PARTICIPATION RIGHTS AND BEST INTERESTS OF THE CHILD: MEDIA INFLUENCE AND PARENTAL ADVOCACY IN END-OF-LIFE DECISIONS

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ABSTRACT

The high-profile cases of Alfie Evans and Indi Gregory highlighted disagreements between parents and medical authorities over ending the life of a very young child. Participation rights of these children were invoked by the parents, the medical and judicial authorities, and even by the media. In both cases, parents began a lively debate on the international public stage about children's rights and medical treatment, which amplified the pre-existing calls for law reform to give more weight to parents' views in critical medical decisions for their children. This research considers first, the participation rights of children in end-of-life decisions when children cannot speak for themselves, and second, the responsibility of the media in protecting the dignity of children when reporting on sensitive healthcare scenarios. While recognizing the responsibility of authorities to uphold the dignity of the child and the crucial role of parents, this research emphasizes the media's potential in advocating for public health reforms and its pivotal role in shaping the future of children's rights.

I.
BEST INTERESTS AND PARTICIPATION OF CHILDREN

The best interests principle is the cornerstone for protecting children's rights, especially within healthcare, ensuring that all decisions prioritize what benefits the child most. Without an extended reflection about the best interests principle and the rights of children, and without identifying the actors responsible for their well-being, it is not possible to protect the rights of children in healthcare. This reflection should be made to ensure better health and development for all children at a policy level and in healthcare practice and to protect the dignity of children, one of the most vulnerable minorities. Every child has unconditional human dignity as a universal human right due to their very existence. The parents, healthcare professionals and authorities should have always that in mind when they make decisions about or on behalf of the child. Dignity of the child "forces involved parties (parents, professionals, state, society) to disclose and moot their interests, values, and aims." Dignity can help from a theoretical point of view, but from a practical point of view, the best interest principle "can prove more useful."[1]

At a global and theoretical level, the best interests principle serves as a general framework advocating for a child-centered approach in policies and practices affecting children's lives.[2] But it is essential to note that this concept differs from legally defined standards, such as those used in U.S courts, where the best interest standard has specific legal criteria guiding decisions and depends on jurisprudence about children's welfare.[3] The English legal system, while likewise based on jurisprudence, also has a codified checklist of key factors for assessing children's well-being.[4]

Article 3 of the Convention on the Rights of the Child (CRC) articulates that the best interests of the child shall be a primary consideration.[5] Even though it is an indeterminate principle — meaning that determining the best interests of the child depends on the specific case and circumstances — the Committee on the Rights of the Child views it as an overarching or "umbrella" concept that encompasses all rights outlined in the Convention on the Rights of the Child.[6] Healthcare and children's rights are inherently connected, as safeguarding children's health requires that healthcare practices respect their rights and prioritize their best interests. Participation rights, articulated in Article 12 of the CRC, hold significant importance as one of the fundamental pillars, alongside the best interests of the child, within the framework of the CRC. Participation rights encourage children's involvement in decisions affecting them according to their age and understanding, including, importantly, healthcare issues. Article 12 establishes the right of the child who is capable of forming their own views to express those views freely in all matters affecting the child, giving due weight in accordance with their age and maturity.[7]

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[1] Jürg C. Streuli, Margot Michel & Effy Vayena, *Children Rights in Pediatrics*, 170 Eur. J. Pediatrics 9, 11 (2011).

[2] *See generally* Karl Hanson & Olga Nieuwenhuy, *A Child-Centered Approach to Children's Rights Law: Living Rights and Translations*, in THE OXFORD HANDBOOK OF CHILDREN'S RIGHTS LAW 100-118 (Jonathan Todres & Shani M. King eds., 2020).

[3] See, e.g., *Troxel v. Granville*, 530 U.S. 57 (2000); *Santosky v. Kramer*, 455 U.S. 745 (1982); *Stanley v. Illinois*, 405 U.S. 645 (1972); Uniform Marriage and Divorce Act 402 (Nat'l Conf. of Comm'rs on Unif. State L. 1970); Cal. Fam. Code 3011 (West 2024).

[4] *See* Children Act 1989, s 1. This checklist helps courts assess a child's well-being by considering key factors such as the child's needs (age, health, education, and emotional well-being), wishes and feelings based on maturity, the impact of any changes, parental capability to provide care, potential risks of harm, and the parents' willingness to cooperate and follow court orders.

[5] *Convention on the Rights of the Child*, art. 3, Nov. 20, 1989, 1577 U.N.T.S. 3. "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."

[6] U.N. Committee on the Rights of the Child, General Comment No. 14, ¶ 4, U.N. Doc. CRC/C/GC/14 (May 29, 2013).

[7] *Convention on the Rights of the Child*, *supra* note 5, at article 12.

Article 5 of the CRC is also important in cases where the child cannot express himself, as it asks for due respect to the rights and responsibilities of the parents to provide guidance in the exercise by children's rights, in accordance with the evolving capacities of the child.[8]

English case law initially recognized the view of the child in 1986 with the case Gillick v. West Norfolk and Wisbech Area Health Authority, through which the House of Lords established important criteria for the consent of minors to medical treatment.[9] One of the judges, Lord Scarman, stated that authorities should respect the views of those children who are capable of understanding or can at least give due weight to their decision.[10] The opinion recognizes the views of the child as part of a well-being principle.[11]

The participation rights of children extend to healthcare treatments without exception. Article 24 of the CRC states that children have the right to the highest attainable standard of health.[12] According to the CRC, the right to the highest standard of health, participation rights, and best interests of the child are intrinsically connected and indispensable for the enjoyment of all the other rights in the Convention. While health stands as one of the primary rights of the child, the right to be heard holds equal prominence.[13] Therefore, it is essential to integrate these two rights to uphold the best interest principle effectively.[14]

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[8] *Id.* at article 5.

