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Cover sheet

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Children's best interests and parents' views: challenges from medical law

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Abstract [212 words]

In many domains there are tensions between the rights and interests of children, parents and the state. In medical law this has come under scrutiny in England and Wales when considering how parental choice can be accommodated in best interests decision-making in relation to the care of critically ill children. This follows a series of high-profile court cases and, in February 2020, the second reading of the Access to Palliative Care and Treatment of Children Bill in the House of Lords. In this article I examine two key proposals in this Bill in relation to the treatment of children with a life-limiting illness: (i) that courts should assume that any medical treatment proposed by those with parental responsibility is in the child's best interests unless it poses a disproportionate risk of significant harm; and (ii) that mediation between parents and health service providers should be mandatory. This analysis elucidates how the Bill, as currently drafted, would modify the ordinary best interests approach in relation to children with life-limiting illnesses both substantively and procedurally. Further, by widening the lens - from the Bill's text to its context - I illustrate challenges inherent in translating the law into meaningful action on the ground, thus shifting the focus from (legal) text to the broader context.

Key words: Medical law; best interests; significant harm; mediation

1. Introduction

As demonstrated by the breadth of contributions to this special issue, the impact of the United Nations Convention on the Rights of the Child (UNCRC)¹ is felt across socio-political domains. In particular, tensions can arise between the interests of children on the one hand, and those of parents on the other, as well as the role of the state. Particular challenges can present in relation to younger children and those with significant disabilities (Twomey and Carroll 2018, Riddell and Weedon 2016). In medical law these challenges have come under the spotlight in relation to how parental choice can be accommodated in best interests decision-making in relation to the care of young children with life-limiting illnesses who lack capacity to make their own decisions about the medical care they should receive. This follows a series of high-profile court cases and, on 7 February 2020, the second reading of the Access to Palliative Care and Treatment of Children Bill in the House of Lords (referred to hereafter as ‘the Bill’).²

In this paper I examine two of the Bill’s key proposals in relation to the treatment of children with a life-limiting illness: (i) that courts should assume that any medical treatment proposed by those with parental responsibility is in the child’s best interests unless it poses a disproportionate risk of significant harm; and (ii) that mediation should be mandatory before an application can be made to court in order to approve the giving or withdrawal of any form of medical treatment for a child. I do so in the context of three recent cases relating to the care of infants – Charlie Gard, Isaiah Haastrup and Alfie Evans – and one young child –

¹ Since its adoption in 1989 the United Nations Convention on the Rights of the Child (UNCRC) is the most widely ratified international human rights instrument United Nations, UN Agency for Children. Signed by the UK on 19 April 1990, it was ratified on 16 December 1991 and came into force on 15 January 1992 (Department for Education 2010).

² At the time of writing, the date for the House of Lords Committee stage (line by line examination of the Bill) is yet to be announced.

Tafida Raqeeb. These cases were all substantively heard within a period of just over two years³ and (apart from *Raqeeb*, where withdrawing life sustaining treatment was *not* found to be in her best interests) were all subject to appeals, both in the UK courts and to the European Court of Human Rights (ECHR). I also build on the growing body of literature in medical law and ethics that scrutinises the best interests test following the case of Charlie Gard (e.g. Pope 2018, Goold *et al.* 2019, Nuffield Council on Bioethics 2019; Austin and Huxtable 2019). Together these provide insights that can inform the Bill, both in terms of the extent to which parental choice is currently taken into account in best interests decision-making by the court, and how this is enacted within and beyond the courtroom.

My analysis proceeds as follows. I first situate the best interests test in the context of medical law in relation to how decisions are made in respect of the care of critically ill children who do not have capacity to do so themselves. Particular attention is paid to the accommodation of parental choice in decision-making. Having done so, I briefly introduce four recent cases considered by the court in the chronological order in which they were heard, relating to: Charlie Gard, Isaiah Haastrup, Alfie Evans and Tafida Raqeeb (Section 2). Next I consider the Bill's proposal that courts should assume that any medical treatment proposed by those with parental responsibility is in the child's best interests unless it poses a disproportionate risk of significant harm (Section 3). Here I argue that 'norms' in respect of the appropriate weight to give to parental views are in fact highly contested and point to ambiguities in the Bill's current drafting in relation to how children's best interests and parents' views are reconciled. I suggest that provisions of the Bill that purport to move away from 'best interests' and towards a 'significant harm' approach may fetter the Court's ability to make a holistic assessment of the best interests of the child and consider the implications of this with

³ Charlie Gard's case was first substantively heard in May 2017. Tafida Raqeeb's case was determined at a hearing in October 2019.

reference to Article 3.1 of the UNCRC. In Section 4, I consider the Bill's proposals for mandatory mediation and highlight issues relating to the evidence base for this move, the need for adequate funding and the potential for unintended consequences in relation to costs and delay. Taken together, this analysis elucidates how the Bill, as drafted, would modify the ordinary best interests approach in relation to children with life-limiting illnesses. It purports to do so both substantively and procedurally, by adding an assumption that any medical treatment proposed by those with parental responsibility is in the child's best interests unless it poses a disproportionate risk of significant harm and by making mediation mandatory. In conclusion I consider the wider implications of these challenges in medical law for how children's rights are defined and interpreted (Section 5). More broadly, I argue that these debates illustrate the challenges inherent in translating the law into meaningful action on the ground, thus shifting the focus from (legal) text to the broader context.

2. Assessing best interests: intellectual milestones and key cases

Before turning to the law, it bears repetition that most decisions about the care of a critically ill child are taken in the context of discussions between the child's carers and their medical team. While this may lead to disagreement, this does not inevitably result in the need for court proceedings (Austin 2018). Those cases that do come before the Courts have tended to have a high media profile and therefore feature more prominently in the public sphere.

