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Article:

Benbow, D.I. (2020) Imogen Goold, Jonathan Herring and Cressida Auckland (eds), Parental rights, best interests and significant harms: medical decision-making on behalf of children post-Great Ormond Street Hospital v Gard. Medical Law Review, 28 (3). fwaa021. pp. 628-632. ISSN: 0967-0742

https://doi.org/10.1093/medlaw/fwaa021

This is a pre-copyedited, author-produced version of an article accepted for publication in Medical Law Review following peer review. The version of record David I Benbow, Imogen Goold, Jonathan Herring and Cressida Auckland (eds), Parental Rights, Best Interests and Significant Harms: Medical Decision-Making on Behalf of Children Post-Great Ormond Street Hospital v Gard, Medical Law Review, , fwaa021, is available online at: https://doi.org/10.1093/medlaw/fwaa021

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Parental Rights, Best Interests and Significant Harms: Medical Decision-Making on Behalf of Children Post-Great Ormond Street Hospital v Gard, IMOGEN GOOLD, JONATHAN HERRING and CRESSIDA AUCKLAND (eds.), Hart, 2019, 256 pp., £60.00, hardback, ISBN 9781509924899

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The Charlie Gard case is one of a number of recent cases which have involved disputes between medical professionals and parents concerning the appropriate treatment for babies and young children.[1] Such cases have reignited pre-existing academic debates as to whether the best interests test, which is determinative in such cases,[2] should be replaced with a significant harm test, and generated public debate about the appropriate ambit of state intervention. *Parental Rights, Best Interests and Significant Harms* illuminates these debates and contains insightful contributions from a range of academics (specialising in medical law and family law) and medical professionals. The contributions are derived from a one-day workshop which took place in Oxford in 2018 (p. 4). The challenge to the existing law is laid out in a quotation from Ian Kennedy in the foreword to the book by Victoria Butler-Cole QC (who acted as a guardian for Charlie) (p. v). Kennedy described the best interests test as 'empty rhetoric' and stated that it allowed lawyers to engage in 'ad hocery'.[3] Whether Kennedy's critique is justified, and the merits and demerits of reforming the current law, are meticulously examined throughout the book.

In their respective chapters, Imogen Goold and Dominic Wilkinson outline nuanced arguments for reforming the current law, but I found the chapters by Rachel Taylor, Giles Birchley and Jo Bridgeman, which defend the current law, more persuasive. Goold contends that a harm threshold should replace the best interests test,[4] whereas Wilkinson believes that the best interests test should be supplemented by a harm threshold, in some instances (p. 98).[5] Goold argues that the aforementioned cases highlight 'the lack of robust normative justification for the current legal position' (p. 33), and that the threshold for intervention in medical cases is 'potentially very low' (p. 38). Both she and Wilkinson note that it is inconsistent with the threshold in cases involving family life and care proceedings (Goold, p 33; Wilkinson p. 92). Goold states that if we are 'to respect difference and work towards a respectful, pluralistic society, we need to leave space to allow for people to make different decisions about important things' (pp. 46-47). In her assessment, the best interests test 'does a poor job of cutting through these issues precisely', as 'once we tolerate difference, we have to tolerate the view that there can be more than one "best" for a person' (p. 47). She avers that a harm threshold is preferable, as it 'offers a clearer, more effective point at which to override parents' (p. 47). In contrast, I have argued elsewhere that the recent judgment in the Tafida Raqeeb[6] case demonstrates the flexibility of the best interests test.[7]

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[1] *Great Ormond Street Hospital* v *Constance Yates, Chris Gard and Charles Gard (A Child by his Guardian Ad Litem)* [2017] EWHC 972 (Fam) [20].

[2] Children Act 1989, S.1(1).

[3] I. Kennedy, 'Patients, Doctors and Human Rights' in R. Blackburn and J. Taylor (eds) *Human Rights for the 1990s* (London: Mansell, 1991).

[4] 'Evaluating "Best Interests" as a Threshold for Judicial Intervention in Medical Decision-Making on Behalf of Children', ch 2.

[5] 'In Defence of a Conditional Harm Threshold Test for Paediatric Decision-Making', ch 5.

[6] *Tafida Raqeeb v Barts NHS Foundation Trust and Others* [2019] EWHC 2531 (Admin).

[7] D. Benbow, '*Tafida Raqeeb v Barts NHS Foundation Trust and Others* [2019]: Bolstering the argument for mediation' (2020) 19 *Medical Law International* 298.

