

# NUFFIELD COUNCIL ON BIOETHICS

## LITERATURE REVIEW

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### **UK processes for resolution of disagreements about the care of critically ill children**

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#### **Note**

The author was commissioned by the Nuffield Council on Bioethics to write this review to inform its work on the disagreements that can arise in the care of critically ill children. Any views expressed in the paper are the author's own and not those of the Nuffield Council on Bioethics.

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## Contents

Summary .....	3
Introduction .....	4
Discussions between families and clinicians .....	5
Second opinion experts.....	9
Clinical Ethics Committees.....	11
Mediation .....	14
Court proceedings.....	16
Conclusion .....	20
Appendix: Summary of significant cases.....	21
References .....	25
Further reading .....	29

## Summary

This report sets out the findings of a rapid review of literature relating to the effectiveness and appropriateness of UK processes for the resolution of disputes about the care of critically ill children. It focuses upon five mechanisms for resolution: discussions between families and clinicians; second-opinion experts (SOEs); clinical ethics committees (CECs); mediation; and court proceedings.

The literature suggests many disputes are resolved through discussion between clinicians and families. The other mechanisms all require the involvement of third parties and are seen as a last resort. As a consequence, discussions may take place over a prolonged period of time before other resolution mechanisms are engaged. This prolongation risks positions becoming entrenched and the dispute becoming intractable, reducing the likelihood of other resolution mechanisms being successful. In addition, where disputes are prolonged, the child may continue to receive treatment that is (putatively) against his or her best interests, which can impact negatively on the child and the healthcare staff compelled to provide the treatment. Further research is needed, therefore, into the timing of different dispute resolution mechanisms, bearing in mind the need to balance speed with due process.

There is little literature on the success of SOEs, CECS and mediation in resolving disputes but potential problems, which could impede their effectiveness, have been identified. Where an SOE is sought by the Trust and/or is based within the UK, the family may perceive the expert's view to be biased in favour of the NHS/treating clinicians. However, if the parents select the expert, they may only look for experts who share their view.

CECs and mediation are both perceived to be quicker, less costly and less adversarial than court proceedings, yet there is a lack of data about their use and further research is needed. CECS are not available in every NHS Trust and the lack of regulation pertaining to membership, constitution and training can lead to uncertainty as to the outcome, or a lack of necessary expertise. Further research is needed into how CECs should be constituted and what expertise they require. Such research could also consider whether CECs and mediation could be combined into one form of dispute resolution as they may have some overlaps in function. In Europe and the United States, clinical ethics support is provided by clinical ethics consultants (often working alone) and further research is needed into the question of what is the most appropriate model for clinical ethics support services

The literature agrees that courts are the least satisfactory method of dispute resolution due to their cost and adversarial nature, which can irreparably damage the relationship of trust between families and healthcare professionals. Despite this, the literature does not address how court proceedings could be altered to overcome these problems and this is an area for future research.

## Introduction

- 1 Within the last five years there have been four high profile UK court cases concerning disagreement about the care of critically ill children (see *Appendix*).<sup>2</sup> These disputes involved disagreement over the withdrawal of end-of-life care and the suitability of alternative treatment. Whilst the court proceedings effectively brought these disputes to an end by providing definitive instruction on what was to be done, the *Appendix* cases highlight the persisting question of how such disputes should be resolved. There is agreement within the literature that adversarial court proceedings are the least satisfactory method of resolution, with alternatives such as mediation being proposed (by judges, as well as commentators). This has led to this review which explores the effectiveness and appropriateness of current UK processes for handling and resolving disagreements about the care of critically ill children.
  
- 2 A rapid review of literature was conducted with the following questions in mind:
  - (i) What are the current UK processes for resolving disagreements between families and healthcare professionals about the care of critically ill children?
  - (ii) What does legal, social and bioethical research conclude about the efficacy of these procedures?
  - (iii) What legal, social and bioethical opinions have been expressed about the appropriateness of these processes?
  - (iv) Are there gaps in the research?
  
- 3 A rapid review of literature was conducted due to the limited time available. 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’.<sup>3</sup> There are varying approaches to rapid reviews. This review focused on the *Appendix* Cases to guide its searches. Westlaw and LexisNexis were utilised to identify literature relating to those cases; further literature was identified through Google Scholar and PubMed, using search terms such as ‘child’, ‘parent’, ‘hospital’, ‘dispute’, ‘resolution’, and variations of these terms; Google Scholar’s ‘articles citing’ function was then used to identify further literature. Relevant references within the literature identified, and from the team’s prior searches, were also noted. Titles and abstracts of identified sources were then considered and a list of literature to review compiled. The literature was then reviewed, and relevant information extracted, evaluated and synthesised for this write-up.<sup>4</sup>

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<sup>2</sup> *Portsmouth City Council v (1) Nagmeh King (2) Brett King (3) Southampton Hospital Trust (4) Ashya King (By his Children’s Guardian)* [2014] EWHC 2964 (Fam); *Great Ormond Street Hospital v (1) Constance Yates (2) Chris Gard (3) Charles Gard (a Child by his Guardian Ad Litem)* [2017] EWHC 972 (Fam); *King’s College Hospital NHS Foundation Trust v (1) Takesha Thomas (2) Laure Haastруп; (3) Isaiah Haastруп* [2018] EWHC 127 (Fam); *Alder Hey Children’s NHS Foundation Trust v (1) Thomas Evans (2) Kate James (3) Alfie Evans (a Child by his Guardian)* [2018] EWHC 308 (Fam). These cases are summarised in the *Appendix* to this Review.

<sup>3</sup> Sara Khangura, Kristin Konnyu, Rob Cushman, Jeremy Grimshaw and David Moher, ‘Evidence Summaries: The Evolution of a Rapid Review Approach’ (2012) 1(1) *Systematic Reviews* 10; Andrea C. Tricco, Jesmin Antony, Wasifa Zarin, Lisa Strifler, Marco Ghassemi, John Ivory, Laure Perrier, Brian Hutton, David Moher, and Sharon E. Straus, ‘A Scoping Review of Rapid Review Methods’ (2015) 13(1) *BMC Medicine* 224.

<sup>4</sup> Although the research questions referred to legal, social and bioethical literature, relevant literature was not excluded on the basis of not being identified as being legal, social and bioethical.

- 4 The rapid nature of this review means that formal quality appraisal was not conducted before papers were included. Where, however, there are obvious limitations to evidence and/or argument this has been highlighted.
- 5 The literature review revealed five processes for resolving disagreements about the care of critically ill children in the UK: (1) discussions between families and clinicians; (2) second-opinion experts (SOEs); (3) clinical ethics committees (CECs); (4) mediation; (5) court proceedings. What each of these entails, and what is known about their effectiveness and appropriateness is addressed in this review.
- 6 The literature reviewed suggested that many disputes are resolved by way of discussions, with court being used as a last resort. Despite support for the role of mediation in the resolution of healthcare disputes, there was a lack of data about its use. There was broad agreement that whilst court proceedings did resolve disputes, they did so at the cost of irreparable damage to the relationship of trust between families and healthcare teams, often leaving neither party satisfied with the outcome.
- 7 Further research is needed to understand: the extent to which different dispute resolution mechanisms are used and when; why and how consensus was reached using a particular resolution method; whether the timing of a particular intervention impacts upon its effectiveness; and improvements needed to particular resolution mechanisms.