However, the position remains that these cases are very much in the minority.

In England and Wales when parents and clinicians cannot agree on the medical care to be provided, an application may be made to court pursuant to the Children Act 1989 and/or under the inherent jurisdiction of the High Court. In such cases a declaration is sought from the Court on the best interests of the child and their future treatment, as a result of which an order may be made with the effect of either approving the giving or withdrawal of medical

treatment. The relationship between the best interests of the child and the interests of her parents is enshrined in the UNCRC.⁴ While Article 3.1 situates the best interests of the child as ‘a primary’ consideration in all state actions concerning children, Article 3.2 notes that the rights and duties of their parent, legal guardian or other person with legal responsibility for them should also be taken into account (UN General Assembly 1989).

As an international treaty, the UNCRC is not directly incorporated into UK law but may be given effect in various ways including through the introduction of new domestic legislation, the interpretation of existing legislation, and the development of the common law ([2015] UKSC 16 at para 137). For example, the Children Act 1989 provides, at Section 1(1), that the child’s welfare shall be the court’s ‘paramount’ concern in its determination of any question in relation to her upbringing (known as ‘the welfare principle’ (Hale 2010, p.17)). In the case of *Charlie Gard* Lady Hale noted that ‘...this provision reflects but is stronger than Article 3.1 of the [UNCRC]’ (UKSC 8 June 2017).

While the analysis in this article focuses on best interests decision-making in the medical arena, the Children Act 1989 is primarily ‘...the key legislation for children in care or receiving children’s social care services in England and Wales’ (Morgan 2010, p. 6).

Reflecting on how this legislation had fared in the higher courts in England and Wales, Lady Hale notes that cases considered under the Act tend to fall into four categories: three of these relate (in summary) to those exploring courts’ and local authorities’ powers and duties in care and other proceedings in respect of children in need (Hale 2010). However, the analysis in this article falls more appropriately into Lady Hale’s final category of case, namely the consideration of ‘...the application of the welfare principle in new or unusual situations’ (Hale 2010, p17).

⁴ Although, as noted in CRC/GC/2013/14, para 2, the concept predates this.

In the medical context the ‘intellectual milestones’ that guide the court’s assessment of a child’s best interests were considered by the Court of Appeal in the case of Charlotte Wyatt ([2005] EWCA Civ 1181). This case reiterated that the welfare of the child is paramount (Children Act 1989, Section 1(1)), decisions should be taken from the perspective of the child and that the presumption in favour of preserving life is not irrebuttable (para 87). Further, ‘bests interests’ should not be construed narrowly; rather this: ‘... encompasses medical, emotional, and all other welfare issues’ (para 87). In deciding this case at first instance the Judge had paid close attention to the views of the parents, noting with some discomfort that he was being asked to override their views on what was best for their child, though having no doubt that he had the jurisdiction to do so ([2004] EWHC 2247 (Fam), para 33). The later case of MB ([2006] EWHC 507 (Fam)) further delineated this approach, noting, amongst other matters, that:

Best interests are used in the widest sense and include every kind of consideration capable of impacting on the decision. These include, non-exhaustively, medical, emotional, sensory (pleasure, pain and suffering) and instinctive (the human instinct to survive) considerations. (para 16(v))

The role of parental choice and the bearing that this may have on an assessment of a child’s best interests was specifically addressed thus:

The views and opinions of both the doctors and the parents must be carefully considered. Where, as in this case, the parents spend a great deal of time with their child, their views may have particular value because they know the patient and how he reacts so well; although the court needs to be mindful that the views of any parents may, very understandably, be coloured by their own emotion or sentiment. It is important to stress that the reference is to the views and opinions of the parents. Their

own wishes, however understandable in human terms, are wholly irrelevant to consideration of the objective best interests of the child save to the extent in any given case that they may illuminate the quality and value to the child of the child/parent relationship. (para 16(x))

Though expressed eloquently on the page, the cases examined in this article illustrate that there are challenges inherent in both making this distinction and justifying best interests decisions externally, particularly to parents and the wider public. At the point when Charlotte Wyatt's case was heard, some 15 years ago, it was noted that 'perhaps uniquely this case has been heard throughout in public' ([2004] EWHC 2247 (Fam), para 42). I next briefly summarise four recent cases that have notably played out in the public eye.

Many will be aware of the high profile case of Charlie Gard ([2017] EWHC 972 (Fam)). After a normal delivery Charlie was admitted to Great Ormond Street Hospital (GOSH) on 11 October 2016 (para 45) and found to have the most severe form of a rare inherited mitochondrial disease (para 52, para 55). There was no proven treatment available but Charlie's mother found reference to the theoretical possibility that nucleoside therapy (NT) might lead to improvement, which was offered by a Professor of Neurology in the US (para 71-72). GOSH considered NT and an application was drafted seeking ethical permission for this treatment (para 79). However, Charlie's condition deteriorated further and the clinical team reached agreement that this would be futile and only prolong his suffering (para 83). Charlie's parents wished to pursue NT and the case was brought before the High Court by GOSH and substantively heard on 3 March 2017. Declarations were sought by GOSH, including to the effect that it was in Charlie's best interests for artificial ventilation to be withdrawn and that it was not in his best interests to undergo NT. Following extensive evidence from Charlie's clinicians, his parents and medical experts (including an expert from

the US, as instructed by Charlie's parents) these declarations were granted. Notably the US expert had conceded in his evidence that the damage to Charlie's brain was worse than he had thought (para 104), that there was no scientific evidence of improvement in a child with Charlie's condition and that while treatment might make a modest difference to life expectancy, it could not reverse his extensive structural brain damage (para 106). This decision was upheld by the Court of Appeal on 23 May 2017 ([2017] EWCA Civ 410)) where Charlie's parents argued, amongst other matters, that the incorrect threshold for court intervention had been applied and the 'significant harm' test should apply (as addressed further below). The Supreme Court subsequently declined to grant permission to appeal on 8 June 2017 (UKSC 8 June 2017). The case was referred to the European Court of Human Rights where the application was found to be inadmissible ([2017] 6 WLUK 575). Finally, the High Court agreed to review new evidence from the US medical expert. However, after his examination of a current MRI scan the expert conceded that it was too late to provide NT. Treatment was withdrawn in accordance with the declaration granted by the Court and Charlie died at a hospice on 28 July 2017.

