
RIGHTS OF THE CHILD OR PARENTAL AUTHORITY IN CHILDREN'S MEDICAL TREATMENT CASES?

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Abstract

Recent cases concerned with the future medical treatment of a child with a life-limiting condition have presented, on appeal, the argument that the threshold for intervention in a parental decision about the child's medical treatment should be significant harm rather than best interests. The basis of the claim is that parents know their child best and, consequently, should have the right or authority to make decisions about their child's future. Although unsuccessful before the courts, these legal arguments have inspired the inclusion of provisions in Bills before Parliament aimed at enhancing parental authority in such cases. This article examines this modern reincarnation of the claim to parental authority, in the context of the medical treatment of a seriously ill child. It argues that reform of the law to re-assert parental authority would be a seriously retrograde development—a contemporary conservative reformulation of the child as object—which would significantly erode the rights of the child. Rather, it is argued that the child should be at the centre of the shared care of parents and professionals focused upon the individual child's needs, interests and rights. This article concludes with a fictional account of an attempt to reform the law to place the interests, rights and voice of the child at the centre of determination of their future medical treatment.

Keywords: children's interests, rights and voice; parental authority; children's medical treatment; best interests or significant harm threshold.

[A] INTRODUCTION

The recent court cases concerned with the future medical treatment of Charlie Gard in April-July 2017 and Alfie Evans in February-April 2018 became lengthy, high-profile, and highly charged disputes as their parents sought in vain to persuade the courts that they, and not the professionals providing treatment, knew what was best for their child.¹ Required to present a legal argument to the appeal courts following the determination of the judges in the Family Division, Francis J and Hayden J respectively, that continued ventilation was not in the best interests of either child, the argument on behalf of the parents, that the threshold for intervention of the court should be significant harm rather than best interests, was premised on the view that parents should have authority to decide on their child's future medical treatment. Whilst unsuccessful in the courts, the parents of Charlie Gard have continued to press for this change to established law through their campaign for "Charlie's Law". Influenced by these cases and with sympathy for the plight of the parents in such cases, amendments to the law have been included in a number of Bills before Parliament. This article argues that these attempts to change the law amount to a modern reincarnation of the claim to parental authority. Enactment would be a seriously regressive development that would significantly erode the rights of gravely ill children whose medical treatment is under dispute. It is argued that the best interests of the children are better secured through shared care between parents and professionals focused upon the needs, interests, and rights of the child.

This article first explains the emergence of claims to parental authority through arguments for a threshold of significant harm in children's medical treatment cases. The legislative proposals, inspired by the arguments in these cases, to reform the law by bringing in a significant harm threshold are then explained. Sympathy amongst the public for enhanced parental authority and academic arguments in support are then considered. This article concludes with a fictional account of an attempt to reform the law to highlight the distinction between enhanced parental authority through concerned care for their child and the placing of the interests, rights and voice of the child as central to determination of a child's future medical treatment.

¹ Case citations and details of both cases and all other reported cases concerning the medical treatment of a child can be found here: [Our Research Projects: Social and Legal Issues in Science and Health, Law Department, University of Sussex](#).

