
Article:

Benbow, D.I. (2020) An analysis of Charlie’s Law and Alfie’s Law. Medical Law Review, 28 (2). pp. 223-246. ISSN: 0967-0742

https://doi.org/10.1093/medlaw/fwz017

This is a pre-copyedited, author-produced version of an article accepted for publication in Medical Law Review following peer review. The version of record David I Benbow, An Analysis of Charlie’s Law and Alfie’s Law, Medical Law Review, , fwz017, is available online at: https://doi.org/10.1093/medlaw/fwz017

AN ANALYSIS OF CHARLIE'S LAW AND ALFIE'S LAW

ABSTRACT

The Charlie Gard and Alfie Evans cases were high-profile cases involving disagreements between the parents of young infants and medical practitioners, which have given impetus to pre-existing calls for law reform that have been rebranded as 'Charlie's Law' and 'Alfie's Law'. I argue against the proposal to replace the best interests test, which is currently determinative in such contentious cases, with a significant harm test, as it would render UK law divergent from international law. I also employ critical theory to rebut the notion that parents are the best decision makers and refute criticisms of clinicians (who reflexively acknowledged the limits of medicine). I utilise theories of distributive justice to demonstrate that legal reform may exacerbate unfairness, and case law to show that it may be unworkable. Nonetheless, I apply critical and Foucauldian theory to critique the lack of patient and public empowerment within the NHS and I endorse the proposal to ensure that mediation is offered in contentious cases, as this may empower patients and their carers. I also aver that the best interests test should be informed by clearer criteria regarding the allocation of finite resources, which the public should influence via the democratisation of the NHS.

KEYWORDS: Best interests, distributive justice, expertise, parental rights, patient and public involvement, significant harm.

I. INTRODUCTION

In the United Kingdom (UK), the best interests test is determinative in cases where there are disputes between parents and medical practitioners regarding the treatment of young infants who lack the capacity to make their own decisions.[1] It is also determinative where there are disputes between parents themselves. The former situation is exemplified by the recent cases concerning the treatment of the infants Charlie Gard and Alfie Evans.[2] In both of those cases, parents disagreed with their children's clinicians and wanted to take their children to hospitals abroad to continue life-sustaining treatment, however, the courts adjudicating on the cases determined that this would not be in the best interests of the infants. The cases have given traction to pre-existing arguments for law reform. Proposed reforms to the law (described as 'Charlie's Law' and 'Alfie's Law' respectively) include substituting the best interests test with a significant harm test (which it is believed would strengthen parental rights) and ensuring that mediation is offered in contentious cases. I argue against replacing the best interests test but in favour of ensuring that mediation is offered in contentious cases.

---

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

[2] *Great Ormond Street Hospital* v *Constance Yates, Chris Gard and Charles Gard (A Child by his Guardian Ad Litem)* [2017] EWHC 972 (Fam) [20] and *Alder Hey Children's NHS Foundation Trust* v *Mr Thomas Evans, Ms Kate James, Alfie Evans (A Child by his Guardian CAFCASS Legal)* [2018] EWHC 308 (Fam) [6].

I outline four arguments as to why substituting the best interests test with a significant harm test is not justified. First, this substitution would render UK law incompatible with international law. Secondly, I contend that some of those who desire this change seem to believe that parents should be afforded more scope to make decisions regarding the medical treatment of infants and that clinicians are often immune to opposing views. In contrast, I draw on critical theory to contend that parents are not always the best decision makers and to refute unwarranted criticisms of medical professionals (who reflexively admitted the limitations of medicine in the Gard and Evans cases[3]). Thirdly, I draw on theories of distributive justice to highlight the unfair distributive effects that such legal reform may exacerbate. Fourthly, case law is used to demonstrate how the proposed substitution could potentially be unworkable in some cases. Nonetheless, I also employ critical theory, and Foucauldian scholarship, to critique the historic and ongoing lack of empowerment of patients and the public within the NHS. I argue that the proposed reform to ensure that mediation is offered in contentious cases, would be a welcome change that could empower patients and their carers. In addition, I contend that the best interests test should be retained and informed by clearer criteria regarding the allocation of finite resources, and that the public should be empowered to have an influence on shaping such criteria via the democratisation of the NHS. Consequently, I argue that rather than strengthening parental rights, efforts to enhance patient and public involvement would be preferable.

---

[3] In this respect, Katie Gollop QC, Counsel for Great Ormond Street Hospital, argued that Charlie would not benefit from further treatment (see K Gollop, 'GOSH's Position Statement Hearing on 24 July 2017' < https://www.gosh.nhs.uk/file/23731/download?token=TWJkSxZu > accessed 19 March 2019) and Michael Mylonas QC, Counsel for Alder Hey Children's Hospital, argued that Alfie's condition was untreatable (see M Mylonas, S Rickard and S Roper, 'Thomas Evans & Kate James v Alder Hey Children's NHS Foundation Trust' < https://www.serjeantsinn.com/news/thomas-evans-kate-james-v-alder-hey-childrens-nhs-foundation-trust/> accessed 10 May 2019.

II. BACKGROUND: DISPUTES BETWEEN PARENTS AND MEDICAL PRACTITIONERS

In circumstances where a child is unwell, parents are generally able to make decisions about their care as part of their parental responsibility.[4] In most cases, the parents of infants, who lack the capacity to make their own choices regarding medical treatment, and doctors, agree on the best course of action regarding the treatment of such infants.[5] The General Medical Council (GMC) states that decisions about the treatment of children must always be in their best interests,[6] as according to the GMC, ‘‘parents play an important role in assessing their child’s best interests and’’ clinicians ‘‘should work in partnership with them when considering decisions about their child’s treatment’’.[7] Where treatments are no longer in the child’s best interests they ‘‘may be withheld, withdrawn or limited’’,[8] which is what the clinicians deemed was in the best interests of Charlie and Alfie respectively. The Royal College of Paediatrics and Child Health (RCPCH) has published guidance which states that ‘‘healthcare teams may…not be justified in providing treatments that are highly expensive or limited in availability and that appear to offer little benefit to the child’’[9] and the expense and disputed benefit of proposed experimental treatment were pertinent issues in the Gard

---

[4] Children Act 1989, S.2 and S.3. Parents must provide children with adequate food, clothing, lodging and medical aid (Children and Young Persons Act (1933), S.1).

[5] D Wilkinson S Barclay and J Savulescu, ‘Disagreement, mediation, arbitration: resolving disputes about medical treatment’ (2018) *The Lancet* 391, 2302.

[6] General Medical Council, *Treatment and Care Towards the End of Life: Good Practice in Decision Making* (Manchester: General Medical Council, 2010) 45.

[7] ibid 46.

[8] V Larcher et al, ‘Making Decisions to Limit Treatment in Life-Limiting and Life-Threatening Conditions in Children: A Framework for Practice’ 2015, *Archives Disease Childhood* 100 (s2).

[9] ibid.

case. In some cases, there may be disputes between parents themselves[10] or between parents and medical practitioners regarding treatment, and such cases may be referred to the courts to adjudicate upon, as occurred in the Gard and Evans cases. The Nuffield Council on Bioethics states that recourse to the courts could be avoided by better communication,[11] but where cases are resolved in court, infants such as Charlie and Alfie, will be given an independent voice through a guardian from the Children and Family Court Advisory Support Service (CAFCASS).[12]

The Children Act 1989 states that where a court determines any question with respect to the upbringing of a child, or the administration of a child's property, "the child's welfare shall be the paramount consideration".[13] It has been confirmed, in relevant case law,[14] that numerous factors will be considered in determining an individual's welfare or best interests. For example, in *Aintree University Hospital NHS Trust v James*,[15] Baroness Hale stated that in considering the best interests of a particular patient "decision-makers must look at his welfare in the widest sense, not just medical but social and psychological".[16] The best interests principle is found in guidelines in numerous countries,[17] however, one problem with the clinical factors that will be taken into consideration is that, given the nature of medicine, they "are often uncertain, changeable and challengeable"[18] and the vicissitudes of medicine may make

---

[10] See for example, *Re C (Welfare of a Child: Immunisation)* [2003] 2 FLR 1095.

[11] Nuffield Council on Bioethics, *Critical Case Decisions in Foetal and Neonatal Medicine: Ethical Issues.* (London: Nuffield Council on Bioethics, 2006) 24.

[12] ibid 145.

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

[14] See, for example, *Portsmouth NHS Trust v Wyatt* [2004] EWHC 2247 (Fam).

[15] [2014] A.C. 59.

[16] ibid [65].

[17] D Wilkinson, *Death or Disability: The 'Carmentis Machine' and Decision Making for Young Children* (Oxford: Oxford University Press, 2013) 47.