Early the next year, on 29 January 2018, eleven-month-old Isaiah Haastrup's case came before Mr Justice MacDonald in the High Court ([2018] EWHC 127 (Fam)). Unlike in *Gard*, Isaiah's delivery was traumatic (para 18) and both parents felt strongly about the circumstances of their son's birth resulting in a 'stark' breakdown in trust (paras 20-21). In the course of the hearing, to consider the Trust's application to withdraw treatment, further expert evidence was sought by the parents and provided to the court (paras 13-15). In particular, this involved Dr L, an expert from Germany, covertly examining Isaiah under the guise of being a friend of the family (para 15). The court noted that these medical services had been offered by 'a supporter' (para 15). In this case there appeared to be no viable option to transfer Isaiah save to a hospice for palliative care and withdrawal of treatment (para 52).

Here the judge found that he was ‘entirely satisfied’ that it was in the child’s best interests to withdraw treatment (para 99). Having considered the views of his mother and father, including Isaiah’s mother’s religious views (para 104), MacDonald J found that these were outweighed by other factors, including that ‘if [Isaiah] feels pain treatment would continue to expose him to this ‘(para 108). Isaiah’s father lodged an application at the High Court for permission to appeal on paper and, if refused, a stay pending an appeal to the Court of Appeal. Permission to appeal was refused on 31 January 2018 and a short stay to 2 February granted ([2018] EWHC 147 (Fam)). The High Court’s decision was not successfully challenged in the domestic courts and an application to the ECHR was declared inadmissible (ECHR application no. 9865/18). Isaiah died shortly afterwards.

Less than a month later, on 20 February 2018, following a failed mediation on 8 January 2018, Alfie Evans’ case was considered by Mr Justice Hayden in the High Court ([2018] EWHC 308 (Fam)). Here the Trust sought a declaration to discontinue Alfie’s ventilator support (para 1). Following a normal delivery, Alfie showed signs of developmental delay (para 5) and was subsequently diagnosed with a ‘progressive, ultimately fatal neurodegenerative condition, most likely a mitochondrial disorder’ (para 16). There was no substantive dispute amongst the experts on Alfie’s prognosis, but the views of an expert identified by the parents (Professor Haas) differed in relation to future treatment, in that he supported further intervention including transportation around the world, indicating that this was without major risk (paras 42-43). This was supported by Dr Hubner of the ‘paediatric air ambulance’ whom it was noted had both examined Alfie in hospital in a ‘clandestine manner’ and provided an opinion without sight of all of Alfie’s records (having claimed he had done so in a witness statement) (para 45). Having reviewed the authorities in *Gard* (para 49) and *Haastrup* (para 50) the judge granted the declaration. In his conclusions he noted that it was ‘unsafe to discount the possibility that Alfie continues to experience pain’ (para 60) and that

while transportation was a theoretical option, it would be burdensome (para 60, para 63) and with no prospect of treatment. On 6 March 2018 the Court of Appeal gave permission to appeal and heard arguments but dismissed the appeal ([2018] EWCA Civ 550)). Here too concerns were voiced in relation to the conduct of some of the expert witnesses (as noted above, and considered further below in Section 4). Subsequently, an application for permission to appeal to the Supreme Court was considered on the papers and dismissed (UKSC 20 March 2018) and an application to the ECHR declared inadmissible on 28 March 2018 (application no. 14238/18). Following the instruction of a new lawyer (described by Hayden J as ‘one in a long succession of lawyers acting on [the parents’] behalf’ (para 7)) an application was made a writ of habeas corpus for Alder Hey Hospital to release Alfie into his parents’ care so that he could be transported abroad for treatment ([2018] EWHC 818 (Fam)). This application was rejected by the High Court and an appeal of this decision was dismissed by the Court of Appeal on 16 April 2018 ([2018] EWCA Civ 805). On 20 April 2018 permission to appeal to the Supreme Court was refused (UKSC, 20 April 2018) and a further application to the ECHR declared inadmissible (application no. 18770/18). On 23 April 2018 ventilation was discontinued and further applications followed. These too were dismissed and on 28 April 2018 Alfie died in hospital.

Finally Tafida Raqeeb’s case came before Mr Justice MacDonald in the High Court on 3 October 2019 ([2019] EWHC 2531 (Admin) [2019] EWHC 2530 (Fam)). In February 2019, aged four, Tafida suffered extensive and irreversible brain damage due to a rare and previously undetected condition (para 8). To maintain life Tafida requires artificial ventilation and all parties accepted that she had suffered catastrophic damage to her brain (para 10). At this hearing there were two sets of court proceedings, the first in relation to a challenge, by way of judicial review, of the Trust’s decision to refuse Tafida’s transfer to Italy to the Gaslini Hospital (without due regard to her European free movement rights) and

the second for a declaration of Tafida's best interests pursuant to the Children Act 1989 and the inherent jurisdiction of the court (para 6). The judicial review application was granted, though without relief, and this summary focuses on the best interests aspect of the case. In this respect it was noted that Tafida's parents are committed Muslims and were raising Tafida in that faith (para 7). In contrast to *Evans*, where a transfer to Italy was also proposed, the court had a much fuller picture from the Italian treating team, who had, with the Trust's cooperation, examined Tafida and agreed to accept her transfer request subject to her parents bearing the costs (para 13). The Italian team had indicated that they could not provide treatment that would lead to an improvement, but that the palliative care they could offer Tafida would make her comfortable and may allow her to go home on long-term ventilation (para 15). It was accepted that the transfer could take place with minimum risk (para 30).