[B] RE-EMERGENCE OF CLAIMS TO PARENTAL AUTHORITY

In the cases concerned with the future medical treatment of Charlie Gard and Alfie Evans, Francis J and Hayden J respectively, in the exercise of the court's inherent jurisdiction applied established law, the welfare or best interests principle, to reach the conclusion that continued ventilation was not in the best interests of the child (*GOSH v Yates & Gard* 2017; *Alder Hey Children's NHS Foundation Trust v Evans* 2018). Arguments presented on appeal on behalf of the parents for a threshold of significant harm, rather than application of best interests, sought to challenge this conclusion through a point of law (*In the Matter of Charles Gard* 2017; *In the Matter of E (A Child)* 2018).² The best interests analysis, it was argued, permits the courts to override any decision made in the exercise of parental responsibility simply on the basis of a different assessment of what is best for the child. Further, that state intervention is only legitimate when what the parents proposed risked causing their child significant harm.³ The parents of Charlie Gard, Connie Yates and Chris Gard, have expressed the view that a significant harm threshold would have prevented the judge from deciding his case and enabled them to have taken Charlie to the United States for a trial of innovative therapy (Charlie Gard Foundation). The position statement of the Trust, Great Ormond Street Hospital (GOSH) for Sick Children, submitted for the hearing on 13 July 2017 expressed the view that Charlie's parents "fundamentally believe that they alone have the right to decide what treatment Charlie has and does not have" (GOSH's Position Statement 2017: paragraph 7). 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" (Position Statement on Behalf of the Parents 2017: paragraph 29). Given that best interests is firmly established as the "sole principle" (*In the Matter of Charles Gard* 2017: paragraph 112), applicable in domestic and international law concerning the upbringing of the child, invocation of a significant harm threshold was inevitably unsuccessful in the attempt to prevent ventilation from being withdrawn from both of these children.

² A detailed analysis of the submissions is provided in Bridgeman (2020: chapter 8).

³ The legal arguments renewed ethical debate in the United Kingdom. The bioethics literature is examined by Birchley (2019) and Wilkinson (2019).

Unsuccessful before the courts, the parents of Charlie Gard have continued to argue for change to the law in children's medical treatment cases within the wider context of seeking to secure a legacy for Charlie through Charlie's Law.⁴ They have worked with NHS professionals, ethicists, and lawyers to develop Charlie's Law, in light of their experiences, seeking to change processes to prevent cases reaching court,⁵ to improve the advice and support provided to families⁶ and to better protect parental rights. Reflecting their argument on appeal, through reform to the law they seek to restrict the involvement of courts to cases where the child is at risk of significant harm. Sympathy for this argument in both Houses of Parliament has resulted in legislative reform proposals aimed at the introduction of a significant harm threshold in cases concerning children's future medical treatment. The provisions have been variously expressed but are clearly influenced by these recent cases and a concern to enhance parental authority and power in children's medical treatment cases.

First, in October 2019, Baroness Finlay introduced to the House of Lords the Access to Palliative Care and Treatment of Children Bill 2019 with specific reference to the cases of *Charlie Gard* and *Alfie Evans*. This would have applied in cases where there is a difference of opinion between parents and doctors responsible for a child with a life-limiting illness on the nature or extent of specialist palliative care or the extent to which palliative care should be accompanied by "disease-modifying treatment" (paragraph 2). In such cases, it provided that reasonable steps should be taken to ensure that the views of the parent are taken into account. When the difference of opinion was before a court, the Bill would have prevented court orders being made to prevent parents seeking disease-modifying treatment when that treatment was not harmful and when another reputable hospital was willing to provide it. In seeking to enhance parental authority to pursue the treatment they want for their child, these provisions would have shifted focus away from the child to the wishes of the parents.

Baroness Finlay introduced a further Private Members' Bill to the House of Lords in January 2020, the Access to Palliative Care and Treatment of Children Bill 2019-21. Clause 2 would have applied when the question of a child's future medical treatment was before the court.

⁴ The [Charlie Gard Foundation](#) invests in research into the treatment of mitochondrial diseases and supports families by providing services to enhance quality of life and with memory-making and campaigning for "Charlie's Law".

⁵ Proposing access to clinical ethics committees, medical mediation and medical reports.

⁶ On ethics and rights to independent second opinions and legal aid.

