properly advised', tweets: [twitter.com/mmpolista/status/990472258853441537](https://twitter.com/mmpolista/status/990472258853441537) and [twitter.com/mmpolista/status/990478302866563078](https://twitter.com/mmpolista/status/990478302866563078).

<sup>147</sup> L Forbat, J Simons, C Sayer, M Davies and S Barclay, 'Training Paediatric Healthcare Staff in Recognising, Understanding and Managing Conflict with Patients and Families: Findings from a Survey on Immediate and 6-Month Impact' (2017) 102 *Archives of Disease in Childhood* 250, 253.

<sup>148</sup> Huxtable (n 8), 473.

<sup>149</sup> Wilkinson et al (n 76), 2304.

<sup>150</sup> Meller and Barclay (n 84), 620.

independence that CECs might lack. Whether the two can and should be brought together looks like a promising line of research. Research into mediation in this context is certainly needed, in order to ascertain when and how it is used and its effectiveness.<sup>151</sup> In Brierley et al's study of dispute resolution, there was no reference made to mediation being used.<sup>152</sup> Research is now underway, primarily through the Medical Mediation Foundation's Evelina Resolution Project, which offers mediation services as well as conflict recognition and management training.<sup>153</sup> However, its data to date has focused upon conflict management training, rather than on mediation.<sup>154</sup> Allen has suggested that the lack of data on the success (or otherwise) of mediation is due to mediation being confidential.<sup>155</sup> However, data on the extent of mediation and whether this has led to resolution could be gathered and reported (subject to the parties' agreement) without breaching confidentiality. In sum, mediation, like clinical ethics support, looks promising, but more research is needed to ascertain the advantages and disadvantages that this approach to paediatric disputes offers.

## 7. Courts

Finally, the courts are available to make decisions in contested cases. Proceedings may be brought under the Children Act 1989, according to which the 'welfare of the child' shall be the court's 'paramount consideration',<sup>156</sup> or under the inherent jurisdiction, where the focus is on the 'best interests' of the child. Although there are procedural differences,<sup>157</sup> the courts have

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<sup>151</sup> The Nuffield Council on Bioethics had previously recommended the benefits of medical mediation be explored: Nuffield Council on Bioethics (n 40), [8.62].

<sup>152</sup> Brierley et al (n 62).

<sup>153</sup> Medical Mediation Foundation, 'Evelina Resolution Project', [www.medicalmediation.org.uk/evelina-resolution-project/](http://www.medicalmediation.org.uk/evelina-resolution-project/).

<sup>154</sup> See: Wilkinson et al (n 76); Forbat et al (n 66); Forbat et al (n 147); L Forbat and S Barclay, 'Reducing Healthcare Conflict: Outcomes from Using the Conflict Management Framework' (2018) *Archives of Disease in Childhood* 1.

<sup>155</sup> Allen (n 141), 95.

<sup>156</sup> Children Act 1989 s 1.

<sup>157</sup> See, eg, R George, 'The Legal Basis of the Court's Jurisdiction to Authorise Medical Treatment of Children', chapter 4 above.

confirmed that welfare and best interests are to be treated as synonymous.<sup>158</sup> Since the early 1980s, the courts have adjudicated on numerous cases involving critically ill infants.<sup>159</sup>

There are various reasons why courts might be considered appropriate and effective fora for resolving such disputes, three of which we will mention here. First, unlike the other mechanisms we have considered, courts provide authoritative judgments about what treatment (or care) may – perhaps must – be given.<sup>160</sup> In short, courts can decide and thereby settle a dispute. Second, in apparent contrast to some of the preceding alternatives, the legal process is rigorous. Judges are, for example, able to evaluate a variety of evidence,<sup>161</sup> and, whilst it is undoubtedly subject to criticism, the legal process aspires to impartiality and does enjoy some credibility as a means of decisively settling disputes. Third, and despite its procedural rigour, the legal process also allows for some flexibility, including in the sorts of evidence to be considered. Judges can, for example, engage with the ethical dimensions of the cases before them – as indeed has occurred in paediatric disputes.<sup>162</sup>

Despite these apparent advantages, recourse to the courts appears to be relatively rare. Although not every ruling is reported, there annually appear to be only two or three such cases coming before the courts.<sup>163</sup> The literature nevertheless indicates that there are many more disputes occurring in paediatric healthcare settings. Brierley et al's study supports this impression, wherein only one of the disputed cases was litigated.<sup>164</sup> Infrequent recourse to the courts might be attributable to their perceived disadvantages, five of which we will note.