[9] *Gillick v. West Norfolk & Wisbech Area Health Authority* [1986] AC 112 (HL). This case determined whether a child under 16 years old could consent to medical treatment without parent consent. Victoria Gillick, mother of five daughters, opposed UK guidelines allowing doctors to prescribe contraceptives to girls without parents' consent. The case determined that in some cases a child under 16 years old can consent to medical treatment (including contraception) without their parent's consent, if they have sufficient capacity and maturity.

[10] *Id.* at 188-89. "As a matter of law the parental right to determine whether or not their minor child below the age of 16 will have medical treatment terminates if and when the child achieves sufficient understanding and intelligence to understand fully what is proposed."

[11] *Id.*

[12] *Convention on the Rights of the Child*, *supra* note 5, at article 24.

[13] Comm. on the Rights of the Child, *General Comment No. 12: The Right of the Child to Be Heard*, U.N. Doc. CRC/C/GC/12 (July 20, 2009); Comm. on the Rights of the Child, *General Comment No. 15: The Right of the Child to the Enjoyment of the Highest Attainable Standard of Health (art. 24)*, U.N. Doc. CRC/C/GC/15 (Apr. 17, 2013); Comm. on the Rights of the Child, *General Comment No. 14: The Right of the Child to Have His or Her Best Interests Taken as a Primary Consideration (art. 3, para. 1)*, U.N. Doc. CRC/C/GC/14 (May 29, 2013).

[14] Comm. on the Rights of the Child, *General Comment No. 14: The Right of the Child to Have His or Her Best Interests Taken as a Primary Consideration (art. 3, para. 1)*, ¶¶ 43, 77, U.N. Doc. CRC/C/GC/14 (May 29, 2013).

II.

PARTICIPATION OF CHILDREN IN HEALTHCARE AND END-OF-LIFE DECISIONS

Participation rights of the child have been the "most revolutionary" part of the Convention.[15] In pediatrics, this right means that healthcare professionals "need to discuss child's care with the child as well as with parents" and obliges health professionals to take all actions with consideration for the best interests of the child. [16] But what happens when the child is unable to speak for himself and a decision must be made about healthcare treatment or even end-of-life decisions? Such were the cases of Alfie Evans, Indi Gregory and Charlie Gard. In cases like these, it is necessary first, to correctly inform the parents and secondly, to consider what is the best interests of the child, which in the case of United Kingdom, has a "paramount" level, over other interests. [17] As has been seen in these high-profile cases, this elevated consideration for the best interests of the child has led to bitter conflicts between parents and healthcare professionals when the child is incapable of consenting to medical decisions. The United Kingdom's Children Act 1989 enumerates a checklist that describes the main issues that the courts must consider when they make decisions related to children.[18] Even if strictly speaking it applies only to care orders,[19] it can be used also as a guideline in these cases, as the first point of this checklist states that the judge must take into account the wishes and views of the child according to their age and understanding, any harm which they have suffered or are at risk of suffering and the capability of the parents to meet the needs of the child.[20] Consolidated case law establishes that a child's best interests are determined by balancing the benefits of proposed treatment against its invasiveness, side effects and the resulting quality of life.[21] While there is a strong presumption in favor of preserving life, it is not absolute and, guided by the Supreme Court's decision in *Aintree v. James*,[22] courts evaluate decisions from the patient's

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[15] Streuli, Michel & Vavena, *supra* note 1 at 12.

[16] *Id.*

[17] Children Act 1989, *supra* note 4, c. 41, § 1(1).

[18] *Id.* The 'welfare checklist' is a key tool for resolution of private law disputes about children and permits that all relevant factors regarding the best interests of children are taken into account. The welfare checklist emphasizes the participation rights of children by directing that courts shall have regard in particular to the ascertainable wishes and feelings of the child concerned. When the checklist was initially approved, the parental role was predominant; however, Section 1(3)(a), which considers the wishes and feelings of children, has since gained greater importance. See more in F. Burton. *Family Law,* at 362 (2nd ed. 2015).

[19] Children Act 1989, *supra* note 4 at s. 31, c. 41 (establishing *care orders*, which allow local authorities to assume parental responsibility for a child who is suffering or likely to suffer significant harm).

[20] *Id.*

[21] Kevin De Sabbata & Abigail Pearson, *Indi Gregory: A Wider Perspective on Children's Best Interests at the End-of-Life*, 32 MED. L. REV. 255, 255 (2024).

[22] *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67; *Airedale NHS Trust v Bland* [1993] UKHL 17; *Manchester University NHS Foundation Trust v Fixsler & Ors* [2021] EWHC (Fam) 1426; *An NHS Trust v MB* [2006] EWHC (Fam) 507; *Wyatt & Anor v Portsmouth Hospital NHS & Anor* [2006] EWCA (Civ) 1181; *Re J (A minor) (Wardship: Medical Treatment)* [1991] 1 Fam 33.

assumed perspective, recognizing that best interests extend beyond medical factors. Parental views are given importance but may be influenced by emotional distress. In disputes between parents and medical professionals, courts generally favor the latter.[23]

Children, especially those of young ages with severe, life-limiting conditions, are particularly vulnerable. For this reason, every action and decision concerning them must be approached with the utmost care and compassion. Although they may not be able to articulate their views vocally, research suggests that even newborns can express comfort or pain through crying or survival-oriented actions.[24] Regardless, their perspectives are typically conveyed through parents, caregivers, authorities and healthcare providers.[25] Therefore, to uphold the participation rights of very young children in healthcare, it is essential for adults to prioritize the child's well-being and consider their perspective. Additionally, it is crucial for authorities and doctors to respect the values of the family and consider the child's specific circumstances.[26]

III.