### Discussions between families and clinicians

- 8 In the *Appendix Cases*, when a healthcare team proposed a particular course of treatment for or the withdrawal of treatment from a critically ill child, there were usually discussions between the child's family and the treating clinicians. Initially, there would be a meeting between the healthcare team to decide what action should be taken in light of the child's condition and likely prognosis. There would then be a separate meeting with the child's family to discuss the child's condition, prognosis and recommended treatment/care plan. More than one meeting or discussion may have taken place between the clinicians and the family.
- 9 Birchley and Huxtable have noted the aim of such discussions is to achieve consensus through 'shared decision-making'.<sup>5</sup> However, they have suggested (based on qualitative research) that in practice such discussions might amount to no more than a consultation of the parents' views, with the true aim being to secure their agreement to the proposed care plan.<sup>6</sup> This was highlighted by the *Appendix Cases* as, in each of those, there was

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<sup>5</sup> Giles Birchley and Richard Huxtable, 'Critical Decisions For Critically Ill Infants', in Catherine Stanton, Sarah Devaney, Anne-Maree Farrell and Alexandra Mullock (eds.), *Pioneering Healthcare Law: Essays in Honour of Margaret Brazier* (2016, Routledge, London and New York), 120. There is, however, no fixed definition of shared decision-making and thus it is not necessarily aimed at consensus: Cathy Charles, Amiram Gafni and Tim Whelan, 'Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango)' (1997) *Social Science and Medicine* 44(5) 681; Christian Munthe, Lars Sandman and Daniela Cutas, 'Person centred care and shared decision-making: implications for ethics, public health and research' (2012) 20(3) *Health Care Analysis* 231.

<sup>6</sup> *Ibid*, Birchley and Huxtable, 121.

reference to numerous discussions taking place, most of which were aimed at persuading the parents to accept the proposed course of action. This can lead to parents feeling they have no real choice in decision-making,<sup>7</sup> calling into question the effectiveness of such discussions in achieving consensus. Furthermore, it seems likely that if parents feel attempts at shared decision-making are disingenuous, this may contribute to the cultivation of bad faith.<sup>8</sup>

- 10 Research by Brierley *et al.* suggested that such discussions are effective at reaching consensus. In a study of their unit at Great Ormond Street Hospital over three years, Brierley *et al.* found that of 203 cases involving recommended withdrawal of treatment from children in intensive care, 186 cases resulted in agreement following the initial discussion when families were advised of the clinicians' views and agreed that further treatment was not in the child's best interests. Further discussions led to resolution in six of the remaining seventeen cases.<sup>9</sup> Thus, discussions were effective in achieving consensus to withdraw treatment in 94.58% of the cases. However, this study was limited, as it only considered children in Great Ormond Street's Paediatric Intensive Care Unit, which is a world-renowned, specialist hospital in paediatric care.<sup>10</sup> The expertise and reputation of the hospital may have contributed to the high rate of consensus finding.
- 11 There is general agreement in the literature that good communication is a key aspect of successful resolution. For example, a study by Forbat *et al.* concluded that communication breakdown was the most common cause of conflict between families and healthcare professionals in children's healthcare.<sup>11</sup> With respect to what constitutes good communication practice, Richards argued that a key feature is the need for clinicians to listen to families and explore their views, including views about different treatment options.<sup>12</sup> Some studies highlighted strategies used by clinicians to achieve resolution through consensus. Clinicians in Birchley *et al.*'s study emphasised the need to reframe conversations in terms that were more acceptable to families when agreement about care could not be reached.<sup>13</sup> Similarly, Waldman and Frader questioned whether clinicians using terms such as 'futile', 'harm' and 'suffering' caused parents to feel that they were being accused of not doing what was best for their child.<sup>14</sup>
- 12 Whilst the detail of the discussions which took place in the *Appendix Cases* is unknown, those cases provided some examples of communication breakdown which may have

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<sup>7</sup> Giles Birchley, Rachael Goberman-Hill, Zuzana Deans, James Fraser and Richard Huxtable, "'Best Interests' in Paediatric Intensive Care: An Empirical Ethics Study' (2017) 102 *Arch Dis Chil* 930, 932.

<sup>8</sup> Chloe Shaw, Elizabeth Stokoe, Katie Gallagher, Narendra Aladangady and Neil Marlow, 'Parental involvement in neonatal critical care decision-making' (2016) 38(8) *Sociology of Health & Illness* 1217.

<sup>9</sup> Joe Brierley, Jim Linthicum and Andy Petros, '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, 573.

<sup>10</sup> *Ibid.*

<sup>11</sup> Liz Forbat, Charlotte Sayer, Phillip McNamee, Esse Menson and Sarah Barclay, 'Conflict in a Paediatric Hospital: A Prospective Mixed Method Study' (2016) 101 *Arch Dis Child* 23, 25.

<sup>12</sup> Tessa Richards, 'When Doctors and Patients Disagree' (2014) *British Medical Journal (online)* [https://www-bmj-com.bris.idm.oclc.org/content/bmj/349/bmj.g5567.full.pdf](https://www.bmj-com.bris.idm.oclc.org/content/bmj/349/bmj.g5567.full.pdf)> 16 August 2018.

<sup>13</sup> Birchley *et al* (n 7) 932.

<sup>14</sup> Elisha Waldman and Joel Frader, 'Charlie Gard: How Did Things Go Wrong?' (2018) 6 *Current Paediatric Reports* 173, 174.

exacerbated the conflict between the families and healthcare staff. For example, in *Gard*, there was reference to an email sent by one of the treating clinicians describing the child's parents as a '*spanner in the works*' in respect of the plan to withdraw life-sustaining treatment.<sup>15</sup> Forbat *et al.* described suggestions by doctors that parents who disagreed with them were being awkward as a factor in the escalation of conflict in paediatric healthcare disputes.<sup>16</sup>

- 13 Forbat *et al.* have suggested that communication breakdown could also occur where families interpret 'futility' and the prognosis differently to clinicians,<sup>17</sup> leading to different understandings of the same phenomena. Fassier and Azoulay explained that this occurred because patients' families weighed 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>18</sup> A clear example of this could be seen in *Evans*, where the trial judge noted that the parents, having been told early on in their child's treatment to prepare for '*the real possibility that [he] might not recover*',<sup>19</sup> viewed his initial recovery as '*indicative of his potential for more general recovery*'.<sup>20</sup>
- 14 Disagreements can also arise within discussions when participants have different views about who should make the decision about the child's care. For example, Forbat *et al.* noted that whilst the majority of families believed that decisions about withdrawal or withholding of treatment should be made jointly between themselves and the clinical team, a small minority believed it should be a matter for the parents alone to decide.<sup>21</sup> The latter reflects frequent research findings that when the child's life was at stake parents often believed the decision ought to rest with them.<sup>22</sup>
- 15 The literature suggests, therefore, that whilst discussions are intended to determine a care plan for the child by reaching consensus, they can also lead to entrenched disagreement between families and clinicians. Wilkinson *et al.* have argued that the simple fact that disagreement occurs does not mean that it will inevitably develop into an intractable conflict.<sup>23</sup> Instead, Fassier and Azoulay have suggested that such discussions could be used to identify disagreement, and therefore the potential for conflict, at an early stage.<sup>24</sup> Forbat *et al.* argued that early identification of conflict could help prevent it escalating into an intractable dispute.<sup>25</sup> Barclay concurred with this view and her research

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<sup>15</sup> *Gard* (n 2) [84].

<sup>16</sup> Liz Forbat, Bea Teuten and Sarah Barclay, 'Conflict Escalation in Paediatric Services: Findings from a Qualitative Study' (2015) *Arch Dis Child* 1, 3.

<sup>17</sup> Forbat *et al.* (n 11) 24.

<sup>18</sup> Thomas Fassier and Elie Azoulay, 'Conflicts and Communication Gaps in the Intensive Care Unit' (2010) 16 *Current Opinion in Critical Care* 654, 661.

<sup>19</sup> *Evans* (n 2) [10].

<sup>20</sup> *Ibid.*

<sup>21</sup> Forbat *et al.* (n 11) 23.

<sup>22</sup> Lynne Gillam and Jane 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(9) *Journal of Paediatrics and Child Health* 594; Birchley *et al.* (n 7) 932.

<sup>23</sup> Dominic Wilkinson, Sarah Barclay and Julian Savulescu, 'Disagreement, Mediation, Arbitration: Resolving Disputes About Medical Treatment' (2018) 391 *The Lancet* 2302, 2304.