Considerable attention was given to whether Tafida could experience pain, with expert evidence indicating that there was no evidence that she did, though noting the complexity of proving this negative (para 24). Experts also specifically addressed the care of other children in a similar position to Tafida who received long-term ventilation at home (para 29). Turning to the parents' views, the Judge heard their evidence on Tafida's progress to date and on what they believed her views would be (para 39). Her mother outlined Tafida's views about the value of life, her daughter's accepting approach to a child with disabilities (para 41) and indicated that she had begun to follow the practices of her faith (para 42). An issue between the parties was what could be, in the words of the Trust, properly drawn, from this evidence (para 67). In particular, the Trust raised whether a four year old could contemplate her current situation and the prospect of a ventilated existence (para 68). The Trust submitted that her parents' religious convictions should be one matter to be weighed in the best interests analysis and not the determining factor, in order to access treatment that was not in Tafida's best interests (para 70). On behalf of her parents it was noted that there was a fully funded

option for Tafida in Italy and that, in the absence of pain and suffering, there was benefit to be derived from life (para 75). It was strongly argued that Tafida's wishes and feelings could be derived from the religious and cultural context in which she was raised, where the sanctity of life is of the highest importance (para 75). In his decision MacDonald J highlighted a number of matters to which he had given weight. These included that there was a consensus that Tafida may be able to be ventilated at home and would not be confined to an ICU (para 177). This was in contrast to his finding in *Haastrup* that Isaiah would never leave hospital. The report from the Italian experts, obtained with the full cooperation of the Trust, were contrasted favourably with those obtained clandestinely in the *Evans* and *Haastrup* cases (para 178).

Mr Justice MacDonald referred directly to the principle that in the usual course of events it will be parents who take decisions affecting the length and quality of a child's life:

There is the scale, at one end of which lies the clear case where parental opposition to medical intervention is prompted by scruple or dogma of a kind which is patently irreconcilable with principles of child health and welfare, widely accepted by the generality of mankind; and at the other end lie highly problematic cases where there is genuine scope for a difference of view between parent and judge. In both situations, it is the duty of the judge to allow the court's own opinion to prevail in the perceived paramount interests of the child concerned, but in cases of the latter end of the scale, there must be a likelihood (though never, of course, a certainty) that the greater the scope of general debate between one view and another the stronger will be the inclination of the court to be influenced by a reflection that in the last analysis the best interests of every child include an expectation that difficult decisions affecting the length and quality of its life will be taken for it by the parent to whom its care has been entrusted by nature. (para 181, citing [1997] 1 All E.R. 906, para 916 to 917)

Nonetheless, he made it clear in his finding - that it was *not* in Tafida's best interests for life sustaining treatment to be removed – that this decision was made without deviation from the ordinary best interests test:

The starting point—and the finishing point too—must always be the judge's own independent assessment on the balance of advantage or disadvantage of the particular medical step under consideration. (para 185, citing [1997] 1 All E.R. 906, para 916 to 917)

Taken together, these four cases form the backdrop to calls for 'Charlie's Law' and 'Alfie's Law' that seek the protection of parental rights through '...restricting court involvement to cases where there is a risk of significant harm to the child' (Charlie Gard Foundation). This move has been positioned as aiming to 're-empower parents', but has raised concerns that this is a serious and retrograde step in relation to the progress and realisation of children's rights (Willow 2018). In the sections that follow, and in the context of these cases, I next turn to the provisions of the Bill which purport to make this shift away from 'best interests' and towards a 'significant harm' approach, and to put mandatory mediation on a statutory footing. These each raise questions around whether the best interests approach is fit for purpose, both in terms of the extent to which parental choice can currently be taken into account and how this is enacted within and beyond the courtroom.

3. Accommodating parents' views: from 'best interests' to 'significant harm'

On 7 February 2020 Baroness Finlay of Llandaff introduced the second reading of the Bill in relation to palliative care and the treatment of children. While this Bill contains important provisions in relation to the availability and funding of palliative care, these will not be addressed here. Rather, this article will examine the clauses in Table 1 below, together with the draft amendment proposed by Baroness Jolly in Table 2.

[Insert Table 1 near here. Table included at end of document]

[Insert Table 2 near here. Table included at end of document]

With Charlie Gard's parents in attendance, Baroness Finlay outlined the purpose of Clause 2(4), in that it aims to:

..give appropriate weight to parental views in the court process, in line with societal and medical norms, in the weighing up of the benefits and disbenefits of a proposed course of action (HL Deb Baroness Finlay of Llandaff 07 February 2020, c2028).

In my analysis below, I first contextualise and dispute this claim, in that I argue that 'norms' in respect of the 'appropriate weight' to give to parental views are in fact highly contested.

Using a novel synthesis of Parliamentary and academic debate, and recent case law, I point to ambiguities in the Bill's current drafting in relation to how children's best interests and parents' views are reconciled. Next, I consider a number of more practical points from the preceding case law about what it might mean for parents to 'put forward' a treatment proposal.

