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A Threshold of Significant Harm (F) or A Viable Alternative Therapeutic Option?

Abstract

This article critically examines the legal arguments presented on behalf of Charlie Gard's parents, Connie Yates and Chris Gard, based upon a threshold test of significant harm for intervention into the decisions made jointly by holders of parental responsibility. It argues that the legal basis of the argument, from the case of Ashya King, was tenuous. It sought to introduce different categories of cases concerning children's medical treatment when, despite the inevitable factual distinctions between individual cases, the duty of the judge in all cases to determine the best interests of the child is firmly established by the case law. It argues that the focus should not have been upon a threshold for intervention but upon whether his parents had established that the therapy they wanted was a viable alternative therapeutic option. In the April hearing, Charlie's parents relied upon the offer of treatment from a US doctor, by July they had an independent panel of international experts supporting their case although by this time the medical evidence was that it was too late for Charlie. One of Charlie's legacies for future disputes may be that his case highlighted the need for evidence as to whether the treatment parents want for their child is a viable alternative therapeutic option before a court can determine which therapeutic option is in the best interests of the child.

Introduction

This article undertakes a critical analysis of the legal arguments presented on behalf of the parents of Charlie Gard, Connie Yates and Chris Gard, in their attempt to persuade the appeal courts to overturn the declarations made by Francis J upon application by Great Ormond Street Hospital (GOSH).ⁱ Given the simplicity and clarity of the law, set out and applied in the judgment of Francis J,ⁱⁱ and the discretion it extends to a judge to determine the best interests of the child, it was necessary for Counsel for Charlie's parents to try to distinguish Charlie's case from all the others in which a court has been asked to authorise the withholding or withdrawal of life-sustaining treatment from a child and, from there, to argue that the law as applied to Charlie's situation should be different. In the Court of Appeal, Counsel sought to bracket Charlie's case with *King*, interpreting that as a case in which parental preference prevailed, and in which Baker J had said,

‘the State – whether it be the court, or any other public authority – has no business interfering 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.’ⁱⁱⁱ

Drawing upon this, the parents' first ground of appeal was that where both parents are agreed, in the exercise of their parental responsibility, to the administration of a viable alternative therapeutic option offered by a doctor, in the exercise of his or her professional opinion, parental preference should be followed except in those cases where it was likely to cause the child significant harm. In his leading judgment, dismissing the appeal, McFarlane LJ concluded that the authorities demonstrated that there was no ‘factor or filter’ before the court evaluates the best interests of the child.^{iv} Furthermore, that as Francis J had found that administration of nucleoside therapy would be futile, be of no benefit and merely prolong Charlie's ‘awful existence’, there

ⁱ *In the Matter of Charles Gard* [2017] EWCA Civ 410.

ⁱⁱ *GOSH v Yates & Gard* [2017] EWHC 972, [39]-[41].

ⁱⁱⁱ *In the Matter of Ashya King* [2014] EWHC 2964, [31].

^{iv} *In the Matter of Charles Gard* [2017] EWCA Civ 410, [94].

was no viable alternative before the court.^v Finally, although it had not been addressed in the court below, McFarlane LJ concluded that had the judge been invited to find whether Charlie was currently suffering significant harm he would have so concluded^{vi} and, it followed, significant harm would result from the continuation of ventilation and Charlie's life in order to administer nucleoside therapy.^{vii} Thus, the judge concluded that the submissions had no foundation in law, were contrary to established principle and could not be supported on the facts.

