Chapter 2

Best Interests: The "Gold Standard" or a Gold Plating? Should Significant Harm be a Threshold Criterion in Paediatric Cases?

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I. Introduction: decision-making in paediatric treatment disputes

> "The gold standard, by which most of these decisions are reached, is an assessment of his best interests."[1]
>
> Lady Hale P, Lord Kerr and Lord Wilson SCJJ, Supreme Court.

Children lack capacity by virtue of their age.[2] Proxy consent is therefore required for child medical treatment.[3] Although parents[4] naturally bear that decision-making burden, parental right is not absolute.[5] The state

[1] *In the Matter of Alfie Evans* (20th March 2018) (Permission Hearing before Lady Hale, Lord Kerr and Lord Wilson SCJJ), para. 14.

[2] For the purposes of this chapter, "children" does not include minors aged 16 or over, statutorily empowered to provide consent to treatment under the Family Law Reform Act 1969, section 8, or those children deemed *Gillick*-competent following *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] AC 112 (HL) per Lord Fraser at 169-74.

[3] S. Pattinson, *Medical Law and Ethics,* fifth edition (London: Thomson Reuters, 2017), 159.

[4] Meaning those persons with parental responsibility under Children Act 1989, section 3.

[5] N. Allen, "Care and Treatment of Those Lacking Decision-Making Capacity," in *Principles of Medical Law*, fourth edition, ed. Judith Laing, Jean McHale (Oxford: Oxford University Press, 2017), 499.

has an interest in the discharging of parental responsibility ('PR') and the raising of children.[6] It is empowered through the court to act as final arbiter if disputes arise between parents and a treating hospital.[7] But when should parental decision-making be so usurped? Is it when an intended decision is deemed inimical to a child's welfare? Or should possible state intervention only be triggered when a higher bar is met, *i.e.* when parental decisions pose a risk[8] of significant harm? In other words, what are the acceptable boundaries of state paternalism?[9]

The law of England and Wales responds in resounding harmony. The test for medical treatment is the best interests of the child ('BI'),[10] a phrase coterminous with that child's welfare being paramount. This test applies whichever legal route is pursued to determine child treatment[11] and is now a "well laid down" principle.[12] The Supreme Court has au-

[6] J. Bridgeman, *Parental Responsibility, Young Children and Healthcare Law* (Cambridge: Cambridge University Press, 2007), 84.

[7] J. Bridgeman, "The Provision of Healthcare to Young and Dependent Children: The Principles, Concepts, and Utility of the Children Act 1989," *Medical Law Review* 25:3 (2017): 371. See also *An NHS Trust v MB (A Child represented by CAFCASS as Guardian ad Litem)* [2006] EWHC 507 (Fam), [2006] 2 FLR 319 per Holman J at para. 14.

[8] Some authors suggest "significant risk," as discussed below.

[9] Identified by Bainham and Gilmore as an acute dilemma in such cases, A. Bainham, S. Gilmore, *Children – The Modern Law*, fourth edition (Bristol: Family Law, 2013), 340.

[10] First applied in this context in *Re B (A Minor) (Wardship: Medical Treatment)* [1982] 3 FLR 117, per Dunn LJ at 123.

[11] There are three possible court applications. First, an application for a specific issue order under Children Act 1989, sections 8 and 1(1). Second, an application to the High Court for declaratory relief under its inherent jurisdiction, see *Re A (Children) (Conjoined Twins: Surgical Separation)* [2001] 2 WLR 480 per Ward LJ at 511E–12E. Third, an application for wardship, see *J v C* [1970] AC 668, per Lord Guest at 697B-H. Wardship is a manner of exercising inherent jurisdiction and suitable when issues are wider than just medical decision-making as the child remains under the protection of the court.

[12] *Great Ormond Street Hospital v Yates, Gard & Gard* [2017] EWHC 972 (Fam), per Francis J at para. 11. See also *Re A (Children) (Conjoined Twins: Surgical Separation)* (n 11), per Ward LJ at 512; *Re Z (Identification: Restrictions of Publication)* [1996] 2 WLR 88, per Sir Thomas Bingham MR at 112H–14C; *Re B (A Minor) (Wardship: Medical Treatment)* (n 10).

thoritatively declared BI to be the decision-making "gold standard."[13] However, there are commentators who contend it masks a bar set too low.[14] They submit it would be wrong to act contrary to parental wishes without establishing a risk, or significant risk, of significant harm attributable to parental choice.

Absent that threshold, do "best interests" plate in gold an unjustified state interference in the private realm of PR? A critique of the legal and ethical bases of the significant harm movement's main arguments should reveal answers. It is to a fuller exposition of those arguments that this chapter first turns.

II. The arguments: its principle proponents

A. The significant harm movement[15]

Diekema's influential article challenged the BI standard.[16] Diekema claims that "significant risk of serious harm" represents the appropriate benchmark for state intervention into parental decision-making.[17] This is the first element of an eight-staged test based on the "harm principle."[18] Significant harm does not supplant BI; it acts as an

[13] *In the Matter of Alfie Evans* (n 1), per Lady Hale P, Lord Kerr and Lord Wilson SCJJ at paragraphs 14 and 16.

[14] D. Diekema, "Parental Refusal of Medical Treatment: The Harm Principle as Threshold for State Intervention," *Theoretical Medicine* 25:4 (2004): 243-264; S. Elliston, *The Best Interests of the Child in Healthcare* (Abingdon: Routledge-Cavendish, 2007), 37-38 and 183; D. M. Hester, K. Lang, N. A. Garrison, D. Diekema, "Agreed: The Harm Principle Cannot Replace the Best Interest Standard … But the Best Interest Standard Cannot Replace The Harm Principle Either," *American Journal of Bioethics* 18: 8 (2018): 38-40; D. Wilkinson, J. Savulescu, "Hard Lessons: Learning from the Charlie Gard Case," *Journal of Medical Ethics* 44:7 (2018): 438 (displaying an assumption that "serious risk of significant harm" is the correct basis for overruling parental decision-making).

[15] Referred to as "a 'harm consensus' movement" by Bester in J. Bester, "The Harm Principle Cannot Replace the Best Interests Standard: Problems With Using the Harm Principle for Medical Decision Making for Children," *The American Journal of Bioethics* 18:8 (2018): 11.

[16] Diekema, "Parental Refusal," 243-264.

[17] Ibidem, 252-253.

[18] Ibidem, 250-253. Diekema's bases were the writings of John Stuart Mill and Joel Feinberg.

enabling trigger to state intervention.[19] Other commentators seek similar thresholds. Elliston,[20] Hester et al[21] and Wilkinson and Savulescu[22] have each supported "significant risk of serious harm" thresholds. Foster defends this standard as a triage test.[23] Both Kopelman[24] and Gillon[25] have advocated formulations of a threshold.[26] Appeals to incorporate significant harm tests into law were made in the proceedings regarding both Charlie Gard ('Charlie') and Alfie Evans ('Alfie'), two children sadly at the edge of life. Those legal arguments merit consideration, starting with Charlie's case.