First, the legal process is *adversarial*, which generates the impression that there are winners and losers.<sup>165</sup> This is not necessarily an appropriate framing, particularly in an ethically

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<sup>158</sup> *Re B* (n 18).

<sup>159</sup> Cited within this chapter and discussed in Huxtable (nn 8, 19).

<sup>160</sup> Courts resist the idea that they *order* doctors, but that is arguably the practical import of their decisions. However, the courts will not always *decide*: for example, in *R v Portsmouth Hospital NHS Trust ex parte Glass* [1999] 2 FLR 905, the court refused to make an order as to the course the doctors should take in the event of future disagreements over treatment. Failure to issue a decision appears rare but, even where (as is usual) decisions are made, these will not always *settle* the dispute: for example, Bridgeman (n 2) notes that the *Wyatt* case came to court at least 11 times.

<sup>161</sup> Wilkinson et al (n 76), 2304.

<sup>162</sup> Huxtable (n 19), 145–46.

<sup>163</sup> Birchley (n 58), 207.

<sup>164</sup> Brierley et al (n 62), 574.

<sup>165</sup> Huxtable (n 19), 147; Birchley and Huxtable (n 56), 122; Huxtable (n 8), 472; Wallis (n 92), 413.

sensitive context such as the present one, which does not necessarily encompass ethical blacks and whites but might instead be replete with ethical shades of grey.<sup>166</sup> Furthermore, and contrary to the earlier observation, the courts will not always be willing or equipped to attend to these complex ethical dimensions.<sup>167</sup>

Second, an adversarial framing can have *adverse effects* on the protagonists and, indeed, on the (already compromised) relationship between them. Fassier and Azoulay noted concerns expressed by ICU staff that court action could amplify the feelings of frustration and grief in such disputes,<sup>168</sup> resulting in the proceedings escalating the conflict and entrenchment of different views, as the focus shifts to the conflict itself, rather than the child.<sup>169</sup> This could then lead to a complete loss of trust between the family and healthcare staff,<sup>170</sup> with the involvement of the media and social media further contributing to a climate of fear and distrust.<sup>171</sup> Brierley et al noted that fear of negative publicity was one reason why healthcare professionals are reluctant to utilise court proceedings.<sup>172</sup> There are also suggestions that, when judicial decisions *are* sought, relationships can suffer – regardless of who ‘wins’ or ‘loses’. If the judge decides that treatment should be withdrawn contrary to the parents’ wishes, then the parents will obviously feel that their assessment of the welfare of their child has been overruled.<sup>173</sup> But even the ‘winning’ clinicians need not be entirely satisfied, since the decision will signal that, whilst they had been seeking resolution, they had been treating the child against his or her best interests.<sup>174</sup> Alternatively, if the judge decides that treatment should be provided, then this might further erode the parents’ trust in the clinicians and create a conflict for the clinicians between honouring the legal ruling and acting in what they perceive to be the best interests of

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<sup>166</sup> Meller and Barclay (n 84), 620.

<sup>167</sup> Huxtable (n 19), 152–53.

<sup>168</sup> Fassier and Azoulay (n 70), 662.

<sup>169</sup> Meller and Barclay (n 84), 619; Forbat et al (n 67), 3.

<sup>170</sup> Waldman and Frader (n 65), 175.

<sup>171</sup> Fassier and Azoulay (n 70), 662.

<sup>172</sup> Brierley et al (n 62), 576.

<sup>173</sup> 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.