Wilkinson contends that the best interests test is vague, as it does not specify how much weight should be given to different benefits (such as continued existence) and harms (such as the discomfort of continued medical treatment) (p. 88). However, as Timothy Endicott has stated, vagueness is ineliminable from law.[8] In addition, a harm threshold also suffers from uncertainty, as what constitutes harm is indeterminate.[9] Butler-Cole notes, in the foreword, that replacing the best interest test with a significant harm test 'may not materially alter the judgements reached' (p. vi). Indeed, both McFarlane LJ[10] and Baroness Hale[11] determined, in the Supreme Court in *Gard*, that a significant harm test would not have led to a different decision. In contrast, Wilkinson contends that the two tests would not produce the same result in *all* cases (p. 94). He cites cases[12] concerning parental disputes over routine immunisation as an example (p. 95). In such cases courts have consistently concluded that immunisation would be in the child's best interests, but Wilkinson does not believe that it is likely that a court would conclude that parental refusal of a routine childhood vaccination would constitute significant harm (p.95). Wilkinson believes that more weight should be given to parents' interests and views as they are in a unique epistemic position to assess their child's interests and are most affected by treatment decisions (p 91). Wilkinson's argument, in this regard, is counterargued in the chapters by Taylor, Birchley, and Sara Fovargue.

Taylor contends that the law already recognises the value of parental freedom, which Wilkinson champions, by emphasising the primary role of parents in determining the welfare of their children (p. 65).[13] Similarly, Birchley refers to empirical data, from the 'Best Interests in Paediatric Care' (BIPIC) project, which demonstrates that clinicians are sensitive to parents' rights (p. 108).[14] In addition, he notes that it has been argued that a harm threshold may have a chilling effect on parental autonomy (p. 126).[15] Drawing on the writings of the utilitarian philosopher, John Stuart Mill,[16] Birchley convincingly argues that questions of parental autonomy and medical authority 'are questions of the power of each party over a child, rather than questions of individual liberty' (p. 131). In Taylor's view, rather than carving out some decisions as exclusive parental rights which are immune from challenge, the upbringing of children should be recognised as a collaborative activity (p. 65). Taylor's argument dovetails with Jonathan Herring's contention, in his chapter, that we need to re-examine what it means to be a parent (p. 201), given the intensification of the pressure on parents to succeed at parenting (p. 199) and the increasing tendency of privatising responsibility for children (p. 200).[17]

The defence of the current law continues in the chapter by Bridgeman.[18] She argues that appreciating that clinicians are seeking a court ruling as 'they have reached the limits of what

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[8] T. Endicott, *Vagueness in Law* (Oxford: Oxford University Press, 2000) 190.

[9] G. Birchley, 'Harm is all you need? Best interests and disputes about parental decision making' (2016) 42 *Journal of Medical Ethics* 111.

[10] *Great Ormond Street Hospital* v *Yates* [2017] EWCA Civ 410 [114].

[11] The Supreme Court Decision of 08 June 2017, in the Matter of Charlie Gard.

[12] *Re SL (Permission to Vaccinate)* [2017] EWHC 125 (Fam); *B (A Child: Immunisation)* [2018] EWFC 56.

[13] 'Parental Decisions and Court Jurisdiction: Best Interests or Significant Harm?', ch 3.

[14] 'The Harm Threshold: A View from the Clinic', ch 6.

[15] K. Gollop and S. Pope, 'Charlie Gard, Alfie Evans and R (A Child): Why a Medical Treatment Significant Harm Test Would Hinder not Help' < http://www.transparencyproject.org.uk/charlie-gard-alfie-evans-and-r-a-child-why-a-medical-treatment-significant-harm-test-would-hinder-not-help/ > accessed 26 March 2020.

[16] JS Mill, *On Liberty* (New York, NY: Dover Publications, 2002) 88-89.

[17] 'Vulnerability and Medical Decisions Concerning Children', ch 10.

[18] 'Beyond Best Interests: A Question of Professional Conscience?', ch 7.

they consider conscionable is important for understanding' the aforementioned case law (p. 138). Bridgeman avers that this also explains why judges tend to agree with clinicians, rather than parents, in these types of cases (p. 151). She posits that such an appreciation may help parents to understand that disputes are not about competing views of what is best for an infant (as Goold argues), but rather signify that the limits of what is professionally possible and permissible have been reached (p. 152). Fovargue's chapter focuses on the interconnected and overlapping concepts of religious-based faith, hope, and trust (p 154).[19] She notes that hope can 'lead to parents grasping at straws', not accepting the opinions of experts which do not match their hopes, and 'undertaking a (global) search of experts who support their view' (p. 157). This explains why Wilkinson's proposal to give more value to parent's interests is problematic. In Fovargue's view, a request for experimental treatment should not automatically be treated as a fair request for a viable alternative, nor should the willingness of a health professional to provide it, or for patients (or parents) to pay for it, be sufficient (p. 167). Rather, she contends that the four questions set out by Butler-Sloss P in *Simms v Simms*[20] are pertinent (p. 167): does a patient have the capacity to decide; does the proposed treatment satisfy the *Bolam*[21] test; is the proposed treatment in the patient's best interests; and, (if questions two and three are answered affirmatively) can the National Health Service (NHS) undertake the treatment.[22]