B. Charlie's case: a significant harm threshold … sometimes[27]

Charlie suffered from an extremely rare, inherited disorder.[28] Great Ormond Street Hospital ('GOSH') sought withdrawal of life-sustaining

[19] D. M. Hester, K. Lang, N. A. Garrison, D. Diekema, "Agreed," 38-40.

[20] S. Elliston, *The Best Interests of the Child in Healthcare*, 37-38 and 183. Elliston's ultimate determiner was the reasonableness of parental choice.

[21] D. M. Hester, K. Lang, N. A. Garrison, D. Diekema, "Agreed," 38-39, describing it as an "intervention principle."

[22] D. Wilkinson, J. Savulescu, "Hard Lessons: Learning from the Charlie Gard Case," 438.

[23] C. Foster, "Harm: As Indeterminate as 'Best Interests', But Useful for Triage," *Journal of Medical Ethics* 42:2 (2016): 121-122.

[24] R. McDougall, L. Notini, "Overriding Parents' Medical Decisions for their Children: A Systematic Review of Normative Literature," *Journal of Medical Ethics* 40:7 (2014): 450.

[25] Gillon suggested a starting assumption that parents should decide their children's best interests unless substantial harms or substantial injustices would result, see R. Gillon, "Why Charlie Gard's Parents Should Have Been the Decision-makers About their Son's Best Interests," *Journal of Medical Ethics* 44:7 (2018): 462.

[26] Wilkinson and Savulescu argue there is "good reason" to think a harm principle should base interference with parental decision-making, D. Wilkinson, J. Savulescu, *Ethics, Conflict and Medical Treatment for Children* (Amsterdam: Elsevier, 2019): 92-94.

[27] This chapter only addresses judgments from Charlie's proceedings that are relevant to significant harm arguments. For a wider consideration of Charlie's case, see the Introductory chapter of this book.

[28] Infantile onset encephalomyopathic mitochondrial DNA depletion syndrome, "MDDS," specifically the RRM2B-related form, *Great Ormond Street*

treatment,[29] supported by Charlie's representative.[30] Charlie's parents sought his transport to the U.S. for nucleoside therapy.[31] Mr Justice Francis granted GOSH's application, finding the experimental treatment's prospects as being "as close to zero as makes no difference […] futile"[32] and that Charlie's awful quality of life should not be sustained without hope of improvement.[33]

Charlie's parents first raised their significant harm argument on appeal.[34] Douglas described it as "bold."[35] Originally pleaded to the effect that a court should not interfere with parental medical treatment decisions save where it risked significant harm,[36] that argument was refined orally. They sought distinct categorisation of cases: "category 1," where BI should apply, and "category 2," where parental preference should only be overridden if it was likely to cause significant harm.[37] The Court of Appeal ('the CA') understood the sifting factor into "category 2" to be the existence of a "viable treatment option."[38] The CA dismissed any legal basis for that argument and determined categorisation was a non-issue in any event because Charlie had no viable treatment op-

Hospital (n 12), per Francis J at para. 52. The syndrome is helpfully explained in Wilkinson and Savulescu, *Ethics*, 4-5.

[29] *Great Ormond Street Hospital* (n 12), per Francis J at paragraphs 5 and 27. GOSH applied under section 8 of the Children Act 1989 and the inherent jurisdiction. See *In the Matter of Charlie Gard* (Supreme Court, 8th June 2017), per Lady Hale at para. 6.

[30] Represented by a children's guardian appointed by the Children and Family Court Advisory and Support Service (CAFCASS) (High Court Team).

[31] *Great Ormond Street Hospital* (n 12), per Francis J at paragraphs 9 and 29.

[32] Ibidem, para. 119.

[33] Ibidem, para. 126.

[34] McFarlane LJ described the submission as "a wholly new point of law," *Yates & Gard v Great Ormond Street Hospital* [2017] EWCA Civ 410, para. 54.

[35] G. Douglas, "Medical Treatment – Inherent Jurisdiction – *Yates and Another v Great Ormond Street Hospital for Children NHS Foundation Trust and Another [2017] EWCA Civ 410*," *Family Law* (2017): 958.

[36] *Yates & Gard* (n 34), per McFarlane LJ at para. 54.

[37] Ibidem, paragraphs 56-71.

[38] Ibidem, paragraphs 36 and 56-59.

tion.[39] Even if he had, Charlie was likely to suffer significant harm whilst attempting treatment.[40]

Before the Supreme Court ('the SC'), the parents confirmed that their significant harm test acted as a threshold to what was justiciable and only applied to "category 2." They argued that the CA had misunderstood; viability of treatment was not the categorising factor. "Category 2" was apparently reserved for those cases where "parents had been able to make a decision."[41] Permission was refused[42] and the European Court of Human Rights ruled an attempted appeal "manifestly ill-founded."[43]

C. Alfie's case: significant harm, discrimination, and human rights[44]

Alfie's parents also challenged the boundaries of state intervention but they approached it from an entirely new angle. Alfie suffered from an undiagnosed rapidly progressive disease that devastated his brain.[45] Alder Hey Children's Hospital sought withdrawal of treatment, supported by Alfie's guardian.[46] Alfie's parents sought his travel to and

[39] Ibidem, para. 49. The first instance factual finding of futility was not challenged on appeal and described by the CA as being of the "utmost importance."

[40] Ibidem, paragraphs 114-115.

[41] Supreme Court, "Permission to Appeal Hearing In the Matter of Charlie Gard," https://www.supremecourt.uk/news/permission-to-appeal-hearing-in-the-matter-of-charlie-gard.html (accessed September 30, 2018). This somewhat nebulous concept was never comprehensibly explained during the permission hearing.

[42] *In the Matter of Charlie Gard* (n 29), per Lady Hale at para. 11.

[43] *Gard & Others v United Kingdom* (application no. 39793/17), para. 125. The Court declared the application inadmissible.

[44] This chapter concentrates only on those decisions from Alfie's proceedings that are relevant to significant harm arguments. For a wider consideration of Alfie's case, see the Introductory chapter of this book.

[45] *Alder Hey Children's NHS Foundation Trust v Evans James & Evans* [2018] EWHC 308 (Fam), per Hayden J at paragraphs 4-17, 29-30 and 57; *Re E (A Child)* [2018] EWCA Civ 550, per King LJ at para 13.

[46] *Alder Hey Children's NHS Foundation Trust* (n 45), per Hayden J at paragraphs 1 and 54.

treatment at Ospedale Pediatrico Bambino Gesù, Rome.[47] Despite declaring that life had intrinsic value and therefore futility did not mean axiomatically withdrawal of ventilation, in a compelling judgment, Mr Justice Hayden granted the NHS Trust's application.[48]

Alfie's parents also raised their significant harm argument for the first time in the CA. They alleged breaches of human rights based upon discrimination.[49] They claimed that parents facing the state removal of children were comparable to parents facing orders regarding disputed paediatric treatment. They further claimed that the latter were unjustifiably treated differently because state-sanctioned child removal requires satisfaction of a significant harm threshold[50] and court-imposed medical treatment decisions do not.[51] The CA flatly rejected any discrimination and principally found the analogy erroneous.[52] The SC described the comparison as "the nub" of the argument and asked itself,

> If significant harm (or its likelihood) has to be established before a child can be removed – perhaps only temporarily – from the home of his parents under a care order, why does it not need to be established before he can be removed, permanently, from them and from everything in this world, by death?[53]

The SC decided that a "powerful extra objective" was in play in care proceedings and was the differentiating factor, namely the avoidance of

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[47] Ibidem, paragraphs 37-39. If treatment failed, the parents were possibly seeking treatment in Munich and thereafter for Alfie to die at home.

