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Tafida Raqeeb v. Barts NHS Foundation Trust and Others [2019]: Bolstering the argument for mediation

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journals.sagepub.com/home/mlj**David I. Benbow** 

School of Law, University of Sheffield, UK

Abstract

The *Tafida Raqeeb* case comprised both a judicial review and a determination of Tafida's best interests. The judicial review concerned Barts Health NHS Trust's (Barts) decision not to permit Tafida's parents to transfer her to Gaslini Children's Hospital (GCH) in Genoa, Italy. Barts requested that a judge declare that the proposed transfer was not in Tafida's best interests. In the High Court, MacDonald J's ruling on the judicial review element of the case was that Barts had not acted unlawfully. In the best interests determination, MacDonald J deemed that continued treatment was in Tafida's best interests, hence Tafida's parents would be permitted to transfer her to GCH. Although medical views of best interests tend to prevail in these types of cases, the *Raqeeb* case, like other previous cases where judges have found in favour of parents, demonstrates that the best interests test is not designed to override the wishes of parents, as its detractors allege, but is flexible enough to allow judges to weigh competing factors in making a determination. In the *Raqeeb* case, in the absence of clear evidence regarding pain and suffering, subjective factors were accorded more weight within the balancing exercise. I argue that the best interests test should be retained and that a reform affording parents a 'right to try' should not be adopted, as this may prolong the pain and suffering of some infants. Nonetheless, the *Raqeeb* case demonstrates the lack of dialogue between parents and clinicians, in some cases. It therefore bolsters the argument that mediation should be offered in these types of cases.

Corresponding author:

David I. Benbow, School of Law, University of Sheffield, Bartolome House, Winter Street, Sheffield S3 7ND, UK.

Email: d.benbow@sheffield.ac.uk

Keywords

Best interests, mediation, European Union rights, significant harm, judicial review

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Introduction

The recent case concerning the treatment of the young girl, Tafida Raqeeb, heard in the High Court of England and Wales, comprised both a judicial review application and a determination of Tafida's best interests. The judicial review concerned Barts Health NHS Trust's (Barts) decision not to permit Tafida's parents to transfer her to Gaslini Children's Hospital (GCH) in Genoa, Italy. Barts requested a court declaration that the proposed transfer was not in Tafida's best interests.¹ The best interests principle is a core principle of medical ethics contained within guidelines in numerous countries² and is determinative where there are disputes between parents and clinicians concerning the appropriate treatment of a young infant within the jurisdiction of England and Wales.³ In the High Court, MacDonald J's ruling on the judicial review element of the case was that Barts had not acted unlawfully. In the best interests determination, MacDonald J deemed that continued treatment was in Tafida's best interests, hence Tafida's parents would be permitted to transfer her to GCH. Although medical views of best interests tend to prevail in these types of cases,⁴ the *Raqeeb* case, like other previous cases where judges have found in favour of parents,⁵ demonstrates that the best interests test is not designed to override the wishes of parents, as its detractors allege,⁶ but is characterised by flexibility which allows judges to weigh competing factors in making a determination.

In the absence of clear objective medical evidence regarding pain and suffering in the *Raqeeb* case, subjective factors were accorded more weight in the balancing exercise. However, Tafida's mother, Shelina Begum, remains convinced that 'the law now needs to be revisited'.⁷ She wants a 'clear law that says if there is a reputable hospital prepared to treat a child then there should be no blocking'.⁸ On the contrary, I argue that the best

1. *Tafida Raqeeb v. Barts NHS Foundation Trust and Others* [2019] EWHC 2531 (Admin).
2. D. Wilkinson, *Death or Disability: The 'Carmentis Machine' and Decision Making for Young Children* (Oxford: Oxford University Press, 2013), p. 47.
3. As per the Children Act 1989, s. 1(1).
4. G. Birchley, 'Deciding Together? Best Interests and Shared Decision-Making in Paediatric Intensive Care', *Health Care Analysis* 22 (2014), pp. 203–222.
5. See, for example, *Re T (A Minor) (Wardship: Medical Treatment)* [1997] 1 WLR 242 and *An NHS Trust v. MB* [2006] 3 WLUK 379.
6. See, for example, Charlie Gard Foundation, 'Charlie's Law'. Available at: <https://www.thecharliegardfoundation.org/charlies-law/> (accessed 8 October 2018).
7. British Broadcasting Corporation (BBC) Website, 'Tafida Raqeeb: "Law Should Be Revisited," Say Parents'. Available at: <https://www.bbc.co.uk/news/uk-england-london-49944602> (accessed 6 December 2019).
8. Op. cit.