In such cases the Bill would have required a court to “assume, unless the contrary is clearly established” that medical treatment proposals put forward by any person holding parental responsibility for the child are in the child’s best interests. The explanation, given in the notes, was that this provision aimed at “reinforc[ing] the socio-medical norm” that those holding parental responsibility are seeking to act in the best interests of the child (Explanatory Notes: paragraph 19[1]-[3]) and sought to give “appropriate weight to parental views” in the courts’ assessment of the benefits and disbenefits of a proposed course of action (Baroness Finlay, HL Hansard, 2020, volume 801, column 2028). In these cases the child’s parents are seeking to secure what they genuinely feel to be in their child’s best interests, but that is different from an assumption that the treatment they want for their child, invariably with complex medical needs, is in the child’s best interests. The Bill further provided that this assumption required clearly established evidence to the contrary in order to be rebutted. So, rather than the evidence of parents and professionals being considered to determine the course that is in the best interests of the child, it would have required evidence to be presented that what the parents wanted was not in the best interests of the child. It is not clear whether this proposed change to the burden of proof would have made any difference in practice given that by the time the issue is before the court the child’s treating team have secured second opinions and independent experts who have confirmed their professional judgement. However, it is at least symbolic of parental authority over their child, a retrograde move away from respect for children’s rights, and a failure to recognize the respective expertise which professionals and parents bring to the decision. The best interests of the child are served and the rights of the child protected by parents and professionals working together, each bringing their own expertise, in a determination which is focused on the interests of the individual child.

A further amendment suggested by Baroness Jolly to be added at the committee stage would have required the court to “consider” any treatment proposal presented by any person holding parental responsibility “unless contrary evidence is established that the proposed treatment poses a disproportionate risk of significant harm” (HL Hansard, 2020, volume 801, column 2034). Judges already “consider” the treatment proposal presented by the holder of parental responsibility given that is the issue under dispute. However, the amendment would have required that the treatment proposed by the parents be provided unless “established” by “contrary evidence” that there are reasonable grounds for the doctor to

refuse to provide it, but no guidance was provided as to when a refusal may be considered reasonable.

In response to these proposals and the only example in the debates on these provisions of engagement with the rights of the child, Baroness Brinton referenced the United Nations Convention of the Rights of the Child (UNCRC), Article 3, to emphasize that the views of loving parents should not come before the interests of the child. Further, she pointed to the role of the children's guardian as the voice of the child and questioned how the clause would sit with recognition of the views and wishes of the Gillick-competent child. Having made these points Baroness Brinton expressed the hope that the Bill could be improved to support both the wishes of parents and the rights of the child (HL Hansard, 2020, volume 801, columns 2054-2055). Development of the law in this area should not be informed by parental rights or authority but focused upon the rights, voice, views and wishes of the child.

Finally, for now, Baroness Finlay moved an amendment to the Health and Social Care Bill 2021 which aimed to improve communication between parents and doctors of a child with a life-limiting illness when there was a disagreement about the nature or extent of specialist palliative care or to which the child should be provided with "disease-modifying treatments". It also placed the burden on the hospital to demonstrate that the proposed treatment would be likely to cause the child significant harm (HL Hansard, 2022, volume 820, column 371). As with all recent proposals this was intended to enhance parental authority and increase parental power in treatment discussions, rather than to ensure that the child is at the centre of decision-making or to protect the rights of the child. None of these Bills met with success, failing due to the prorogation of Parliament, parliamentary closures due to the Covid-19 pandemic, and lack of government support.

[C] PUBLIC SYMPATHY FOR CLAIMS TO PARENTAL AUTHORITY

The court proceedings concerning the future medical treatment to be administered to Charlie Gard and Alfie Evans were conducted amidst intense, worldwide media scrutiny and considerable comment on social media platforms. There was understandably much sympathy for the parents who had recently been confronted with their child's diagnosis of a progressive and fatal medical condition, had to navigate his care in a paediatric intensive care ward in a specialist children's hospital and then had been thrust into the alien environment of the courts and legal

process. There was also much endorsement of their view that as parents, as the ones who knew their child best, they should have the right to decide about medical treatment and that the Trust and the courts were wrong to prevent them from doing so.