PARENTAL ROLE IN END-OF-LIFE DECISIONS

An end-of-life decision is one made "as foregoing life-sustaining medical treatment (LMT) either by withdrawing or withholding."[27] End-of-life decisions can include withdrawing or withholding medical treatment, such as in cases of coma with no hope of recovery, or discontinuing nutrition and hydration. Another common decision is palliative sedation, which alleviates pain and suffering in terminally ill patients without hastening death.[28] In all jurisdictions, the decision should always be in the best interests of the patient and includes considering risks, burdens and benefits of the treatment.[29]

The CRC protects families from unjust state interference, ensuring that children have the right to parental guidance as well as state protection if parents fail to provide adequate care.[30] Parental responsibility is crucial for end-of-life decisions regarding

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[23] De Sabbata & Pearson, *supra* note 21 at 255.

[24] Priscilla Alderson, Johanna Hawthorne & Margaret Killen, *The Participation Rights of Premature Babies*, in *Children's Rights: Progress and Perspectives: Essays from the International Journal of Children's Rights* 31, 39 (Michael Freeman ed., 2011).

[25] *Id.* at 44.

[26] *Id.* at 43.

[27] Jane Sullivan, Lynn Gillam & Paul Monagle, *Parents and End-of-Life Decision-Making for Their Child: Roles and Responsibilities*, 5 BMJ Supportive & Palliative Care, 240 (2015).

[28] Kathryn L. Weise, Alexander L. Okun, Brian S. Carter & Cindy W. Christian, *American Pediatric Association, guidance on forgoing life sustaining medical treatment*, *Pediatrics*, vol. 140, no. 3 (2017) at 2.

[29] *Id.* at 2. See also UK General Medical Council, *Treatment and care towards the end of life: good practice in decision making*, at 92, https://www.gmc-uk.org/-/media/documents/treatment-and-care-towards-the-end-of-life---english-1015_pdf-48902105.pdf (last visited Nov. 23, 2024).

[30] Committee on the Rights of the Child, *General Comment No. 20*, U.N. Doc. CRC/C/GC/20 (2016) at 19.

a small child. The CRC states in Article 18 that parents and legal guardians have the primary responsibility for the upbringing of their children and that parents should ensure their children's rights are respected. According to the CRC, parents should take all appropriate measures to protect their children's best interests. Only if parents fail to protect their child's best interests should authorities should intervene to ensure the safety and well-being of the child.[31] Parental responsibility is not a power, but a duty to protect the best interests of the child and to contribute to their development; this duty is recognized both by the CRC[32] and several jurisdictions, including the United Kingdom.[33] When a child is unable to express themselves, parents are usually the primary decision-makers on their behalf, though not the only ones. This responsibility is based on their duty to protect the child's well-being and support their development, with authorities stepping in only when the child's best interests are at risk.[34]

In the cases of Alfie Evans and Indi Gregory, parents and doctors disagreed about continuing medical treatment, leading to disputes over the decision to end these children's lives against the will of the parents. Precedential cases included *Great Ormond Street Hospital for Children NHS Foundation Trust v. Yates* [35] and *King's College Hospital NHS Foundation Trust v. Haastrup*,[36] which similarly involved disputes over the best interests of the child in end-of-life situations among parents, doctors and courts. All four cases were brought before the High Court in England and Wales, where the opinion of medical professionals played a crucial role in the decision-making process of the High Court.

In each instance, the court ruled against the parents and in favor of the medical professionals' opinion to withdraw life-sustaining treatment or transition to

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[31] Convention on the Rights of the Child, *supra* note 5, arts. 18 and 19.

[32] Convention on the Rights of the child, *supra* note 5. See also *General Comment No 20, supra* note 30, at 19; Committee on the Rights of the Child, General Comment No. 8, *The Right of the Child to Protection from Corporal Punishment and Other Cruel or Degrading Forms of Punishment (arts. 19; 28, para. 2; and 37, inter alia)*, U.N. Doc. CRC/C/GC/8 (Mar. 2, 2007) at 13.

[33] Children Act 1989, *supra* note 4, at c. 41, s 3 (3).

[34] See David Archard, Emma Cave & Joe Brierley, *How Should We Decide How to Treat the Child: Harm Versus Best Interests in Cases of Disagreement*, 32 Med. L. Rev. 158 (2024); Cressida Auckland & Imogen Goold, *Parental Rights, Best interests and significant harms: Who should have the final say over a child's medical care?*, 78 Cambridge L.J. 287, 288 (2019); NUFFIELD COUNCIL ON BIOETHICS, *CRITICAL CASE DECISIONS IN FOETAL AND NEONATAL MEDICINE: ETHICAL ISSUES* 4 (2006).

[35] *Great Ormond Street Hosp. for Children NHS Found. Tr. v. Yates*, [2017] EWHC (Fam) 972 (Eng.) This case involved a legal battle over the life support treatment of Charlie Gard, a critically ill child with a mitochondrial disease. His parents fought to have him transferred to the United States for experimental treatment. UK courts ruled that the treatment would not benefit Charlie and would only prolong his suffering. The courts ultimately found that Charlie's best interests were best served by allowing him to die. He died in July 2017.