interests test should be retained and that such a 'right to try' should not be adopted, as this may prolong the pain and suffering of some infants. Nonetheless, the *Raqeeb* case, like previous high-profile cases in England and Wales involving disputes between parents and clinicians (such as the cases involving the infants Ashya King,⁹ Charlie Gard¹⁰ and Alfie Evans¹¹), demonstrates the need for legal reform to ensure that mediation is offered where such disputes arise.¹² The threat of litigation, in such cases, may fuel conflict and entrench the polarised positions of clinicians and parents.¹³ In addition, protracted disputes are stressful for both parents and clinicians.¹⁴ Mediation (which is also sometimes referred to as conciliation) 'is a private, voluntary, informal process in which an impartial third person facilitates a negotiation between people in conflict and helps them find solutions that meet their interests and needs'.¹⁵ It is used in other jurisdictions, such as the United States (US), where it often prevents disagreements crystallising into conflicts.¹⁶ Mediation also plays a significant role in Australia, New Zealand, Canada and parts of mainland Europe.¹⁷ Mediation is consensual, flexible, relatively quick and relatively cheap.¹⁸ Reform requiring that mediation be offered in these types of cases, within England and Wales, may facilitate understanding between parents and clinicians and potentially result in mutual agreement that could prevent expensive, time-consuming and stressful litigation.

Facts

Tafida Raqeeb was born on the 10th of June 2014 to Shelina Begum and Mohammed Abdul Raqeeb (who are citizens of both the United Kingdom and the People's Republic of Bangladesh) in Newham, East London. In his judgment, MacDonald J described

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9. *Re King* [2014] 2 FLR 855.
 10. *Great Ormond Street Hospital v. Constance Yates, Chris Gard and Charles Gard (A Child by his Guardian Ad Litem)* [2017] EWHC 972 (Fam) [20].
 11. *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) [6].
 12. At the moment, while some NHS trusts and foundation trusts may offer mediation (which may be formal or informal), it is not mandatory that this be offered where disputes arise.
 13. J. Bridgeman, 'Misunderstanding, Threats and Fear of the Law in Conflicts over Children's Healthcare: *In the Matter of Ashya King* [2014] EWHC 2964', *Medical Law Review* 23 (2015), pp. 477–489.
 14. J. Bridgeman, '*Gard and Yates v GOSH*, the Guardian and the United Kingdom: Reflections on the Legal Process and the Legal Principles', *Medical Law International* 17 (2017), pp. 285–302.
 15. N. Dubler and C. Liebman, *Bioethics Mediation: A Guide to Shaping Shared Solutions Revised and Expanded Edition* (Nashville, TN: Vanderbilt University Press, 2011), p. 11.
 16. Nuffield Council on Bioethics, *Critical Case Decisions in Foetal and Neonatal Medicine: Ethical Issues* (London: Nuffield Council on Bioethics, 2006), p. 146.
 17. A. Ward Platt, *Conciliation in Healthcare: Managing and Resolving Complaints and Conflict* (Oxford: Radcliffe, 2008), p. 4.
 18. S. Meller and S. Barclay, 'Mediation: An Approach to Intractable Disputes Between Parents and Paediatricians', *Archives of Disease in Childhood* 96 (2011), pp. 619–621.

Tafida's parents as 'committed Muslims'.¹⁹ In February 2019, Tafida complained of a headache and thereafter stopped breathing. Tafida was escorted by ambulance to Newham University Hospital, where an examination revealed a large blood clot on her brain.²⁰ The blood clot, caused by *arteriovenous malformation*, was deemed to be life threatening and to require immediate surgical intervention.²¹ After surgery, on the 9th of February, Tafida was treated in the paediatric intensive care unit of Kings College Hospital. She was subsequently transferred to the Royal London Hospital, which is part of Barts, on the 3rd of April 2019.²² Since her surgery, Tafida has been kept alive by artificial ventilation.²³ In March 2019, her clinicians recommended palliative care.²⁴ In the view of Dr Martin Smith (a consultant in paediatric neurology at the Oxford John Radcliffe Hospital, who was asked by Barts to examine Tafida), any chance of Tafida 'regaining any level of awareness or increased awareness is negligible'.²⁵