Ranjana Das has demonstrated how the social media campaign in support of “Charlie’s Army” presented “the Establishment”—the healthcare system, doctors and judiciary—as evil, wrong and harmful and the “ordinary people” as a vulnerable group whose voices needed to be heard (Das 2018: 79). In the campaign, professional judgement and expertise about Charlie’s condition, prognosis and future care were rejected in favour of personal anecdote (Das 2018: 81). The campaign, Ranjana Das argued, was symptomatic of, and fed into, critical judgement of public services including the National Health Service (NHS), drawing upon and contributing to the “rhetoric of suspicion and disdain for public services”, fuelling parental anxiety and mistrust in both the experts and the service (Das, 2018: 83). Rather than considering the issues raised by a disagreement between the parents and doctors caring for a child with a life-limiting condition in terms of partnership, shared care, professional duties and parental responsibilities, or the rights, interests and voice of the child, the debate became dominated by parental rights and authority.

[D] ACADEMIC RESPONSES TO THE ARGUMENTS FOR A SIGNIFICANT HARM THRESHOLD

Support within popular opinion for greater parental authority over their child rather than a focus upon the rights of the child may have been understandable as an emotional response to parents seeking to do what they considered to be best for their child in unimaginably difficult circumstances. However, there has also been support for a move to a threshold of significant harm within the academic literature, as a critique of the best interests principle, from the perspective of parental authority, and in support of the imposition of greater limits upon state intervention in family life.

Cressida Auckland and Imogen Goold’s analysis reflected upon the extensive worldwide media attention in the *Charlie Gard* case which they considered highlighted the “substantial disjunction between what the legal position is and what many people believe it ought to be: that parents should have the final say in decisions about their child’s care” (Auckland & Goold 2019: 291). Elsewhere, Imogen Goold has interpreted the law to be that courts have the authority to intervene in parental decision-making

whenever an application is made to court on an issue of child welfare and expressed the view that this is “an exceptionally large intrusion by the state into the private decisions of parents” (Goold 2019: 39). This would indeed be so were any of the multitude of minor decisions parents make daily concerning their child’s upbringing referred to court. Many day-to-day decisions made by parents do not require special skills, are neither “complex or difficult”, nor do they have a significant impact upon the child, so there is no reason why anyone else is better placed to make them than the child’s parents, who can also take into consideration other relevant factors such as the needs of other children or family members or resources (Auckland & Goold 2019: 298). However, Cressida Auckland and Imogen Goold argued that in the case of a child’s medical treatment, which may have very serious consequences for the child’s future, parents ought to have authority as those who know the child best and are most personally concerned for the child’s welfare (Auckland & Goold 2019: 298). They understood the *Charlie Gard* case to have solely involved a value judgement about the possible harms and benefits of the proposed nucleoside therapy, that is “a decision about which chances are worth taking and at what cost, about which there cannot be a ‘right’ or ‘wrong’ answer” but rather to which there is a variety of reasonable decisions, which parents are as able to make as others. Leaving the decision to parents, they argued, respects their value judgements and “supports their authority” (Auckland & Goold 2019: 300-301).

That may be so, if these cases are merely about different value judgements. However if, as I have argued elsewhere (Bridgeman 2019), by the time the cases are before the courts, the treating doctors have reached the conclusion, supported by second opinions, that what the parents consider to be best for their child is, in the professional judgement of the treating doctors, contrary to “professional conscience” (*Re Wyatt* 2005: paragraph 30) or “unethical” (*An NHS Trust v AB* 2016: paragraph 23), these are not merely different value judgements about harms, risks and benefits. Parents do not and should not have the authority to require a doctor to administer treatment to a child that, in their professional judgement, the doctor considers to be unethical.