<sup>174</sup> Waldman and Frader (n 65), 176; D Wilkinson and J Savulesca, ‘Hard Lessons: Learning from the Charlie Gard Case’ (2018) 44 *Journal of Medical Ethics* 438, 440.

the child. In short, an adversarial process can impose costs on the parties, including, of course, on the child.<sup>175</sup>

Third, the costs are not only emotional or relational, but also *financial*.<sup>176</sup> There will be the costs associated with providing ongoing treatment to the child until the judicial decision is issued (and that decision, of course, might be that treatment should not be given).<sup>177</sup> There are also the costs of the legal proceedings themselves. Such costs will often be borne by Trusts, but one might wonder whether this is a good use of the limited NHS budget, when cheaper, potentially less divisive mechanisms exist. If, instead, parents must fund the proceedings, then there is a paucity of legal aid funding, but even where this is available, it will not always cover the entire costs.<sup>178</sup> The parents in *Gard* managed to secure pro bono representation, but this will not be available to all parents; the judge in *Gard* understandably expressed the view that, in such cases, legal aid should be available.<sup>179</sup> Turning to the child, the state will also meet the costs of the Children's Guardian, who will appear to represent the child. This appears to be legitimate expenditure, since the Guardian represents the interests of the child independent of the views of his or her parents or doctors; however, Meller and Barclay have queried whether the Guardian is truly independent, given the apparent frequency with which the Guardian concurs with medical opinion.<sup>180</sup>

Fourth, the courts' *reasoning* about the best interests of the child can appear inconsistent, opaque and unpredictable. The parties to a case will receive a determinate outcome but the judgments arguably fail to issue guidance that is sufficient to inform future decision-makers. The Children Act only enumerates some of the factors to be considered,<sup>181</sup> with the judges enjoying a great deal of discretion in the interpretation of a child's best interests.<sup>182</sup> The factors

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<sup>175</sup> Morley et al (n 83), 6.

<sup>176</sup> *ibid*; Forbat et al (n 67), 2; Birchley and Huxtable (n 56), 122, 123.

<sup>177</sup> Huxtable (n 8), 472. This might imply that treatment should not *have been* given.

<sup>178</sup> *ibid*.

<sup>179</sup> *Great Ormond Street Hospital for Children NHS Foundation Trust v Yates and Others* [2017] EWHC 1909, [17].

<sup>180</sup> Meller and Barclay (n 84), 619. See, eg, *Gard* (n 45), [117]; *Haastrup* (n 51), [67]; *Evans* (n 52), [54].

<sup>181</sup> C Lim, MC Dunn and JJ Chin, 'Clarifying the Best Interests Standard: The Elaborative and Enumerative Strategies in Public Policy-Making' (2016) 42 *Journal of Medical Ethics* 542.

<sup>182</sup> M Hedley, *The Modern Judge: Power, Responsibility and Society's Expectations* (Bristol, Jordans, 2016).



– and the weight accorded to them – that inform best-interests decisions appear to vary between cases.<sup>183</sup> Close et al have called on the courts to be clearer in their written judgments about the factors that influenced their decision, the weight given to those factors and the reasons for this.<sup>184</sup> The language used can also add confusion; for example, there may be references to treatment being ‘futile’, without judges explaining how that has been interpreted in a particular case.<sup>185</sup> The perceived lack of clarity might explain Brierley et al and Birchley et al’s findings that healthcare professionals were reluctant to seek court orders because of uncertainty as to the likely outcome.<sup>186</sup> Such findings raise the concern that clinicians will only seek court hearings if they are confident that the court will support their decision about treatment (a concern which echoes that of parents ‘cherry-picking’ second-opinion experts). Further research could usefully explore whether there are better alternatives to the best-interests standard, such as the ‘harm standard’ (which featured in *Gard*<sup>187</sup>),<sup>188</sup> or whether there might be better approaches to the interpretation and operationalisation of the existing standard.