[18] E Cave and E Nottingham, 'Who Knows Best (Interests)? The Case of Charlie Gard' (2018) *Medical Law Review* 26, 500.

disagreements more likely.[19] The best interests test has been criticised for being vague by both members of the judiciary[20] and academics, with Taylor LJ stating that the test was “easily said but not easily applied”.[21] Douglas Diekema similarly argued that the test may provide little meaningful guidance in practice,[22] and Theodor Adorno criticised legal norms for neglecting particularity for the sake of an “unbroken systematic”.[23] The best interests test can however, be defended on the basis that it is sufficiently malleable to take into account the particular circumstances of individual cases.[24] In the Gard and Evans cases, the parents of the respective infants disagreed with the determinations of their children’s medical practitioners that continued medical care was not in their best interests and desired to transfer their children to hospitals abroad to continue life-sustaining treatment. However, they failed to persuade the courts that transferring them to foreign hospitals was in their best interests.

Following the respective cases, the Charlie Gard Foundation (CGF) was established and has proposed reforms, which are known as ‘Charlie’s Law’. Similarly, Steven Woolfe (a former UK Independence Party (UKIP) member and an MEP for the North West region) and the think tank Parliament Street have advocated reforms, known as ‘Alfie’s Law’.[25] While there is no information about ‘Alfie’s Law’ on Parliament Street’s

---

[19] D Wilkinson and J Savulescu, *Ethics, Conflict and Medical Treatment for Children: From Disagreement to Dissensus* (London: Elsevier, 2019) 121.

[20] L McCrossan and R Siegmeth, ‘Demands and requests for ‘inappropriate’ or ‘inadvisable’ treatments at the end of life: what do you do at 2 o’clock in the morning when …?’. (2017) *British Journal of Anaesthesia* 119, i90.

[21] *Re J (A Minor)* [1992] 4 ALL ER 614.

[22] D Diekema, ‘Parental Refusals of Medical Treatment: The Harm Principle as Threshold for State Intervention’ (2004) *Theoretical Medicine and Bioethics* 25, 243.

[23] T Adorno, *Negative Dialectics* (London: Continuum, 1973), 309.

[24] Jonathan Herring also supports the welfare principle, in part, due to its flexibility. See J Herring, ‘Farewell Welfare?’ (2005) *Journal of Social Welfare and Family Law* 27, 159.

[25] This has been reported in national newspapers. See, for example, H Christodoulou, ‘RIGHT TO DECIDE: What are Charlie’s Law and Alfie’s Law, what rights would they give parents over their children’s care and who has backed them?’, *Sun*, 3 September 2018, M Robinson, ‘‘If we can make a

website, there is information about ‘Charlie’s Law’ on CGF’s website.[26] According to CGF’s website, it’s vision “is to enhance the quality of life for mitochondrial [mito] sufferers through innovative research, family support, and raise much needed awareness for this devastating condition”.[27] The aim of CGF is to “ensure we provide mito sufferers with every opportunity to get the very best out of life”.[28] It wants a change to the law to prevent cases reaching court (by ensuring that mediation is offered in contentious cases), to ensure that families are provided with advice and support and to protect parental rights by replacing the best interests test with a significant harm test.[29] In subsequent paragraphs, I describe the facts of both cases, the relevant court decisions and wider responses. As I note below, many of those who commented on the cases appear to not have known all of the clinical facts, and some ideologists used the cases to unjustifiably criticise socialised medicine and medical professionals. I outline the reality of the cases in order to critique ideological comments concerning them. As Adorno stated, “ideologies...become false only by their relationship to…reality”.[30] This exposition of the facts, and critique of ideology,[31] informs my analysis of the proposed legal reforms.

---

difference like he did, I’ll die a happy man’: Charlie Gard’s parents discuss ‘Charlie’s Law’ on one-year anniversary of tot’s tragic death’, *Daily Mail*, 27 July 2018, S Kettley, ‘Alfie Evans update: What is Alfie’s Law? MPs urged to introduce new legislation’, *Daily Express*, 27 April 2018 and P Hurst, “Alfie’s Law” bid launched to give parents of terminally-ill children more say in their end of life care’, *Daily Mirror*, 26 April 2018.

[26] Charlie Gard Foundation < https://www.thecharliegardfoundation.org/charlies-law/ >accessed 08 October 2018.

[27] Charlie Gard Foundation <https://www.thecharliegardfoundation.org/mission-statement/ > accessed 08 October 2018.

[28] ibid.

[29] Charlie Gard Foundation (n 26).

[30] T. Adorno, ‘Ideology’ in Frankfurt Institute of Social Research (ed) *Aspects of Sociology* (London: Heinemann,1973) 182, 198.

[31] I do not contend that the views of all of those who favoured different outcomes in the Gard and Evans cases are ideological, but rather that some ideologists used the cases to unjustifiably criticise socialised medicine and medical professionals.

A. CHARLIE GARD

Charlie Gard was born to parents Christopher Gard and Constance Yates, in London, in August 2016. Charlie was born with a rare genetic disorder, known as mitochondrial DNA depletion syndrome (MDDS), in which the synthesis of nucleosides in mitochondria (organelles in cells) is impaired. MDDS causes progressive brain damage and muscle failure. Charlie was taken to Great Ormond Street Hospital (GOSH), in October 2016. He was put on a mechanical ventilator and fed by a nasogastric tube. The diagnosis of MDDS was confirmed by a genetic test, in November 2016. The genetic test showed that Charlie had two mutated versions of the gene coding for the RRM2B protein, for which there are currently no treatments. Nonetheless, an experimental treatment for MDDS, involving nucleoside supplementation, has been used on humans and mice with a mutation in a different gene, thymidine kinase 2 (TK2), which also impairs the synthesis of nucleosides in mitochondria, ‘‘with some recorded benefit’’.[32] Charlie's doctors were considering attempting the experimental treatment at GOSH in January 2017. They prepared an application for approval from the Rapid Response Clinical Ethics Committee and invited an expert neurologist, Professor Michio Hirano (of the Neurological Institute of New York), to examine Charlie[33] after Constance Yates had communicated with him following her own internet searches.

---

[32] *Great Ormond Street Hospital* (n 2) [20].

[33] Gollop (n 3).

However, Charlie began having epileptic seizures, in January 2017, which were deemed to have rendered him brain damaged. Scans of Charlie's brain indicated that he did not have a sleep/wake cycle, which is indicative of severe brain atrophy and his clinicians determined that the experimental treatment would be futile. An expert team from Barcelona, Spain, providing a second opinion, arrived at the same conclusion.[34] While there was a lack of either animal or human data to support the nucleoside treatment, there was evidence that Charlie had severe neurologic injury that could not be reversed.[35] Despite this, Charlie's parents wanted to take him to New York to receive the nucleoside treatment, which Professor Hirano (who eventually examined Charlie in person in July 2017) was prepared to try. The Bambino Gesu Hospital in Rome, Italy, also offered to allow Charlie to receive the experimental treatment there. Charlie's parents forwent their privacy in order to raise funds for the treatment that they desired for him.[36] They launched an appeal on a crowdfunding website, GoFundMe,[37] at the end of January and had raised over one million pounds by the end of April.

GOSH asked the High Court to exercise its inherent jurisdiction to make the following orders: that Charlie, by reason of his minority, lacked capacity to make decisions regarding his medical treatment; that it would be lawful, and in Charlie's best interests, for artificial ventilation to be withdrawn; that it would be lawful, and in Charlie's best interests, for his treating clinicians to provide him with palliative care only; and, that it

---

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

[35] R Truog, 'The United Kingdom sets limits on experimental treatment: The case of Charlie Gard' (2017), *The Journal of the American Medical Association* 318, 1001.

[36] R Hurley, 'How a fight for Charlie Gard became a fight against the state'. *British Medical Journal* 2017;358:j3675.

[37] GoFundMe <https://www.gofundme.com/please-help-to-save-charlies-life > accessed 08 October 2018.

would be lawful, and in Charlie's best interests, for him not to undergo nucleoside therapy.[38] The case attracted worldwide media attention and comment, including being the subject of tweets by United States (US) President, Donald Trump, and the head of the Roman Catholic Church, Pope Francis. Those championing the cause of Charlie's parents became known as 'Charlie's Army' and some commentators on the case, politicians and supporters of Charlie's parents "attacked the hospital, the doctors, and the health system".[39] Charlie's situation was used in political propaganda by religious fundamentalists, neoliberals and opponents of Obamacare.[40] The former holding the vitalist belief that life is an absolute good.[41] However, it has been argued that the sanctity of life is not a fundamental tenet of a civilised society[42] and case law has established that it is not absolute.[43] Many of those venturing opinions and offering treatments apparently did so "without knowledge of the full clinical circumstances"[44] and some of the commentary on the case may have given Charlie's parents false hope.[45] Ranjana Das's discourse analysis of posts made by supporters of Charlie's parents on the social network Facebook found that they displayed a range of 'markers' of populism.[46] Such markers included the creation of ethical-moral distinctions between a vulnerable in-group and an evil out-group, blame attribution to produce professionals as evil and generate a rhetoric of vulnerable ordinariness and the

---

[38] *Great Ormond Street Hospital* (n 2) [5].