Cressida Auckland and Imogen Goold argued that the cases of *Charlie Gard* and *Alfie Evans* raised the issue of the authority of parents to make private decisions affecting their families without state intervention. They considered that a significant harm threshold would protect parental authority whereas best interests left “all parental decisions ... vulnerable to court interference” (Auckland & Goold 2018: 41). In their view, a significant harm threshold, “better reflects the boundaries between our

private lives and those areas into which the state can rightly intervene, is the most ethically justified and strikes the most appropriate balance between parental *authority* and protecting the vulnerable” (Auckland & Goold 2019: 288-289, emphasis added). The view that a significant harm test is “most ethically justified” is premised on giving “priority and protection to the autonomy of parents” (Archard 2019: 105) over the rights, interests, or protection of the child. That would be a retrograde step, a return to prioritization of parental authority over their child away from recognition of the rights of the child and the responsibilities of parents and of the state emphasized in the Children Act 1989 and the UNCRC.

Dave Archard has explained that the claim that a parent should choose what is in the best interests of their child is a claim of “a position of privileged knowledge” and not of “moral entitlement to choose” and is based in the interests of the child not in the status of the parent. In other words, it is a claim that the best should be done for the child and that whoever is best placed to decide what this is should do so (Archard 2019: 105). Furthermore, as Dave Archard argued, just because parents are motivated to do the best for their child does not mean that they alone are best placed to decide (Archard 2019: 105), perhaps especially so in cases of the complex medical treatment of a seriously ill child which also involve issues of clinical expertise.

To raise the threshold to significant harm would be a retrograde step because it would revert to the position prior to the challenge to parental authority made in the initial cases concerning a child’s medical treatment first brought before the courts in the 1980s. In 1981, consultant paediatrician Dr Arthur went on trial for the attempted murder of John Pearson, a baby with Down’s Syndrome, who had died after Dr Arthur prescribed nursing care only and the administration of a sedative following his parents’ rejection of him (*R v Arthur* 1981). Dr Arthur, who was acquitted by the jury, maintained that his professional conscience was clear as he had acted as a responsible paediatrician respecting the authority of the parents (Osman 1981). In the next case, despite the court giving consent to surgery to remove an intestinal blockage from Baby Alexandra, who also had Down’s Syndrome, the surgeon declined to operate, respecting the wishes of her parents that it was in her best interests to be allowed to die, sedated to ensure she did not suffer any pain (*Re B* 1981). The surgeon explained that he considered that the “great majority of surgeons faced with a similar situation” would have reached the same decision despite unanimous medical evidence that the procedure was clinically indicated (*Re B* 1981: 1423). The matter was settled by the Court of Appeal, which authorized the procedure,

establishing the duty of the judge to reach an independent assessment of the best interests of the child and not to accede to professional respect for parental authority.

In its review of child law, the Law Commission expressed the view that the concept of parental rights was misleading as the paramountcy of the welfare of the child imposed a duty upon parents and justified interference by the state to promote child welfare (Law Commission 1985: paragraph 1.11). The resultant Children Act 1989 introduced the concept of parental responsibility, defined in section 3(1). Inevitably, understandings of a concept such as parental responsibility evolve over time. Parental responsibilities are specific in response to the particular needs of the child. How responsibilities are understood by a parent of a six-month-old child with a degenerative condition being cared for in the paediatric intensive care unit will be very different from those of a parent of a child of the same age without such a condition. The responsibilities of parent to child are also general, determined by current social norms, as illustrated by a comparison of the responses of the parents of John Pearson and Baby Alexandra in the 1980s to the responses of the parents of Charlie Gard and Alfie Evans over 30 years later, and the contemporary commentary on them.⁷ Jonathan Herring has reflected upon the cases of *Charlie Gard* and *Alfie Evans* in the context of parenting literature which places increasing pressure on parents for the safety of their children and for ensuring that they “succeed in life” (Herring 2019: 197). This pressure is “reinforced”, he argued, by the message from public institutions and the Government that decisions made by parents have a significant impact upon the welfare of children and that parents are to blame for anything that goes wrong for or with their children. Professionals, public services, the Government and the state cannot be relied upon to protect the child. This, Jonathan Herring argued, sends the message that the responsibility for, and to protect, children rests solely with their parents. He argued that, consistent with hyper-parenting, involving “excessive lengths to make the child the best possible child” (Herring 2019: 199), the parents in these cases did everything in their power to fulfil their sense of responsibility to fight for their child, doing everything they possibly could in the attempt to save their child’s life.