<sup>24</sup> Fassier and Azoulay (n 18) 661.

<sup>25</sup> Forbat *et al.* (n 16) 4.

found that training healthcare staff to recognise and manage conflict at an early stage could aid dispute resolution.<sup>26</sup>

- 16 Discussions between families and clinicians can be an appropriate and effective means of resolving disagreements about the care of critically ill children. However, they are not always successful and, where there is a breakdown in communication and trust that is not resolved, this can lead to both sides becoming entrenched in their positions, making third party intervention necessary.<sup>27</sup> It is in these scenarios where further discussion might exacerbate dispute, rather than resolve it. Brierley *et al.* noted that, in their sample, when agreement could not be reached then often the first step was to take more time to engage in further discussions with patient's families.<sup>28</sup> Further discussion, however, could entrench positions, with each party simply repeating their position,<sup>29</sup> suggesting that in some instances it would be more effective and appropriate to move to some form of third-party intervention. However, both Brierley *et al.* and Birchley *et al.* all noted a reluctance of practitioners to institute court proceedings for fear of costs, negative publicity, inconsistent decisions, or being seen as a failure by colleagues.<sup>30</sup> Whilst courts are not the only form of third-party intervention available, the fear of court proceedings may encourage clinicians to continue with discussions that actually escalate the conflict, rather than achieving resolution. Birchley and Huxtable have pointed to a lack of clarity around the point at which discussions should be deemed to have failed and third-party intervention sought.<sup>31</sup>
- 17 Another concern around the appropriateness and usefulness of discussion is that when resolution is not quickly achieved, and discussion is prolonged, the status quo will likely be maintained and the child may continue to receive the very treatment that lies at the heart of the dispute and which is argued by one side not to be in his or her best interests.<sup>32</sup> Not only can this directly harm the child, it can also adversely impact on the healthcare professionals looking after the child who may 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>33</sup>

### Summary

- 18 The literature in this area suggests that discussions between clinicians and families are usually used as the starting point to identify and resolve disagreements over the care of a critically ill child. Whilst such discussions can be an effective and appropriate means of finding consensus and resolving disagreement, where discussion is prolonged, with no

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<sup>26</sup> Sarah Barclay, 'Recognising and Managing Conflict Between Patients, Parents and Health Professionals' (2016) 26(7) *Paediatrics and Child Health* 314, 314.

<sup>27</sup> Ibid; Richard David William Hain, 'Voices of Moral Authority: Parents, Doctors and What Will Actually Help' (2018) 44(7) *Journal of Medical Ethics* 458, 460; Wilkinson et al (n 23) 2304.

<sup>28</sup> Brierley et al (n 9) 573.

<sup>29</sup> Forbat et al (n 16) 3.

<sup>30</sup> Brierley et al (n 9) 576; Birchley et al (n 7) 932.

<sup>31</sup> Birchley and Huxtable (n 5) 121.

<sup>32</sup> Brierley et al (n 7) 576.

<sup>33</sup> Ibid; Georgina Morley, Caroline Bradbury-Jones, Jonathan Ives, 'Moral Distress in End-of-Life Care' (2018) to be published, 6.

alteration in either party's stance, they can serve to exacerbate conflict whilst exposing the child to treatment not necessarily in his or her best interests. This has implications for the wellbeing of the child, the family and the healthcare professionals involved.

- 19 There is a lack of clarity in the literature, however, as to the point at which clinicians should recognise that discussion is no longer effective and should seek third-party intervention. It is also unclear what effect protracted discussion might have upon the likelihood of reaching resolution without the need for court proceedings. For example, once the parties' positions are entrenched, are alternative methods such as referral to a CEC and mediation less likely to be successful?

## Second opinion experts

- 20 If discussions do not resolve disagreement about the plan for the child, the literature reviewed suggested that clinicians may seek a second opinion from another healthcare professional, from either within the same institution or external to it.<sup>34</sup> Families may also seek a second opinion expert (SOE) themselves, either a clinician based in the UK, or one outside of the jurisdiction.<sup>35</sup> Independent expert opinions may also be sought by either party as part of court proceedings.<sup>36</sup>
- 21 Wilkinson *et al.* suggested that SOEs were an appropriate recourse when the family's interpretation of the medical facts were different to the treating clinicians'.<sup>37</sup> For example, in the *Gard* case the parents were advised that treatment of their son was futile, but internet research by the mother suggested the possibility of an experimental treatment, which led to the instruction of an SOE from the United States.<sup>38</sup> However, where (as occurred in *Gard*) the SOE contests the view of the treating clinicians,<sup>39</sup> the conflict may be exacerbated.<sup>40</sup> Forbat *et al.* noted that disagreement about treatment was the second most common cause of conflict between healthcare professionals and the patient's family.<sup>41</sup>
- 22 The *Gard* case also highlighted that cultural differences in medical practice may lead to families being offered treatment overseas which would not meet the UK threshold of best interests. Although the U.S. doctor ultimately agreed with the treating clinicians that the experimental treatment was unlikely to work, he said that, in America, the practice is to treat if the parents want the child to be treated.

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<sup>34</sup> Brierley et al (n 9) 576; Simon Meller and Sarah Barclay, 'Mediation: An Approach to Intractable Disputes Between Parents and Paediatricians' (2011) 96 *Archives of Disease in Childhood* 619, 619.

<sup>35</sup> In the *Appendix Cases*, the parents in each case instructed both UK and non-UK experts for second opinions.

<sup>36</sup> This occurred in three of the *Appendix Cases*: *Gard* (n 2), *Haastrup* (n 2) and *Evans* (n 2).

<sup>37</sup> Wilkinson et al (n 23) 2304.

<sup>38</sup> *Gard* (n 2) [71]-[72].

<sup>39</sup> In the court hearings, the US expert acknowledged that Charlie Gard's situation was futile and the treatment unlikely to work, although he felt if the parents wanted to try it then it should be done, given the lack of other treatment options: *Gard* (n 2) [18]-[19].

<sup>40</sup> Colin Wallis, 'When Paediatricians and Families Can't Agree' (2018) 103(5) *Arch Dis Child* 413, 413.

<sup>41</sup> Forbat et al (n 11) 25.

- 23 There is a lack of literature addressing the effectiveness of SOEs in resolving disputes over treatment. Brierley *et al.*'s study noted that of the 203 cases where withdrawal of treatment was recommended, SOEs were sought in six of those cases. Of those six, none were resolved as a consequence of the SOE. However, Brierley *et al.* suggested that this was due to the intractable religious views held by the parents in those cases,<sup>42</sup> and the study does not provide evidence that SOEs, in general, are ineffective.
- 24 There is also a lack of literature on how often SOEs are employed, whether these are obtained by the hospital or the parents, and who determines which expert is instructed.
- 25 Despite the lack of research into their prevalence and effectiveness, the literature nonetheless identified potential problems with SOEs as a mechanism for resolving disagreements about paediatric healthcare. For example, Meller and Barclay noted that when the clinicians, rather than the family, selected the SOE, the family may not have regarded the SOE as truly independent and may have had a perception of doctors colluding with one another if the SOE agrees with the treating clinicians. Meller and Barclay suggested that one way of overcoming this could be to allow the family to select the SOE.<sup>43</sup> However, in *Hastrup* the father did instruct his own SOE, yet still saw that expert as colluding with the NHS when the SOE took the same view as the treating clinicians.<sup>44</sup>
- 26 Meller and Barclay also raised the concern that allowing families to select the SOE may lead to families 'doctor-shopping', or cherry-picking experts likely to share their view.<sup>45</sup> For example, in *Gard*, prior to seeking an opinion from the US clinician, Charlie's mother had found out about the nucleoside therapy he offered through internet research.<sup>46</sup>

### Summary

- 27 SOEs may be used if discussions between clinicians and families do not resolve disagreements over the care of a critically ill child. There is, however, a gap in existing research in terms of how often this mechanism is used, its effectiveness and, if it is ineffective, why this is so.