[39] D Wilkinson, 'Restoring balance to "best interests" disputes in children'. *British Medical Journal* 2017;358:j3666.

[40] Hurley (n 36).

[41] D Wilkinson (n 39) 27.

[42] H Kuhse and P Singer (1985) *Should the baby live? The Problem of Handicapped Infants* (Aldershot: Gregg Revivals, 1985) 98.

[43] Larcher et al (n 8).

[44] Hurley (n 36).

[45] Cave and Nottingham (n 18)/N Modi, 'Foreword 2' in D Wilkinson and J Savulescu, *Ethics, Conflict and Medical Treatment for Children: From Disagreement to Dissensus* (London: Elsevier, 2019), ix.

[46] R Das, 'Populist discourse on a British social media patient-support community: The case of the Charlie Gard support campaign on Facebook' (2018) *Discourse, Context & Media* 24, 76.

rejection of expertise with ‘common sense’.[47] I argue, below, that the latter is part of a broader trend in modern societies.

In April 2017, Francis J ruled, by declaration that it was in Charlie’s best interests for him to accede to GOSH’s applications.[48] In his judgment, Francis J noted that ‘‘no one in the world has ever treated this form of MDDS with nucleoside therapy’’ and that there was ‘‘no evidence that nucleoside therapy can cross the blood/brain barrier which it must do to treat RRM2B’’.[49] In determining Charlie’s best interests, Francis J considered whether Charlie could experience pain.[50] The GOSH team believed that Charlie could ‘‘probably experience pain, but is unable to react to it in a meaningful way’’.[51] While Francis J stated that it could be possible to transport Charlie to the US for treatment, in his view, this would be ‘‘futile’’ as ‘‘the prospect of the nucleoside treatment having any benefit is as close to zero as makes no difference’’.[52]

The parents appealed unsuccessfully to the Court of Appeal[53] and the Supreme Court refused a further appeal.[54] In the Court of Appeal, Richard Gordon QC, acting on behalf of the parents, argued that Francis J had not used the correct legal test. He averred that Francis J had failed to distinguish between two different types of cases: cases involving parents who oppose the course of treatment for which the treating clinicians apply, but who do not have a viable alternative treatment, and cases where

---

[47] ibid.
[48] *Great Ormond Street Hospital* (n 2) [23]
[49] ibid [20].
[50] ibid [22].
[51] ibid [22].
[52] ibid [119].
[53] *Great Ormond Street Hospital* (n 34).
[54] The Supreme Court Decision of 08 June 2017, in the Matter of Charlie Gard.

the parents propose a viable alternative treatment option to the one proposed by the treating clinicians.[55] Gordon argued that Charlie's case fell into the second category and sought to rely on Baker J's judgment in *Re King*.[56] That case involved a five-year-old boy, named Ashya King, and had also attracted worldwide media attention. Ashya had a medulloblastoma (malignant brain tumour) removed through surgery, at Southampton General Hospital (SGH), in July 2014. His parents wanted his cancer to be treated with proton therapy, which they thought was less harmful than conventional radiotherapy (the side effects of which include intellectual and cognitive impairment[57]). Although the proton therapy was not then available in the UK (it became available in 2017[58]), NHS England had authorised and funded the provision of the treatment to some English patients in foreign hospitals.[59] Nevertheless, the therapy was not recommended for medulloblastoma due to concerns about logistics and delays.[60] Ashya's parents feared that if they questioned the treatment plan, an emergency protection order would be sought.[61] Consequently, in late August 2014, they took him out of the hospital, without informing the medical team, leading to an international search. Ashya's clinicians feared that if his nasogastric tube (which his parents had no training in respect of) became displaced, he could choke to death.[62] Ashya was found with his parents two days later in Velez Malaga, Spain. He was made a ward of the High Court which ruled, in September 2014, that he could receive proton therapy in Prague, Czech Republic. In his judgment, Baker J stated that:

---

[55] *Great Ormond Street Hospital* (n 2) [58].

[56] [2014] 2 FLR 855.

[57] J Bridgeman, 'Misunderstanding, Threats and Fear of the Law in Conflicts over Children's Healthcare: In the Matter of Ashya King [2014] EWHC 2964' (2015) *Medical Law Review* 23, 477.

[58] Wilkinson and Savulescu (n 19) 82.

[59] *Re King* (n 56) [9].

[60] ibid [10].

[61] Bridgeman (n 57).

[62] *Re King* (n 56) [13].

> ‘‘In most cases, the parents are the best people to make decisions about a child and the State – whether it be the court, or any other public authority – has no business interfering 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’’.[63]

Gordon contended that *Re King* demonstrated that a parent’s preferred treatment option should only be overridden if it is established that the option would likely cause the child “significant harm”.[64]

McFarlane LJ delivered the leading judgment in the Court of Appeal. He noted that Ashya’s and Charlie’s cases differed as, in the former, SGH advised the High Court that it would not oppose Ashya receiving treatment in Prague as long as funds were made available.[65] McFarlane LJ concluded that Baker J’s judgment did not provide any basis for saying that significant harm is the relevant test[66] in respect of medical treatment (he noted that Baker J did not refer to medical treatment in the relevant part of his judgment[67]) and that if he had intended to say this then he was ‘‘plainly in error’’.[68] The Court of Appeal therefore rejected the appeal on the basis that the correct legal test had been used.

---

[63] ibid [31].

[64] *Great Ormond Street Hospital* (n 34) [55]

[65] ibid [62]/ *Re King* (n 51) [18].

[66] *Great Ormond Street Hospital* (n 34) [104].

[67] ibid [102].

[68] ibid [105].

In the Supreme Court, Baroness Hale also responded to the argument that the wrong test had been used. She noted that the Children Act 1989, S.1(1), reflects but is stronger than the United Nations (UN) Convention on the Rights of the Child (CRC), Article 3(1),[69] as it states that a child's welfare is the ''paramount consideration'', whereas the CRC states that:

> "in all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration."[70]

Baroness Hale also noted that the European Court of Human Rights (ECtHR) has stated that in any judicial decision where the rights under Article 8 of the European Convention on Human Rights (ECHR),[71] the right to respect for the private and family life of the parents and the child are at stake, the child's rights must be the paramount consideration and must prevail if there is any conflict.[72] Charlie's parents also made an application to the ECtHR, on the basis that their rights had been infringed, but this was declared inadmissible in June 2017.[73] In July 2017, the case returned to the High Court, as Charlie's parents wanted the court to consider new evidence from Professor Hirano.[74] Francis J confirmed the previous declarations he had made in April (which had been stayed), which Charlie's parents ceased to oppose as they ultimately

---

[69] Convention on the Rights of the Child (signed 19 April 1990; entered into force 15 January 1992) 1577 U.N.T.S. 3.

[70] The Supreme Court Decision of 08 June 2017 (n 54) [10].

[71] (ETS 5) (Signed 4 November 1950; entered into force 3 September 1953) 213 U.N.T.S. 222. This was incorporated into UK law via the Human Rights Act (1998).

[72] The Supreme Court Decision of 08 June 2017 (n 54) [10].

[73] *Gard* v *United Kingdom* Application No. 39793/17 (2017) 65 E.H.R.R. SE9.

[74] Cave and Nottingham (n 18).

determined that the window of opportunity for Charlie to improve had passed.[75] The High Court also made declarations concerning Charlie's end of life care, namely that his artificial ventilation could be withdrawn.[76] Charlie died within minutes of the withdrawal.

B. ALFIE EVANS

Alfie Evans was born in Liverpool, in May 2016, to parents Thomas Evans and Kate James. He was admitted to Alder Hey Children's Hospital (AHCH) in December 2016 due to a history of coughing, high-temperature and rhythmic jerking of his jaw and four limbs.[77] It was determined that he had an undiagnosed neurological condition. Throughout December 2016 and January 2017 Alfie was "very unwell with severe bilateral pneumonia, such that the treating clinicians felt that they had no alternative but to broach with the parents the real possibility that" he "might not survive".[78] Nonetheless, Alfie did not succumb to the pneumonia. Hayden J noted that this had an impact on his father's views about continued treatment.[79] Alfie underwent three magnetic resonance imaging (MRI) scans in November 2016, February 2017 and August 2017. The last MRI scan revealed that 70% of his brain had been destroyed.[80] Doctors from the Bambino Gesu Hospital examined Alfie in September 2017. They determined that they could offer Alfie prolonged ventilator support but noted that

---

[75] ibid.

[76] *Great Ormond Street Hospital for Children NHS Foundation Trust* v *Yates and others* (No.2) [2017] 4 WLR 131.

[77] *Alder Hey Children's NHS Foundation Trust* (n 2) [6].