The second ground of appeal, also dismissed, was that the application by GOSH to prevent another providing treatment in the reasonable exercise of their professional judgement was beyond the powers of the hospital as a public authority and in the absence of significant harm outside the court's jurisdiction.^{viii} The argument was that whilst the Trust could apply to court and the court could make a declaration that it was lawful for the hospital not to provide nucleoside therapy, it could not seek by way of a court order to prevent the parents from taking up the offer of treatment elsewhere. The Court of Appeal preferred the submission of Ms Gollop QC for GOSH that the issue had arisen between the parents and the clinicians which the Trust had properly brought before the court for a judge to decide according to the best interests of the child.^{ix}

In this article, it is argued that the legal basis for the arguments grounded in the earlier case of *Ashya King* was tenuous. It sought to introduce different categories of cases concerning children's medical treatment into the law when, despite the inevitable factual distinctions between individual cases, the duty of the judge in all cases to determine the best interests of the child is firmly established by the case law. However, consideration of the cases of *King* and *Gard* together reveal the need for parents to secure evidence that what they want is a viable alternative therapeutic option before the court can determine which option is in the best interests of the child. To develop that argument this article critically examines the arguments taking each of the conclusions of McFarlane LJ in the Court of Appeal in turn.

No 'factor or filter' before the court considers best interests

The Children Act 1989 places primary responsibility for the welfare of children with their parents, including the responsibility to make decisions as to the medical treatment their child will receive from the options available, according to their judgement of the best interests of the child.⁽⁴⁾ If disagreement between parents and clinicians about a child's medical treatment cannot be resolved, the matter must be referred to court by a party with an interest in the issue.⁽⁵⁾ The test applied by the judge is the 'well being, welfare or best interests'⁽⁶⁾ of the child.

In submissions to the Court of Appeal two previous cases were noted when, it was argued, there had been an attempt to 'establish bespoke sub-categories, to which a different test might apply',^x *Re J* (1991) (7) and *Re T* (1997).⁽⁸⁾ As is apparent from the dates of these two cases both were early in the jurisprudence of the court on children's medical treatment. *Re J* (1991)⁽⁷⁾ concerned an application to withhold ventilation from a child whilst the court in *Re T* (1997) was asked to override parental refusal of consent to a liver transplant operation for their child. In the first, Counsel for the Official Solicitor submitted that the principle of the sanctity of life meant that a court

^v *In the Matter of Charles Gard* [2017] EWCA Civ 410, [97].

^{vi} *In the Matter of Charles Gard* [2017] EWCA Civ 410, [114].

^{vii} *In the Matter of Charles Gard* [2017] EWCA Civ 410, [115].

^{viii} *In the Matter of Charles Gard* [2017] EWCA Civ 410, [84].

^{ix} *In the Matter of Charles Gard* [2017] EWCA Civ 410, [88], [117].

^x *In the Matter of Charles Gard* [2017] EWCA Civ 410, [79], referring to the submission of Ms Butler-Cole for the Guardian.

is 'never justified in withholding consent to treatment which could enable a child to survive a life-threatening condition' or, in the alternative, submitted that the court could sanction the withholding of life-saving treatment only where the child's life would demonstrably be intolerable. Their Lordships restated the law that, in wardship cases, the paramount consideration is the best interests of the child in determination of which there is a 'very strong presumption in favour of a course of action which will prolong life' but that 'intolerability' was not, as had been submitted to the court, 'a quasi-statutory yardstick.'^{xi}

In one of the few cases in which the parental appeal succeeded on both point of law and in overturning the decision of the first instance judge, the Court of Appeal in *Re T* held that the judge had been wrong to ask whether the decision of the child's parents was reasonable. On behalf of the parents, Mr Francis QC (who was the judge in the Charlie Gard case) challenged the judge's conclusion that the parents' refusal of consent to the transplant was unreasonable and submitted that 'where the welfare of a child required a family decision that decision if reasonable ought to be respected and the inherent jurisdiction of the court ought not to be exercised to overrule it.'^{xii} Rejecting that submission, Butler-Sloss LJ explained that it was clearly established that in an application under the court's inherent jurisdiction the welfare of the child is paramount.^{xiii} On both occasions the Court of Appeal affirmed the best interests test.