Similarly to the parents in the *King, Gard* and *Evans* cases, Tafida's parents contacted hospitals worldwide seeking help for their daughter.²⁶ One of the hospitals they contacted was GCH. The doctors at GCH averred that Tafida could be weaned off a ventilator following a tracheostomy (a medical procedure whereby an opening is created in a patient's neck so that a tube can be inserted) and determined that this option required further investigation.²⁷ In their view, following a successful tracheostomy, Tafida could be managed at home by well-trained caregivers.²⁸ According to Shelina, Kings College Hospital had stated that Tafida would be given a tracheostomy, but this did not occur following her transfer to the Royal London Hospital.²⁹ In July, Tafida's parents asked for her to be transferred to GCH.³⁰ They also set up an online campaign in order to fund treatment for their daughter in Italy.³¹ The doctors at Barts did not acquiesce to the transfer, as they deemed that it would not be in her best interests. Tafida's parents submitted an application for a judicial review of the decision of Barts not to permit the transfer of their daughter to the Italian hospital, to the High Court. Concurrently, Barts submitted an application to the High Court seeking a declaration that such a transfer would not be in Tafida's best interests. The hearing took place at the High Court in September and the judgment was published in October.

19. *Tafida Raqeeb* at para 7.

20. *Tafida Raqeeb* at para 8.

21. *Tafida Raqeeb* at para 8.

22. *Tafida Raqeeb* at para 9.

23. *Tafida Raqeeb* at para 10.

24. *Tafida Raqeeb* at para 9.

25. *Tafida Raqeeb* at para 36.

26. *Tafida Raqeeb* at para 13.

27. *Tafida Raqeeb* at para 26.

28. *Tafida Raqeeb* at para 27.

29. *This Morning*, 1 August 2019 (ITV).

30. *Tafida Raqeeb* at para 13.

31. GoFundMe, 'Save Tafida'. Available at: <https://www.gofundme.com/f/save-tafida> (accessed 7 October 2019).

Judicial review

At the High Court, the legal team of Tafida's parents argued that the corollary of the right to provide services (including intensive care and palliative care) within European Union (EU) law³² is the right to receive them.³³ They contended that such rights cannot be restricted, unless there is an imperative public policy reason.³⁴ As the trust failed to consider Tafida's right to receive services, in making the decision not to permit her transfer to Italy, the legal team of Tafida's parents argued that it was unlawful on public law principles.³⁵ In addition, they contended that the trust had acted unlawfully, for the purposes of the Equality Act 2010,³⁶ that the trust had deprived Tafida of her liberty,³⁷ and that the trust had failed to engage with the rights contained within the NHS Constitution.³⁸ MacDonald J determined that the decision of Barts was amenable to judicial review as it is a public body exercising statutory functions under the NHS Act 2006.³⁹ In addition, the NHS Constitution states that patients have the right to a judicial review if they 'have been directly affected by an unlawful act or decision of an NHS body or local authority'.⁴⁰ MacDonald J rejected the argument that Barts' decision deprived Tafida of her liberty.⁴¹ Counsel for the parents of Charlie Gard and Alfie Evans had made similar arguments in those cases, which had been rejected by the European Court of Human Rights and the UK Supreme Court, respectively.⁴² MacDonald J also rejected the arguments that Barts' decision discriminated against Tafida for the purposes of the Equality Act 2010 and that the trust had failed to consider the NHS Constitution.⁴³

32. Consolidated version of the Treaty on the Functioning of the European Union (TFEU), OJ C [2016] 202, Article 56 read in conjunction with Directive 2011/24/EU of the European Parliament and of the Council of 9 March 2011 on the application of patients' rights in cross border healthcare, OJ L 88, 4 April 2011.

33. *Tafida Raqeeb* at para 47.

34. *Tafida Raqeeb* at para 48/TFEU, Article 52, read in conjunction with European Union, Charter of Fundamental Rights of the European Union, 26 October 2012, 2012/C 326/02, Article 24 (the rights of the child).