[36] *King's Coll. Hosp. NHS Found. Tr. v. Haastrup*, [2018] EWHC (Fam) 127 (Eng.). Isaiah Haastrup had severe brain damage due to a birth complication. Doctors of the King's College Hospital thought that further treatment would not improve his condition and advised ending life support treatment. The parents went to court, but the judge ruled that the treatment should be withdrawn, as further treatment would continue Isaiah's suffering. The parents were forced to accept the decision, and Isaiah passed away in February 2017.

palliative care. The High Court applied the best interests principle, focusing on factors such as the potential of recovery, the level of pain and suffering and the overall quality of life. Alfie Evans suffered from an undiagnosed neurodegenerative condition. Born in 2016, Alfie's condition began to deteriorate in December 2016. In February 2018, Alder Hey Children's Hospital, where Alfie was receiving treatment, asked the courts to withdraw his life support. Alfie's parents disagreed with the hospital's decision and fought a legal and media battle to keep their son alive and continue his life support.[37] The case garnered widespread public attention due to the parents' advocacy in the media, initially asking the courts and the hospital to maintain Alfie's life support and, at a second stage, asking permission to transfer him to Rome for further treatment. However, the High Court ultimately sided with the hospital,[38] agreeing that continued treatment would be 'futile' and not in Alfie's best interest, due to the extent of his brain damage.[39] Consequently, the court ruled that life support – including oxygen-support and feeding tubes – could be withdrawn.[40] Alfie Evans passed away four days after the removal of artificial ventilation at the age of 23 months.[41]

The case of Indi Gregory[42] is similar to Alfie Evans case, but occurred more recently, in 2023. Indi had a mitochondrial genetic condition and required life support to survive. Doctors recommended withdrawing life-sustaining treatment, considering it would only prolong her suffering without hope of improvement and that it would be in her best interests to receive palliative care. Parents opposed this decision, advocating for continuing the life-sustaining treatment and considering the possibility of transferring Indi to Italy, where the Bambino Gesu Hospital in Rome had offered to continue treatment. However, the High Court ruled against the parents and ordered that Indi be transferred to a hospice to receive palliative care. Indi died on November 13, 2023.[43]

The cases of both Alfie and Indi involve children who were too young to speak for themselves, and therefore depended on the parents and the healthcare system to make decisions for them. Also, their conditions were so severe that the decision was between life – with a very complex situation for the child – and death.

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[37] *Evans v. Alder Hey Children's NHS Foundation Trust*, [Feb. 20, 2018] EWHC 818 (Fam).

[38] See *id.* at 25.

[39] *Id.* at 66.

[40] *Id.*

[41] David Benbow, *An analysis of Charlie's Law and Alfie's Law,* 28 Med. L.Rev. 223, 232 (2020).

[42] *Nottingham University Hospitals NHS Foundation Trust v. Indi Gregory and others* [2023] EWHC 2782 (Fam). *See also* reports made by BBC, Indi Gregory: Critically ill baby dies after life support turned off, https://www.bbc.com/news/uk-england-derbyshire-67400915 (last visit, July 11, 2024)

[43] Greig Watson & PA News, *Indi Gregory: Latest End of Life Care Appeal Turned Down*, BBC News (Nov. 10, 2023), https://www.bbc.com/news/uk-england-derbyshire-67378132 (last visited Nov. 23, 2024); J. Halliday, *Indi Gregory, Baby Girl at Centre of Legal Battle, Dies after Life Support Removed*, The Guardian (Nov. 13, 2023), https://www.theguardian.com/uk-news/2023/nov/13/indi-gregory-baby-girl-at-centre-of-legal-battle-dies-after-life-support-removed (last accessed Feb. 2, 2025); see also De Sabbata & Pearson, *supra* note 21 at 7.

Both cases sparked bitter debates, not only in the media but also in academia about parental rights, the best interests principle and the role of healthcare professionals and the courts in making decisions about the care of severely ill children.[44] In both cases – and others that happened before and after – parents, courts and healthcare professionals were scrutinized by the public. Some people felt that the state interfered greatly with parental responsibility and the freedom of the parents to decide for their children, in end-of-life decisions.[45] Newspaper reports demonstrate that the debate was emotionally driven and superficial, with little to no reflection about the condition of those children, the situation of the parents and the rights of the children, including children's right to life and the best interests principle.[46] The media coverage of the Alfie Evans and Indi Gregory cases often employed emotionally charged language, framing the situations as "battles" between parents and medical authorities.[47] This portrayal positioned grieving parents as

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[44] Richard Peña, *Fight Over Alfie Evans, a Brain-Damaged Baby, Divides U.K.*, N.Y. Times (Apr. 26, 2018), https://www.nytimes.com/2018/04/26/world/europe/alfie-evans-doctor-parents.html (last visited Nov. 23, 2024); Alison Shepherd, *Anger as Alfie's Army Protests Outside Alder Hey*, BMJ, Apr. 25, 2018, at 361; Eleanor Steafel, *The Full Heart-Wrenching Case of Alfie Evans and the Journey That Led His Parents to a Dramatic U-Turn*, Telegraph (Apr. 27, 2018), https://www.telegraph.co.uk/news/2018/04/26/tragic-case-alfie-evans-parents-wont-allowed-take-home-die/ (last visited Nov. 23, 2024); Will Jefford, *Indi Gregory: Critically ill baby dies after life support turned off*, BBC (Nov. 13, 2023), https://www.bbc.com/news/uk-england-derbyshire-67400915 (last visited Nov.24, 2024); Kevin De Sabbata & Abigail Pearson, *Indi Gregory: A Wider Perspective on Children's Best Interests at the End-of-Life*, 32 Med. L. Rev. 255, 255–63 (Spring 2024); *see also* Dominic Wilkinson, *In Defense of a Conditional Harm Threshold Test for Paediatric Decision-Making, in* Parental Rights, Best interests and Significant Harms: Medical Decision-Making on Behalf of Children Post Great Ormond v. Yates 1. 85. (Imogen Goold, Jonathan Herring & Cressida Auckland eds., Hart Publishing 2019); Benbow, *supra* note 41.

[45] See Auckland & Goold, *supra* note 34, at 314; Richard Hurlley, *How a fight for Charlie Gard became a fight against the state*, 358, BMJ 1 (2017).