[48] Ibidem, paragraphs 51 and 64-66.

[49] *Re E (A Child)* (n 45), per King LJ at paragraphs 62-75. The parents argued a breach of the European Convention on Human Rights, Article 14 (the right against discrimination, coupled with Article 8 (the right to respect of private and family life) [due to Article 14 being parasitic of other rights]), and a breach of Article 8.

[50] Children Act 1989, section 31. Any order placing a child in the care, or interim care, of a local authority would in fact be made in accordance with BI under Children Act 1989, section 1.

[51] Although the parents' argument concentrated on the inherent jurisdiction of the High Court, a threshold would not be required under section 8 of the Children Act 1989 either.

[52] *Re E (A Child)* (n 45), per King LJ at paragraphs 80-111.

[53] *In the Matter of Alfie Evans* (n 1), para.12.

social engineering.[54] It refused permission to appeal[55] and an attempted appeal to Strasbourg was also dismissed.[56]

III. A (not so) solid legal foundation?

The foregoing arguments beg a question: is there any force to the legal arguments for a significant harm threshold in child medical treatment disputes?

A. Statutory basis: conspicuous by its absence

An NHS Trust seeking court determination of disputed medical treatment, such as in Alfie and Charlie's cases, really has two options. One is an order under the High Court's inherent jurisdiction, originating from the Crown's protective prerogative power as *parens patriae*.[57] The other is a specific issue order (SIO) pursuant to the Children Act 1989.[58] Although significant harm supporters draw analogy to forced state removal in public children law, the latter schema's significant harm threshold is a creature entirely of statute and confined to use by local authorities[59] based upon substandard parenting or a child being beyond parental control.[60] Unequivocally, there is no legislative provision for parents to pray in aid a significant harm threshold to prevent state interference with parental medical decision-making. That was a legislative choice.

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[54] Ibidem, paragraphs 15-16.

[55] Ibidem, para. 18.

[56] *Evans v United Kingdom* (application no. 14238/18).

[57] Defined as the state in its capacity as provider of protection to those unable to care for themselves, B. Garner, ed., *Black's Law Dictionary,* tenth edition (Minnesota: Thomson Reuters, 2014): 1287; N. Allen, "Care and Treatment," 485, 494-5 and 497.

[58] Children Act 1989, section 8. NHS Trusts require permission to apply for section 8 orders, under Children Act 1989, section 10. In practice, permission is unproblematic. An NHS Trust should normally apply for both a SIO and declaratory relief, *Re JM (A Child)* [2015] EWHC 2832 (Fam), [2016] 2 FLR 235, per Mostyn J, paragraphs 20-28.

[59] Children Act 1989, section 31(1). An NHS Trust will not fall within the narrow definition of "authorised person" under section 31(9).

[60] Ibidem, section 31(2).

B. A common law basis: is a threshold justified under jurisprudence?

Does the rich common law of England and Wales save significant harm supporters? In the CA, Charlie's parents attempted to argue that a previous High Court authority, *Re King*,[61] identified the potential application of a significant harm threshold to some medical treatment cases.[62] Charlie's parents have company. Coulson-Smith et al, whilst defending BI, import a "significant harm" threshold into decision-making based upon *Re King*.[63] Is their contention sustainable?

Re King involved a five-year-old boy, Ashya, who suffered from brain cancer and was being treated by an NHS Trust. His parents, who disputed the hospital's proposed treatment plan and sought alternative treatment in Prague, took him abroad without hospital agreement.[64] The local authority was concerned Ashya was at risk of significant harm and out of the country. They applied for wardship.[65] By the time of Mr Justice Baker's first instance decision, all medical treatment issues were uncontested.[66] The judgment is therefore, understandably, a mainly narrative historical account. Within a short summary of the law, the following passage appears (later used by Charlie's parents to base their significant harm argument):

> In most cases, the parents are the best people to make decisions about a child and the State – whether it be the court, or any other public authority – has no business interfering

[61] *Re King* [2014] EWHC 2964 (Fam), [2014] 2 FLR 855.

[62] *Yates* (n 34), per McFarlane LJ, paragraphs 54 and 62-63.

[63] P. Coulson-Smith, A. Fenwick, A. Lucassen, "In Defense of Best Interests: When Parents and Clinicians Disagree," *American Journal of Bioethics* 18:8 (2018): 68.

[64] Ashya suffered from a medulloblastoma in the area of the cerebellum and posterior fossa. He had undergone brain surgery, which resected the tumour. The hospital proposed chemotherapy and radiotherapy and the parents sought a type of radiotherapy called proton therapy. *Re King* (n 61), per Baker J at paragraphs 3-11.

[65] Following a lawful removal of a child abroad and lawful retention there, if the Hague Convention does not apply, the only basis upon which a child can be returned to the jurisdiction of England and Wales is through wardship, *Re S (Wardship: Peremptory Return)* [2010] EWCA Civ 465, 2 FLR 1960, per Wall LJ at para. 14.

[66] *Re King* (n 61), per Baker J at paragraphs 20-26.

> with the exercise of parental responsibility unless the child is suffering or is likely to suffer significant harm as a result of the care given to the child not being what it would be reasonable to expect a parent to give.[67]

Bridgeman described this as a "tenuous" basis for Charlie's parents' argument.[68] Context is crucial to avoid misunderstanding the impact, if any, of *Re King*. Mr Justice Baker's comment was made at first instance, without legal argument, regarding a local authority's application for the exercise of wardship (not an NHS Trust's application for treatment decisions), and in circumstances where medical treatment was unopposed and might always have been.[69] The comment was of a general nature about applications in public children law (note the reference to substandard parenting)[70] and it was necessary in light of a crucial factor: the applicant local authority's aim was "to track down and apprehend the parents."[71] Notwithstanding the foregoing, as Lord Justice McFarlane outlined in Charlie's case, even if Mr Justice Baker had been applying a significant harm test to child treatment decisions,

> a one sentence statement in the course of a short judicial endorsement of a consent order where no point of law had been an issue, no authority had been cited, and where the judge makes no attempt to justify such a radical development of, or departure from, previous, long-established authority, provides the very weakest of bases for [parents' counsel's] weighty submissions.[72]

Bridgeman was evidently too kind.

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[67] Ibidem, para. 31.

[68] J. Bridgeman, "A Threshold of Significant Harm f(or) a Viable Alternative Therapeutic Option," *Journal of Medical Ethics* 44:7 (2018): 466.