The final drawback of legal proceedings is that these entail *delay*.<sup>189</sup> Proceedings that make it to court can be time consuming. Bridgeman has noted that, despite being fast-tracked, the proceedings in *Gard* lasted for five months, including the appeals.<sup>190</sup> As already noted, during this time, the healthcare team are continuing to treat the child, potentially contrary to what they consider to be in the child’s best interests. This was recognised by the Supreme Court in *Gard*

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<sup>183</sup> Huxtable (n 19), 146; Huxtable (n 8), 472.

<sup>184</sup> E Close, L Wilmott and BP White, ‘Charlie Gard: In Defence of Law’ (2018) 44 *Journal of Medical Ethics* 476, 478.

<sup>185</sup> See, eg, *Evans* (n 52), [24], [25], [35], [37], [51] and [66]. In contrast, in *Gard* (n 45), the judge explained his interpretation of ‘futile’ as ‘pointless or of no effective benefit’ [93]. We highlighted in section 2 of this chapter the potentially damaging effect that terms such as ‘futile’ can have in the context of such disputes. C Auckland, ‘Futility’, chapter 9 above.

<sup>186</sup> Brierley et al (n 62), 576; Birchley and Huxtable (n 56), 122.

<sup>187</sup> *Gard* (n 47), [113].

<sup>188</sup> See, eg, Birchley et al (n 60), 933; Taylor (n 65); I Goold, ‘Evaluating Best Interests as a Threshold for Judicial Intervention’, chapter 2 above.

<sup>189</sup> Celia Kitzinger and Jenny Kitzinger have written about the difficulty of delays in court proceedings in the context of withdrawing/withholding life-sustaining treatment from adults: C Kitzinger and J Kitzinger, ‘Court Applications for Withdrawal of Artificial Nutrition and Hydration from Patients in a Permanent Vegetative State: Family Experiences’ (2016) 42 *Journal of Medical Ethics* 11.

<sup>190</sup> Bridgeman (n 173), 299.

when they considered whether to continue to stay proceedings whilst the parents pursued the appeals:

The hospital finds itself in an acutely difficult ethical dilemma: although the stays have made it lawful to continue to provide him with AVNH [artificial ventilation, nutrition and hydration], it considers it professionally wrong for it to have continued for over two months to act otherwise than in his best interests.<sup>191</sup>

Similar timescales were seen in *Haastrup* (three months) and *Evans* (five months), although in *Haastrup* there was no substantive appeal hearing. Some cases are quicker: *King* was dealt with within two weeks, but the key difference there was that the Trust did not oppose the parents' desire for alternative treatment. The courts need to balance procedural fairness with expediency,<sup>192</sup> but the prospect of delays can deter clinicians from seeking judicial resolution.<sup>193</sup> Yet, this is not the only reported reason for clinicians' reluctance. Birchley et al found that some clinicians saw the avoidance of court as a measure of personal and professional success.<sup>194</sup> This implies that courts are used only as a last resort, and Wallis notes that paediatricians are usually advised only to seek a judgment when the dispute has become entrenched and reached an impasse.<sup>195</sup> However, waiting for this impasse could further undermine the trusting relationship and encourage an adversarial approach towards proceedings, thus further contributing to the sense that courts are not appropriate mechanisms for resolving paediatric healthcare disputes.

In summary, the courts have their benefits – not least in issuing authoritative decisions that settle disputes – but they also have various drawbacks. In addition to investigating alternatives to the courts, future research could usefully explore how legal processes, approaches and the best-interests standard might be amended to address these problems, as we presume there will always remain some role for the courts to play, particularly in intractable disputes.

## 8. Conclusion

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<sup>191</sup> *In the matter of Charlie Gard* [2017] UKSC 94, [15].

<sup>192</sup> Close et al (n 184), 479.

<sup>193</sup> Fassier and Azoulay (n 70), 662.

<sup>194</sup> Birchley et al (n 60), 932.

<sup>195</sup> Wallis (n 92), 413.