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<sup>42</sup> Brierley et al (n 9) 574.

<sup>43</sup> Meller and Barclay (n 34) 619.

<sup>44</sup> *Hastrup* (n 2) [46].

<sup>45</sup> Meller and Barclay (n 34) 619.

<sup>46</sup> *Gard* (n 2) [71]-[72].

## Clinical Ethics Committees<sup>47</sup>

- 28 CECs are based within NHS Trusts and healthcare institutions and provide analysis and guidance/advice upon ethical issues arising from patient care.<sup>48</sup> They usually consist of health professionals, lay members and legal members but they have no fixed structure, function, or membership criteria, and their constitution varies between Trusts and institutions.<sup>49</sup> The number of CECs appears to be declining as Larcher noted there were 85 registered CECs in 2009,<sup>50</sup> but at the time of writing there are only 77.<sup>51</sup>
- 29 In contrast to the UK, an alternative model of clinical ethics support services in Europe and the United States is clinical ethics consultants (who may work alone or with others).<sup>52</sup> Despite this difference, there was limited discussion in the literature about what is the more appropriate model for clinical ethics support<sup>53</sup> and this is an area for further research.
- 30 Given their ethical focus, CECs can be used in value-based disputes. For example, 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>54</sup> This was so in the *Haastrup* case.<sup>55</sup> Wilkinson *et al.* have suggested that CECs could play an important role in the resolution of such disputes as they could facilitate identification of the ethical values underpinning the dispute and the identification of common ground for the purposes of negotiating a resolution.<sup>56</sup> Huxtable shared this view, noting that CECs' explicit

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<sup>47</sup> In the context of adults lacking capacity to consent, the House of Lords are currently debating the Mental Capacity (Amendment) Bill. Lord Mackay and Baroness Hollins have proposed the Bill be amended to include provision for the Secretary of State to make regulations enabling all NHS bodies to have access to Clinical Ethics Committees. The proposed amendment includes provision for regulations to be made as to their membership, funding and constitution. See: <[https://publications.parliament.uk/pa/bills/lbill/2017-2019/0117/18117-l\(a\).pdf](https://publications.parliament.uk/pa/bills/lbill/2017-2019/0117/18117-l(a).pdf)> accessed 8 September 2018.

<sup>48</sup> Morten Magelssen, Reidar Pedersen and Reidun Førde, 'Sources of Bias in Clinical Ethics Case Deliberation' (2014) 40(10) *Journal of Medical Ethics* 678, 678; UK Clinical Ethics Network, 'What are Clinical Ethics Committees?' <<http://www.ukcen.net/committees/introduction>> accessed on 29 August 2018. Some CECs are called 'clinical ethics advisory groups', and explicitly do not offer guidance but offer advice.

<sup>49</sup> Birchley and Huxtable (n 5) 123; UK Clinical Ethics Network (ibid).

<sup>50</sup> Vic Larcher, 'The Development and Function of Clinical Ethics Committees (CECs) in the United Kingdom' (2009) 22 *Diametros* 47, 48.

<sup>51</sup> UK Clinical Ethics Network, 'CEC Member List', <[http://www.ukcen.net/committees/member\\_list](http://www.ukcen.net/committees/member_list)> accessed 29 August 2018.

<sup>52</sup> Reidar Pedersen, 'Review: Clinical Ethics Consultation: Theories and methods, Implementation, Evaluation' (2011) *Bioethics* 25(7) 425, 425. Whilst there may be clinical ethicists in the UK (for example, John Bridson at the Royal Liverpool and Broadgreen University Hospital NHS Trust), the common model of clinical ethics support in the UK is CECs.

<sup>53</sup> For a discussion of the benefits that clinical ethics consultations can offer clinical ethics support services see: Evan G. DeRenzo, Nneka Mokwunye and John J. Lynch, 'Rounding: How everyday ethics can invigorate a hospital's ethics committee' (2006) 18(4) *HEC Forum* 319; Evan G. DeRenzo, Janicemarie Vinicky, Barbara Redman, John J. Lynch, Philip Panzarella and Salim Rizk, 'Rounding: a model for consultation and training whose time has come' (2006) 15(2) *Cambridge Quarterly of Healthcare Ethics* 207.

<sup>54</sup> Brierley et al (n 9) 576.

<sup>55</sup> *Haastrup* (n 2) [54].

<sup>56</sup> Wilkinson et al (n 23) 2304.

reflection upon ethical issues allowed the conflicting views to be translated into the common language of ethics, within which compromise could be reached.<sup>57</sup>

- 31 The literature suggested, however, that CECs were infrequently utilised as a mechanism of dispute resolution.<sup>58</sup> Brierley *et al.* noted that of the 186 cases in their study where withdrawal of treatment was not agreed, only six received ethical review and, in those cases, ethical review was unsuccessful in reaching a resolution. According to Brierley *et al.*, this was due to the parents' decisions being driven by fundamentalist religious beliefs that they were not prepared to discuss.<sup>59</sup>
- 32 Whilst there is a lack of other data in the literature demonstrating the extent to which CECs are utilised in disputes about the care of critically ill children, the *Appendix Cases* suggest CECs are infrequently used. *Gard* was the only case referred for ethical review, both in the context of approving the proposed alternative therapy and in resolving the treatment/withdrawal dispute.<sup>60</sup>
- 33 In addition to the lack of data regarding how often CECs are used in this setting, there is a lack of data about whether CEC's advice is accepted or rejected.<sup>61</sup> However, the literature revealed that, when CECs are used to help resolve healthcare disputes, the parties report high satisfaction rates.<sup>62</sup>
- 34 As well as their ability to address value disputes, and their potential for negotiating compromise between different value positions, CECs are seen as preferable to court proceedings because they are quicker, less costly, more inclusive and less adversarial.<sup>63</sup>
- 35 Despite these putative benefits, the literature also revealed a number of concerns about CECs' potential effectiveness and/or appropriateness in paediatric healthcare disputes. Whilst they may have a role to play in negotiating compromise between different value positions, Birchley and Huxtable noted a concern of some clinicians that even when a CEC supported one position over another, given that its role was to offer advice rather than to determine the outcome, it did not have the ability to formally resolve the dispute.<sup>64</sup>
- 36 Concerns have also been expressed about CECs' perceived independence, given that they are located in hospitals and referrals to CECs are clinician led.<sup>65</sup> Magelssen *et al.*

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<sup>57</sup> Richard Huxtable, *Law, Ethics and Compromise at the Limits of Life: To Treat or Not to Treat?* (2013, Routledge, London and New York), 156-157.

<sup>58</sup> Autumn Fiester, 'The Failure of the Consult Model: Why "Mediation" Should Replace "Consultation"' (2007) 7(2) *The American Journal of Bioethics* 31, 32.

<sup>59</sup> Brierley *et al.* (n 9) 574.

<sup>60</sup> *Gard* (n 2) [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>61</sup> Fiester (n 58) 31.

<sup>62</sup> Fassier and Azoulay (n 18) 662.

<sup>63</sup> Richard Huxtable, 'Clinic, Courtroom or (Specialist) Committee: In the Best Interests of the Critically Ill Child?' (2018) 44(7) *Journal of Medical Ethics* 471, 473.

<sup>64</sup> Birchley and Huxtable (n 5) 126.