[78] *E (A Child)* [2018] EWCA Civ 550 [9].

[79] *Alder Hey Children's NHS Foundation Trust* (n 2) [10].

[80] *E (A Child)* (n 78) [12].

transporting him to Rome could provoke further seizures and damage to his brain.[81] However, the doctors at the Bambino Gesu Hospital were not offering a different diagnosis or treatment.[82] The Italian government issued a citizenship certificate to Alfie to enable him to travel to Italy,[83] and Dr Matthias Hubner, the Medical Director of the Paediatric Air Ambulance in Munich, Germany, also examined Alfie, surreptitiously, and determined that he was fit to fly.[84] Hubner was subsequently criticised, by King LJ, for clandestinely examining Alfie, for not reading all of his notes and for recommending an inappropriate anticonvulsant medical regime.[85]

While Alfie's parents wanted him to be transferred to Rome (and if this did not lead to any improvement, then subsequently to Munich), his doctors determined that it was in his best interests for his life-support to be switched off, as there was no hope for Alfie and continued treatment was inhumane. Similarly to the Charlie Gard case, the dispute generated worldwide media interest and Alfie's parents garnered supporters who described themselves as 'Alfie's Army'. 'Alfie's Army' mobilised through Facebook, gathered outside AHCH[86] and even attempted to storm AHCH.[87] Again the dispute was utilised by those promoting their own ideological agendas.[88] Such ideologists included religious fundamentalists (the London based Christian Legal Centre represented Alfie's parents through their unsuccessful legal appeals) and US conservatives, who used it to criticise socialised medicine.[89] The latter is undermined

---

[81] ibid [21].
[82] ibid.
[83] U Schuklenk, 'Bioethics culture wars-2018 edition: Alfie Evans' (2018) *Bioethics* 32, 270.
[84] *E (A Child)* (n 78) [23].
[85] ibid [24].
[86] C Dyer, 'Alfie Evans Case: Proposed Law aims to prevent conflicts between parents and doctors'. *British Medical Journal* 2018;361:k1895.
[87] Schuklenk (n 83).
[88] *Alder Hey Children's NHS Foundation Trust* (n 2) [64].
[89] Dyer (n 86).

by the fact that for-profit health insurance companies, which dominate healthcare in the US, do not typically fund futile care.[90]

Similarly to the Gard case, as the parents and clinicians could not resolve the dispute it proceeded to court. In the High Court**,** Hayden J determined that continued ventilatory support was no longer in Alfie's best interests.[91] Alfie's parents appealed to the Court of Appeal contending that Hayden J had not properly weighed their views in the best interests decision (in breach of ECHR, Article 14, which requires that the rights and freedoms of the convention be applied without discrimination, and Article 8),[92] had not properly considered what would be an appropriate palliative care pathway[93] and had failed to assess matters relevant to best interests or to weigh up the available alternatives.[94] The Court of Appeal did not find merit in the grounds of appeal and upheld the High Court's decision. The parents launched further appeals, but the Supreme Court refused their permission to appeal in March 2018[95] and the ECtHR ruled the case inadmissible, as no human rights had been violated.[96]

In the Supreme Court, Baroness Hale again addressed arguments that the significant harm test was the relevant test, advanced by the parent's counsel, Stephen Knafler QC. Baroness Hale noted that Knafler contended that:

---

[90] Schuklenk (n 83).
[91] *Alder Hey Children's NHS Foundation Trust* (n 2) [66].
[92] *E (A Child)* (n 78) [49].
[93] ibid.
[94] ibid.
[95] *Thomas Evans, Kate James* v *Alder Hey Children's NHS Foundation Trust, Alfie Evans (by his Children's Guardian)* [2018] WL 03440352.
[96] *Evans* v *United Kingdom* [2018] application no.14238/18.

> “if significant harm (or its likelihood) has to be established before a child can be removed – perhaps only temporarily – from the home of his parents under a care order, why does it not need to be established before he can be removed, permanently, from them and from everything in this world, by death?”[97]

In respect of the removal of a child from their parents, the Children Act 1989 provides that a court may, following an application from a local authority, make a care order or a supervision order if it is satisfied that the child concerned is suffering, or is likely to suffer, significant harm[98] and that the harm or likelihood of harm, is attributable to the care given to the child, or likely to be given to him if the order were not made, not being what it would be reasonable to expect a parent to give to him[99] or the child’s being beyond parental control.[100] Harm is defined as ill-treatment or the impairment of health (physical or mental) or development.[101]

Baroness Hale reiterated that the Children Act 1989, S.1(1), required that the child’s welfare be the “paramount consideration” of the court[102] and that this reflected the aforementioned international law. She explained that the difference with care proceedings was that Parliament determined that there should be an initial hurdle (significant harm) before an assessment of the child’s best interests “to avoid social

---

[97] *Thomas Evans* (n 95) [12].
[98] S.31(2)(a).
[99] S.31(2)(b)(i).
[100] S.31(2)(b)(ii).
[101] S.31(9)(b).
[102] *Thomas Evans* (n 95) [14].

engineering'' and protect families from a ''too ready'' removal of children.[103] Baroness Hale averred that no qualification was required in cases concerning the contested medical treatment of an infant, where the imperative was for doctors to know what is required of them.[104] She also stated that Alfie's parents had not been discriminated against as their situation was ''not comparable with that of the parents of children who are taken away from them by the state to be brought up elsewhere''.[105] Alfie's life support was ultimately withdrawn in late April 2018 and he died a few days afterwards and following Alfie's death, his case has continued to be used within ideological narratives. For example, John Allman (former parliamentary candidate for the Christian People's Alliance) submitted an application for judicial review on the grounds that the relevant Senior Coroner (Andre Rebello) should have conducted an investigation[106] of Alfie's death, as he was allegedly in state detention (an argument which had already been rejected by the Supreme Court[107]). The application was refused by Cockerill J on the basis that it was totally without merit.[108]

III. EVALUATING THE PROPOSED LEGAL REFORMS

Prior to the Gard and Evans cases, there had been academic debates concerning whether the law in this area should be reformed. For example, Diekema argued that the significant harm test was preferable to the best interests test[109] and other

---

[103] ibid [15].
[104] ibid [16].
[105] ibid [17].
[106] As per the Coroners and Justice Act (2009), S.1(2)(c).
[107] The Supreme Court Decision of 20 April 2018, in the Matter of Alfie Evans (No.2).
[108] *R (On the Application of John Allman) v HM Senior Coroner for Liverpool Area and Wirral Area*, CO/3230/2018.
[109] Diekema (n 22).

academics have advocated a zone of parental discretion (ZPD), which has been defined as “a protected space in which parents may legitimately make decisions for their children”.[110] The high-profile nature of the Gard and Evans cases has given impetus to the desire for legal change. In contrast, before those cases were decided, the Nuffield Council on Bioethics determined that the best interests principle is “appropriate and sufficient”.[111] In response to the cases, some, such as Eliana Close et al,[112] have defended the capacity of the best interests test to settle disputes. However, I agree with Neera Bhatia that if the best interests test is preserved, it should be informed by clearer criteria (particularly pertaining to the allocation of finite healthcare resources).[113] Raanan Gillon has argued that in Charlie Gard’s case the courts did not adequately examine some considerations relevant to the best interests test, namely: “people’s enormously variable attitudes to pursuing low probabilities of benefit in order to seek cures or ameliorations of disease disability and illness”,[114] and the belief of a sector of the population “that it is never in a person’s best interests to have his or her life deliberately ended by either withholding or withdrawing an available life-prolonging treatment”.[115] In respect of the former, if the courts took this into account, it could homogenise such attitudes by legitimising the views of those who desire low probabilities to be pursued, thereby potentially generating more disputes and having deleterious distributive effects. In respect of the latter, the fact that many hold this view does not necessarily mean that the law should take it into account. If

---

[110] See, for example, L Gillam, ‘The Zone of Parental Discretion: An Ethical Tool for Dealing with Disagreement between parents and doctors about medical treatment for a child’. *Clinical Ethics* 11, 1.

[111] Nuffield Council on Bioethics (n 11) xxv.

[112] E Close, L Willmott and B White, ‘Charlie Gard: In Defence of the Law’ (2018) *Journal of Medical Ethics* 44, 476.

[113] N Bhatia, *Critically Impaired Infants and end of life Decision Making: Resource Allocation and Difficult Decisions* (London: Routledge, 2015) 67.

[114] R Gillon, ‘Why Charlie Gard’s parents should have been the decision-makers about their son’s best interests’ (2018) *Journal of Medical Ethics* 44, 462.