[46] See Udo Schuklenk, *Bioethics Culture Wars – 2018 Edition: Alfie Evans*, 32 Bioethics 270, 270–71 (2018); Brian Farmer, *Judge Considers Where Critically Ill Baby Should Receive 'End of Life' Care*, The Independent (Nov. 7, 2023), https://www.independent.co.uk/news/uk/crime/alfie-evans-giorgia-meloni-high-court-justice-court-of-appeal-b2443098.html (last visit, Nov. 23, 2024); Laura Smith-Spark, *British toddler Alfie Evans dies after life support is withdrawn*, CNN (April 28, 2018) https://edition.cnn.com/2018/04/28/health/alfie-evans-british-toddler-dies-intl/index.html (last visited Aug. 19, 2024); Ajay Nair, *Judge warns of 'darker side' to Alfie Evans support as police issue warning*, Sky News (Apr. 27, 2018) https://news.sky.com/story/judge-warns-of-darker-side-to-alfie-evans-support-as-police-issue-warning-11346684 (last visited Nov. 19, 2024); Sophie Evans, *Alfie Evans Dead: Supporters Fill Skies with Balloons in Emotional Tribute to Toddler Five Days After Life Support Machine Switched Off*, The Mirror (Apr. 28, 2018), https://www.mirror.co.uk/news/uk-news/breaking-toddler-alfie-evans-dead-12412650 (last visited Nov. 13, 2024).

[47] *How parents fought to save Alfie*, Sky News (April 28, 2018), https://news.sky.com/story/timeline-the-fight-to-keep-alfie-evans-alive-11344694#:~:text=Alfie%27s%20parents%20argue%20he%20is,decisions%20of%20Mr%20Justice%20Hayden (last visit, Feb. 2, 2025); Rachel Burnett, *The heartbreaking life of Alfie Evans: How sick toddler became centre of one of most tragic legal battles in history*, The Mirror (April, 24 2018), https://www.mirror.co.uk/news/uk-news/heartbreaking-life-alfie-evans-how-12419455 (last visit, Feb. 2, 2025).

"tigers" opposing the State,[48] a narrative amplified through news outlets and social media platforms.

Participation rights of the children in cases like these are limited. A doctor stated regarding Alfie's case, "I believe that is it unlikely that Alfie feels pain or has sensation of discomfort, but I cannot be completely certain of this since Alfie has no way of communicating…"[49] Therefore, participation rights in such cases were exercised by parents, healthcare professionals and even the wider public. By advocating for Alfie's life, the media, Alfie's parents and the public perceived themselves as the 'voices' representing these vulnerable children. People posted statements on social media and considered themselves to be 'Alfie's Army,' who stood in front of the Alder Hey Hospital to protest against the doctors.[50] Similarly, the courts and the hospital also took on this responsibility.

Due to the recurrence of such cases as Alfie's and Indi's – and before, those of Charlie Gard and Isaiah Haardrup – coupled with intense media scrutiny, there has been increased public debate and calls for legal reforms.[51] The main proposal came from Charlie's and Alfie's parents, who advocated for reforming the law to outline the rights of parents in these situations. The bill was proposed to the House of Commons by the laborist Bambos Charalambous in 2020 as the Children (Access to Treatment) Bill.[52] The COVID pandemic shifted legislative priorities, but advocacy continues from parents, including those of Charlie Gard (organized through Charlie Gard Foundation), Alfie Evans and Indi Gregory.

Other advocates have also called for clearer guidelines outlining the rights of parents in making decisions for their children, especially in situations where there is disagreement between parents and doctors.[53] Proposed changes, dubbed 'Alfie's Law' or 'Charlie's Law,' include:

- **Clarifying the circumstances under which life-sustaining treatment can be withdrawn**. The proposed legal reform replaces the best

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[48] *See, ex.*, Gaby Hingig, *Alfie Evans' parents needed help. The vultures came instead*, The Guardian (April 26, 2018), https://www.theguardian.com/commentisfree/2018/apr/26/alfie-evans-parents-activists (last visit, Feb. 2, 2025) (Alfie's parents "fought like tigers both in and out of court").

[49] *Evans v. Alder Hey Children's NHS Foundation Trust v. Evans*, [Feb. 29, 2018] EWHC 308 (Fam) at 9.

[50] BBC News, *Who are Alfie's Army?* (April, 25, 2018), https://www.bbc.com/news/av/uk-43894293 (last visit, Feb. 2, 2025).

[51] Catherine Burns, *Charlie Gard's Parents Want "Charlie's Law"*, BBC News (Jun. 20, 2018) https://www.bbc.co.uk/news/health-44334306 (last visited Aug. 19, 2024); Holly 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?*, The Sun (Sept. 3, 2018) https://www.thesun.co.uk/news/6156576/alfies-law-charlies-law-rights-parents-care-alfie-evans-charlie-gard (last visited Aug. 16, 2024).

[52] *Children (Access to Treatment) Bill*, Private Members' Bill (Presentation Bill), Session 2021-22, H.C. Bill (UK Parliament 2021), https://hansard.parliament.uk/commons/2020-03-18/debates/845228D6-29F8-49DE-B074-67B7021B89FE/Children(AccessToTreatment).

[53] Clare Dyer, *Alfie Evans case: Proposed law aims to prevent conflicts between parents and doctors*, 361 BMJ 1895 (2018).

interests test with a harm test.[54] Some authors believe that this proposal contradicts all European standards of medical practice, as it replaces the principle of best interests with the harm test, which is still under study. This approach goes against the traditional standard in Europe and is not included in international frameworks.[55] While the harm test is considered in certain ethical and legal contexts, it is not universally adopted in international medical practice guidelines, such as in the UNESCO Universal Declaration on Bioethics and Human Rights, where the principle of best interests remains predominant.[56]

- **More cooperation between parents and healthcare providers** and the option to go to mediation on disputes to determine the best outcome for the child. However, the primary focus of the proposed law is to ensure that the parents' voices are heard and to guarantee that they are the final decision-makers.[57]
- **Establish independent review** processes for disputed medical decisions.[58]

To support the proposed legal reform, the media played a key role in highlighting the need for change, shaping public opinion and influencing both parents and policymakers. This connection between media coverage and legal reforms mirrors the broader role the media plays in shaping health policies and on the participation rights of children.