⁷ Support at the time for the parents of John Pearson and Baby Alexandra is considered by Freeman (1983) and Kennedy (1983).

[E] RIGHTS, INTERESTS AND VOICE OF THE CHILD AT THE CENTRE OF SHARED CARE

Parents do have authority to make decisions about their child's medical treatment, to decide when to seek a professional opinion, to choose between treatment options offered by doctors in the exercise of their professional judgement, working together with professionals ensuring that their knowledge of their child and their values, preferences and beliefs affecting their child's wellbeing are factored into decision-making alongside professional judgement. The Children Act placed primary responsibility for the welfare of children with their parents, including the responsibility to make decisions about the medical treatment their child will receive from the options available (*Re A* 2001: 179), according to their judgement of the best interests of the child. Doctors cannot treat a child, who is too young to give consent on their own behalf, without the consent of the child's parents or the court.

The Government has not supported these recent reform proposals, taking the view that it is necessary to look at the "whole process" and develop "systemwide solutions" to avoiding, recognizing, and managing disputes (Earl Howe, HL Hansard 2022, volume 820, column 379). Section 177 of the Health and Social Care Act 2022 required the Secretary of State to arrange for a review into the causes of disputes between persons with parental responsibility for a critically ill child and those responsible for their medical treatment. The Nuffield Council on Bioethics was commissioned to undertake an independent review focused upon the causes of disagreements about a child's future medical treatment, factors influencing what happens to those disagreements and mechanisms for resolving them. The report made 18 recommendations focused on education, continuing professional development, resources, guidance, further research and the provision of information (Nuffield Council on Bioethics 2023: 51). The report briefly considered the criticism of the best interests test and debate about significant harm that had been identified in the literature review and raised in the evidence and concluded that there was insufficient evidence to support a change to the law (Nuffield Council on Bioethics 2023: 6). Any change to the law should not be a reversion to parental authority over children. If there is to be a change to the law it should be to ensure that seriously ill children are provided with shared care focused upon the needs, interests, voice and rights of the individual child. To conclude, I finish with a fictional example of a parliamentary debate on a Bill to reform the law informed by claims of parental authority challenged by recognition of the voice of the child.

Placing the Child at the Centre of Medical Treatment Decisions

Baroness Hart: It is with the greatest respect to the experience and expertise of Lord Smythe, who has had a long and distinguished career in private law and campaigning for public funding of palliative care services, that I have to speak against the proposed Parental Authority over Children's Medical Treatment Bill. I know that my Lord has worked closely with the parents of Ava, a baby with a rare genetic condition that left her dependent on ventilation and artificial feeding in the paediatric intensive care unit at London Children's Hospital. Their dispute with the doctors treating her was determined in the High Court amid worldwide press attention and comment on social media platforms as they sought to raise money to take her to the United States for experimental therapy offered by a doctor in Chicago. Parents, for whom we would all wish to express our sympathy, who were highly critical of the legal process that determined the future of their child and their family.

My views are similarly based on the experiences of family members but family members who are usually not heard in discussions about the future medical treatment of a child. A child, we should remind ourselves, who unable to articulate their own interests depends upon others to speak for them. I was contacted by, and had the privilege of spending time in the company of, a 15-year-old I shall call Nova whose parents have also in recent years been in dispute with doctors about taking her younger sibling to Europe for experimental treatment for a rare cancer. This family did not waive anonymity in the legal proceedings so I shall refer to Nova's sister as Aurora.

Nova, a bright, articulate young woman, contacted me knowing this Bill was coming before this House, wanting to share the experience of what Aurora and her family went through. Nova told me about the days she spent with Aurora in hospital as treatment options were tried and failed to work and then as legal proceedings were conducted. Days in which she saw in her sister's face the pain her condition was causing her—not quite managed by medication—discomfort, and the indignity of the procedures necessary to keep her alive.