[115] ibid.

this view did influence the law, it could again have negative distributive effects by potentially never legitimising the withdrawal of treatment. Nevertheless, the notion that medicine has limited utility for some patients has ancient roots.[116] As the Athenian philosopher Plato stated, Asclepius (the Greek God of medicine) "did not attempt to prescribe regimens for those whose bodies were riddled with disease, so that…he could make their life a prolonged misery".[117]

As mentioned above, right-wing ideologists[118] have sought to utilise the contentious cases in a spurious effort to portray publicly funded and provided healthcare negatively. This is exemplified by Woolfe's comment that the state should no longer be regarded as the champion of the child "when it's the parents who should be the champion of the child".[119] Similarly, CGF wants the 'best interests' test to be replaced with a 'significant harm' test (which counsel for the parents of Charlie and Alfie contended was the correct legal test in the aforementioned appeals) as the former "provides a broad platform for the overruling of parent's wishes".[120] While it is uncommon for judges to rule against medical opinion,[121] in some cases the views of parents have been determinative in deciding best interests.[122] CGF contend that:

---

[116] J Paris, B Cummings, M Moreland and J Batten, 'Approaches to parental demand for non-established medical treatment: reflections on the Charlie Gard case' (2018) *Journal of Medical Ethics* 44, 443.

[117] ibid/Plato, *Republic* (Indianapolis, IN: Hackett Publishing, 2004) 91.

[118] Such as Donald Trump and Senator Ted Cruz (see 'Sen. Cruz Issues Statement on Alfie Evans' <https://www.cruz.senate.gov/?p=press_release&id=3760> accessed 11 May 2019) in the US and Steven Woolfe in the UK.

[119] C Willow, 'Alfie's Law could undo decades of progress on children's rights', *Guardian*, 10 May 2018.

[120] Charlie Gard Foundation (n 26).

[121] Bhatia (n 113) 50.

[122] See, for example, *Re T (A Minor) (Wardship: Medical Treatment)* [1997] 1 WLR 242.

> "In Charlie's case, Chris and Connie firmly believe that there was insufficient evidence to prove that moving Charlie from one hospital to another would have risked *significant harm*. If this is correct, Charlie's Law would have prevented the judge from making a court order precluding such movement…"[123].

CGF seem to believe that changing the test would mean that parent's wishes would be more likely to be determinative. Charles Foster notes that "the use of the word 'harm' is more protective to parents than the more nuanced term 'best interests'" as "it sets the bar for intervention higher".[124] However, while the best interests test has been criticised for being vague, the same criticism has been levelled at the significant harm test. For example, Giles Birchley notes that what constitutes a harm is likely to be contested.[125] Birchley therefore contends that a significant harm test would suffer from the same level of indeterminacy as the best interests test.[126] Consequently, given the vague nature of both tests, they could produce the same result. Indeed, both McFarlane LJ and Baroness Hale averred in the Charlie Gard case that undergoing the experimental treatment would cause 'significant harm' to Charlie (although as indicated above, this may be contested).[127] Similarly, it has been argued that the aforementioned ZPD may not provide greater clarity.[128] Thus even if the law were changed, it is possible that if an identical case to the one involving Charlie Gard arose, it may be decided in the same way. If this were to occur, CGF's efforts to reform the

---

[123] Charlie Gard Foundation (n 26).

[124] C Foster, 'Harm: as indeterminate as 'best interests', but useful for triage' (2016) *Journal of Medical Ethics* 42, 121.

[125] G Birchley, 'The Harm Threshold and Parents' Obligation to benefit their children' (2016) *Journal of Medical Ethics* 42, 123.

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

[127] *Great Ormond Street Hospital* (n 34) [114]; The Supreme Court Decision of 08 June 2017 (n 54).

[128] P Alderson, 'Children's Consent and the Zone of Parental Discretion' (2017) *Clinical Ethics* 12, 55.

law would have been in vain. A reformed law may not alter the outcome in a Charlie Gard type case but would suffer from several problems outlined in the following paragraphs.

Firstly, as Baroness Hale's comments in both the Gard and Evans cases highlight, the current law in the UK is consistent with international law. If UK law is reformed to strengthen parental rights, it would be incompatible with such international law, namely the aforementioned CRC and the jurisprudence of the ECtHR, which require the best interests of a child to be the primary, or paramount, consideration of welfare institutions, courts and others in considering cases involving children. This would no longer be the case if legal reform installs a harm threshold, which must be met before a question can be referred to the courts, or if the principle guiding the decisions of courts is whether the treatment favoured by the parents would be capable of causing the child significant harm. Carolyne Willow (Director of the children's rights charity Article 39) has contended that reform could ‘‘undo decades of progress in establishing the rights of children- as human beings with individual worth and integrity'' rather than chattel.[129] The ZPD notion has been criticised for the same reason.[130]

Secondly, I contend that installing a legal principle which is more protective of parents is not justified or normatively preferable. It has been argued that parent's interests should be afforded greater weight given that decisions are likely to have a long and

---

[129] Willow (n 119).

[130] Alderson (n 128).

profound impact on them.[131] However, as Birchley argues, overruling parental interests may protect parents from the devastating effect that making a particular decision may have on their well-being.[132] It has also been argued that parents should make decisions about the medical treatment of infants as they make other decisions regarding their children (some of which may be suboptimal).[133] However, I agree with Birchley that the goods conferred by medical treatment are of a fundamentally different order to everyday goods, which justifies different rules.[134] In addition, some of those advocating reform, such as CGF and Woolfe, appear to believe that parents would make better decisions than clinicians in these types of cases, if legal reform afforded them the scope to do so. I utilise critical theory to challenge this belief in the next two paragraphs.

Parents may seek to justify themselves being the ultimate decision makers regarding the treatment of their children on the basis that they have more intimate knowledge of their children than others. Francis J gave succour to such claims by stating, in his decision in the Charlie Gard case, that ‘‘there is no doubt, of course, that the parents know Charlie immeasurably better than anybody else does, professional or otherwise’’ given the number of hours that they had spent with their son.[135] However, the parents in the Gard and Evans cases held views and made claims that could be validated or refuted by medical professionals. For example, Constance Yates testified that ‘‘she

---

[131] D Wilkinson and T Nair, ‘Harm isn’t all you need: Parental Discretion and Medical Decisions for a child’ (2016) *Journal of Medical Ethics* 42, 116/ R McDougall, ‘Indeterminacy and the Normative Basis of the Harm Threshold for Overriding Parental Decisions: A Response to Birchley’ (2016) *Journal of Medical Ethics* 42, 119.
[132] Birchley (n 125).
[133] Wilkinson and Nair (n 131).
[134] Birchley (n 125).
[135] *Great Ormond Street Hospital* (n 2) [107].

did not think that Charlie's brain function is as bad as everyone else is saying''.[136] She disputed the GOSH clinicians determination that Charlie ''did not have a sleep/wake cycle'' claiming that she knew ''full well when he is awake and when he is asleep''[137]. In the Evans case, Alfie's father, Thomas, disputed the diagnosis of the doctors at AHCH and claimed that his son ''looks him in the eye'' and ''wants help''.[138] The claims of the parents in such cases drew on their closeness to their children and may have been fuelled by understandable emotions, unconscious biases and misplaced hope. Religious attitudes (which were evident in both cases) can influence belief in miracles.[139] In addition, the information age has increased public awareness of medical technology.[140] Bhatia contends that advancements in technology and medical science have entrenched an expectation that everything that can be done should be done.[141] She avers that as medical professionals are now able to save infants who may have died as little as two decades ago, there is often an unrealistic expectation that they can keep critically ill infants alive.[142] The beliefs held and claims made by parents are not privileged or immune from criticism but can often be corroborated or refuted. If the law is reformed to strengthen parental rights, this could potentially encourage such misplaced hope in future cases and thereby generate more acrimony.

Medical opinion is also not privileged or immune from criticism. As noted above, medical opinion evolves, hence practices and treatments change over time. The

---

[136] ibid [112].
[137] ibid.
[138] Press Association, 'Father of seriously ill boy tells court he 'looks me in the eye' for help', *Daily Mail*, 6 February 2018.
[139] Bhatia (n 113) 5.
[140] ibid 4.
[141] ibid 199.
[142] ibid 106.

success of medical innovation and technologies over the last century has led some to mistaken conclusions, such as the notion that infectious diseases had been conquered.[143] The dialectic of enlightenment, identified by the Frankfurt School critical theorists Theodor Adorno and Max Horkheimer, was that reason can engender unreason.[144] Consequently, Adorno and Horkheimer contended that progress should be accompanied by critique rather than affirmation.[145] The application of critical thinking to medicine would emphasise the many challenges it faces (such as increasing anti-microbial resistance) and the many diseases (such as Alzheimer's and the MDDS that afflicted Charlie Gard) for which it currently offers no cures, as well as the advancements that have been achieved. The belief that there is no illness which medicine cannot, or will not ultimately, cure, together with hope, may be unscrupulously exploited by those offering unproven treatments. The process of trialling new medicines and treatments offers protection from false hope and quackery. In the Gard and Evans cases, the medical practitioners who reflexively acknowledged the limits of medicine (in contrast to the parents) were denigrated. Woolfe's comments concerning the Evans case, exemplify this point:

> "the vast weight of medical evidence delivered by one set of professionals can become a rolling stone, trampling over opinions from all other experts. There is a danger, also, that once the hospital decides on a certain course of action, they get tunnel vision; they become closed to all other arguments or evidence''.[146]

---

[143] B Beaty and W Marquardt, 'Preface to the first edition' in W Marquardt (ed) *Biology of Disease Vectors Second Edition* (Burlington, MA: Elsevier, 2004).