The quote from the judgment of Baker J in *King* relied upon by Counsel and quoted above was the third legal principle the judge stated that he must apply. The first and most important was that 'Ashya's welfare is my paramount consideration',^{xiv} the second was to have regard to Ashya's human rights under Articles 2 (right to life) and 8 (right to respect for a private and family life) of the European Convention of Human Rights.^{xv} Baker J did not consider whether the treatment preference of Ashya's parents would cause him to suffer significant harm. The judge decided that it was in Ashya's best interests to be provided with the medical treatment his parents proposed in a 'coherent and reasonable' treatment plan and for which they had funding and transport. Their plan was not opposed by his doctors, CAFCASS or the local authority so there was no reason for the judge to oppose the plan.^{xvi} The *King* case did not establish different a category of case and therefore offered a tenuous basis for the development of one based upon a threshold of significant harm where parents have identified an alternative treatment option. Whilst the individual facts of cases will invariably differ and they could be brought together in broad groupings, in terms of the law there are no distinct categories of cases. Forty years of case law has established that, without exception, decisions made by the courts on behalf of children are made according to the principle of the best interests of the child. But a decision about what is best for the child necessarily requires options from which to choose.

Evidence of a Viable Alternative Therapy?

At the hearing in April, the first question for Francis J was whether it was in Charlie's best interests to undergo a trial of nucleoside bypass therapy. A recognised expert in the field was offering what Charlie's parents believed was a viable alternative to the withdrawal of ventilation and provision of palliative care which the clinicians at GOSH considered to be in Charlie's best interests. However, at that time, the weight of evidence before the judge from the GOSH clinicians, second opinions and

^{xi} *Re J (a minor) (wardship: medical treatment)* [1991] Fam 33, 46.

^{xii} *Re T (Wardship: Medical Treatment)* [1997] 1 WLR 242, 248.

^{xiii} *Re T (Wardship: Medical Treatment)* [1997] 1 WLR 242, 250.

^{xiv} *In the Matter of Ashya King* [2014] EWHC 2964, [29].

^{xv} *In the Matter of Ashya King* [2014] EWHC 2964, [30].

^{xvi} *In the Matter of Ashya King* [2014] EWHC 2964, [33], [34].

the consultant instructed by the family was that, given the deterioration in Charlie's condition caused by the seizures he had suffered from January, the therapy was futile. Against this stood the view of Professor Hirano who considered there to be a theoretical possibility that the therapy would be effective in Charlie's condition and might make a modest difference to his life expectancy.^{xvii} Charlie's parents could not understand why they were prevented from accepting the offer of treatment from an expert made in the exercise of his professional judgement. At that point, Francis J observed, Professor Hirano had been given access to Charlie's medical notes but had not examined Charlie. As Francis J explained in his July judgment, '[i]t seems to me to be a remarkably simple proposition that if a doctor is to give evidence to this court about the prospect of effective treatment in respect of a child whose future is being considered by the court, that Dr should see the patient before the court can sensibly rely upon his evidence.'⁽⁹⁾ In July, Charlie's parents asked GOSH to return to court for consideration of new evidence from an independent panel of international experts, including two who had examined Charlie and remained willing to treat him.^{xviii} A full body MRI performed at this time revealed the extent to which he had suffered irreversible muscle atrophy. As Charlie's parents observed 'when on the verge of being able to satisfy this Court (by new evidence and/or a new appreciation of existing evidence) that treatment was in Charlie's best interests' '[f]or Charlie, it is now too late.'^{xix} In April, Francis J's conclusion that trial of the therapy was not in Charlie's best interests was inevitable given the lack of evidence that it was a viable alternative therapeutic option. There was no doubt that Professor Hirano was an expert in the field but his opinion was theoretical rather than a professional opinion that the therapy would be effective in the treatment of Charlie. Had Charlie's parents amassed by April the evidence they had three months later, they may well have been able to demonstrate that nucleoside therapy was a viable alternative therapeutic option. Best interests is, as is well known, wider than the clinical interests and the judge could still have decided that it was not in Charlie's best interests to undergo a trial of the therapy. But if the court does not have before it evidence that what the parents want is a viable alternative therapeutic option for their child, it cannot be an option from which the court can select in deciding upon the best interests of the child.