Commenting on a high-profile ruling back in 2005, Margaret Brazier asked whether there are alternatives to court proceedings, when disputes about a child's healthcare become intractable or threaten to do so.<sup>196</sup> Alternatives certainly exist, including discussions between families and healthcare professionals, as well as recourse to other parties, such as second-opinion experts, CECs and mediators. However, despite the benefits they may bring, each of these alternatives has their own problems and there appears to be a reluctance amongst healthcare professionals to seeking external input when such disputes arise, with such recourse being seen to be a 'last resort'. Discussions between the parties appear, overwhelmingly, to be the preferred method of dispute resolution but, as we have seen, such discussion might have the effect of exacerbating the conflict, as well as potentially being contrary to the child's interests. Further research is needed, however, to identify the point at which clinicians (or, indeed, other parties) should recognise that discussion is no longer effective and third-party intervention should be sought. The question then becomes: which form(s) of third-party intervention are indicated, and in which circumstances?

Second-opinion experts may be beneficial in demonstrating to the family that the clinicians' proposed course of action is the 'right' one. Yet, the cases of *Gard*,<sup>197</sup> *Haastrup*<sup>198</sup> and *Evans*<sup>199</sup> are stark reminders that a second (or even third) opinion might not resolve the dispute if the parties are unwilling to accept an opinion that differs from their own. This is, however, an under-researched means to resolution and further research could explore how often second opinions are sought, how the process works, and whether it is effective at resolving disputes.

Clinical ethics support services also have the potential to resolve such disputes and, in light of the Charlie Gard Foundation's campaign for access to CECs as part of 'Charlie's law',<sup>200</sup> there may be growing public support for this mechanism. Access alone, however, is not enough, and to ensure this is an effective resolution mechanism, further research is needed to understand how often CECs are used and the extent to which their advice is accepted and/or resolves disputes. There are also questions to be addressed around the nature of their composition,

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<sup>196</sup> Brazier (n 33).

<sup>197</sup> *Gard* (n 45).

<sup>198</sup> *Haastrup* (n 51).

<sup>199</sup> *Evans* (n 52).

<sup>200</sup> Charlie Gard Foundation (n 94).

expertise, training, impact, evaluation and so on, and whether CECs offer the best model of ethics support or whether there are (in some sense) better alternatives.

There is also growing support, including amongst judges, for mediation as a means of resolving disputes about the healthcare of children.<sup>201</sup> The creation of the Medical Mediation Foundation means that mediators are available in these cases. However, more data is needed on how often mediation is used and when it is ‘successful’. The Evelina Resolution Project is collecting data, which should provide some answers to these questions in due course. But further research might usefully explore whether mediation could be combined with ethics support, so as to enable the impartial and independent steering of negotiations, where those negotiations are alert to their ethical dimensions.

Finally, whilst courts are used infrequently and as a last resort for resolving such disputes, it is likely their input will continue to be necessary in those cases that are truly intractable. The courts therefore should not be absent from future research agendas. Pertinent research questions include when recourse to court (as opposed to some other mechanism) is necessary and how the court should approach the best-interests standard. The latter standard underpins decisions in this context, but is this the right standard, understood and operationalised in appropriate ways, or are adjustments or alternatives required? Work to address questions around the best-interests standard is underway in the Balancing Best Interests in Health Care, Ethics and Law (BABEL) project, a five-year programme of work funded by the Wellcome Trust. The project asks how the best interests of incapacitated patients should be understood: which factors and values should be considered, who should be involved, and indeed is ‘best interests’ the best approach?<sup>202</sup>

In sum, further work is needed to understand, in the context of resolving child healthcare disputes, what the current situation actually *is* and what the situation *should be*. Such research could explore: when, why, how and the extent to which the different resolution mechanisms are used; how they serve to secure resolution; how (if at all) existing mechanisms should be amended; and, ultimately, which process (or processes) should be used in these cases of conflict? Some progress towards answering these questions has been made since Brazier’s

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<sup>201</sup> *Gard* (n 45).

<sup>202</sup> *Balancing Best Interests in Health Care, Ethics and Law*, <https://www.bristol.ac.uk/population-health-sciences/centres/ethics/research/babel/>.

inquiry in 2005, but the recent suite of widely discussed rulings suggests that more work is needed in this area.