[144] T. Adorno and M. Horkheimer, *Dialectic of Enlightenment* (London: Verso, 1997) xvi.

[145] ibid xii.

[146] S Woolfe, 'The Alfie Evans case has proven that we need to change the law in favour of parents', *Independent*, 27 April 2018.

Such comments misrepresent medical enquiry as a monolith immune from influence. However, as Adorno argued, in the modern sciences "ratio peers over the wall it itself erects that it snatches a snippet of what does not agree with its own ingrained categories".[147] Woolfe's comments do not fit well with the facts of either the Gard or Evans cases, where other opinions were considered by both the treating clinicians and the courts. Other opinions were not trampled on in the Gard or Evans cases and there was no evidence to suggest that the course of action favoured by the parents could have helped Charlie or Alfie. Nonetheless, I argue below that there is a need to empower patients within the NHS and that the enhanced involvement of patients and their carers (such as parents) in the NHS may be helpful in promoting dialogue and understanding where disputes arise.

A third argument against replacing the best interests test with a significant harm test is that it could have negative impacts in respect of distributive justice. The theory of distributive justice (how a society should allocate resources) goes back at least two millennia.[148] Bhatia avers that major theories of justice (such as utilitarianism) are generally consistent with a distributive justice approach to the allocation of important and finite resources.[149] But, if the law allows parents to be the final decision makers, Dominic Wilkinson and Julian Savulescu argue this could consume limited medical resources thereby compromising "the ability of health professionals and the health

---

[147] T Adorno, *Critical Models: Interventions and Catchwords* (New York, NY: Columbia University Press, 2005) 251.
[148] J Roemer, *Theories of Distributive Justice* (London: Harvard University Press, 1996) 1.
[149] Bhatia (n 113) 158.

system to treat other children and distribute resources fairly".[150] One could conceivably argue that as Charlie Gard's parents were able to crowd fund the money for treatment, there would be no negative distributional effects if they had been permitted to take him to New York to receive the treatment.[151] However, while such crowdfunding may be a means to alleviate some injustices pertaining to health systems, it poses a number of ethical questions in relation to potential fraud or misrepresentation, fairness and the commodification of healthcare.[152] A morally relevant question is whether it is right for an individual to contribute money to a fund to pay for experimental treatment for a child, which in all likelihood will not work, when they could, alternatively, contribute the money to funds for other children in the world who are dying from diseases, which could be easily remedied by treatments which are of proven effectiveness.

The Gard and Evans cases have already had a detrimental impact with regard to distributive justice by diverting money from medical care to lawyers. GOSH reportedly incurred legal costs of £205,000 (including VAT) in the Gard case, AHCH incurred legal costs of £218,000 (excluding VAT) in the Evans case and CAFCASS incurred legal costs of £32,500 in the former case and £17,000 in the latter case.[153] In addition, RCPCH has expressed concern that the criticism of medical professionals in recent cases could make it harder for the NHS to recruit and retain vital staff, which could

---

[150] D Wilkinson and J Savulescu, 'Alfie Evans and Charlie Gard—should the law change?' *British Medical Journal* 2018;361:k1891.
[151] See, for example, P Singer, 'Foreword 1' in D Wilkinson and J Savulescu, *Ethics, Conflict and Medical Treatment for Children: From Disagreement to Dissensus* (London: Elsevier, 2019), viii.
[152] J Snyder, 'Crowdfunding for Medical Care: Ethical Issues in an Emerging Health Care Funding Practice' (2016) *Hastings Centre Report* 46, 36.
[153] B Farmer and P Hurst, 'Charlie Gard and Alfie Evans cases cost NHS half a million in legal fees after lengthy court battles', *Independent*, 14 October 2018.

ultimately negatively impact the services that are available to all families.[154] If the law is reformed as has been suggested, it may exacerbate negative distributive effects as more parents may be emboldened to demand treatments of questionable effectiveness, thereby diverting funds to such treatments, meaning that less resources are available for other patients. Wilkinson and Tara Nair argue that this could be avoided by installing a cost threshold to overrule the preferences of parents, even where a harm threshold is not exceeded.[155] However, it is questionable whether a cost threshold could offset all of the negative distributional effects of a change to the law. Jeremy Snyder contends that crowdfunding fosters norms of competition, privatization, corporatization and the market.[156] Such crowdfunding may thus exacerbate health inequalities by furnishing privileged persons with another means of accessing health care which disadvantaged groups are unable to access.[157] If the law is reformed to strengthen parental rights, this could thus potentially increase inequalities in respect of its impact on access to resources both within and outside of the NHS, and undermine the ethos of the NHS by encouraging commodification. I argue that enhancing patient and public involvement within the NHS is preferable to commodification, as facilitating such involvement could potentially empower all patients rather than a few.

A fourth argument against replacing the best interests test is that this proposed reform may prove unworkable in many instances, particularly as it has been confirmed in numerous cases that the courts will not compel a doctor to treat. For example, Lord

---

[154] C Burns, 'Charlie Gard's parents want 'Charlie's Law', *BBC*, 20 June 2018.
[155] Wilkinson and Nair (n 131).
[156] Snyder (n 152).
[157] ibid.

Donaldson MR stated in *Re J (A Minor) (Wardship: Medical Treatment)* that the courts cannot "insist on treatment".[158] This has been reaffirmed in subsequent cases.[159] If the best interests test was replaced with a significant harm test, the fact that the courts will not compel doctors to undertake specific treatments means that clinicians would not be legally required to provide treatments which they disagreed with, but which parents were insisting on. Consequently, parent's desires for particular treatments to be tried may still be frustrated even if the test is changed. In theory, the law could also be changed to compel doctors to treat in such circumstances, to prevent the parent's wishes being thwarted. However, a legal change compelling clinicians to treat (contrary to their professional judgment) would deprive clinicians of their ability to meaningfully exercise their professional judgment. Such a change would thereby involve the degradation, or proletarianization, of medical labour, which Harry Braverman identified in the workforces of contemporary capitalist societies.[160] The phenomenon of the degradation of labour is linked to commodification, which as mentioned above may also be exacerbated by legal reform in this area. Although without such a change, clinicians could not be compelled to undertake specific treatments, they would still need court permission to discontinue life support where disputes arise. Some parents who have sufficient resources (or can accrue them through charity) may be able to seek treatments abroad, but this option may not be available to all parents. The four arguments outlined above demonstrate that replacing the best interests test with a significant harm test, to strengthen parental rights, is undesirable. Nonetheless, the best interests test should be informed by clearer criteria,

---

[158] [1990] 3 All ER 934.

[159] See for example, *Burke* v *GMC* [2005] 2 WLR 431 and *AVS* v *NHS Foundation Trust* [2011] EWCA Civ 7.

[160] H Braverman, *Labour and Monopoly Capital: The Degradation of Work in the Twentieth Century* (New York, NY: Monthly Review Press, 1998).

which the public should have a role in shaping. In addition, reform to ensure that mediation is offered in cases where disputes arise would be a welcome means of empowering patients and, where relevant, their carers.

IV. PATIENT AND PUBLIC EMPOWERMENT

The disputes in the Charlie Gard and Alfie Evans cases, and the campaigns and media coverage that they engendered, are symptomatic of a broader trend of the diminishing esteem in which various kinds of expertise is held. In the medical context, parents are now more likely to question the judgment of healthcare professionals than they were in the past.[161] This tendency in modern societies of the dwindling esteem in which expertise is held may have some justification but can also have pernicious effects. For example, the World Health Organisation (WHO) has stated that misinformation regarding vaccinations has contributed to a spike in the number of measles cases worldwide.[162] Nonetheless, although the questioning of experts may often be a populist endeavour, it is necessary to critically engage with the relationship between experts and service-users across the public services. When the NHS was established, in 1948, it was a professionally dominated service, leading the Foucauldian scholars, Peter Miller and Nikolas Rose, to describe it as a medical enclosure.[163] Similarly, the critical theorist, Jurgen Habermas, argued that welfare state bureaucracies had

---

[161] Nuffield Council on Bioethics (n 11) 38-39.

[162] World Health Organisation, 'Measles cases spike globally due to gaps in vaccination coverage' < https://www.who.int/news-room/detail/29-11-2018-measles-cases-spike-globally-due-to-gaps-in-vaccination-coverage > accessed 20 March 2019.