The chapters by Rob George and Cressida Auckland focus on legal and conceptual confusions that are evident in some court decisions in this area. George examines the use of the High Court's inherent jurisdiction.[23] He argues that judges have used it in cases where the Children Act 1989 applies, but that they should only resort to the inherent jurisdiction where that statute is 'inadequate to the task' (p. 83). Auckland identifies two different understandings of the concept of futility which have been used by the courts in different contexts (p. 177).[24] The first understanding of futility is that medical treatment is 'incapable of working or achieving a certain outcome', which, as Auckland notes, 'is an objective and binary assessment' (p. 177). The second understanding (the approach taken within the *Gard* and *Evans*[25] cases) is the inability of treatment to 'provide an effective benefit', which 'involves a value laden assessment of what constitutes a meaningful benefit or advantage' (p. 177). Auckland believes that, as a result of this conceptual confusion, the courts often fail to honestly and openly confront the crux of the disputes, namely, whether medical treatment 'can achieve a quality of life that justifies its application' (p. 177).

One of the advantages of this collection is that it provides different perspectives on the legal and ethical issues that cases such as *Gard* involve. This includes an assessment of the vulnerabilities of different actors, such as parents, medical professionals and judges, in Herring's chapter. He persuasively argues that universal vulnerability theory, the notion that all human life is vulnerable due to 'our embodied, finite and socially contingent existence',[26] provides valuable insights (p. 191). According to Herring, cases such as *Gard* garner controversy as adults project the fear of their own vulnerability onto children (p. 186), whom

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[19] 'Preserving the Therapeutic Alliance: Court Intervention and Experimental Treatment Requests', ch 8.

[20] [2003] Fam 83.

[21] *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582.

[22] *Simms* (n 20) [46].

[23] 'The Legal Basis of the Court's Jurisdiction to Authorise Medical Treatment of Children', ch 4.

[24] 'Futility', ch 9.

[25] *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].

[26] W. Rogers, C. Mackenzie and S. Dodds, 'Why Bioethics Needs a Concept of Vulnerability' (2012) 5 *International Journal of Feminist Approaches to Bioethics* 11, 12.

they intuitively feel they need to protect (p. 195). Similarly, in Emily Harrop's chapter, the perspectives of parents and clinicians are thoughtfully considered.[27] This includes extracts of statements from parents Ana (pp. 9-10) and Richard (pp. 10-12), who had to make difficult decisions for their sick children, Nadia and Joseph, respectively. Both Harrop (p. 8) and Herring (p. 202) acknowledge the potential of less adversarial approaches, such as mediation. Nonetheless, as Louise Austin and Richard Huxtable note, data about alternative means of resolving disputes, such as mediation and clinical ethics consultation, is lacking (p. 208).[28] They correctly argue for further research into such alternatives (p. 224), as well as in relation to other pertinent issues, such as the use of second opinions (p. 217).

This collection was inspired by 'considerable support for a shift in the law's position' (p. 2). Campaigns for law reform in this area have been dubbed Charlie's law and Alfie's law.[29] Bambos Charalambous (Labour MP for Enfield Southgate) has introduced a private members' bill,[30] to reform the law, into the House of Commons, hence there will be Parliamentary debate on this issue shortly. The key arguments are cogently articulated and rigorously analysed within this collection, which will be of use to both academics and students of medical law. One can only hope that Parliamentarians avail themselves of this collection to inform their future deliberations. Whether the best interests test is retained (as Taylor, Birchley and Bridgeman support) or a harm threshold is introduced (as Goold and Wilkinson advocate), there is a need for the courts to resolve the legal and conceptual confusions that George and Auckland highlight, and for more scrutiny of experimental treatments (as Fovargue contends). Similarly to Harrop and Herring, I have argued that there is untapped potential in alternative means of dispute resolution,[31] but I agree with Austin and Huxtable that more research is needed in this respect. Whatever approach is ultimately taken, it may not satisfy everyone. As Herring avers, the adopted approach may never be seen to be fair, as 'childhood illness simply is unfair' (p. 202).

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[27] 'Setting the Scene – Supporting and Informing Shared Decision-Making at the Bedside: Avoiding and De-escalating Conflict between Clinicians and Families', ch 1.

[28] 'Resolving Disagreements about the Care of Critically Ill Children: Evaluating Existing Processes and Setting the Research Agenda', ch 11.

[29] D. Benbow, 'An Analysis of Charlie's Law and Alfie's Law', *Medical Law Review* DOI: doi/10.1093/medlaw/fwz017.

[30] Children (Access to Treatment) Bill (2019-21) [119].

[31] Benbow (n 29).