Given that the Bill was developed '...following several publicised cases where the parents of a child with a life-limiting prognosis sought other treatment options' (HL Deb Baroness Finlay of Llandaff 07 February 2020, c2027) the analysis below is conducted in the context of *Gard* and the three significant cases that followed. Each of these cases relate to the medical care of infants (or in one case, a very young child) without capacity to consent, nor the ability to express their own views. However, it is worthy of note that the Bill defines a 'child' more widely than this, as 'a person under the age of 18' (Access to Palliative Care and Treatment of Children Bill HL Bill (2019-21) 13, Clause 3). The position of the mature minor is beyond the scope of this article, but it is hard to see how an assumption that parents' views

on alternative treatment should prevail could be sustained in the context of an older child (see comments from Baroness Butler-Sloss and Baroness Brinton, HL Deb 07 February 2020, c2043 and c2054).

Returning to *Gard*, a departure from the best interests approach in circumstances where there is a choice between two ‘viable treatment options’ was first submitted on behalf of Charlie Gard’s parents before the Court of Appeal ([2017] EWCA Civ 410, para 36). Here it was argued that:

...the law affords both priority and protection to the privileged position of a parent giving or withholding consent to medical treatment for their child so that the parents’ preferred treatment option should only be overridden if it is established that the pursuit of that option is likely to cause the child to suffer ‘significant harm’. (para 58)

In his judgment, McFarlane LJ robustly dismissed this submission, both on the law and on the facts of the case. In particular, he noted that previous case law had provided no basis for such a ‘radical development of, or departure from, previous long-standing authority’ (para 104) and that the ‘significant harm’ test did not have direct application to medical treatment cases (para 108). The effect of such an approach would be to allow parents’ views to prevail over a child’s best interests in the absence of significant harm and that there was, in fact, ‘...no viable, alternative treatment for poor Charlie’ (para 113). To the extent that previous case law may have provided scope for an expansion of the ordinary best interests approach via the common law, the effect of this judgment was to curtail this development. The judgments in *Haastруп* (MacDonald J, para 71), *Evans* (Hayden J, para 49) and *Raqeeb* (MacDonald J, para 104) all explicitly cite the finding in *Gard* that:

‘...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.’ ([2017] EWCA Civ 410, para 112).

Together, this firmly points to any change in the application of this well-established case law requiring legislative action. Some welcomed this confirmation of the role of the court to ensure that a child’s best interests remain the paramount consideration in disputed decisions about medical care (Hammond-Browning 2017). In their analysis of the multiple facets of this case, Cave and Nottingham (2017) endorse this ‘child-centred approach [that] accommodates the views of parents, but does not substitute them for a best interests determination’ (p. 510). Taylor (2019) further indicates that the court was right to reject the requirement that there must be ‘harm’ before it can intervene in relation to medical care cases in accordance with the welfare principle and best interests test, and that to have found otherwise would have ‘..challenged the foundations of child law’ (p. 66). In contrast Gillon (2017) argues that the court was wrong and that Charlie’s parents should have been the decision-makers and allowed to exercise their ‘normal moral and legal right and responsibility to decide on their child’s best interests’ (p. 462). Auckland and Goold (2019) provide a detailed argument that the current best interests threshold for intervention by the courts is too low, and that parental choice to select between treatment options should only be overridden where there is a ‘serious risk of significant harm’ (p. 287). In the course of their consideration they argue that ‘...by drawing the line at significant harm, we make a real commitment to respect for *differences* of value, while still protecting children when they need it’ (p. 323). However they note too that ‘...a meaningful commitment to pluralism means we must sometimes allow parents to make decisions that expose children to low-level harms’ (p. 316).

Within these debates, there is not only contention over the construction of the law, but also the practical implications of a change. For example, both those who argue for and against a change in the law address concerns held by, amongst others, Gollop and Pope (2018), that a focus on significant harm may further and damagingly entrench positions (Auckland and Goold 2019, Birchley 2019). On this point, Auckland and Goold (2019) caution against assumptions, in the absence of empirical evidence, about how parents may feel or act in these circumstances. However, Birchley (2019), while identifying shortcomings in the best interests approach, counsels against a shift to a harm threshold, suggesting that such a move may ‘...equally...involve radical changes’ (p. 133).

Taking the range of views above together, as expressed by the courts and in the literature, it is clear that the appropriate weight to be given to parental views – the issue to which Clause 2(4) of the Bill and its draft amendment are directed - is highly contested. More recently, *Raqeeb* provides a counterpoint to the outcomes in *Gard*, *Haastrup* and *Evans* in that the court found, against medical opinion, that it was *not* in Tafida’s best interests for life sustaining treatment to be removed. To the extent that arguments against the best interests test are based on the view that it is ‘designed to override the wishes of parents’ (Benbow 2020, p. 1), this provides an example of where its application had the effect of endorsing Tafida’s parents preferred course of action (she was subsequently transferred to the Gaslini Hospital for continued treatment). It may be that the decision in *Raqeeb* is used to argue in favour of retaining the current test as being sufficiently flexible to accommodate parental views. Indeed, supporters of maintaining the best interests approach have expressed concern that this case already goes too far in that it ‘...blurs the distinction between the child’s point of view and that of her parents’ (Cave *et al.* 2019, p. 9), perhaps even to the extent that this constitutes an erosion of the status quo and ‘parental rights by the back door’ (Cave *et al.* 2019, p. 9). As noted above, MacDonald J, while explicitly not departing from a best

interests approach, nodded to ‘...a reflection that in the last analysis the best interests of every child include an expectation that difficult decisions affecting the length and quality of its life will be taken for it by the parent to whom its care has been entrusted by nature’ (([2017] EWCA Civ 410, para 181). However, what also emerges from the preceding discussion is that the decision in *Raqeeb* – even with its acknowledgement of the role of parental choice – does not go far enough for those who consider that, absent the risk of significant harm, the ultimate treatment decision should not rest in the hands of the court.