Was Charlie Suffering Significant Harm?

McFarlane LJ concluded that Charlie would suffer significant harm from a trial of the therapy given the conclusion of Francis J 'that it would be of no benefit for Charlie and that he would need to continue with the regime of life-sustaining treatment, which the judge concluded was not otherwise in his best interests, so that the nucleoside therapy could be administered.'^{xx} In the Court of Appeal, the judge inevitably drew from conclusions reached in the court below in which there had been no submissions on a threshold of significant harm, according to the existing legal framework, about Charlie's best interests. There was little consideration in the submissions to the Court of Appeal as to how a threshold of significant harm would apply in the context of the medical treatment of a child generally or specifically of a terminally ill child requiring artificial ventilation to sustain life whose parents wished him to receive innovative therapy.^{xxi}

^{xvii} *GOSH v Yates & Gard* [2017] EWHC 972, [101], [106].

^{xviii} Position statement on behalf of the parents, 24th & 25th July, [4]-[8], <https://www.serjeantsinn.com/news/charlie-gard-position-statements/> [last accessed 23/01/18].

^{xix} Position statement on behalf of the parents, 24th & 25th July, [31], [18], <https://www.serjeantsinn.com/news/charlie-gard-position-statements/> [last accessed 23/01/18].

^{xx} *In the Matter of Charles Gard* [2017] EWCA Civ 410, [115].

^{xxi} Joe Brierley and Vic Larcher defined innovative therapy as 'any newly introduced treatment, or a new modification to an existing therapy with unproven efficacy and side

Giles Birchley has critically examined the literature which advocates for a harm principle as the appropriate threshold for state intervention in parental decisions about their child's medical treatment.(12) For example, considering parental *refusal* of recommended medical treatment, Douglas Diekema argued that the relevant question is not whether the treatment refused is in the best interests of the child but whether 'the decision of a parent places the child at substantial risk of serious harm.(13) But, he does not define what he understands by substantial risk, harm, or serious harm. Giles Birchley argued that concepts of harm are as complex as those of best interests;(12) no less applied to a seriously ill child to whom innovative therapy, although unproven, offered a theoretical chance of improving his quality of life. The harms caused to a child by artificial ventilation do not change significantly over time, rather the benefits of continued ventilation do or the potential benefits of other treatment made possible by life-sustaining ventilation. Yet, significant harm is a threshold to be crossed not, like in determination of best interests, a balance of benefits and burdens. Furthermore, beyond harm to dignity the harms of artificial ventilation are arguably more significant to a child who can experience pain than one who cannot. As Dominic Wilkinson and Julian Savulescu have asked, how does assessment of significant harm apply to a child who may have been 'beyond experience' and thus unable to experience any pain or discomfort from intensive care? And, would it then be significant harm to keep him in intensive care and administer the therapy if that would mean the chances of the treatment having the effect his parents hope for is as a consequence reduced?(14)