35. *Tafida Raqeeb* at para 49.

36. In not taking into account the European Convention on Human Rights (ECHR) (which was incorporated into UK law via the Human Rights Act 1998), Articles 9 (the right to freedom of thought, conscience and religion) and 10 (the right to freedom of expression).

37. In contravention of Article 5 of the ECHR (the right to liberty and security), read in conjunction with Article 8 (the right to respect for one's private and family life), Article 9 and Article 14 (which prohibits discrimination).

38. *Tafida Raqeeb* at para 54/Department of Health (DOH), *The NHS Constitution* (London: DOH, 2015).

39. *Tafida Raqeeb* at para 141.

40. DOH, *The NHS Constitution*, p. 10.

41. *Tafida Raqeeb* at para 143.

42. *Gard v. United Kingdom* Application No. 39793/17 (2017) 65 E.H.R.R. SE9/The Supreme Court Decision of 20 April 2018, in the Matter of Alfie Evans (No. 2).

43. *Tafida Raqeeb* at para 143.

Nevertheless, MacDonald J determined that the trust's decision was *prima facie* unlawful, and not compliant with the usual standards of administrative law, as the trust had failed to direct itself to applicable EU law.⁴⁴ MacDonald J deemed the trust's decision to be a plain interference with directly effective EU rights.⁴⁵ Nonetheless, he resolved that if the trust had considered Tafida's EU rights, it would have deemed that interference with such rights was justified on public policy grounds.⁴⁶ The trust had argued that they were unable to acquiesce to the wishes of Tafida's parents in circumstances where they had made an application to the High Court in order to determine her best interests. MacDonald J determined that the best interests determination procedure does not conflict with the primacy of EU law, is not discriminatory on the grounds of nationality or otherwise⁴⁷ and is proportionate to its objective.⁴⁸ MacDonald J also stated that it would have been contrary to Tafida's best interests for her to be transferred to GCH where there was an extant dispute regarding her best interests.⁴⁹ Therefore, MacDonald J did not grant relief in respect of the judicial review. If the United Kingdom leaves the EU, the rights which were claimed on behalf of Tafida in this case will not be applicable in future cases where parents want to transfer a sick child to a hospital situated within a member state of the EU. Nonetheless, parents will still be able to argue that transfer to a foreign hospital (including hospitals outside of the EU, as in the *Gard* case) may be in their children's best interests.

Best interests

MacDonald J was not persuaded by the contention of the parents' legal team that where the parents of a sick child and a body of reputable medical opinion are in agreement, as to the treatment of that child, 'this negates the need for the court to be involved at all'.⁵⁰ In the best interests determination, MacDonald J averred that 'substantial factors tend to support the case made by the trust'.⁵¹ However, he also thought that there were compelling factors on the opposite side of the balance.⁵² Ultimately, he determined that 'the latter prevail over the former'⁵³ and dismissed the applications made by Barts.⁵⁴ In MacDonald J's view, where there is an absence of clear facts regarding pain or awareness of suffering (as there was in this case), 'the answer to the objective best interests tests must be looked for in subjective or highly value-laden ethical, moral or religious

44. *Tafida Raqeeb* at para 144.

45. *Tafida Raqeeb* at para 145.

46. *Tafida Raqeeb* at para 146.

47. *Tafida Raqeeb* at para 149.

48. *Tafida Raqeeb* at para 154.

49. *Tafida Raqeeb* at para 153.

50. *Tafida Raqeeb* at para 112.

51. *Tafida Raqeeb* at para 165.

52. *Tafida Raqeeb* at para 165.

53. *Tafida Raqeeb* at para 165.

54. *Tafida Raqeeb* at para 159.

factors extrinsic to the child'.⁵⁵ Such factors include futility, 'dignity, the meaning of life and the principle of the sanctity of life'.⁵⁶ MacDonald J acknowledged that such factors may 'mean different things to different people in a diverse, multicultural, multifaith society'.⁵⁷