To what extent, then, does Clause 2(4) of the Bill, as drafted, meet the concerns of those who argue robustly for a shift to a harm threshold and an expansion of parents’ decision-making powers? Baroness Butler-Sloss notes that:

If I were sitting as a judge, I would feel that that [Clause 2(4)] constrained me from the utmost flexibility that I would need in deciding what, in my judgment, the best interests of the child were. (HL Deb 07 February 2020, c2043)

Further, Lord Hunt of Kings Health references a briefing from the charity Together for Short Lives, which:

...has some reservations about the wording of Clause 2(4). Its initial analysis is that this provision might qualify what we understand as the child’s best interests. (HL Deb 07 February 2020, c2031)

Implicit in these comments is an ambiguity in the relationship between Clause 2(4) and the best interests test and how these interrelate. However, on the basis of the submissions in *Gard* and discussions in the academic literature, it seems likely that this fettering of the Court’s ability to determine the best interests of the child is exactly what the drafting is directed to achieve.

A further consideration is whether this would be compatible with Article 3.1 of the UNCRC, which provides that the best interests of the child shall be *a primary* consideration. As raised by Baroness Brinton (HL Deb 7 February 2020, c2054) and Benbow (2020) to allow parents' views to impede a holistic consideration of a child's best interests could fall short of this standard. The General Comment of the UN Committee on the Rights of the Children on Article 3.1 (CRC/GC/2013/14) positions best interests as a dynamic and context specific concept (para 1, para 11) that aims to ensure both the rights in the convention and the 'holistic development' of the child. This includes '...the child's physical, mental, spiritual, moral, psychological and social development' (CRC/GC/2013/14, para 4 note 2, CRC/GC/2003/5, para 12). The distinction between the best interests of the child being a 'primary' or 'paramount' consideration is also elaborated. While the latter indicates that the child's best interests are the 'determining factor' (CRC/GC/2013/5, para 38), the former is also seen as a 'strong position' where '...the child's best interests may not be seen on the same level as other considerations' (CRC/GC/2013/14, para 37). As the General Comment cautions: 'If the interests of children are not highlighted, they tend to be overlooked' (CRC/GC/2013/14, para 37). In any event, the current provisions in domestic law (where the child's welfare shall be the court's paramount concern) clearly exceed this standard (Taylor 2016). As a result, the proposed changes would, at the minimum, represent a rolling back from this position. Whether this is acceptable to Parliament, in the interests of respecting parental autonomy, remains to be seen.

My second, more practical, point on these provisions relate to what it means for parents to 'put forward' a treatment proposal. In the *Gard* case, this was initially couched in terms of a 'viable' treatment option, but this wording has not been pursued in the drafting of the Bill or the explanatory notes. This is relevant as a gulf can exist between parents' proposed treatment and what medical opinion considers to be feasible. This is illustrated in *Haastrup*,

where Isaiah’s parents wanted him to be weaned off ventilation and for him to return home, or alternatively for a tracheostomy to be performed so that he could be ventilated at home ([2018] EWHC 127 (Fam), para 64). However, the Court heard, and ultimately accepted, evidence that if Isaiah was to continue to receive treatment, then this would only be possible if he remained in hospital in receipt of Level 2 ICU care for the duration of his life (para 98). Given this potential for a mismatch in medical and parental expectations, a further facet of this issue relates to the message that the Bill may (albeit inadvertently) signal. Following the *Raqeeb* judgement, Giles Birchley noted his concern that:

... the nuances in the case and the judgment may not be recognised by other parents of children whose circumstances and level of suffering differ from those of Tafida. My concern is that the message the public receives from the case might make negotiating appropriate levels of treatment much more difficult. (Science Media Centre 2019).

These sentiments could equally apply to Clause 2(4) of the Bill which states that ‘...*any* medical treatment proposals put forward by any person holding parental responsibility for the child are in the child’s best interests’ [emphasis added]. Baroness Butler-Sloss also commented that the caveat that anything to the contrary must be ‘clearly established’ appears to indicate that this requires:

... a higher standard of proof than the first-past-the-post, more than 50%. It is not as high as a criminal requirement, but it would require a standard that would lead me, if I were sitting as a judge, to wonder whether I had the power to say that I did not really think that the parents had got it right (HL Deb 7 February 2020, c2043).

A counter view may be that parents’ expectations would be tempered both by the proposed amendment to the Bill (that provides that such treatment options must not ‘pose a

disproportionate risk of significant harm’) and that clinicians and health service bodies cannot be required to provide medical treatment which they ‘refuse[s] on reasonable ground to provide to a child’ (Clause 2(5)). However, it is not yet clear how these caveats will work in practice, nor is this merely a concern in the abstract. As Cave *et al.* (2019) note, in the *Raqeeb* case, a statement to the effect that doctors cannot be required to carry out treatment against their professional judgment still resulted in an order that either the treating NHS Trust or the hospital that had accepted Tafida’s transfer in Italy would have to continue her life sustaining treatment. An alternative (and perhaps more charitable) reading of Clause 2(5) of the Bill might be that this is designed to avoid such an order. However, even in these circumstances it is not clear what the touchtone will be for what is ‘reasonable’. This may also be seen as encouraging the undesirable scenario envisaged by MacDonald J in *Haastrup* whereby desperate parents are forced into ‘...scouring the world for medical experts’ who provide a different ‘medical, moral or ethical approach’ ([2018] EWHC 127 (Fam), para 83).