<sup>65</sup> *Ibid* 124, 126; Huxtable (n 63) 473. Charlie Gard's parents are seeking legislation to ensure access to clinical ethics committees in disputes involving the care of critically ill children: Charlie Gard Foundation, 'Charlie's Law' <<https://www.thecharliegardfoundation.org/charlies-law/>> accessed 25 September 2018.

highlighted concerns that this risked CECs being biased towards the views of clinicians.<sup>66</sup> However, Birchley's study found that parents and nurses were supportive of the involvement of CECs in such disputes, although the participants questioned had not had experience of CECs. Birchley and Huxtable have suggested that allowing parents and nurses to refer cases to CECs might increase CECs' involvement in such disputes.<sup>67</sup>

- 37 Other concerns about CECs related to their expertise. There are no formal requirements for the expertise or training required to sit on such committees,<sup>68</sup> and Birchley's study noted that one of the criticisms paediatric clinicians had of CECs was their lack of paediatric experience.<sup>69</sup> Fiester argued that lack of training and expertise may call into question CECs' right to be involved in decisions affecting the lives of others.<sup>70</sup> Although CECs in the UK are advisory only, and do not make decisions, a lack of respect for their expertise may make it easier for parties to a dispute to reject advice with which they disagree, or indeed dispute CEC involvement at all.
- 38 Whilst one of the key benefits of CECs is their ability to deal with value disputes, in Birchley's study, clinicians expressed a concern that CECs have too great a legal focus.<sup>71</sup> Legal scholars, however, have conversely queried whether CECs sufficiently attend to legal concerns, such as those associated with due process.<sup>72</sup> Huxtable recommended that CECs should have regard to both ethics and law by seeking to reach a principled compromise between different values whilst not overstepping the legal boundaries dictating what is or is not permissible in the care of a critically ill child.<sup>73</sup>
- 39 Whilst the informal nature of CECs and its group decision-making were seen by some as benefits over other dispute resolution mechanisms (such as courts), these were also seen as potential weaknesses, as that informality risks a lack of transparency that could in turn suggest a lack of consistency in decision-making.<sup>74</sup> Again, this could lead to clinicians feeling reluctant to involve CECs in decision-making, or to follow their advice.
- 40 Given the concerns about the effectiveness and appropriateness of CECs as a mechanism to resolve paediatric healthcare disputes, the literature contained various suggestions as to how they could be improved. These included:
  - training in communication and conflict management;<sup>75</sup>
  - having specialist committees with subject-specific expertise;<sup>76</sup>
  - ensuring a mix of clinical, legal, ethical and lay representation on committees;<sup>77</sup>

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<sup>66</sup> Magelssen et al (n 48) 680.

<sup>67</sup> Birchley and Huxtable (n 5) 124, 127.

<sup>68</sup> Huxtable (n 57) 159.

<sup>69</sup> Birchley and Huxtable (n 5) 125.

<sup>70</sup> Fiester (n 58) 31.

<sup>71</sup> Birchley and Huxtable (n 5) 125.

<sup>72</sup> Sheila A. M. McLean, 'Clinical Ethics Committees: A Due Process Wasteland?' (2008) 3 *Clinical Ethics*, 99.

<sup>73</sup> Huxtable (n 57) 157.

<sup>74</sup> *Ibid* 160, 162.

<sup>75</sup> Fassier and Azoulay (n 18) 662.

<sup>76</sup> *Ibid*; Birchley and Huxtable (n 5) 127; Huxtable (n 63) 473. This is arguably already the case with GOSH's CEC.

<sup>77</sup> Huxtable (n 57) 160, 169.

- formalising committees with requirements for regular, minuted meetings, open to the public subject to confidentiality;<sup>78</sup>
- an appeals process; and auditing and evaluation of decision-making.<sup>79</sup>

The calls for improvements, together with the parental and nursing support for CECs,<sup>80</sup> suggested a general agreement within the literature that CECs had the potential to play an effective role in dispute resolution in the future. However, before this could be done, Huxtable has highlighted the need for further research to flesh out the detail of such changes, for example, the nature of the expertise required.<sup>81</sup>

### Summary

- 41 There was a lack of data about the use or effectiveness of CECs in paediatric healthcare disputes. However, the existing literature did suggest CECs had benefits and a valuable role to play, although further research is needed on the changes and improvements necessary to maximise their effectiveness, at least with regard to dispute/conflict resolution.

### Mediation<sup>82</sup>

- 42 Mediation is a flexible, confidential process which involves a neutral third party helping the parties in dispute towards a negotiated resolution, although the parties have the final say as to whether agreement is reached and, if so, on what terms.<sup>83</sup> It is increasingly recognised as an appropriate method for resolving paediatric healthcare disputes, following the establishment of the Medical Mediation Foundation in 2010<sup>84</sup> and a judicial call for mediation in disputes such as *Gard*.<sup>85</sup>
- 43 Wilkinson *et al.* noted that mediation could be utilised to resolve conflict at any stage in a dispute. However, participation in mediation should be voluntary<sup>86</sup> because, in order for mediation to be effective, the parties must be willing to move from their respective (initial) standpoints.<sup>87</sup> For example, in *Evans*, mediation was said to have been unsuccessful, but

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<sup>78</sup> Ibid 160, 170.

<sup>79</sup> Ibid 160, 171.

<sup>80</sup> Birchley and Huxtable (n 5) 124.

<sup>81</sup> Huxtable (n 63) 474.

<sup>82</sup> As part of the proposed amendments to the Mental Capacity (Amendment) Bill being debated in the House of Lords (n 47), Lord Mackay and Baroness Hollins have proposed the Bill be amended to include provision for the Secretary of State to make regulations concerning the provision of medical mediation. See: <[https://publications.parliament.uk/pa/bills/lbill/2017-2019/0117/18117-l\(a\).pdf](https://publications.parliament.uk/pa/bills/lbill/2017-2019/0117/18117-l(a).pdf)> accessed 8 September 2018.

<sup>83</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)> accessed on 29 August 2018.

<sup>84</sup> Meller and Barclay (n 34) 620.

<sup>85</sup> *Gard* (n 2) [130]. The legislation Charlie Gard's parents are seeking (n 65) also provides for access to medical mediation where disputes as to the care of critically ill children arise.

<sup>86</sup> Wilkinson (n 23) 2304.

<sup>87</sup> Tony Allen, 'A New Way to Settle Old Disputes: Mediation and Healthcare' (2005) 73 *Medico-Legal J.* 93, 99.

tweets posted by the Trust's legal counsel suggested that this was due to the family and their advisors' lack of genuine engagement with the process.<sup>88</sup>

- 44 Despite the current emphasis on the importance and benefits of mediation, there is a lack of data about the use and/or success of mediation in these types of dispute. In Brierley *et al.*'s study of dispute resolution, there was no reference made to mediation being used.<sup>89</sup> Whilst the Medical Mediation Foundation's *Evelina Resolution Project* offers mediation services as well as conflict recognition and management training,<sup>90</sup> data about this project published to date has focused upon conflict management training, rather than on mediation.<sup>91</sup> Allen has suggested that the lack of data on the success of mediation is due to mediation being confidential.<sup>92</sup> However, data on the number of mediations and whether mediation has led to resolution could be gathered and reported (subject to the parties' agreement) without breaching confidentiality.
- 45 Despite the lack of data on its use, the literature suggests mediation is an appropriate resolution mechanism for paediatric healthcare disputes because it allows for open discussion, which could restore trust and communication in relationships which have broken down.<sup>93</sup>
- 46 Mediation is also considered to have a number of benefits over going to court. In addition to being less costly and non-adversarial, it is flexible about who can be involved in the process.<sup>94</sup> In Brierley *et al.*'s study, it was concluded that involving religious leaders in discussions of end-of-life care aided resolution of disputes,<sup>95</sup> illustrating the benefits of involving others beyond the family and treating clinicians – something that cannot be accommodated within the court process.<sup>96</sup>

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<sup>88</sup> Michael Mylonas Q.C., 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] Retrieved from <<https://twitter.com/mmpolista/status/990472258853441537>> and <<https://twitter.com/mmpolista/status/990478302866563078>> retrieved 29 August 2018.

<sup>89</sup> Brierley et al (n 9).