In reaching his decision, MacDonald J considered different aspects of the case relevant to the best interests test, including the medical evidence and the religious convictions of Tafida's parents, which they had begun to instil into their daughter. In MacDonald J's view, making the orders requested by Barts would not be a necessary or proportionate justification for interference with Tafida's parent's rights to a private and family life.⁵⁸ MacDonald J was explicit that a number of factors tipped the balance in favour of Tafida's parents. Similarly to the *Gard* and *Evans* cases, the question as to whether Tafida could feel pain was an important consideration at the hearing.⁵⁹ In an interview, on *Good Morning Britain (GMB)*, Shelina stated that Tafida was not in pain and expressed the view that she would have agreed with her doctors concerning her treatment if she was.⁶⁰ Tafida's parents contended that Tafida was improving on a daily basis. In this respect, they contended that she has a sleep/wake cycle, can control her urinary functions for a period of time, can move in response to her parents, moves her body in response to physiotherapy, reacts to painful stimuli and reacts to her mother's voice.⁶¹ MacDonald J stated that the possibility of pain could not be excluded.⁶² Nonetheless, he concluded that Tafida was 'not in pain and [was] medically stable'.⁶³ Significantly, while in the *Gard* and *Evans* cases, the proposed transfer of children to hospitals in the US and Italy, respectively, portended a possible worsening of the condition of the respective infants in those disputes,⁶⁴ in Tafida's case, Barts conceded that transferring her to the GCH could occur with minimal risk.⁶⁵ In MacDonald J's view, Tafida could be safely transported to Italy 'with little or no impact on her welfare'.⁶⁶

MacDonald J stated that he was satisfied that Tafida's current medical condition is substantially irreversible and that she will remain profoundly neurologically disabled for the rest of her life.⁶⁷ Nonetheless, he noted that whether Tafida can be weaned off a

55. *Tafida Raqeeb* at para 191.

56. *Tafida Raqeeb* at para 191.

57. *Tafida Raqeeb* at para 191.

58. *Tafida Raqeeb* at para 182/ECHR, Article 8.

59. *Tafida Raqeeb* at para 65.

60. *Good Morning Britain*, 12 August 2019 (ITV).

61. *Tafida Raqeeb* at para 40.

62. *Tafida Raqeeb* at para 65.

63. *Tafida Raqeeb* at para 186.

64. For example, in the Alfie Evans case, doctors at the Bambino Gesù Hospital, in Italy, determined that transporting him to Rome could provoke further seizures and damage to his brain *E (A Child)* [2018] EWCA Civ 550 [21].

65. *Tafida Raqeeb* at para 72.

66. *Tafida Raqeeb* at para 186.

67. *Tafida Raqeeb* at para 163.

mechanical ventilator is a question which the Italian medical team believe requires further evaluation.⁶⁸ MacDonald J determined that the burden of the treatment to keep Tafida in a minimally conscious state is low and that it was relevant that a responsible body of medical opinion considered that Tafida could be maintained on life support (with the aim of ultimately enabling her to be cared for at home on ventilation by her family, as children in similar situations are cared for).⁶⁹

MacDonald J averred that the right to freedom of thought, conscience and religion⁷⁰ must be accorded weight in the balancing exercise.⁷¹ Nonetheless, he was clear that although religious convictions were an aspect to be considered in the best interests determination, they did not confer on parents the right to access treatment which was not in a child's best interests.⁷² MacDonald J dismissed the argument (based on an equivalence between the Children Act 1989 and the Mental Capacity Act 2005) that the religious convictions of Tafida, and her relatives, should be particularly pre-eminent in the best interests analysis.⁷³ MacDonald J stated that 'the wishes and feelings of the child do not carry any presumption of precedence over any of the other factors in the welfare checklist'.⁷⁴ MacDonald J determined that in cases under the Children Act 1989, particularly those concerning younger children and infants, it is not useful to seek to import principles wholesale from the Mental Capacity Act 2005.⁷⁵ Such an importation posed the risk of imputing to a child matters beyond their comprehension.⁷⁶ The evidence indicated that Tafida had a growing understanding of the religion of Islam, but in MacDonald J's view, she would have had 'no concept or contemplation of her current situation, or of the complex and grave legal, moral and ethical issues it raises'.⁷⁷ However, he mused that, if asked, Tafida would not reject her current situation 'out of hand'.⁷⁸ MacDonald J concluded that the continuation of life-sustaining treatment was consistent with 'the religious and cultural tenets by which Tafida was being raised'.⁷⁹

The difference between the *Raqeeb* case and its immediate predecessors (the *Gard* and *Evans* cases) is therefore that where there is a lack of clear evidence as to whether a child is in pain or aware of suffering and there are clinicians who are of the opinion that they could be cared for at home (in the same manner as children in similar situations), subjective factors (such as religious belief) may be more influential in a determination regarding an infant's best interests. In the *Gard* and *Evans* cases, the religious beliefs of the parents were also a prominent factor behind the litigation. However, in those cases,

68. *Tafida Raqeeb* at para 164.