4. Mandatory mediation

The second key provision of the Bill in relation to the treatment of children with a life-limiting illness makes mediation mandatory before an application can be made to court, apart from in specified exceptions, as set out in full in Table 3 below.

[Include Table 3 near here. Table included at end of document]

This proposal received, overall, a warmer welcome than Clause 2(4) and its associated provisions, reflecting a unifying theme in the case law and literature that we must find alternative ways to resolve disputes between clinicians and parents at an earlier stage (see, for example, Cave and Nottingham 2017, Huxtable 2017, Austin 2018, Austin and Huxtable 2019, Auckland and Goold 2019, Benbow 2020). Those who have argued both for and

against a change in the legal position have agreed that in the majority of cases the courts are not the best place for such disputes to be resolved for children, parents or clinicians.

Austin and Huxtable (2019) provide a comprehensive review of five key processes they identify for resolving disputes: ‘discussions between families and clinicians; second-opinion experts; clinical ethics committees; mediation; and court proceedings’ (p. 208). Given their careful analysis of the pros and cons of these various options, I do not seek to repeat this discussion here. However, there are two key points that speak directly to the provisions of the Bill. The first is simply that there is, as yet, a lack of data on the success or otherwise of medical mediation. While there are studies ongoing, and Austin and Huxtable (2019) describe medical mediation as ‘promising’, they also call for ‘more research...to ascertain the advantages and disadvantages that this approach to paediatric disputes offers’ (p. 224). On a second and connected point, while mediation is an option that drew judicial comment from Francis J in *Gard* by reason of its absence ([2017] EWHC 972 (Fam), para 130) it also has ‘drawbacks and uncertainties’ (Austin and Huxtable 2019, p. 223). Indeed, on the data that is available, simple discussions between parents appear to be by far the most successful way of resolving disputes (Austin and Huxtable 2019, p214-215, referring to Birchley *et al.*’s finding that suggested that discussions between clinicians and families resolved 94.58% of the cases in their 2017 study). Turning to the case law, in *Evans*, mediation was attempted without success ([2018] EWCA 984 (Civ), para 1). Given the need for parties in a mediation to willingly engage, it is hard to see how this could ever have been successful in *Haastrup*, where Isaiah’s parents considered that the Trust had caused their son’s injuries and there had been a ‘stark’ breakdown of trust (para 21). On a different but related point, in *Raqeeb*, it was Tafida’s parents who first issued an application for judicial review, before the Trust issued its own application for a best interests declaration. Given that the mandatory requirements for mediation attach solely to a health service body, this could lead to an inconsistent approach

where other parties are able to bypass this requirement. Taken together, these issues serve to highlight important questions as to whether the time is right to elevate the status of mediation over other options by putting this on a statutory footing and, if so, whether these proposals are workable.

If mediation *is* to be mandated, then it flows from this that it must be properly funded. Both this and also, by inference, the need for more evidence of efficacy, were referenced in the second reading of the Bill in terms of the need for funding for a pilot programme (HL Deb 7 February 2020 Lord Hunt of Kings Heath c2031, Baroness Butler-Sloss c2042, Baroness Finlay of Llandaff c2062). In this respect, there are clear lessons to be learned from shortcomings in funding to support parents in court proceedings of this type. Cave and Nottingham (2017) echo the courts' consternation about the lack of legal aid funding for Charlie Gard's parents, calling this 'a travesty' (p. 502). Looking across the four cases of *Gard*, *Haastrup*, *Evans* and *Raqeeb*, this lack of support for parents can manifest itself in delay and changes of legal team (for example see *Evans*) and in parents representing themselves at hearings (for example Thomas Evans, Alfie's father, and Lanre Haastrup, Isaiah's father, at various hearings). This may be distressing for parents but also for clinicians who are subject to hostile cross examination. In *Haastrup* it was noted that Isaiah's father made 'outlandish and unevicenced claims ... during the course of presenting his case, including allegations of racism on the part of the medical team and attempts by them to deliberately harm Isaiah' ([2018] EWHC 127 (Fam), para 55).

The need to attract funding may also require that the profile of these case be raised, with the effect that they are played out in the public glare. One of the most worrying aspects of this is the need for parents to have recourse to 'supporters', providing potentially unregulated and/or unhelpful legal and medical advice. For example, in *Evans*, in the Court of Appeal, McFarlane LJ was deeply critical of the covert medical examination of both Isaiah Haastrup

and Alfie Evans and concerned that ‘... the representation of the parents [in *Evans*] may have been infiltrated or compromised by others who purport to act on their behalf’ ([2018] EWCA Civ 984, para 40).

A final point, that goes both to the timing and workability of mediation, relates to how these provisions will be interpreted by healthcare bodies and enforced by the courts. The vexed issue of delay was considered in *Wyatt* with reference to *Glass v UK* ([2004] 1 FLR 1019). Here the Trust had been criticised for delay and it was acknowledged that:

...a hospital should come to the court in good time and not wait to be overwhelmed in a crisis. Clearly a balance has to be struck between preserving autonomy and parental decision making in the light of developing circumstances on the one hand and the need to avoid being overwhelmed in a crisis on the other ([2005] EWHC 693 (Fam), para 20)

On the other hand, the health care body who, in seeking to avoid a crisis, moves too soon could, if they are not able to make out one of the exceptions in Clause 2(3) of the Bill, be subject to a costs application against them. In *Raqeeb*, costs were sought by Tafida and her parents against the Trust ([2019] Costs L.R. 2143). This was both in respect of the judicial review proceedings (where 80% of Tafida’s costs were granted, para 60) and the proceedings under the Children Act 1989 (where no order was made as to costs, para 59). Even though the usual position is that costs do not follow the event in Children Act proceedings (para 41) a strong argument was made that this case, which was brought by a Trust and not a Local Authority, did not engage the same policy considerations that would usually mitigate against the award of costs. In the context of *Raqeeb*, these points were firmly rejected by the judge who placed some reliance on the fact that the Trust was obliged to make such an application to discharge its duty of care to Tafida and its statutory responsibilities (para 55). However,

MacDonald J specifically noted that concerns about the ‘chilling effect’ that such an order could have in deterring applications from health care bodies in difficult and finely balanced cases was not ‘merely fanciful’ (para 56).