IV.

THE IMPACT OF MEDIA ON HEALTH POLICIES AND CHILDREN

During the pandemic, we saw how the media can be important to spread awareness about the situation of the medical system and to inform the public about the limits and rules of healthcare regulations and policies. We also saw, through COVID, the need to adjust protocols and policies to account for the real needs of citizens and to develop policies that prevent problems before they start and solve problems that already exist.

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[54] *Children (Access to Treatment) Bill*, *supra* note 52; Wilkinson, *supra* note 44 at 84; Carlo Bellieni, *The Pain Principle: An Ethical Approach to End-of-Life Decisions.* 36. Ethics & Med. 41, 43 (2020); Douglas Diekema, *Parental refusals of medical treatment: the harm principle as threshold for state intervention*. 25. Theor. Med. & Bioethics, 243, 250 (2004).

[55] Benbow, *supra* note 41, at. 235. *See also*, Nuffield Council on Bioethics, *supra* note 34 at 47.

[56] *See* UNESCO, Universal Declaration on Bioethics and Human Rights, art. 6, at 1 (Oct. 19, 2005).

[57] Raanan Gillon, *Why Charlie Gard's parents should have been the decision-makers about their son's best interests*, 44 J. Med. Ethics, 462 (2018); Lynn Gillam, *The zone of parental discretion: An Ethical Tool for Dealing with Disagreement Between Parents and Doctors about Medical Treatment for a Child',* 11 Clin. Ethics, 1 (2016); Sullivan, Gillam and Monagle, *supra* note 27, at 242.

[58] *Children (Access to Treatment) Bill*, supra note 52.

Media advocacy is an instrument to advance these goals. Through reporting, the press can transform public views in society about health issues and promote legislation and policies,[59] as we have seen during the pandemic.[60] The cases involving Alfie Evans and Indi Gregory – as well as others, like that of Charlie Gard – sparked controversy; media coverage of them highlighted the young age of the children and the challenges faced by their parents.[61] Faced with a lack of support from the judiciary, parents sought to amplify the voices of their children through the media. Given the significant influence of traditional media in shaping public opinion, parents turned to this platform, as well as social media, in an attempt to ensure their children's voices were heard. While in 2017 there were 78 media reports on Alfie's case, in 2018 the number of reports exploded to 3,000, most of them in the last weeks of Alfie's life,[62] some stemming from parental advocacy in social media and the fight between parents and medical professionals in the courts in a very brief period of time.[63]

Media advocacy highlights the political and social issues that need attention, and "agenda setting" and "framing" are key communication theories[64] that explain how mass media influence public opinion by focusing on these issues. The theory of agenda setting suggests that the media determine what society discusses by

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[59] Lori Dorfman & Ingrid Daffner Krasnow, *Public Health and Media Advocacy*, 35 Ann. Rev. Pub. Health 293, 295 (2014).

[60] *See generally* Katharine J. Mach, Raúl Salas Reyes, Brian Pentz, Jennifer Taylor, Clarissa A. Costa, Sandip G. Cruz, Kerronia E. Thomas, James C. Arnott, Rosalind Donald, Kripa Jagannathan, Christine J. Kirchhoff, Laura C. Rosella & Nicole Klenk, *News Media Coverage of COVID-19 Public Health and Policy Information*, 8 Humanities & Soc. Sci. Communications, 220 (2021).

[61] See media reports highlighting Alfie Evans and Indi Gregory were toddlers, in Joshua Taylor, *Alfie Evans' parents beg people to stop spreading 'nasty rumours' after distressing reports in Italian press* (May 2, 2018), https://www.mirror.co.uk/news/uk-news/alfie-evans-parents-beg-people-12466045 (last visited Nov. 24, 2024); Sarah Pulliam Baley, *Alfie Evans, the sick British toddler at the center of a fierce legal battle, has died*, The Washington Post (Apr. 28, 2018), https://www.washingtonpost.com/news/acts-of-faith/wp/2018/04/28/alfie-evans-the-sick-british-toddler-at-the-center-of-a-fierce-legal-battle-has-died/; George Torr & PA News Agency, *Indi Gregory: Critically Ill Baby Girl Is Dying, Judge Told*, BBC News (Oct. 9, 2023), https://www.bbc.com/news/uk-england-derbyshire-67054598 (last visited Nov. 24, 2024).

[62] Research made through Factiva and Dow Jones; see also, e.g., *Alfie Evans: Legal battle toddler dies*, BBC (April 28, 2018) https://www.bbc.com/news/uk-43933056 (last visited Aug. 20, 2024); Laura Smith-Spark, *supra* note 46; *Der kleine Alfie Evans ist tot – monatelang hatten seine Eltern für seine Weiterbehandlung gekämpft*, Neue Zürcher Zeitung (Apr. 28, 2018) https://www.nzz.ch/panorama/todkrankes-britisches-kleinkind-alfie-evans-gestorben-ld.1381606 (last visited Aug., 20 2024); Luigi Ippolito, *Alfie Evans è morto. Il padre su Facebook: «Il mio piccolo gladiatore è volato via»*, Corriere della Sera (Apr. 18, 2018) https://www.corriere.it/cronache/18_aprile_28/alfie-evans-morto-annuncio-genitori-facebook-2d718c8e-4aa8-11e8-a20b-2428d6d2b4b0.shtml (last visited Aug. 20, 2024).