<sup>90</sup> Medical Mediation Foundation, 'Evelina Resolution Project' <<http://www.medicalmediation.org.uk/evelina-resolution-project/>> accessed 29 August 2018.

<sup>91</sup> See: Barclay (n 26); Forbat et al (n 11); Liz Forbat, Jean Simons, Charlotte Sayer, Megan Davies and Sarah 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 *Arch Dis Child* 250; Liz Forbat and Sarah Barclay, 'Reducing Healthcare Conflict: Outcomes from Using the Conflict Management Framework' (2018) *Arch Dis Child* 1.

<sup>92</sup> Allen (n 87) 95.

<sup>93</sup> *Ibid*, 98; Meller and Barclay (n 34) 620; Huxtable (n 63) 473.

<sup>94</sup> Meller and Barclay (n 34) 620.

<sup>95</sup> Brierley et al (n 9) 573.

<sup>96</sup> 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]).

- 47 Despite those putative benefits, and the absence of substantial criticism of mediation as a mechanism of paediatric healthcare dispute resolution within the literature, Forbat *et al.* found that healthcare staff see mediation as a last resort.<sup>97</sup> The risk of using mediation as a last resort is that by the time it is finally used it may be too late, with the positions of disputing parties so entrenched, and with such acrimony and mistrust, that they cannot meaningfully engage in the process - as seemed to occur in *Evans*. There is, however, a lack of research into the timing of different interventions in such disputes and the impact of timing on their effectiveness.
- 48 Huxtable has also raised concerns that mediation may miss the '*ethical dimensions*'<sup>98</sup> of a dispute, particularly if the disagreement is values-based. Wilkinson *et al.* suggested that, to avoid this, mediation should be underpinned by an ethical framework and have in mind the need to achieve an ethical outcome.<sup>99</sup> Meller and Barclay have suggested that for mediation to be effective in paediatric healthcare disputes, mediators needed knowledge of medical law and medical ethics, an understanding of paediatric issues, and access to independent expert advice.<sup>100</sup> When we compare these suggestions to those about improving CECs discussed earlier, it appears that CECs and mediation could perform the same functions albeit in different guises. Whilst mediation has the apparent impartiality and independence that CECs might lack, CECs are already capable of dealing with the 'ethical dimension'. Therefore, it may be beneficial for research to explore the possibility of either CECs or mediation fulfilling the functions of both.

### Summary

- 49 There is a lack of data about the use and success of mediation as a way of resolving paediatric healthcare disputes, but the literature nonetheless suggests it is an appropriate dispute resolution mechanism with several benefits. Its potential disadvantage lies in whether it is able to address the ethical dimension of disputes. There may be potential for combining mediation and CECs, which may provide the benefits of both whilst avoiding some of the disadvantages.

## Court proceedings

- 50 Court proceedings are the final mechanism available for resolution of paediatric healthcare disputes, and the court will resolve the dispute in accordance with the child's best interests.<sup>101</sup> Courts are an effective mechanism if the only outcome considered is ultimate resolution, as they provide an authoritative judgement about the child's care and

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<sup>97</sup> Forbat *et al.* (2017) (n 91) 250, 253.

<sup>98</sup> Huxtable (n 63) 473.

<sup>99</sup> Wilkinson *et al.* (n 23) 2304.

<sup>100</sup> Meller and Barclay (n 34) 620.

<sup>101</sup> There is debate around whether a 'significant harm' standard should be applied instead when parents are seeking alternative treatment (see: Birchley *et al.* (n 7) 933). Those debates are not considered here as disputes could still arise with the application of a different standard. For example, on appeal in *Gard*, part of the dispute related to the viability of the proposed alternative treatment: (1) *Constance Yates* (2) *Christopher Gard v (1) Great Ormond Street Hospital for Children NHS Foundation Trust* (2) *Charles Gard (a Child, by his Guardian)* [2017] EWCA Civ 410, [113].

treatment.<sup>102</sup> However, they appear to be used infrequently, with Brierley *et al.*'s study noting that of the disputed cases, only one was taken to court<sup>103</sup> and Birchley *et al.* commenting that recourse to courts in these disputes was rare.<sup>104</sup> Their infrequent use reported in these studies appeared to relate to concerns about the appropriateness of courts as a mechanism for resolution of paediatric healthcare disputes.

- 51 Whilst court proceedings do result in a clear and definitive outcome, it can be one that leaves neither side happy, particularly when withdrawal of treatment is approved.<sup>105</sup> In such cases, for the parents who want treatment provided, their view about their child's best interests has been overruled and, for the clinicians, it is confirmation that whilst they had been seeking resolution they had been knowingly treating the child against their best interests.<sup>106</sup> Not only can that have a negative impact on the child, it can also have a negative impact on the clinical staff.<sup>107</sup> Equally, if withdrawal of treatment is not approved, this may reinforce any loss of trust between the parents and the clinicians, and create a conflict for clinicians between the legal ruling and their perception as to what is in the child's best interests.
- 52 Huxtable has noted that a drawback of court proceedings in this arena is the court's failure to issue sufficient guidance on the interpretation of 'best interests', with the weight given to different factors varying from case-to-case.<sup>108</sup> Close *et al.* have also called on courts to be clearer in their written judgments about the factors that influenced their decision about best interests, the weight given to those factors and why.<sup>109</sup> This lack of clarity may 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>110</sup> That finding raises the concern that clinicians only seek court hearings if confident the court will support their decision about treatment – similar to the concern about parents 'cherry-picking' SOEs.
- 53 Whatever the outcome, in a court proceeding the judge must adjudicate between the conflicting viewpoints of the family and the healthcare institution. This makes a winner and loser mentality inevitable, creating an adversarial arena where 'the winner takes all'.<sup>111</sup> Meller and Barclay have argued that this 'win or lose' approach masks the ethical complexity of such disputes by reframing them as black and white questions, when in

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<sup>102</sup> This is not always the case. See, for example, *R v Portsmouth Hospital NHS Trust ex parte Glass* [1999] 2 FLR 905 where the court refused to make an order as to the course the doctors should take in the event of future disagreements as to treatment. Bridgeman has also cited the *Wyatt* case which came to court at least 11 times: Jo Bridgeman, 'Editorial: Critically ill children and best interests' (2010) 5 *Clinical Ethics*, 184, 187 [n 11]).

<sup>103</sup> Brierley *et al.* (n 9) 574.

<sup>104</sup> Birchley *et al.* (n 7) 930.

<sup>105</sup> Jo Bridgeman, '*Gard v Yates v. GOSH, the Guardian and the United Kingdom: Reflections on the legal process and the legal principles*' (2017) 17(4) *Medical Law International* 285, 292.

<sup>106</sup> Waldman and Frader (n 14) 176; Dominic Wilkinson and Julian Savulesca, 'Hard Lessons: Learning from the Charlie Gard Case' (2018) 44(7) *Journal of Medical Ethics* 438, 440.

<sup>107</sup> Morley *et al.* (n 33) 6.

<sup>108</sup> Huxtable (n 57) 146; Huxtable (n 63) 472.

<sup>109</sup> Eliana Close, Lindy Wilmott, Benjamin P. White, 'Charlie Gard: In Defence of Law' (2018) 44(7) *Journal of Medical Ethics* 476, 478.

<sup>110</sup> Brierley *et al.* (n 9) 576; Birchley and Huxtable (n 5) 122.

<sup>111</sup> Huxtable (n 57) 147; Birchley and Huxtable (n 5) 122; Huxtable (n 63) 472; Wallis (n 40) 413.

reality they reflect ethical shades of grey.<sup>112</sup> Huxtable also noted a reluctance within the law to openly engage with ethical issues, which could lead to them being ignored.<sup>113</sup> This stands in contrast to CECs, where the ethical elements of a dispute are openly acknowledged and addressed.