While the examples above may illuminate, by implication, potential concerns around mediation, they also speak directly to shortcomings in our court system. During the second reading of the Bill, experienced practitioners, such as Baroness Butler-Sloss, past-president of the Family Division, spoke positively about the impact of mediation in family law, suggesting that much can be learned from this arena (HL Deb 7 February 2020, c2042).

However, notwithstanding this support, the preceding discussion raises questions about the timing and workability of putting mediation on a statutory footing, and whether the use of the law in this way is indeed the best way to promote the early resolution of disputes between clinicians and parents. Further, the success of such a scheme (be this in law or policy) will depend on adequate funding to support parents and clinicians to work constructively towards reaching agreement.

5. Conclusion

The discussion in the paper has analysed the introduction of a Bill that would modify the ordinary best interests approach in relation to children with life-limiting illnesses. It purports to do so both substantively and procedurally, by adding an assumption that (i) any medical treatment proposed by those with parental responsibility is in the child’s best interests unless it poses a disproportionate risk of significant harm and (ii) by making mediation mandatory. Of course, only a minority of private members’ bills make it onto the statute books, yet the impact of the publicity these generate can raise awareness of the issues addressed and has the potential to affect legislation indirectly. Further, the context of the Bill – following a series of high profile cases and growing scrutiny of the best interests test – means that these vital

discussions on the interplay between the rights and interests of children, parents and the state are both urgent and timely.

Through a novel synthesis of Parliamentary and academic debate, proposed legislation and recent case law, the preceding analysis contributes both to a deeper understanding of the implications of the proposed Bill for the rights and interests of the child, as well as elucidating the challenges inherent in translating the law into meaningful action on the ground. In my scrutiny of the Bill's relevant clauses above - in relation to the weight to be given to parents' views on alternative treatment - I have drawn attention to ways in which the law, as stands, is able to accommodate parental views and have argued that the appropriate weight to give these is highly contested. In doing so, I have identified ambiguities in the current drafting of the Bill, for example in relation to how children's best interests and parents' views are reconciled. While an aim of the Bill is to give appropriate weight to parental views in the court process, my analysis has made explicit the impact this may have on children's rights and interests. In particular, I point to the potential for the Bill's proposals to fetter the court's ability to undertake a holistic best interests assessment and therefore to represent a retrograde step in terms of compliance with Article 3.1 of the UNCRC. Here we must heed the warning of the UN Committee on the Rights of the Child, in that if children's interests are not highlighted, they are liable to be overlooked.

Widening the lens - from the Bill's text to its context - I have indicated concerns around ways that its provisions may be understood by parents and enforced by the courts. This illustrates the challenges inherent in translating the law into meaningful action on the ground - for example, the need for adequate funding of mediation and the potential for unintended consequences in relation to costs and delay. We often focus on the limits of the law and these are certainly evident here. However, so too is the law's ability to stimulate debate and signal

areas of particular social significance. On any interpretation, the manner in which we care for children with life-limiting illnesses comes within this category.

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Tables and Figures

Access to Palliative Care and Treatment of Children Bill [HL] (HL Bill 13)

2. Treatment of children with a life-limiting illness
- (1) This section applies where a health service body is considering making an application to the High Court under the Children Act 1989 or under the inherent jurisdiction of the High Court for an order which has the effect of approving the giving or withdrawal of any form of medical treatment for a child.
- (4) In determining any application of a type referred to in subsection (1), the court shall assume, unless the contrary is clearly established, that any medical treatment proposals put forward by any person holding parental responsibility for the child are in the child's best interests.
- (5) Nothing in subsection (4) requires, or may be relied upon to require, the provision of any specific medical treatment to a child by either a doctor or a health service body which a doctor or a health service body refuses on reasonable grounds to provide to a child.

Table 1

Draft amendment proposed to be inserted after Clause 2(4):

"Any medical treatment proposals put forward by any person holding parental responsibility for the child must be considered by the court, unless contrary evidence is established that the proposed treatment poses a disproportionate risk of significant harm." (HL Deb Baroness Jolly c2034)

Table 2

Access to Palliative Care and Treatment of Children Bill [HL] (HL Bill 13)

- (2) No application of a type referred to in subsection (1) may be made unless—
- (a) the health service body has followed a process of mediation with an independent mediator in an attempt to resolve any differences between the health service body and any person who has parental responsibility for the child or is recognised by the health service body to have an interest in the welfare of the child, and
- (b) that process has been unsuccessful in reaching substantial agreement about the medical treatment to be given or not to be given to the child.
- (3) Subsection (2) does not apply where either—
- (a) the health service body satisfies the court that there is substantial urgency and it is in the best interests of the child to proceed to a court hearing without having a mediation process; or
- (b) the health service body satisfies the court that it has made all reasonable attempts to undertake a mediation process but it has not been possible to undertake such a process due to the actions or omissions of anyone holding parental responsibility or having an interest in the welfare of the child.

Table 3