[69] *Re King* (n 61), per Baker J at paragraphs 20-26. Regarding proton therapy, it was confirmed that the NHS Trust had been unable to offer it but supported it subject to reliable arrangements, funding and safe transfer.

[70] See the words "as a result of the care given to the child not being what it would be reasonable to expect a parent to give"; J. Bridgeman, "The Provision of Healthcare," 389.

[71] *Yates* (n 34), per McFarlane LJ at paragraphs 100-102.

[72] Ibidem, para. 104.

C. Do human rights provide a lifeline to parental proxies?

In Charlie's case, the European Court of Human Rights expressly avoided determining the significant harm test point. They treated it as non-determinative in light of the domestic courts' findings of risk to Charlie.[73] Although there is a danger of that non-determination sowing the seeds of hope for significant harm supporters, there are good reasons to conclude human rights provide infertile ground for significant harm arguments to grow.

It should be remembered that the European Court of Human Rights noted the "broad consensus – including in international law – in support of the idea that in all decisions concerning children, their best interests must be paramount."[74] The Supreme Court shares that view[75] and it is established that conflict between a parent's right to respect of private and family life and a child's must be balanced fairly.[76] The European Court of Human Rights dismissed Alfie's parents' application as not even having the appearance of violating rights and freedoms.[77] Add in that private family law routinely interferes with PR, that it has done since the inception of the Children Act 1989 and that that overarching framework, in part utilised for paediatric decision cases, is undoubtedly human rights-compliant.

IV. Underlying justifications: (false) analogy, parental rights and focusing on the right interests

Setting aside the extant illegality of any significant harm threshold (the law can be fickle), this chapter now addresses whether its underlying rationales are compelling. Starting by examining analogies to public children law, this section then moves to parental rights claims and concludes with the question of whether such a focus on harm is appropriate.

[73] *Gard* (n 43), paragraphs 119-120.
[74] Ibidem, para. 118.
[75] *In the Matter of Alfie Evans* (n 1), para. 14.
[76] European Convention on Human Rights, Article 8; A. MacDonald, *The Rights of the Child: Law and Practice* (Bristol: Family Law, 2011), 461.
[77] *Evans* (n 56).

A. Public children law: a good comparator?

Some significant harm supporters contend that state removal of children is comparable to orders regarding disputed paediatric decisions.[78] Analysis of that analogy must commence with an understanding of state removal, enacted in England and Wales by a suite of orders collectively referred to as public children law.

Broadly, a local authority may apply for orders invading PR to safeguard a child, including by their removal into local authority care, under a care order.[79] That order creates corporate parenting by providing PR to a local authority.[80] Such state removal is primarily based on substandard parenting[81] and when drafting legislation it was a deliberate decision not to achieve that aim merely under BI.[82] As the Supreme Court noted in Alfie's case, "[f]amilies need protection from too ready a removal."[83] The framework's aim is therefore to limit the availability of compulsory child removal to cases that genuinely warrant it.[84] Although BI are the ultimate decider,[85] draconian options only become available upon satisfaction of a threshold:

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[78] Charlie's parents; Alfie's parents; D. Wilkinson, J. Savulescu, "Alfie Evans and Charlie Gard – Should the Law Change?" *British Medical Journal* 361:8151 (2018): K1891 (by stating "[…] it would make legal decisions about medical treatment consistent with the standard applied to other types of decision").

[79] Children Act 1989, sections 31, 33 and 35. A local authority's plan could be for that child to be rehabilitated to parents, placed with other family members, live with foster parents or be placed for adoption, severing the parent/child relationship in law, often for the child's minority. Interim emergency measures are also available to the court, Children Act 1989, sections 38 and 44.

[80] Ibidem, section 33(3)(a). Under a care order, a local authority has the power to determine the extent to which parents may exercise their PR, section 33(3)(b).

[81] Ibidem, section 31(2).

[82] S. Cretney, *Family Law in the Twentieth Century* (Oxford: Oxford University Press, 2003), 726-727.

[83] *In the Matter of Alfie Evans* (n 1), para. 15.

[84] *Re J (Children) (Care Proceedings: Threshold Criteria)* [2013] UKSC 9, [2013] 1 AC 680, per Lady Hale, paragraphs 1-2; Nigel Lowe and Gillian Douglas, *Bromley's Family Law*, eleventh edition (Oxford: OUP, 2015), 553-557.

[85] Children Act 1989, section 1. If adoption is sought, a similar welfare-based test and checklist apply to any application for a placement order, to permit the

> A court may only make a care order or supervision order if it is satisfied
> - that the child concerned is suffering, or is likely to suffer, significant harm; and
> - that the harm, or likelihood of harm, is attributable to the care given to the child, or likely to be given to him if the order were not made, not being what it would be reasonable to expect a parent to give to him; or the child's being beyond parental control.[86]

Care proceedings actually protect children from poor parental care. Child neglect and child abuse are not comparable *per se* to the parenting in child medical treatment decision cases.[87] For example, at first instance in Charlotte Wyatt's case, Mr Justice Hedley explained that the court was not considering the care given to her but an "entirely organic" condition.[88] In a parenting sense, parents such as hers are blameless. Clinging to the last ounce of hope when faced with the unbounded tragedy of your own child's premature mortality is not falling short of good enough parenting. In Alfie's case, Lady Justice King expressed the following view:

> These unhappy parents, finding themselves the victims of an appalling twist of fate, are not the types of parents who find themselves the subject of care proceedings.[89]

The Supreme Court echoed a similar view.[90] An NHS Trust is not seeking to parent, it seeks guidance in respect of whether treatment is

local authority to place the child with potential adopters, and then to any adoption order, Adoption and Children Act 2002, section 1.

[86] Children Act 1989, section 31(2).

[87] For example, see the positive terms used to describe Charlie's parents, *Great Ormond Street Hospital* (n 12), per Francis J at paragraphs 10 and 128, and Alfie's parents, *Alder Hey Children's NHS Foundation Trust* (n 45), per Hayden J at para. 54.

[88] *Re Wyatt (A Child) (Medical Treatment: Parents Consent)* [2004] EWHC 2247 (Fam), [2005] 1 FLR 21 [33], affd [2005] EWCA Civ 1181, [2005] 1 WLR 3995.

[89] *Re E (A Child)* (n 45), per King LJ at para. 101.

[90] *In the Matter of Alfie Evans* (n 1), para. 17.

or is not best for that patient. The aims and effects of public children law are distinguished.

B. Private children law: the true comparator

Significant harm supporters have conveniently ignored that the state routinely interferes with PR without clearing a care order's high hurdle.[91] Through the court in private family law cases[92] the state interferes with PR regularly[93] upon the application of a parent or person sufficiently connected to the child.[94] Courts make orders determining important matters of upbringing in accordance with BI,[95] never requiring "significant harm."[96] Court-sanctioned overriding of PR is the general scheme. Removal into state care has been singled out for special treatment by the creation of a threshold. Overriding parental wishes on BI alone, courts can force matters of upbringing on parents, *e.g.* making children available to see someone, live with someone, travel abroad or attend a particular school. Is medical treatment not just another important matter of child upbringing?