[163] P Miller and N Rose, *Governing the Present: Administering Economic, Social and Personal Life* (Cambridge: Policy Press, 2008) 75.

reifying effects as they “treated [people] as objects”.[164] Peter Beresford contends that the dominant strand in social policy, at the time, Fabianism, involved a top down elitist approach and a cult of the expert, hence there was a failure to adequately involve citizens, patients and service users.[165]

The NHS was designed to be accountable to the public through ministerial accountability to Parliament. However, a Royal Commission on the NHS, in the 1970s, determined that “detailed ministerial accountability” was “largely a constitutional fiction”.[166] The National Health Service Act (1946), transferred the responsibility for hospitals from local authorities (which administered municipal hospitals[167]) to appointed bodies (Regional Hospital Boards) accountable to the Minister of Health. This transfer was unsuccessfully opposed, on democratic grounds, in the cabinet of the Labour government which introduced the NHS, by Herbert Morrison (Deputy Prime Minister between 1945 and 1951), and by backbenchers, such as Frederick Messer, who lamented the “loss of faith in the elected principle”.[168] Aneurin Bevan (Minister of Health between 1945 and 1951) subsequently conceded that “election is a better principle than selection”.[169] Bevan hoped that a future reform would democratise the system.[170] However, this has not transpired.

---

[164] J. Habermas, *The Theory of Communicative Action Volume 2: Lifeworld and System: A Critique of Functionalist Reason* (Cambridge: Polity Press, 2006) 370.

[165] P Beresford, *All our Welfare: Towards Participatory Social Policy* (Bristol: Policy Press, 2016) 152-153.

[166] A Merrison, *Report of the Royal Commission on the National Health Service*, Cmnd 7615 (London: HMSO, 1979) 298.

[167] Local Government Act (1929), S.1.

[168] H.C. Deb. 30 April 1946, Vol.422, Col.140.

[169] A Bevan, *In Place of Fear* (London: Quartet, 1990) 114.

[170] M Foot, *Aneurin Bevan 1945-1960* (St Albans: Granada, 1982) 133.

The neglect of the voices of patients and the public led to numerous patient's rights groups being established from the 1960s onwards to fight for patient's rights.[171] As Alex Mold notes, by the 1990s, such groups had secured rights to access medical records[172] and to complain,[173] in addition to the right to consent to treatment, despite professional resistance.[174] In addition, Community Health Councils (CHCs) were established in the 1970s, to represent patient voices within the NHS.[175] The Association of Community Health Councils for England and Wales (ACHCEW) was established in 1978 to assist CHCs.[176] Both voice and choice are potential means of empowering patients.[177] Neo-liberalism became the dominant strand in social policy in the 1970s, and Beresford contends that neo-liberal social policy is no more participatory than Fabian social policy and reflects the same commitment to self-defined experts (such as consultants).[178] Since the 1990s, the main emphasis of successive governments has been on empowering patients via furnishing them, or purchasers acting on their behalf (such as Clinical Commissioning Groups (CCGs) since 2013), with choices facilitated by the marketization of the NHS. However, as Mold notes, ''choice was an attractive way to package NHS reform: it was not always about giving the patient more to choose from''.[179] For example, the market introduced

---

[171] R Porter, *Blood and Guts: A Short History of Medicine* (London: Penguin, 2004) 167-168.

[172] To electronic records via the Data Protection Act (1984) and paper records via the Access to Health Records Act (1990).

[173] Hospitals Complaints Procedure Act (1985).

[174] A Mold, *Making the Patient Consumer: Patient Organisations and Health Consumerism in Britain* (Manchester: Manchester University Press, 2015) 94.

[175] National Health Service Reorganisation Act (1973), S.9(3)(a).

[176] The National Health Service (Association of Community Health Councils) Regulations SI 1977/874.

[177] A. Hirschman, *Exit, Voice and Loyalty: Responses to Decline in Firms, Organisations and States* (London: Harvard University Press, 1970).

[178] Beresford (n 165) 160.

[179] Mold (n 174) 170.

by the Health and Social Care Act (2012) was justified on the basis that it would extend patient choice,[180] but this policy has taken a backseat.[181]

Although successive governments within the neo-liberal era have also persisted with voice mechanisms, these have been weakened. CHCs were abolished in England (they endure in Wales) in the early 2000s[182] and their functions were taken over by several successor bodies, such as the Independent Complaints Advocacy Service (ICAS), the Patient Advocate and Liaison Services (PALS) (which took on the advisory role of CHCs) and Patient and Public Involvement Forums (PPIFs) (which took over the role of CHCs in monitoring and reviewing services).[183] The latter were subsequently replaced by Local Involvement Networks (LINKs).[184] The Conservative-Liberal Democrat coalition government replaced LINKs with Local Healthwatch (LHW) organisations[185] and also created Healthwatch England,[186] which is part of the Care Quality Commission (CQC), to enhance the collective voice of patients.[187] LHWs are weaker than their predecessors as they are prohibited from advocating a change in law or policy.[188] Healthwatch England's lack of independence, due to it being part of

---

[180] See Department of Health (DOH), *Equity and Excellence: Liberating the NHS* (London: DOH, 2010).

[181] C Ham, B Baird, S Gregory, J Jabbal and H Alderwick, *The NHS under the Coalition government part one: NHS Reform* (London: Kings Fund, 2015) 18.

[182] National Health Service Reform and Health Care Professions Act (2002), S.22.

[183] ibid, S.15.

[184] Local Government and Public Involvement in Health Act (2007), S.221.

[185] Local Government and Public Involvement in Health Act (2007), S.221 as amended by the Health and Social Care Act (2012), S.182.

[186] Health and Social Care Act (2012), S.181.

[187] Department of Health (DOH), *Equity and Excellence: Liberating the NHS* (London: DOH, 2010) 3.

[188] J Tritter and M Koivusalo, 'Undermining Patient and Public Engagement and Limiting its Impact: The Consequences of the Health and Social Care Act 2012 on Collective Patient and Public Involvement' (2013) *Health Expectations*, 16, 115/National Health Service Bodies and Local Authorities (Partnership Arrangements, Care Trusts, Public Health and Local Healthwatch) Regulations, SI 2012/3094, R.36(1)(a)(i) and (ii).

the CQC, has led to it being described as “toothless”.[189] The various reforms to patient and public involvement within the NHS have been criticised. For example, the Francis Report (published following the public inquiry into poor care and high mortality rates at Mid Staffordshire NHS Foundation Trust) contained a damning indictment of Labour’s reforms.[190] The House of Commons Health Committee determined, in 2007, that patient and public involvement had been conflated leading to “muddled initiatives and uncertainty”.[191] Patient involvement is a response to medical paternalism, while public involvement draws on democratic theory.[192] In the following paragraphs I argue that both can be enhanced to empower patients and the public.

The proposed reform to ensure that mediation is offered in contentious cases is a welcome means of potentially empowering patients and their carers, and the Nuffield Council on Bioethics noted that mediation is used in the US and can prevent disagreements crystallising as conflicts.[193] Recognising that mediation would not provide an answer to every dilemma, the Nuffield Council on Bioethics also stated that it could provide for better communication, reduce acrimony and narrow down the issues requiring formal adjudication by the courts.[194] Mediation may have helped in the Gard case where Constance Yates notes that “matters quickly became antagonistic”.[195] The protracted dispute in that case was traumatic for Charlie’s

---

[189] J Davis, J Lister and D Wrigley, *NHS for Sale: Myths, Lies & Deception* (London: Merlin Press, 2015) 123.

[190] K Newbigging, ‘Blowin’ in the wind: The Involvement of People who use services, carers and the public in health and social care’ in M Exworthy, R Mannion and M Powell (eds) *Dismantling the NHS? Evaluating the Impact of Health Reforms* (Bristol: Policy Press, 2016), 301, 306.

[191] Health Committee, *Patient and Public Involvement in the NHS: Third Report House of Commons Session 2006-07, Vol.1* (London: Stationery Office, 2007) 3.

[192] M Fredriksson, and J Tritter, ‘Disentangling Patient and Public Involvement in healthcare decisions: Why the difference matters’ (2017) *Sociology of Health and Illness* 39, 95.

[193] Nuffield Council on Bioethics (n 11) 146.

[194] ibid.