Further, as Giles Birchley observed, arguments of significant harm have connotations of substandard parenting which seem inappropriate in the context of disagreements between parents and professionals over what is best for a seriously ill child. In broad terms, a likelihood of significant harm is the threshold for the courts to exercise public law child protection powers with respect to children and it would be contrary to established law and policy to bring considerations of significant harm into either parental responsibilities or its own duties with respect to the treatment of seriously ill children. Dominic Wilkinson and Tara Nair rightly observed that the decision of the court to override the sincerely held views of parents about their child's treatment will cause distress whether it is explained in terms of best interests or harm.(15) But, as Giles Birchley responded, using the language of best interests rather than harms is important in the public judgments of the court which relay messages to others beyond the parties to the case, in this context about the standards expected in the care of children.(16) In response to the view of Charles Foster that a harm threshold serves as a hurdle to challenging parental decisions thus serving to protect parental decisions by setting the bar for intervention higher,(17) Birchley rightly observes that a threshold of significant harm for intervention in the decisions of parents suggests a society in which children are treated as objects of parental autonomy(18, 19) and not as individuals with rights worthy of protection (20) when law and policy are gradually giving recognition to the latter. Finally, he points out that communication between professionals and parents is vital to maintaining the relationship of trust upon which the shared care of children is delivered and the terms used can contribute to the breakdown in relationship which leaves referral to court as the only option. The legal argument amounted to a claim from Charlie's parents that the treatment they wanted for him would not amount to significant harm, when in reality they were trying to secure for their son a chance of a better quality of life.

effect profile, which is being used in the best interests of a patient, often on an experimental and/or compassionate basis'(11).

State Intervention in the Exercise of Parental Responsibility: NHS Trusts and Courts

GOSH was critical of Charlie's parents claiming that they believed that 'they alone have the right to decide what treatment Charlie has and does not have.'⁽²¹⁾ In contrast, his parents explained that they had fought for Charlie's 'right to receive appropriate medical treatment' believing that they 'ought to have been entrusted with the decision (as supported by scientific rationale and their international and world-renowned experts in mitochondrial disease) as to what was in their own child's best interests'.^{xxii} Their claim was thus based in the joint exercise of their parental responsibility to protect the right of their child to a viable alternative therapy.

Charlie's parents were right in the view that, except for the public law powers conferred by the Children Act 1989 upon local authorities, intervention by the state, in the form of an application by a public institution to court for a judge to make a decision about the best interests of their child, is otherwise unparalleled in family life. The Children Act 1989 sets out the applicable principles when there are disagreements between parents, those with parental responsibility or otherwise involved in the day to day care and upbringing of children. This, of course, was not such a case, Charlie's parents were united in their determination to secure for him the therapy they believed offered him a chance of a better quality of life.

Further, the Act whilst giving public authorities powers to intervene into family life in the interests of child protection imposes clear and principled limits upon their exercise. The underpinning premise of the Act, as explained by the Law Commission whose review led to the Act, is that children are best raised by their parents, that public authorities should support parents to take responsibility for their children and only intervene compulsorily where the child is at risk of significant harm.⁽²²⁾ As Francis J observed in his second, July, judgment, '[t]o most like-minded people, a National Health Service trust is as much an arm of the state as is a local authority'. Furthermore, the judge said he could think of 'few more profound cases' than an application by an NHS Trust to have active treatment withdrawn from, and palliative care provided to, a child whose parents believe there is a therapy which offers a chance of improvement in his quality of life.^{xxiii} However, as Lady Hale stated when giving the reasons for refusing permission to appeal to the Supreme Court, 'although a child can only be removed from home if it has been established that the child is likely to suffer significant harm, the significant harm requirement does not apply to hospitals asking for guidance as to what treatment is and is not in the best interests of their patients.'⁽²³⁾ The hospital was entitled to ask a judge to decide about Charlie's future medical treatment and the judge was entitled to do so.

In *Gard*, McFarlane LJ observed that Baker J's comment in *King*, quoted above, was made with respect to the actions of the public authorities – the local authority and police - when Ashya was removed by his parents from hospital without the knowledge of his doctors. His parents had acted according to their judgement of what was best for their child trying to secure post-operative treatment, following surgery to remove a malignant brain tumour, which they considered offered him the best possible chance with the fewest detrimental effects. However, Ashya had been removed from hospital care at a time when he urgently required post-operative treatment. Furthermore, he was fed by naso-gastric tube and those responsible for his medical care thought that his parents

^{xxii} Position statement on behalf of the parents, 24th & 25th July, [29], <https://www.serjeantsinn.com/news/charlie-gard-position-statements/> [last accessed 15/12/17].