[91] During the permission hearing in Charlie's case, Lady Hale commented that the state, as a court, intervenes in circumstances without significant harm "all the time" when parents disagree, Supreme Court, "Permission to Appeal Hearing."

[92] Pursuant to orders made under Children Act 1989, section 8; *Re E (A Child)* (n 45), per King LJ at paragraphs 88-94.

[93] In the period April 2017-March 2018, CAFCASS received a total of 41,864 new private children law cases and between April 2016-March 2017 it received 40,536 new private law cases, "Private Law Data," CAFCASS website. https://www.cafcass.gov.uk/about-cafcass/research-and-date/private-law-data/ (accessed November 25, 2018).

[94] Children Act 1989 section 10; *Re A (Children) (Conjoined Twins: Surgical Separation)* (n 11), per Ward LJ at 511E–12E.

[95] Arrangements to live with or see people are known as "child arrangements orders" and orders specifying or prohibiting specific matters of parental responsibility, aside from child arrangements, are known as "specific issue orders" or "prohibited steps orders" respectively, under Children Act 1989, section 8.

[96] Ibidem, section 1.

C. Parental rights: a dangerous deism

In the circumstances of children such as Charlie and Alfie, some commentators also argue towards a justifying rationale of parental rights. This contention faces two forceful challenges that will be addressed in turn.

i. Parental rights: parasitic of fidelity to welfare

To understand the true value of parental authority, one must understand its basis. Parenting is not a right exercised *over* children but a set of responsibilities *to* them.[97] A "logically necessary corollary" of those duties is the power to make decisions.[98] That power is not absolute.[99] The *obiter* comments of Mr Justice Ward poignantly illustrate this *in extremis*,

> Parents may be free to become martyrs themselves, but it does not follow that they are free in identical circumstances to make martyrs of their children [...].[100]

Parental authority is clearly not exercised for parental benefit but for the benefit of the child[101] and any power is derived from a parent's ability to advance their child's BI.[102] The Children Act 1989 intentional-

[97] J. Bridgeman, "Provision of Healthcare," 377.
[98] R. Hain, "Voices of Moral Authority: Parents, Doctors and What Will Actually Help," *Journal of Medical Ethics* 44:7 (2018): 459.
[99] J. Herring, *Medical Law and Ethics*, seventh edition (Oxford: Oxford University Press, 2018), 192; R. Harper, *Medical Treatment and the Law: Issues of Consent, The Protection of the Vulnerable: Children and Adults Lacking Capacity*, second edition (Bristol: Family Law, 2014), 12; M. Brazier, E. Cave, *Medicine, Patients and the Law*, sixth edition (Manchester: Manchester University Press, 2016), 456; *Re C (HIV Test)* [1999] 2 FLR 1004 (F & CA) per Butler-Sloss at p. 1021.
[100] *Re E* [1993] 1 FLR 386 (F), per Ward J at p. 394, citing U.S. judge, Justice Holmes, in *Prince v Massachusetts* (1944) 321 US Reports 158.
[101] N. Allen, "Care and Treatment," 502; *Gillick* (n 2), per Lord Fraser at 171; Brazier and Cave, *Medicine*, 449; T. Engelhardt, "Beyond the Best Interests of Children: Four Views of the Family and of Foundational Disagreements Regarding Pediatric Decision Making," *Journal of Medicine and Philosophy* 35:5 (2010): 510.
[102] G. Birchley, "Charlie Gard and the Weight of Parental Rights to Seek Experimental Treatment," *Journal of Medical Ethics* 44:7 (2018): 449.

ly used the term "parental responsibility" rather than "parental right" to emphasise parenthood's main attribute and sole justification of status.[103] Deviation from the righteous path of BI renders a parent powerless. If parental views coincidentally accord with their child's welfare, they should be followed. If not, they should be overridden. Welfare is king. This position is uncontroversial in family law. When determining a child's upbringing, parental choice is never put on a dais.[104] In Charlie's case, Lord Justice McFarlane discusses parental views,

> It goes without saying that in many cases, all other things being equal, the views of the parents will be respected and are likely to be determinative […] it is well recognised that parents in the appalling position that these and other parents can find themselves may lose their objectivity and be willing to "try anything," even if, when viewed objectively, their preferred option is not in a child's best interests […] the sole principle is that the best interests of the child must prevail and that must apply even to cases where parents, for the best of motives, hold on to some alternative view.[105]

It is not contended that parental views are irrelevant but there is a difference between giving respect and giving weight.[106] Realistic options are rightly considered but they are not preferred simply because a particular party has proposed them.[107] Attaching weight to an argument solely because it is a parent's is both illogical and dangerous. In these sometimes-dreadful circumstances, are parents not vulnerable to making choices that serve their own psychological or emotional

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[103] S. Cretney, *Family Law*, 724; Lord Mackay, "Joseph Jackson Memorial Lecture – Perceptions of the Children Bill and Beyond," *New Law Journal* 139:6403 (1989): 505.

[104] Arguably the most intrinsic weight given to parents' views is when they are facing a placement order or adoption order, under Adoption and Children Act 2002, sections 21(3) & 47(2) respectively. Broadly speaking, their consent is required for the court to make those orders. However, parental consent can be dispensed with if required by welfare, sections 21(3), 47(2) and 52(1)(b).

[105] *Yates* (n 34), per McFarlane LJ at para. 112.

[106] See the approach taken at first instance in *Re Wyatt (A Child) (Medical Treatment: Parents' Consent)* (n 88), per Hedley J at paragraphs 32- 34.

[107] *Yates* (n 34), per McFarlane LJ at para. 95.

needs?[108] Why should the views of parents inherently and automatically carry independent weight? By the sheerest of fluke a court would be forced to elevate options above others. Would this weight not create a presumption in favour of following parental wishes? Would this approach reframe the focus towards parental decision-making and/or its reasonableness?[109] How would that serve child welfare?

ii. Parental rights: casting the issue incorrectly

Is it even appropriate to view the argument as incorporating a parental right to choose treatment? Fenton-Glynn persuasively suggests that parental-rights arguments place too much weight on the "adult perspective" and adopt the wrong starting point by searching for the limit to assumed parental power rather than viewing it "solely from the perspective of the child."[110] It is wise to remember that the child is the subject of the decision, not the parents. Birchley's explanation of the basis of a parental rights argument typifies the problem. Birchley claims a foundation stone of proprietarianism, *i.e.* children being parental property.[111] Such views stab at the heart of modern children law. Children are not the passive property of another, but separate entities whose rights and interests can and should be protected, distinct from the interests of their parent(s).[112] Casting these cases in terms of parental rights or attaching weight to rights so-called is tantamount to sacrificing the welfare of children at the altar of parental power.

[108] U. Schuklenk, "Bioethics Culture Wars – 2018 Edition: Alfie Evans," *Bioethics* 32:5 (2018): 271.

[109] A difficulty with such an approach would be that assessments of the reasonableness or otherwise of parental views can be keenly disputed, *e.g.* do you take into account a parent's religious view? Is a religious view based on blind faith ever "reasonable"? See the disagreement between Wilkinson and Savulescu in D. Wilkinson, J. Savulescu, *Ethics*, 114.