[63] Ranjana Das, *Alfie's Army, misinformation and propaganda: The need for critical media literacy in a mediated world*, (Apr. 30, 2018), https://blogs.surrey.ac.uk/sociology/2018/04/30/alfies-army-misinformation-and-propaganda-the-need-for-critical-media-literacy-in-a-mediated-world/ (last visit, Nov. 24, 2024)

[64] Agenda setting and framing are the primary communication theories regarding how mass media influence public opinion. *See* Walter Lippmann, *Public Opinion*, 13-17 (Macmillan Co. 1957) (1922); Maxwell McCombs, *Setting the agenda: the mass media and public opinion* 5, 81 (2d ed. 2014).

highlighting stories and events that affect society and policymaking. Framing refers to the perspective or context the media use when covering an issue, emphasizing its effects, causes and accountability. In the cases of Alfie Evans, Indi Gregory, and Charlie Gard, parental advocacy, coupled with extensive media coverage, played a critical role in driving legislative changes within the legal frameworks governing these complex situations. These cases, marked by intense public scrutiny, underscored the challenging dynamics between parents, healthcare providers and legal authorities when determining the best course of action for critically ill children. Social media emerged as a particularly influential platform, amplifying the voices of parents and supporters, which allowed for widespread dissemination of their messages, even internationally. This action on social media and its broad impact shaped public opinion on child welfare issues, complementing the influence of traditional media outlets. The convergence of both social media and traditional media ensured that the concerns and perspectives of parents were not only heard but also resonated with a global audience, thereby influencing the broader debate on the rights of parents in making end-of-life decisions.

However, the portrayal of ill children in the media often tends to be superficial and emotionally charged, as noted *supra*, and can lead to misunderstandings.[65] Therefore, policymakers and institutions must be cautious not to be swayed by the emotions stirred by media coverage in these cases and should focus on how policies can better serve the interests of the child. A study of pediatric healthcare trainees revealed that, regarding press and social media involvement in these high-profile cases, incoming healthcare professionals feel vulnerable and think that public discourse can lack an understanding of medical facts.[66] Many healthcare professionals have called for more targeted communication and mediation training, as well as enhanced education in legal and ethical issues, to better navigate challenging conversations with parents and avoid conflict with them.[67]

Reporting these cases, the media actively shaped the narrative around parental involvement in critical medical decisions, bringing to the public the complex ethical implications of these decisions and prompting a reevaluation of existing policies and protocols.[68] Specifically because of social media and traditional media attention,

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[65] *See* Ian Freckelton, *Responding better to desperate parents: Warnings from the Alfie Evans Saga*, 25 J. L. & MED. 899, 918 (2018).

[66] *See* Clare Bell, Mariana Dittborn & Joe Brierley; *What is the impact of high-profile end-of-life disputes on Pediatric Intensive Care trainees?*, 108 ARCHIVES OF DISEASE IN CHILDHOOD 719, 723 (2023).

[67] *Id*. at 721.

[68] The 'Alfie's Law' and the reevaluation of the best interests standard are clear examples of this phenomenon. Another important example is the reconsideration of health and work policies during the COVID-19 pandemic and how the media must address health policies in a way that the public can understand. *See generally* S. Ternullo, *"I'm Not Sure What to Believe": Media Distrust and Opinion Formation During the COVID-19 Pandemic*, 116 *Am. Pol. Sci. Rev.* 1096, 1096–1109 (2022); Lina Vyas, *"New Normal" at Work in a Post-COVID World: Work–Life Balance and Labor Markets*, 41 *Pol'y & Soc'y* 155, 155–67 (2022). Bell et al, *supra* note 66.

academics and policy-makers began to seek changes in health policy,[69] which before was not a pivotal issue.[70] This focus on the role of parents in end-of-life decisions significantly contributed to the development of proposed legal reforms aimed at ensuring that parental input is adequately considered in similar cases and to greater academic discussion about mediation in end-of-life decisions.[71] The debate regarding Alfie Evans and other children in similar situations also led to a greater debate about the balance between parental responsibility, medical expertise and the child's best interests.[72] This discussion influenced legislative efforts to address these sensitive situations with more clarity and compassion. The media's role was pivotal in raising awareness and fostering greater public discussion on the topic, which ultimately could contribute to shaping policy changes aimed at better protecting children's best interests and amplifying parents' wishes. Media could also amplify family values, promoting parents as the main parties responsible for children and those who will be most affected by the consequences of their decisions.[73]

In fact, the emphasis on respecting family values is one of the primary changes proposed under the reforms informally referred to as 'Alfie's Law' or 'Charlie's Law.' The initiative aims to avoid bitter disputes and acknowledge that parents are responsible for their children and consider their voices to be primary because they are children's legal guardians. As some authors state, parents often are better situated than others to make decisions about the child, as they "understand the unique needs" of their children.[74]

Effective media advocacy is not only about informing the public, but also targets a specific, much smaller audience of policy makers.[75] Targeting policy makers, such as healthcare professionals and courts, can be a crucial aspect of this advocacy, particularly in cases like those of Alfie Evans and Indi Gregory. In those instances, the parents became advocates not only for their own children but also for broader policy changes that could benefit others facing similar challenges. By sharing their personal stories through the media, they garnered public support and brought attention to the issues at hand. Additionally, they engaged directly with

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[69] Wilkinson, *supra* note 44 at 85; Bellieni, *supra* note 52 at 43; Peña, *supra* note 44; De Sabbata & Pearson, *supra* note 21, at 260.

[70] For precedents prior to Charlie Gard case, Rosalind McDougall & Lauren Notini, *Overriding Parents' Medical Decisions for Their Children: A Systematic Review of Normative Literature*, 40 *J. Med. Ethics* 448, 448–52 (2014).

[71] See Bell et al, *supra* note 66; Wilkinson, *supra* note 44.