^{xxiii} Commenting upon the lack of legal aid in such cases and the pro bono representation of Charlie's parents, *Re Gard (A Child)* [2017] EWHC 1909, [17].

had neither the equipment nor skills necessary to administer food to him. There were reasonable grounds for social workers to conclude that his parents' actions placed him at risk of significant harm and for the application by the local authority for leave to apply for Ashya to be made a ward of court.^{xxiv}

McFarlane LJ explained that, in contrast to the limitations imposed upon local authorities by the Children Act, there is no threshold of significant harm in cases where the Trust refers to court disagreements about the medical treatment that is in the best interests of a child. There is 'no statutory requirement for a hospital to go through the Section 100 loop.'^{xxv} The other cases cited by Mr Gordon QC in support of his submission, *Barnett* and *Re C*, were also applications by the local authority which required leave of the court and not, as in *Gard*, an application by an NHS Trust with respect to a child in its care, which does not.^(25, 26) There was much criticism, in the years preceding the Children Act, of the exercise by local authorities of their child protection powers, which can result in the supervision of parenting, or the temporary or permanent removal of a child from the family. In response, the Act imposed specific safeguards upon local authorities and the courts in the exercise of their public law powers. Despite Francis J's observation that Trusts may seem to be an arm of the state, cases concerning the medical treatment of children are private, not public, law cases referred to court by a party with an interest in the welfare of a child, that is, on behalf of the clinicians with legal duties of care to the child. The alternative, to referring unresolved disagreements between parents and professionals to court, as had been argued in *Royal Wolverhampton Hospital NHS Trust*,⁽²⁷⁾ was that the medical treatment of a child is a matter of clinical judgement. Rather than let the opinion of parents or professionals, both concerned to secure what is best for the child but each unable to agree with the other, to prevail the court exercises its protective jurisdiction offering an independent judgement of the best interests of the child.

Conclusion

In his judgment, making the declarations sought by GOSH, Francis J set out the well-established legal framework which he then applied to the facts before him. The Court of Appeal, Supreme Court and European Court of Human Rights affirmed that there currently is no threshold before the court determines which of the treatment options is in the best interests of the child. The attempt to draw on the case of Ashya King to introduce a threshold of significant harm was fraught with difficulties and was emphatically rejected by the courts. The legal arguments raised important questions about the limits of state intervention into family life which were not best formulated in terms of significant harm but rather in terms of whether there was sufficient evidence that what the parents wanted was a viable clinical option which they or the court could select according to judgements of the best interests of the child. Whilst the parents of Ashya King wanted their child to have non-conventional treatment it was a recognised viable therapeutic option. Charlie's parents worked tirelessly to secure the expert evidence they required to demonstrate that what they wanted for Charlie was a viable alternative treatment option. That they may have been able to convince the court of this at a time when 'due to the considerable delay in the commencement of treatment

^{xxiv} *In the Matter of Ashya King* [2014] EWHC 2964, [32], quoted by McFarlane LJ, *In the Matter of Charles Gard* [2017] EWCA Civ 410, [62].

^{xxv} *In the Matter of Charles Gard* [2017] EWCA Civ 410, [99]-[109]. Andrew Bainham has suggested that there is an argument for a threshold where the dispute is not between parents but between parents and another party, such as an NHS Trust although he does not suggest what that should be,⁽²⁴⁾.

that right and the window of opportunity has been lost for Charlie^{xxvi} was personally devastating. One of Charlie's legacies for future disputes may be that his case highlighted the need for evidence as to whether the treatment parents want for their child is a viable alternative therapeutic option before a court can determine which is in the best interests of the child.

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^{xxvi} Position statement on behalf of the parents, 24th & 25th July, [32], <https://www.serjeantsinn.com/news/charlie-gard-position-statements/> [last accessed 23/01/18].