[110] C. Fenton-Glynn, "Life-sustaining Treatment and the Best Interests of the Child: *Re Charlie Gard*" *Family Law* (August 2017): 811.

[111] G. Birchley, "Charlie Gard," 449 and 451.

[112] A. MacDonald, *The Rights of the Child*, 25-26. See also the development of modern child care legislation in S. Cretney, *Family Law*, 719-721.

D. Focusing on harm: a treacherously narrow scope

There is another flaw weakening the roots of significant harm threshold arguments. According to Diekema, the biggest problem with BI is that it "represents the wrong standard" and a state's sights should be aimed only at decisions that place children at "significant risk of serious harm."[113] In a similar vein, Wilkinson and Savulescu rhetorically ask why a court should step in if a decision does not pose significant harm?[114] Is such focus on harm too narrow? First, there is a danger of undervaluing harm's current role in the BI standard. Harm is already a key component. Conceptually it is one of the grounding principles,[115] legally it is subsumed within welfare[116] and practically it is far from ignored.[117] Second, some authors have suggested that harm-based views present harm avoidance as a decision-maker's prime moral obligation.[118] This is problematic when one recognises that painless acts can still be against a person's interests. As Dworkin explains,

> My interests are in play in these circumstances not because of my capacity to feel pain but because of a different and more complex set of capacities: to enjoy or fail to enjoy, to form affections and emotions, to hope and expect, to suffer disappointment and frustration. Since a creature can be killed painlessly, even after it has capacity to feel pain, it is these more complex capacities, not the capacity to feel pain, that ground a creature's interests in continuing to live.[119]

The consequences of a threshold's focus on harm are also puzzling. It would create some medical treatment decisions where parents could

[113] D. Diekema, "Parental Refusal," 253.
[114] D. Wilkinson, J. Savulescu, *Ethics*, 92-93.
[115] J. Bester, "The Harm Principle," 14.
[116] Children Act 1989, section 1(3)(e).
[117] Alfie's case and Charlie's case are prime examples of a court's in-depth consideration of harm.
[118] E. De Clercq, K. Ruhe, "The Best Interest Standard: An Exhaustive Guide for Medical Decision Making in Pediatrics," *American Journal of Bioethics* 18:8 (2018): 69; J. Bester, "The Harm Principle," 15; Birchley raises similar arguments in G. Birchley, "Harm is All You Need? Best Interests and Disputes About Parental Decision-Making," *Journal of Medical Ethics* 42:2 (2016): 113.
[119] R. Dworkin, *Life's Dominion* (New York: Alfred A. Knopf, 1993), 17-18.

act in a way that is not in the best interests of their child,[120] *e.g.* the child could come second to their wishes. In Alfie's case, that notion was something Lady Justice King felt was "instinctively wrong."[121] Douglas described the idea of parents doing whatever they like to their child regardless of BI as "startling" and one that would have "overturned a hundred years of legal progress in recognising the rights of children."[122] GOSH have a mission: *The child first and always*.[123] Imagine its worrying rebranding in a post-threshold world: *The child first and always (only if parental decision-making risks significant harm)*.

There are further puzzling consequences of focusing on harm as a gateway to decision-making. Imagine a child, Ianto, suffering from such difficulties in his brain that he is beyond experiencing pain, or at least it could not be found on the balance of probabilities.[124] Withdrawal of Ianto's life-sustaining treatment would inevitably lead to his death. Could parents of a strong pro-life disposition with the help of a similarly minded hospital maintain his life forever in such a parlous state? Ianto cannot feel pain, true, but any positives have also been removed from the scale that could be tipped towards continuing life. The court is deprived of the ability to undertake a sophisticated, nuanced analysis of Ianto's global interests because it cannot be said that Ianto can feel pain. This treacherously narrow scope would place some children outside of the protective reach of the court.

V. The consequences of a significant harm threshold

Ignoring its dubious legal and ethical scaffolding, if a significant harm threshold were enacted would it be workable? Several previously

[120] See Lady Hale's perceptive questioning during submissions in the permission hearing in Charlie's case in Supreme Court, "Permission to Appeal Hearing, *In the Matter of Charlie Gard*."

[121] *Re E (A Child)* (n 45), per King LJ at para. 124.

[122] G. Douglas, "Medical Treatment – Evans and Another."

[123] GOSH, "Who We Are," https://www.gosh.nhs.uk/about-us/who-we-are (accessed November 22, 2018).

[124] Family proceedings, including applications for a specific issue order for medical treatment, treat alleged facts in a binary manner and the standard of proof required is the balance of probabilities, *Re B (Children) (Sexual Abuse: Standard of Proof)* [2008] UKHL 35, [2009] 1 AC 11, per Lord Hoffman at paragraphs 2 and 13; and per Lady Hale at paragraphs 32 and 70.

expressed problems with such a threshold can be overcome. It is important to expose the weaknesses of those arguments. However, one concern appears insurmountable and has hitherto been overlooked: namely, the inherent illogicality that a threshold would introduce into the law.

A. Surmountable concerns

i. Non-issue: a pejorative finding?

Birchley alleges it is arguable that judges see "evaluative overtones" in a conclusion that a parent is harming their child, not present when findings are expressed in BI terms.[125] The latter are argued to be "less pejorative."[126] This is a curious concern. Why is being pejorative or not even raised? If it is *not* being suggested that judges would avoid findings because they are pejorative, any incidental unpleasantness to judicial determinations is irrelevant. If it *is* being suggested that courts avoid making pejorative findings, that is a bold claim and requires persuasive evidence.[127] Practice teaches that courts do not balk at making findings of harm. In care proceedings these must be pejorative due to the legal test, *i.e.* the harm being attributable to the *care* given to the child, or likely to be given to him if the order were not made, *not being what it would be reasonable to expect a parent to give to him*.[128] It is pejorative by definition. However, medical treatment cases invariably assess the harm attached to treatment options. Parents happen to support or op-

[125] G. Birchley, "Harm is All You Need?" 113.

[126] Ibidem. See also G. Birchley, "The Harm Threshold and Parents' Obligation to Benefit Their Children," *Journal of Medical Ethics* 42:2 (2016): 123.

[127] Birchley cites three cases about Jehovah's Witnesses refusing blood products for their children wherein judges did not use the word "harm," at G. Birchley, "Harm is All You Need?" 113. However, those cases do not establish that courts avoid findings of harm. First, only three cases are cited. Second, one of them, *Birmingham Children's NHS Trust v B* [2014] EWHC 531 (Fam), is a very short unopposed judgment and of no use in identifying general approach. Third, although the other two cases do not mention the word "harm," it is obviously considered. In *An NHS Trust v B* [2014] EWHC 3486 (Fam), Moylan J discusses risk of death at paragraphs 10 and 17; and in *M Children's Hospital NHS Foundation Trust v Mr and Mrs Y* [2014] EWHC 2651 (Fam), Cobb J discusses life expectancy at paragraphs 6 and 12.