- 54 The literature suggested the adversarial nature of court proceedings impacted on the already compromised relationship between families and healthcare professionals. Fassier and Azoulay noted concerns expressed by ICU staff that court action could amplify the feelings of frustration and grief in such disputes,<sup>114</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>115</sup> This could then lead to a complete loss of trust between the family and healthcare staff,<sup>116</sup> with the involvement of the media and social media contributing to a climate of fear and distrust.<sup>117</sup> Brierley *et al.* noted that fear of negative publicity was one reason why healthcare professionals were reluctant to utilise court proceedings.<sup>118</sup>
- 55 In addition to the emotional costs associated with court proceedings, the literature highlighted concern about financial costs.<sup>119</sup> For healthcare institutions, those costs are not limited to the costs of court proceedings, but also include the continuing costs of the putatively futile treatment being provided to the patient whilst court proceedings progress.<sup>120</sup>
- 56 There are also cost implications for the parents as legal aid is not always available and, where it is available, it may not cover all the costs of proceedings.<sup>121</sup> Whilst the parents in the *Gard* case managed to secure pro bono representation, not all parents could do so, and the judge in *Gard* expressed the view that, in such cases, legal aid should be available.<sup>122</sup>
- 57 In court, the child will be represented by a Children's Guardian, the cost of which is met by the State. It has been noted in the literature that this is the only time within a dispute that the child receives representation independent of his or her parents and the treating clinicians.<sup>123</sup> However, Meller and Barclay questioned the extent to which this should be considered a benefit of court proceedings given the tendency of the Guardian to concur

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<sup>112</sup> Meller and Barclay (n 34) 620.

<sup>113</sup> Huxtable (n 57) 152-153.

<sup>114</sup> Fassier and Azoulay (n 18) 662.

<sup>115</sup> Meller and Barclay (n 34) 619; Forbat *et al.* (n 16) 3.

<sup>116</sup> Waldman and Frader (n 14) 175.

<sup>117</sup> Fassier and Azoulay (n 18) 662.

<sup>118</sup> Brierley *et al.* (n 9) 576.

<sup>119</sup> *Ibid.*; Forbat *et al.* (n 16) 2; Birchley and Huxtable (n 5) 122, 123.

<sup>120</sup> Huxtable (n 63) 472.

<sup>121</sup> *Ibid.*

<sup>122</sup> *Great Ormond Street Hospital for Children NHS Foundation Trust v Yates and Others* (No. 2) [2017] EWHC 1909 [17].

<sup>123</sup> Meller and Barclay (n 34) 619.

with medical opinion, as happened in the *Appendix* cases of *Gard*,<sup>124</sup> *Haastrup*<sup>125</sup> and *Evans*.<sup>126</sup>

- 58 Another key concern about court proceedings is delay. Bridgeman has noted that despite the *Gard* case being fast-tracked, the proceedings lasted for five months, including appeals.<sup>127</sup> Similar timescales were seen in *Haastrup* and *Evans*, which took three months and five months respectively, although in *Haastrup* there were no appeals. In contrast, the case of *King* was dealt with within 2 weeks. A key difference in *King*, however, was that the Trust was not opposing the child receiving the alternative treatment, whereas in the other *Appendix* cases, withdrawal/withholding treatment was contested. Thus, whilst delays may be a factor in clinicians' reluctance to take disputes to court,<sup>128</sup> Close *et al.* have noted that the courts do need to balance procedural fairness with expediency.<sup>129</sup>
- 59 Contributing to delays in court resolution are delays in *seeking* a court hearing. Birchley *et al.*'s research found that some clinicians felt resolving healthcare disputes without recourse to court was a measure of both personal and professional success.<sup>130</sup> This suggested that courts are used as a last resort, and Wallis noted that paediatricians are usually advised to only seek a court judgment when the dispute has become entrenched and reached an impasse.<sup>131</sup> However, waiting for this impasse before going to court may increase the likelihood of a complete loss of trust between the parties and an adversarial approach towards proceedings, factors cited in the literature as rendering courts inappropriate mechanisms to resolve paediatric healthcare disputes.
- 60 Despite these concerns, it has been argued that courts have some benefit in the resolution of paediatric healthcare disputes. Huxtable noted that courts are open to, and have some experience of engaging in, value enquiries, making them suitable arenas to address ethical, as well as legal, questions. Their decisions are also authoritative and have procedural rigour.<sup>132</sup> Wilkinson *et al.* also pointed to their impartiality and ability to evaluate evidence and its credibility.<sup>133</sup> However, these benefits could be factored into CECs or mediation, pending further evaluation of those resolution mechanisms.

### Summary

- 61 Whilst courts have been an effective method of resolving disputes about paediatric healthcare, they have been infrequently used due to concerns about their

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<sup>124</sup> *Gard* (n 2) [117].

<sup>125</sup> *Haastrup* (n 2) [67].

<sup>126</sup> *Evans* (n 2) [54].

<sup>127</sup> Bridgeman (n 105) 299.

<sup>128</sup> Fassier and Azoulay (n 18) 662.

<sup>129</sup> Close *et al* (n 109) 479.

<sup>130</sup> Birchley *et al* (n 7) 932.

<sup>131</sup> Wallis (n 40) 413.

<sup>132</sup> Huxtable (n 57) 145-146.

<sup>133</sup> Wilkinson *et al* (n 23) 2304.

appropriateness. Despite these concerns, there was an absence of discussion in the literature about how court processes could be improved to overcome their problems.<sup>134</sup>

- 62 Whilst court proceedings were recognised to have some benefits, those benefits could putatively be secured within a less confrontational environment by incorporating them into models of CECs or mediation, although further research is needed to explore how this could be done.

## Conclusion

- 63 Of the five mechanisms available for resolution of paediatric healthcare disputes, Brierley *et al.*'s study suggested that the overwhelming majority in their sample were resolved by way of discussions between the family and the treating team.<sup>135</sup> However, those discussions can take place over a prolonged period of time and, whilst they continue, the child may be being treated against the healthcare team's view as to the child's best interests. Not only does this have implications for the child, but it may also create a conflict of professional duties for the healthcare staff and may lead to moral distress and associated problems.<sup>136</sup> In addition, reluctance to involve third party intervention can mean that by the time third parties are involved the conflict has escalated to a state of entrenchment and impasse, making it less amenable to resolution.
- 64 Where discussions fail to resolve paediatric healthcare disputes, third party intervention can be sought utilising SOEs, CECs, mediation or court proceedings. Brierley *et al.*'s study suggested that clinicians adopted SOEs and CECs as their preferred mechanism of third-party intervention,<sup>137</sup> yet there is uncertainty around their effectiveness. SOEs seem to be appropriate for resolution of factual disputes about the child's medical condition, prognosis and available treatment, but where conflicts have become entrenched and involve values, the parties may not be willing to accept an SOE whose view is contrary to their own.
- 65 CECs can be an appropriate mechanism for resolution of value disputes, but the literature identified a number of shortcomings. If CECs are to be used to the greatest effect, further research is needed into how CECs should best be constituted and run.
- 66 The literature suggested mediation is an appropriate mechanism for resolution of paediatric healthcare disputes, however, there was a lack of data on its use and effectiveness. In addition, there are concerns over its ability to adequately address the ethical elements of a dispute. This concern, together with suggestions about the training and experience a mediator needed and the areas in which CECs fell short, indicated that if these concerns were met for CECs and mediation, they may be fulfilling the same function, albeit in different guises. Further research could address whether these two mechanisms could be combined into one.

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<sup>134</sup> Contrast this with the literature on CECs which discusses possible solutions to the problems associated with CECs.

<sup>135</sup> Brierley *et al* (n 9) 573.

<sup>136</sup> Morley *et al* (n 33) 6.

<sup>137</sup> Brierley *et al* (n 9) 574.