69. *Tafida Raqeeb* at para 186.

70. ECHR, Article 9.

71. *Tafida Raqeeb* at para 184.

72. *Tafida Raqeeb* at para 70.

73. *Tafida Raqeeb* at para 120.

74. *Tafida Raqeeb* at para 122.

75. *Tafida Raqeeb* at para 123.

76. *Tafida Raqeeb* at para 124.

77. *Tafida Raqeeb* at para 166.

78. *Tafida Raqeeb* at para 168.

79. *Tafida Raqeeb* at para 186.

subjective factors were less influential where there were concerns about the continued pain and suffering of the infants involved, which could be exacerbated by travel, and these were not applicable in the *Raqeeb* case. The day following the High Court's judgment, Alistair Chesser (Barts Chief Medical Officer) confirmed that the trust would not be appealing against the ruling.⁸⁰ Tafida was subsequently taken to Italy on the 16th of October 2019.⁸¹

Reform

Although Tafida's parents were successful, they have indicated that they support reforming the current law. For example, Shelina stated, in an interview on *This Morning*, that 'parents should have the right to decide for the best interests of their child'.⁸² While the *Gard* and *Evans* cases led for a clamour among some to replace the best interests test, one positive aspect of the judgment in Tafida's case is that it reminds us that medical opinion does not always prevail and that the test is sufficiently malleable to enable decision makers to take account of the particularities of the cases brought before them.⁸³ Nonetheless, Shelina's other comments in television interviews evidence the problematic lack of dialogue between parents and clinicians in some cases. For example, in one interview, Shelina stated that 'I don't know why they [Barts] don't agree. They have never made anything clear to me'.⁸⁴ In another interview, Shelina stated that:

I have written to all the directors, all the trustees. No one has come to speak to us. Instead they've rushed in and submitted this court case to actually terminate Tafida's life.⁸⁵

Such comments indicate that reform is needed to enhance communication between parents and clinicians where disputes arise. In this respect, mediation may help to facilitate dialogue between parents and clinicians, enabling them to achieve 'mutual agreement and understanding',⁸⁶ which the German philosopher Hans-Georg Gadamer deemed was crucial to the relationship between clinicians and their patients (or carers). Mediation may therefore also potentially prevent the need for litigation. The use of mediation in these types of cases was recommended by Francis J in the *Charlie Gard*

80. Barts Health NHS Trust Press Office, 'Media Statement Regarding Our Care of Tafida Raqeeb'. Available at: <https://www.bartshealth.nhs.uk/news/updated-statement-tafida-raqeeb-0310-6626> (accessed 7 October 2019).

81. British Broadcasting Corporation (BBC) Website, 'Tafida Raqeeb: Brain Damaged Girl Arrives in Italy'. Available at: <https://www.bbc.co.uk/news/uk-england-london-50068246> (accessed 16 October 2019).

82. *This Morning*, 1 August 2019.

83. Jonathan Herring has also defended the best interests test on the basis of its flexibility. See J. Herring, 'Farewell Welfare?', *Journal of Social Welfare and Family Law* 27 (2005), pp. 159–171.

84. *This Morning*, 1 August 2019.

85. *Good Morning Britain*.