[195] C Yates., ‘No other family should be put through our heartache’, *Daily Mail*, 5 September 2018.

parents and stressful for his clinicians.[196] The use of mediation in such cases was suggested by Francis J[197] and has received academic support,[198] Although it has been underused in the NHS due to a lack of awareness and dedicated funding mediation used successfully in other countries.[199] Currently, where mediation is used within the NHS, this may be informal or formal. The former involves issues being resolved within an NHS entity via PALS, a Complaints Team or an independent person or advocate.[200] Where a dispute cannot be resolved informally, it may go to formal mediation, although not all NHS entities offer this.[201] Nonetheless, there is increased interest in mediation across the NHS as a whole, as a potential means of reducing the costs of claims and disputes. For example, NHS Resolution (an arms-length body of the Department of Health and Social Care, which manages claims and disputes) committed to extending mediation in its five-year strategy published in 2017.[202]

In contrast to litigation, which is adversarial, inflexible, backward-looking, time-consuming, costly and results in an externally imposed judgment, mediation is consensual, flexible, forward-looking, relatively quick, relatively cheap and may lead to a mutually agreed solution.[203] The Department of Health awarded the Medical Mediation Foundation (MMF) a grant to pilot a mediation service.[204] In addition to legal

---

[196] J Bridgeman, 'Gard and Yates v GOSH, the Guardian and the United Kingdom: Reflections on the Legal Process and the Legal Principles' (2017) *Medical Law International* 17, 285.
[197] *Great Ormond Street Hospital* (n 2) [130].
[198] Wilkinson, Barclay and Savulescu (n 5).
[199] T Hamlin and T Leigh, 'NHS Complaints and why mediation matters', *Health Services Journal*, 15 March 2013.
[200] NHS England, *A Bite Size Guide to: Mediation between patients, carers and the NHS* (London: NHS England, 2016), 3
[201] ibid.
[202] NHS Resolution, *Delivering fair resolution and learning from harm: Our strategy to 2022 (London: NHS Resolution, 2017) 4.*
[203] S Meller and S Barclay, 'Mediation: an approach to intractable disputes between parents and paediatricians', 2011, *Archives of Disease in Childhood*, 96, 619.
[204] ibid.

reform to ensure that mediation is offered where contentious cases arise, MMF's work indicates that improved staff training may also ameliorate potential tensions. There is evidence that staff can be trained to focus on empathy and communication skills to enable them to more ably recognise conflict triggers and to de-escalate conflicts.[205] Such training has benefited staff at both Evelina Children's Hospital (part of Guy's and St Thomas' NHS Foundation Trust) in London and SGH.[206]

Lord Mackay and Baroness Hollins proposed an amendment to the Mental Capacity (Amendment) Bill,[207] to ensure that medical mediation be offered in contentious cases.[208] In addition, they proposed an amendment for the Secretary of State for Health and Social Care to make provision for all NHS bodies to have access to a Clinical Ethics Committee and to require certain cases (such as those where a dispute has arisen) to be referred to such committees.[209] Currently, in cases where there is a referral to such committees, there is variation in terms of patient involvement.[210] Consequently, thought should also be given as to how to improve the involvement of patients and their carers in the work of such committees. The proposed reforms are unlikely to be effected by the Mental Capacity (Amendment) Bill as Lord O'Shaughnessy (the Parliamentary Under Secretary of State at the Department of Health and Social Care) has advised that such reform is best pursued elsewhere[211]

---

[205] L Forbat, J Simons, C Sayer, M Davies and S Barclay, 'Training Paediatric healthcare staff in recognising, understanding and managing conflict with patients and families: findings from a survey on immediate and 6-month impact', 2016, *Archives of Disease in Childhood*, 102, 250.

[206] J Dreaper, 'Stopping conflict 'boiling over' at children's hospitals', *BBC*, 25 August 2017.

[207] [HL] 2017-19. This bill is primarily concerned with amending the Mental Capacity Act (2005) in respect of the procedures for which a person may be deprived of their liberty where they lack capacity.

[208] ibid Amendment 83(a).

[209] ibid Amendment 50(a).

[210] A Slowther, L McClimans, and C Price, 'Development of Clinical Ethics Services in the UK: A National Survey' (2012) *Journal of Medical Ethics* 38, 210.

[211] H.L. Deb. 15 October 2018, Vol.793, Col.387.

and the aforementioned proposal to substitute the best interests test with the significant harm test was not part of the amendments put forward. If the law is changed to ensure that mediation is offered where contentious cases arise in the future, this should ensure that such mediation is adequately funded and may prevent cases proceeding to court, a goal shared by those across the law reform debate in this area.

In respect of public involvement, as mentioned above, voice mechanisms within the NHS have been weakened in recent years. Beresford argues that attenuated government strategies for public feedback, such as consultations, are of limited effectiveness, tend not to be valued by service users and can discourage more effective involvement.[212] The government has recently conducted consultations on whether the NHS should continue to provide some treatments of questionable effectiveness[213] and on NHS reorganisation, via the development of Integrated Care Partnerships (ICPs).[214] Such consultations seem unlikely to enable the public to have a meaningful influence on the shape of the health service and the treatments it offers. In defending the current law, Close et al stated that it is "justifiable that resource trade-offs are left to administrative decision makers, rather than the courts".[215] In contrast, I contend that this task should not be left solely to administrators. Rather, as the Alma Ata Declaration stated, "people have the right and duty to participate individually and collectively in the planning and implementation of their health care".[216] Bhatia contends that both the medical and legal professions have been unwilling to take the

---

[212] Beresford (n 165) 266.

[213] NHS England et al, *Evidence-Based Interventions: Consultation Document* (London: NHS England, 2018).

[214] NHS England, *Draft ICP Contract: A Consultation* (London: NHS England, 2018).

[215] Close, Willmott and White (n 112).

[216] Declaration of Alma-Ata. *International Conference on Primary Health Care*. 1978. Alma-Ata, USSR: World Health Organisation, Article IV.

lead in meaningful dialogue in this area.[217] However, in contrast to Bhatia, who regards Parliament as the appropriate arena for such dialogue regarding resource realities,[218] I advocate democratisation of the NHS to empower patients to have more influence in this respect.

The NHS (Reinstatement) Bill, drafted by Allyson Pollock and Peter Roderick, which has been introduced in Parliament on several occasions, would, if enacted, re-establish CHCs within the NHS.[219] It would also restructure the NHS by replacing CCGs with Health Boards, to assess needs and plan services.[220] Although CHCs compare favourably to their aforementioned successors, they may not enhance democratic control within the service as this was not the intention behind their original creation in the 1970s.[221] Consequently, if CHCs are re-established, they should also be reformed to ensure that they are representative (one criticism of CHCs was that they were not sufficiently representative[222]) and given powers to effect wider changes in the health service (something which their previous incarnations had limited ability to do[223]). If a national association of CHCs were also re-established, it could co-ordinate public consultations regarding alterations to the structure of the NHS and the treatments that it provides. It would have the advantage of being a permanent body, in contrast to the aforementioned ad hoc consultations. The election of decision makers within the NHS has also been advocated as a means of democratising the

---

[217] Bhatia (n 113) 99.
[218] ibid 213.
[219] National Health Service H.C. Bill (2017-19) [250], cl.16.
[220] ibid cl.7.
[221] C Hogg, *The Public and the NHS* (London: Association of Community Health Councils for England and Wales, 1986) 33.
[222] V Navarro, *Class Struggle, the State and Medicine: An Historical and Contemporary Analysis of the Medical Sector in Great Britain* (Oxford: Martin Robertson and Co., 1978) 61.
[223] Mold (n 174) 43.

service.[224] Elections to re-established CHCs or Health Boards could stimulate democratic deliberation within the NHS and enhance social learning.[225] Ultimately, democratising the NHS could afford the public, informed by medical opinion and evidence, the opportunity to influence, through deliberation, what treatments (including experimental treatments when they arise) should be available. The pertinent questions of distributive justice raised by the Gard and Evans cases could thus be more clearly answered through the process of democratic deliberation before contentious individual cases arise. This would empower the public without contravening international law and may remove the need for court involvement, although, in some instances, clinicians may still retain discretion, hence the courts will have a role where disputes arise.

V. CONCLUSION

The Charlie Gard and Alfie Evans cases have led to calls for the reform of the law concerning disputes between parents and medical practitioners regarding the treatment of infants. I argued against the proposal to substitute the best interests test with a significant harm test for the following reasons: the change would make UK law incompatible with international law; parents are not always the best people to make decisions about their children's medical treatment (for example, because grief and hope may incline them to not accept the limits of medicine); reform could have adverse distributive consequences; and, the proposed change may ultimately be unworkable,

---

[224] See for example, F Messer, *The National Health Service: A Miracle of Social Welfare. Can it be saved?* (London: Co-op Political Committee, 1971) 12 and W Hutton, *New Life for Health: The Commission on the NHS Chaired by Will Hutton* (London: Vintage, 2000) 6.
[225] P Vincent-Jones, 'Embedding Economic Relationships through social learning? The Limits of Patient and Public Involvement in Healthcare governance in England', 2011, *Journal of Law and Society*, 38, 215.

if parents cannot find doctors to treat their children in accordance with their wishes. Although I argue that the current trend of the questioning of expertise may have pernicious consequences, I also concede that reforms are needed to empower patients and the public within the NHS. It is clear that the proposal to ensure that mediation is offered in cases where disputes arise could empower patients and their carers and that the NHS should be democratised to afford the public more say over its structure and the services it provides.