Nova saw her parents frantic with the hope of possibility from the offer of therapy in another European country. At the time, Nova thought that her lack of understanding as to why the doctors who had cared for Aurora with such close attention to her needs and wellbeing did not think she should have the therapy was due to her childlike lack of comprehension. But, in the years since, she has read more and reflected and now is

saddened that the offer of a therapy, not scientifically or clinically proven, by a clinic with far less experience than the expertise in the specialist children's hospital caring for Aurora, may in reality have been a false hope. She wishes the legal process had helped everyone to understand whether that was so.

Nova saw her parents consumed by the abject anxiety of how they were going to raise the money for private treatment abroad in a very limited time. She worries that Aurora, whilst not knowing the detail of the plans to sell the family home, picked up on this additional anxiety. Yet, she is glad that her parents did not feel they had no option but to use social media to help them to raise the funds—as other families have done—so that images of her sister as she drained away in the last weeks of her life were not shared across the world.

Nova spent time with Aurora watching her favourite films, reading aloud to her, lying alongside her in her bed listening to music or just talking sharing her memories of precious times together as a family, of beach holidays, walking their family dog in the woods as the autumn leaves fell, baking together pretending they were contestants on “Bake Off”, dressing up as princesses, teachers, and yes, inspired by the “Barbie” film, as Supreme Court Justices!

A few years older than her sister, Nova was old enough to remember Aurora as a content, smiley baby who had grown into a child who saw the joy in life and helped everyone else to see it too, in rain on a summer's day, splashing in a muddy puddle, studying intensely the first flower of spring. So, naturally, Aurora did not complain. Nova saw the concerned look in her eyes as her parents exchanged terse whispers in the corner of the hospital room in response to yet another email from the clinic abroad or returned from meetings with the clinical teams, with mediators, with solicitors. She understood, and knows that Aurora had understood, that her parents considered it their responsibility to leave no stone unturned in the hope that they could save the life of the child they so loved, that their responsibility was to never give up fighting for their daughter. In a very sad way, their all-consuming focus on doing all they could for their child took from them all time to share those little moments of family life that could still be shared in the clinical environment and were so precious to them all, cuddles, a funny story of Aurora's antics as a baby, a family joke. She knows her parents were determined in pursuit of the hope they wanted to be in Aurora's best interests, driven by their family's past and their hopes for its future. But she wondered whether Aurora's interests, as the child she was, somehow became lost in the dispute

between her parents and the doctors and the legal proceedings which were meant to, objectively, identify her best interests. Whilst Aurora should not have been asked directly or been expected to decide, Nova felt that opportunities to hear her little voice were missed. Nova stressed to me that I should appreciate that she was in no way criticizing her parents who were amazing in a truly horrible situation but that it must surely be the job of the professionals to ensure that the voice of the child is clearly heard.

So, My Lords, I don't think the present Bill which would require the treatment parents want for their child to be administered unless it causes significant harm is the right solution to the problems these cases present. This Bill seems to me to focus upon the rights of the parents, inadvertently returning to ideas of parental authority which risks positioning the child, for whom everyone is seeking to do what is best, as an object of the entirely understandable concern. Together with experts in children's rights, I have been in discussion with the Secretary of State for Children and Families, to take forward the principles set out in the 1989 Children Act and the UNCRC in a Children's Act which will impose a duty on public bodies, including the courts, to place the interests and rights of the child at the centre of all decisions affecting their upbringing, including those concerning future medical treatment. Respect for the voice, participation and agency of the child will ensure that the welfare of the child is the primary or paramount consideration in important decisions affecting their future.

About the author

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- Access to Palliative Care and Treatment of Children Bill 2019-21
- Children Act 1089
- Health and Social Care Bill 2021
- Health and Social Care Act 2022

Cases

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