[128] Children Act 1989, section 31.

pose them. A judgement on the risks of treatment does not have to be pejorative of parenting. They are often conducted with the utmost respect and sympathy for parents, as exemplified by Lord Justice McFarlane's judgment in Charlie's case.[129] Significant harm in paediatrics would not have to be pejorative nor would it matter if it were.

ii. Non-issue: the indeterminacy of significant harm

Attacks on significant harm thresholds have targeted their indeterminacy and subjectivity. Birchley contends that harm has elements of indeterminacy[130] and can "contain complex value judgements."[131] Birchley is right but not on the basis of the "miracle baby" cases he cites. They are presented as having "strong similarities" yet different results, thereby proving significant harm's indeterminacy. But "strong similarities" do not necessarily lead to identical results. The devil is in the detail. These authorities are poor comparators because they are distinguished from each other regarding harm.[132] Better evidence of the indeterminacy of significant harm is presented by considering different views taken on the same facts, *e.g.* Wilkinson and Savulescu's disagreement about the level of harm in Charlie's case.[133]

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[129] *Yates* (n 34), paragraphs 9-10 (outlining very positive findings about the parents and their love and dedication to Charlie), and para. 114 (finding a risk of significant harm attributable to their proposal).

[130] G. Birchley, "The Harm Threshold," 123.

[131] G. Birchley, "Harm is All You Need?" 112-113.

[132] In *London Borough of Lambeth v Mr and Mrs O* [2011] EWHC 3453 (Fam) (Parker J), referred to as *Re E* by Birchley, findings in respect of significant harm are unclear and it is therefore of no assistance. *London Borough of Haringey v Mrs E* [2004] EWHC 2580 (Fam), [2005] 2 FLR 47, concerned a risk of significant harm arising from a child's future being founded on a parental lie, *i.e.* the child being raised as a miracle baby, see Ryder J at paragraphs 83-89. *Re D (A Child) (Nigerian Fertility Clinic: Fact-Finding)* [2012] EWHC 4231, [2013] 2 FLR 1417 (HHJ Coleridge) concerned no such intended future lie and in *London Borough of Hillingdon v AO* [2014] EWHC 75 (Fam), referred to as *Re A (a Child) (Fact Finding Hearing: Biological Parents)* by Birchley, focus of harm was on past events and not how parents would raise A and whether they would persist in any miraculous birth view, see Hogg J at paragraphs 84-86.

[133] D. Wilkinson, J. Savulescu, "Hard Lessons," 438.

As Bester states, significant harm is "at least as indeterminate, ambiguous, and complex" as best interests.[134] Is this indeterminacy fatal? No: it is only wounding. The reasoning is straightforward. Neither judges nor doctors are automatons and sometimes in these awful cases it is difficult to determine whether a child suffers harm, if so its degree and whether any triggering level of "significant" is reached. Any ethical principle is "vulnerable to disagreement based on differing value judgements."[135] Legislation and/or jurisprudence could theoretically be developed, refining a definition and steering analysis.

B. An insurmountable hurdle: illogicality

If the foregoing criticisms are surmountable, putting aside any undesirability, could a threshold work in practice? It must be the case that significant harm supporters referring to risk attributable to parental choices more accurately refer to the choices of those with PR. Caring arrangements in modern society dictate that non-parent family members, such as step-parents, sometimes raise children and children may lack a relationship with a parent(s). A threshold connected to parental choices could only operate on our social and legal planes by meaning those with PR. That is how it will be interpreted. The workability of any threshold hypothesis can be tested with a thought experiment.

Picture two parents in a post-threshold legal framework disagreeing with each other in respect of medical treatment for their child, Efa. If they cannot agree, they need someone to decide. If there is no risk of significant harm, in the face of obstinate parents Efa's treatment is beyond resolution. Significant harm supporters would therefore probably agree that the legal test for these warring parents must be BI. The views of either parent A or parent B will be overridden by the state in the form of the court. Imagine that parent A has the unequivocal backing of Efa's hospital, all medical evidence supports treatment. Medical evidence is merely expert evidence assisting the court and the BI standard still applies.

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[134] J. Bester, "The Harm Principle," 15.

[135] J. Bester, "The Best Interest Standard and Children: Clarifying a Concept and Responding to its Critics," *Journal of Medical Ethics* (September 2018), 5. doi:10.1136/medethics-2018-105036.

Now imagine the same scenario except Efa's parents are united against treatment. The hospital, convinced of treatment being best for Efa, would not be able to seek the court's guidance and determination. Their failure to establish a significant harm threshold would estop their application. Is this logical? The scenarios involve the same patient; the same options; the same medical evidence and the same orders. Why can a court readily override the views of parent B on the basis of BI when faced with parental *disharmony* but not override parent B arguing the same thing, about the same child, with the same medical evidence, when parents *agree*? What is so special about parental harmony? Why is it elevated above BI?

Further concerns arise from Efa's case. Would you need the agreement of everyone with PR to switch to imposing a threshold? Would the views of someone with PR less involved in that child's life have the same affect? How would the disagreement of a biological father without PR but with full-involvement impact on the presence or not of a threshold? Would the PR of a special guardian[136] carry different weight? What about the corporate PR of a local authority? Why does the choice of legal test turn on parental views rather than on the orders sought and/or the actual circumstances of the child? Would a threshold apply to challenging unified PR views on other matters of child upbringing? How could a significant harm threshold be conceptually justified as being confined to medical matters? Legally speaking, would it not bleed into other matters obtained under SIOs or the inherent jurisdiction?

It is submitted that a significant harm threshold could create a sea change in the relationship between the court and families and whether issues are or are not justiciable. It is the duty of those seeking a threshold to tackle these questions, ill addressed thus far. At best, the answers are troubling. At worst, they expose the systemic illogicality of introducing a threshold into paediatric treatment decisions.

VI. Best interests: plating sin with gold?

Rallying calls for significant harm thresholds such as those considered in this chapter are often paired with criticisms of the BI standard. The

[136] A special guardianship order provides PR to a non-parent which can be exercised to the exclusion of any other person with PR, including a parent, apart from another special guardian, under Children Act 1989, section 14A-G.

most vociferous criticism is that BI provides no clear guidance to tribunals[137] and it allows subjective whim to be veneered in objectivity. Tackling these arguments closes the chapter.