- 67 The literature agreed that, despite their general effectiveness in definitively resolving disputes, court proceedings are not an appropriate way to resolve paediatric healthcare disputes as they exacerbate conflict and destroy trust between families and healthcare professionals. In addition, the delay associated with court proceedings, whilst necessary to ensure each party has the opportunity for a fair hearing, results in the child continuing to receive treatment which may not be in his or her best interests. There is a lack of discussion in the literature about whether alterations to court processes could overcome these problems.
- 68 Whilst the literature addresses problems with the different mechanisms for resolution of paediatric healthcare disputes, it generally fails to address the reasons why particular mechanisms were successful in a given case. In addition, there is a lack of research about the timing of such interventions, and the impact timing has upon their likelihood of effectively resolving a dispute.

## Appendix: Summary of significant cases

### Ashya King

*Portsmouth City Council v (1) Nagmeh King (2) Brett King (3) Southampton Hospital Trust (4) Ashya King (by his Children's Guardian)* [2014] EWHC 2964 (Fam)

#### Background

Ashya King was 5 years old. He had undergone surgical removal of a brain tumour and his doctors proposed further treatment by way of chemotherapy and radiotherapy. His parents wanted him to receive proton beam therapy (PBT) instead. This would have to be provided overseas and NHS funding for this was refused. His parents, however, located a centre in Prague, which was willing to provide PBT, which the parents said they would fund. 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 proposal to take him to Prague for PBT. On the basis of the medical evidence, the judge concluded the proposed treatment was reasonable and Ashya was not at risk of harm.

#### Dispute Resolution Mechanisms

##### Second Opinion Expert

Ashya's parents located an alternative healthcare facility which was willing and able to provide PBT but this did not resolve the dispute. However, it is unclear whether this was because the Trust refused to agree to a transfer and threatened to institute child protection proceedings (as the parents asserted) or because the parents wrongly believed that was the Trust's position (as the Trust asserted).

## **Charlie Gard**

*Great Ormond Street Hospital v (1) Constance Yates (2) Chris Gard (3) Charles Gard (A Child by his Guardian Ad Litem)* [2017] EWHC 972 (Fam)

### Background

Charlie Gard was 8 months old. He had a form of mitochondrial DNA depletion syndrome and his treating clinicians concluded that his quality of life was poor with no hope of recovery such that continued ventilation would be futile. His parents opposed withdrawal of ventilation on the grounds an experimental treatment was available in the United States which might help him. Initially, the hospital was prepared to consider that treatment but, following Charlie's deterioration, his treating clinicians concluded that treatment would be futile. Charlie's parents maintained he should be transferred to the US.

In light of the medical consensus that the treatment was unlikely to work and further treatment would be futile, the trial judge concluded it would be in Charlie's best interests for the treatment to be withdrawn.

Charlie's parents unsuccessfully appealed this decision. Subsequently, they sought a further hearing on the basis of new evidence from the US clinician. During the course of the second hearing, the US doctor met with the treating clinicians and reviewed up-to-date scans, leading him to conclude there was no possibility of the nucleoside therapy having any effect. Charlie's parents thus withdrew their opposition to the proposal to withdraw ventilation.

### Dispute Resolution Mechanisms

#### Second Opinion Experts

Charlie's parents sought a second opinion as to treatment from a US consultant based upon their own research. Initially that had a positive impact on the dispute from their perspective as it led to discussions with Charlie's doctors who were willing to consider the treatment. However, once Charlie's condition deteriorated, the possibility of that treatment became a source of conflict. Ultimately, the US doctor agreed the treatment was unlikely to work but said that, in America, the practice is to treat if the parents want the child to be treated. This highlights that cultural differences in medical practice may lead to families being offered treatment overseas which would not meet the UK threshold of best interests.

#### Ethical Reviews

Ethical advice was sought by the clinicians in respect of the decision to withhold long-term ventilation. That advice concurred with the clinicians' views and it is unclear if the parents were involved in that review. When the parents initially sought treatment of Charlie with nucleoside therapy the treating clinicians had intended to seek ethical approval for this treatment but Charlie's subsequent deterioration meant that did not take place.

#### Mediation

There is no indication in the judgment that mediation had taken place in this case but, in a subsequent press interview, Charlie's parents said they sought mediation several months before Charlie's death, but the hospital had refused to mediate. GOSH said mediation was

offered in the last few days of Charlie's life. See: <https://www.bbc.co.uk/news/health-44334306> (accessed 31 August 2018).

## **Isaiah Haastrup**

*King's College Hospital NHS Foundation Trust v (1) Takesha Thomas (2) Laure Haastrup (3) Isaiah Haastrup* [2018] EWHC 127 (Fam)

### Background

Isaiah Haastrup was 11 months old at the time of the court hearing to consider whether ventilation should be withdrawn on the grounds that such treatment was futile. He had been born by emergency caesarean-section due to uterus rupture, which led to him sustaining a severe hypoxic ischaemic injury to his brain. The judgment notes that the circumstances of his birth had led to a complete breakdown of trust between the parents and the hospital. This was exacerbated when, shortly after his birth, his parents were advised he was unlikely to recover and the possibility of palliative care was raised, following which Isaiah appeared to become more responsive.

Isaiah was reviewed by a number of different doctors in addition to his treating clinicians, all of whom concluded further treatment was futile and ventilation should be withdrawn. The reviewing clinicians included doctors at other paediatric intensive care units. The treating hospital had sought to transfer Isaiah to another unit in order to overcome the trust issues that had arisen with the parents. However, the other units refused to accept Isaiah due to the futility of further treatment.

Within the court proceedings, the court authorised Isaiah's parents to obtain independent expert evidence for two other experts. Both those experts concurred with the treating clinicians' views and the court authorised withdrawal of treatment from Isaiah.

### Dispute Resolution Mechanisms

#### Second Opinion Experts

Numerous alternative experts were instructed by both the Trust and the family. However, these did not aid resolution of the dispute. When they concurred with the treating clinicians, Isaiah's parents took the view that those experts were colluding with the clinicians and were more concerned with loyalty to the NHS than their duty to Isaiah.

When the independent experts instructed by the parents as part of the court proceedings supported the treating clinicians, Isaiah's parents approached experts based in Poland and Germany. The German doctor submitted a brief opinion which appeared to support the parents' position that ventilation should continue based on the approach that would be taken in Germany. The court, however, refused to consider this evidence as cultural differences were not relevant to the assessment of best interests.

## **Alfie Evans**

*Alder Hey Children's NHS Foundation Trust v (1) Mr Thomas Evans (2) Ms Kate James (3) Alfie Evans (a Child by his Guardian CAFCASS Legal)* [2018] EWHC 308 (Fam)

## Background

Alfie Evans was nearly two years old at the date of the court hearing to determine whether withdrawal of ventilation was in his best interests. Within 6 months of his birth he was noted to have developmental delay and was admitted to Alder Hey Hospital with seizures. The seizures persisted and he 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 damage to his brain that there was no prospect of recovery and so the hospital wished to withdraw ventilation. Alfie's parents contested this and wanted him 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, the trial judge concluded it would be in Alfie's best interests for treatment to be withdrawn. The parents unsuccessfully appealed and subsequently brought further court actions seeking the same outcome on various different legal grounds. In each of these hearings the courts maintained that the determinative standard for medical treatment of a child was the child's best interests.

## Dispute Resolution Mechanisms

### *Second Opinion Experts*

Prior to court proceedings being commenced, the hospital had sought an external second opinion as to Alfie's underlying diagnosis. The parents also instructed three independent experts within the court proceedings. In later court hearings they obtained correspondence from doctors in Italy willing to accept Alfie in their hospital for continued ventilation. However, all the experts accepted further treatment was futile and whilst that enabled the court to resolve the dispute, it did not alter the parents' position in the dispute that Alfie should be allowed to continue to receive life support.

### *Mediation*

The judgment simply records that mediation was unsuccessful without explaining why. However, tweets subsequently posted by the Trust's counsel (referred to in this Review) suggested that mediation failed due to the parents and their advisors arriving late in the day or engaging in arguments rather than mediated discussion.

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