[72] Peta Coulson-Smith, Angela Fenwick & Anneke Lucassen, *In Defense of Best Interests: When Parents and Clinicians Disagree*, 18 Am. J. Bioethics 67, 67–69 (2018); Rosalind McDougall, *Identifying Who and What, Then How: Attending to the Role of Decision-Maker in the Normative Debate About the Best Interests Standard*, in *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* 5, 5-16 (Imogen Goold, Cressida Auckland & Jonathan Herring eds., Oxford Univ. Press 2020).

[73] *See* Auckland & Goold, *supra* note 34, at 310, 314.

[74] Diekema, *supra* note 54 at 244; *see also* Rob Heywood, *Parents and Medical Professionals: Conflict Cooperation and Best Interests*, 20 Med. L. Rev. 29, 34 (2012).

[75] Dorfman & Daffner, *supra* note 59, at 295.

policymakers, advocating for legislative changes or improvements in healthcare practices.[76]

The tragic outcomes in the cases of Alfie Evans and Indi Gregory highlight the importance of media advocacy in raising awareness and advocating for change. While the parents' efforts did not lead to immediate policy changes, they contributed to ongoing discussions and attempts to improve healthcare systems and support families facing similar circumstances in the future, such as the Health and Care Act 2022. Section 177 of the Act is immediately related to Alfie and Indi's cases, as it mandates a review by the authorities into disputes between parents and medical professionals regarding the treatment of critically ill children.[77] If a policy change emphasizing mediation between parents and doctors and refining the "best interests" standard were introduced earlier, it could have significantly benefited critically ill children in disputes like those seen in the Alfie Evans or Indi Gregory cases. These changes could ensure more collaborative decision-making processes, reduce the emotional toll of legal battles, and prioritize both the medical needs and emotional well-being of the child. By fostering understanding and agreement through mediation, such a policy might align parental aspirations with medical expertise, ultimately improving outcomes and protecting vulnerable children.

However, to balance the participation rights of the child and the best interests principle, media outlets should strive to delve deeper into welfare issues, providing more comprehensive and nuanced coverage about children to foster a better understanding among the public. Media can play a crucial role in ensuring children's participation in discussions about their welfare by adopting practices that prioritize the child's perspective. For children old enough to articulate their views, journalists can highlight their voices in a sensitive and ethical manner. This involves framing news stories with the child's experience at the center, respecting their autonomy, portraying their perspectives accurately, and advocating for more child–centric solutions.

V.

POLICIES, PARENTS AND MEDIA: FOR THE BEST INTERESTS OF THE CHILD

Parental and media advocacy should be thought of as a part of the participation rights of children, because these channels do not just deliver a message; they also amplify voices in a democratic process and leverage policy to change systems and conditions.[78]

As we have seen, in end-of-life decisions and high-profile cases in healthcare, some actors play a large role in defending children's participatory rights. In the cases

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[76] See proceedings before *Children (Access to Treatment) Bill*, Private Members' Bill (Presentation Bill), Session 2021-22, H.C. Bill (UK Parliament 2021); *Children (Access to Treatment) Bill, supra* note 52, at c. 31, § 177 (UK).

[77] Health and Care Act 2022, c. 31, § 177 (UK).

[78] Dorfman & Daffner, *supra* note 59, at 295.

of Alfie Evans and Indi Gregory, while the children themselves may have been too young to directly articulate their preferences, the concept of children's participation still holds relevance. Here, parents sought to represent the best interests of their children, striving to ensure that their voices, though implicit, were heard and respected in decisions concerning their care. However, parents, media and other actors that amplify the perspectives of children must be careful to consider all factors regarding the case when deciding how to articulate and defend the wishes of the child.

The media's role in amplifying the perspectives of parents and advocates can indirectly contribute to fulfilling the child's right to participation and therefore, the best interests of the child. As the CRC already pointed out, participation rights are part of the best interests of the child and contribute to the fulfilling of the principle.[79] By bringing attention to the experiences and wishes of children – often by giving a platform to parents, caregivers or legal representatives – the media play a vital role in ensuring that the children's wishes are considered within the broader public discourse surrounding such cases. Through extensive coverage, investigative journalism, and the amplification of a wide range of voices, the media act as a powerful tool in raising awareness, fostering public debate, and advocating for policies that protect and promote the rights of children.

The Alfie Evans and Indi Gregory cases, which captured widespread media attention, are prime examples of how media coverage can influence public opinion and, more importantly, policymaking. These cases were not only instrumental in raising awareness about ethical dilemmas faced by families and healthcare professionals, but also in highlighting the urgent need for legislative changes. The subsequent promotion of legislative reforms aimed at fostering collaboration between families and healthcare professionals in resolving disagreements underscores the media's paramount role in safeguarding children's rights. This is especially important in ethically sensitive situations, where children's welfare is at stake. The media's influence in these areas serves as a powerful testament to its capacity to drive social change and ensure that the rights and voices of children remain central to public discourse.

The media play a vital role in advocating for children's rights to occupy an active role in shaping public understanding and policy discussions. By shedding light on these complex cases, presenting different perspectives, and encouraging dialogue between stakeholders such as policymakers, medical professionals, families, and the public, the media ensure that children's voices are heard and their rights are protected. Their ongoing coverage promotes an informed and compassionate approach to children's rights, underscoring the media's indispensable role in influencing public opinion and safeguarding ethical standards in child welfare.

Recognizing the participation right of children goes beyond direct engagement with children but also needs to incorporate diverse avenues for their voices to be

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[79] Committee on the Rights of the Child, *supra* note 6.

heard, including through parents, caregivers, and advocates. This approach fosters a more inclusive dialogue on children's rights, ensuring their needs are respected even when they personally cannot articulate them. Media organizations take profound responsibility in shaping these conversations, not as passive observers but as active champions of children's rights. By prioritizing the best interests of the child, they can influence policy discourse, protect children's dignity, and become catalysts for progress in creating a society that values the well-being and voice of its most vulnerable members.