A. Subjectivity in sheep's clothing

Huxtable powerfully suggests that there is "radical subjectivity in the law, albeit in the guise of objectivity, which is tailored to the 'individual' situation presented by the patient's plight."[138] It is an inescapable truth that BI contains components of subjectivity and objectivity. So too does all judicial decision-making, including any assessment of a significant harm threshold, *e.g.* there is subjectivity in determining whether X or Y amounts to a harm and/or what that level of harm is and/or whether it amounts to being "significant"? However, in every important sense, the BI standard is objective. Kopelman described BI as being subjective because it is shaped by the surrogate decision-maker's values and objective because it is "'grounded in sound logic, good information, and scientific findings."[139] Mr Justice Holman captured a truly objective element of the process,

> I am <u>not</u> deciding what decision I might make for myself if I was, hypothetically, in the situation of the patient; nor for a child of my own if in that situation; nor whether the respective decisions of the doctors on the one hand or the parents on the other are reasonable decisions.[140]

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[137] D. Diekema, *Parental Refusal*, 246; J. Savulescu, "Debate: The Fiction of an Interest in Death? Justice for Charlie Gard," *British Medical Journal,* Blog, published on April 26, 2017, https//blogs.bmj.com/medical-ethics/2017/04/26/debate-the-fiction-of-an-interest-in-death-justice-for-charlie-gard/; R. Huxtable, *Law Ethics and Compromise at the Limits of Life To Treat or Not to Treat* (Abingdon: Routledge, 2013), 89; A. MacDonald, *The Rights of the Child*, 184; Savulescu's view in D. Wilkinson, J. Savulescu, *Ethics*, 161; E. Salter, "Deciding for a Child: A Comprehensive Analysis of the Best Interests Standard," *Theoretical Medicine and Bioethics* 33, (2012): 189-191.

[138] R. Huxtable, *Law Ethics and Compromise*, 95.

[139] L. Kopelman, "Why the Best Interests Standard is Not Self-Defeating, Too Individualistic, Unknowing, Vague or Subjective," *American Journal of Bioethics* 18:8 (2018): 35-6.

[140] *An NHS Trust v MB (A Child represented by CAFCASS as Guardian ad Litem)* [2006] EWHC 507 (Fam), [2006] 2 FLR 319, per Holman J at para. 16 iii.

The judge is not determining what they would do in a given situation. They are applying the law, exercising an "independent and objective judgment" in the child's best interests.[141] It is plainly as objective a standard as one can be.

B. Is the BI test unclear?

Consciously coupled with an alleged lack of objectivity is the claim that BI lacks clarity. Huxtable contends that BI are difficult to "know."[142] Deconstructing BI in the abstract, he is probably right. BI is hard to pin down without facts, as it is the child's circumstances that dictate which interests become the magnetic factors in decision-making. The BI test's individualism and adaptability is not only its greatest source of criticism, here lies its greatest strength. One could not improve on the words of Mr Justice Hedley to justify the absence of a definition,

> [t]he infinite variety of the human condition never ceases to surprise and it is that fact that defeats any attempt to be more precise in a definition of best interests.[143]

Huxtable's criticism also misunderstands the nature of BI as a standard. It is a general foundational principle and as such is not meant to provide "specific guidance."[144] The facts do the heavy lifting. If critics like Huxtable were correct, the BI standard would be unworkable in practice. Its regular successful use, nationally and internationally, persuasively proves its effectiveness.[145]

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[141] *Great Ormond Street Hospital* (n 12), per Francis J at paragraphs 11-12; N. Allen, "Care and Treatment," 509.

[142] R. Huxtable, *Law Ethics and Compromise*, 89.

[143] *Re Wyatt* (n 88), per Hedley J at para. 23. See also J. Herring, "Re B (Wardship: Medical Treatment) [1981] 'The Child Must Live': Disability, Parents and the Law," in *Landmark Cases in Medical Law*, ed. J. Herring, J. Wall (Oxford and Portland: Bloomsbury, 2017), 76. See also *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [2014] AC 591, per Lady Hale at para. 36; A. MacDonald, *The Rights of the Child*, 185; A. Bainham, S. Gilmore, *Children – The Modern Law*, 341.

[144] J. Bester, "The Best Interest Standard and Children," 5 and 7.

[145] T. Pope, "The Best Interests Standard for Health Care Decision Making: Definition and Defense," *American Journal of Bioethics* 18:8 (2018): 36-37.

Regarding its familiarity, Kopelman argues that considerable information has been amassed as to how to promote best interests.[146] This is no truer than in the domain of paediatric decision-making. There is a rich seam of authority dating back to *Re B*[147] that shapes the welfare analysis.[148] One looks to these judicial pronouncements to better understand the standard and fully appreciate its calibre. From the "intellectual milestones" outlined by the Court of Appeal in *Re Wyatt (A Child) (Medical Treatment: Continuation of Order),*[149] further expanded upon by Mr Justice Holman in *An NHS Trust v MB (A Child represented by CAFCASS as Guardian ad Litem)*,[150] to the recent recapping of principle by Mr Justice MacDonald in *Kings College Hospital NHS Foundation Trust v Thomas*,[151] the sophisticated, guided BI assessment can be gleaned. It is far from rudderless and summarised as follows:

1. The judge must decide what is in the best interests of the child (an objective approach);
2. The welfare of the child is paramount;
3. The judge must look at the question from the assumed point of view of the child;
4. There is a (very) strong presumption in favour of a course of action which will prolong life, but that is not absolute and may be outweighed if for example the pleasures and quality of life are sufficiently small and the pain and suffering or other burdens of living be sufficiently great;
5. The term "best interests" is used in the widest possible sense and includes every kind of consideration capable of impacting on the decision, encompassing medical, emotional, sensory (pleasure, pain

146 L. Kopelman, "Best Interests Standard," 35.

147 *Re B (A Minor)* (n 10).

148 In addition to case law, there is guidance produced by the medical profession that provides ethical frameworks for decision making, including for decisions about life-sustaining treatment, see Vic Larcher et al, "Making Decisions to Limit Treatment in Life-limiting and Life-threatening Conditions in Children: A Framework for Practice," *Archives of Disease in Childhood* 100, Suppl 2 (2015): s 1 – 26.

149 [2005] EWCA Civ 1181, [2005] 1 WLR 3995, per Wall J at para. 87.

150 [2006] EWHC 507 (Fam), [2006] 2 FLR 319, per Holman J at para. 16.

151 [2018] EWHC 127 (Fam), [2018] 2 FLR 1028, per MacDonald J at para. 69.

and suffering) and instinctive (the human instinct to survive) considerations and all other welfare issues;
6. A court is not bound to follow clinical assessment;
7. Each case is fact specific; and
8. The court must conduct a balancing exercise in which all of the factors are weighed (although it is impossible to do so mathematically).

VII. Conclusion

The argument for a significant harm threshold in paediatric cases fractures under close examination. It has no legal basis and rationales that undergird appeals to amend the law are fundamentally flawed. Comparisons between child medical treatment cases and state removal are uncritical in their thinking; ignorant of the crucial distinguishing feature, *i.e.* poor parenting, and ignorant of the myriad other ways courts invade PR in private family law absent a threshold.

Putting aside the ethical difficulties of having a significant harm threshold, its introduction into child medical treatment cases is highly likely to create illogicality in family law. Supporters of significant harm arguments have inadequately, if at all, addressed its impact on that area's wider framework.

What is the value of BI, the decision-making standard employed in the absence of a threshold? The answer: BI is the most precious standard available by which to safeguard the interests of children, including some of this world's most vulnerable such as Charlie and Alfie. Allegations of indeterminacy misunderstand the nature of BI, overlook the wealth of jurisprudence guiding the welfare analysis and/or miscategorise as weakness its strongest attribute, *i.e.* its adaptability to a particular child's unique circumstances. This flexibility provides the BI test a fineness befitting its hallmark as the "gold standard."

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