86. H. Gadamer, *The Enigma of Health: The Art of Healing in a Scientific Age* (Stanford, CA: Stanford University Press, 1996), p.113.

case.⁸⁷ It also received the support of Charlie Gard's mother, Constance Yates,⁸⁸ and of academics.⁸⁹ There is, however, a need for more data on the current use and effectiveness of mediation within England and Wales.⁹⁰ Kartina Choong argues that in medical futility cases, where there is an absence of a middle ground and the courts frequently side with doctors, the ability for mediation to lead to a satisfactory resolution is limited.⁹¹ Consequently, the courts should retain a role if a dispute cannot be successfully mediated. Nonetheless, US research indicates that mediation can be an effective means of reaching a principled resolution to disputes.⁹²

In response to the Charlie Gard case, Baroness Jolly stated that she would propose an amendment to the Access to Palliative Care Bill (APCB),⁹³ at the committee stage in the House of Lords. Baroness Jolly stated that her proposed amendment would do the following:

First, it would require the Secretary of State to put in place measures to improve access to mediation where conflict was in prospect. Secondly, it would provide for ethics advice and the means necessary to obtain second opinions swiftly. Thirdly, it would prevent court orders being made to prevent parents seeking treatment where that treatment was not harmful and where another reputable hospital was willing to provide it. In essence, this final provision is about the right to try.⁹⁴

As the APCB was a private members bill, it was not carried over when Parliament was prorogued on the 8th of October. The Labour MP, Bambos Charalambous, has indicated that he is planning to introduce another bill (the Children (Access to Treatment) Bill) into Parliament to reform the law.⁹⁵ Such reform would include ensuring access to mediation and replacing the best interests test with a significant harm test.⁹⁶ The problems with adopting a significant harm test are that: it may not lead to a different outcome in some cases (as McFarlane LJ and Baroness Hale highlighted in the *Gard* case⁹⁷); it would

87. *Great Ormond Street Hospital* at para 130.

88. C. Yates, 'No Other Family Should Be Put Through Our Heartache', *Daily Mail*, 5 September 2018.

89. See, for example, D. Wilkinson, S. Barclay and J. Savulescu, 'Disagreement, Mediation, Arbitration: Resolving Disputes About Medical Treatment', *The Lancet* 391 (2018), pp. 2302–2305.

90. L. Austin, *UK Processes for Resolution of Disagreements About the Care of Critically Ill Children* (London: Nuffield Council on Bioethics, 2018).

91. K. Choong, 'Can "Medical Futility" Conflicts Be Mediated?', *Journal of Medical Law and Ethics* 6 (2018), pp. 41–53.

92. Dubler and Liebman, *Bioethics Mediation*, p. 14.

93. H.L. Bill (2017–2019) [33].

94. H.L. Deb 14 June 2019, Vol. 798, Col. 637.

95. C. Yates, 'I Lost My Son Charlie After a Lengthy Court Dispute. Now I'm Campaigning to Revolutionise NHS Care', *Independent*, 27 September 2019.

96. Op Cit.

97. *Great Ormond Street Hospital v. Yates* [2017] EWCA Civ 410 [114]; The Supreme Court Decision of 8 June 2017, *In the Matter of Charlie Gard*.

render UK law divergent from international law⁹⁸; it is seen as a more conducive test to the desires of parents, which could encourage misplaced hope and prolong the suffering of some infants; it may have negative effects in terms of distributive justice; and it may be unworkable (e.g. if a parent cannot find a clinician to undertake the treatment that they want for their child).⁹⁹

Conclusion

The *Raqeeb* case demonstrates the flexibility of the best interests test, which is determinative where there are disputes between clinicians and parents regarding the medical treatment of young infants. It shows that the best interests test is not designed to override the wishes of parents, as its detractors allege. Rather it allows judges the flexibility to take into account the particularities of the cases that they are adjudicating upon. As the evidence regarding pain or suffering was unclear in the *Raqeeb* case, unlike in the earlier *Gard* and *Evans* cases, other factors were accorded more weight within the best interests determination. Nonetheless, the *Raqeeb* case is similar to previous cases in revealing a lack of dialogue between parents and clinicians. It therefore bolsters the case for legal reform to ensure that mediation is offered in these types of cases in the future to facilitate communication between parents and clinicians. Mediation may facilitate mutual understanding between clinicians and parents and therefore prevent the need for recourse to costly, time-consuming and stressful litigation.


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ORCID iD

David I. Benbow  <https://orcid.org/0000-0002-2266-0611>

98. Namely, Article 3(1) of the Convention on the Rights of the Child (signed 19 April 1990; entered into force 15 January 1992) 1577 U.N.T.S. 3, which states that ‘in all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration’.

99. D. Benbow, ‘An Analysis of Charlie’s Law and Alfie’s Law’, *Medical Law Review* (2019). DOI: 10.1093/medlaw/fwz017.