

Nuffield Council on Bioethics

LITERATURE REVIEW

**Disagreements in the Care of Critically Ill Children: Causes, Impact
and Possible Resolution Mechanisms**

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April 2023

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List of Abbreviations

ADHD	Attention Deficit Hyperactivity Disorder
CEC	Clinical Ethics Committee
CLC	Christian Legal Centre
CMF	Conflict Management Framework
ECHR	European Convention on Human Rights
ECtHR	European Court of Human Rights
GOSH	Great Ormond Street Hospital
HCP	Health Care Professional
NHS	National Health Service
PICU	Paediatric Intensive Care Unit

Executive Summary

Disagreements arising between families and healthcare professionals in the care of critically ill children can be emotionally, legally and ethically challenging. They confront us with important questions about the position of parents, the relationship between healthcare professionals and families, the weight of religious and moral values, and the role of the state in intervening in family life. Following on from the well-known cases of *Charlie Gard* and *Alfie Evans*, there have been five subsequent high-profile cases in the last 5 years which have continued to bring these issues to both public and political attention.

As part of a programme of work commissioned by the Department for Health and Social Care, this thematic review sought to examine the literature and evidence base between 2017-2023 relating to three questions. First, what are the causes of disagreement in the care of critically-ill children in England? Second, what are the impacts of these disagreements on the child, their family, the healthcare professionals, the NHS and wider society? Third, what are the possible mechanisms for avoiding, recognising, managing and resolving disagreement?

Eight possible causes of disagreement are identified, which have been grouped into internal, relational and external causes. Internal causes such as psychological responses, differences relating to religious beliefs and moral values, and expectations of medical science and the “good parent” are often manifested initially. These internal views can affect the relational interactions between healthcare professionals and families both in terms of communication, and behaviours. Breakdown of relational trust may then lead to external causes, such as families turning to the internet and social media or the involvement of third-party organisations. Finally, the growing recognition by families of the possibility of innovative treatments or care abroad can add to conflict.

A number of studies detailing the impact of disagreement on healthcare professionals point to moral distress, compassion fatigue, staff burnout and fears for career prospects. Yet, there is a significant evidential gap in the literature relating to the impact on the child, leaving merely assumptions that disagreement and court proceedings are detrimental to the child. For families, the literature paints a more nuanced picture, with accounts of psychological trauma, moral distress and relationship deterioration arising from experiences both within the hospital and the courtroom. Yet, for some parents the opportunity to have their voice heard and views examined by the courts is highly valued. Identified impacts on the NHS and wider society include policy changes and defensive practices, financial and staffing implications, reputational damage, and an increasing climate of public critical opinion.

Appropriate mechanisms for resolving disagreement can be matched with the severity of the dispute. Internal approaches are suitable for mild conflicts, with the literature outlining the merits of sensitive, well-timed communication and shared decision-making, situated within Conflict Management Frameworks including elements such as structured communication tools, managerial processes and psychologist involvement. Escalation to moderate disagreement may call for third-party intervention, but doubts are expressed in the literature of the effectiveness of the common approach of seeking expert second opinion. The use of Clinical Ethics Committees is seen as more promising in bringing parties together, with even the potential for determinative decision-making, but a major re-orientation of its role and remit would be required. Mediation has received sustained attention, with suggestions that its early use can be effective, although success may be limited where disagreements turn on religious beliefs or moral values. The strength of its voluntary nature is stressed, urging the avoidance of mandated participation. Legal resolution is generally needed in severe dispute and changes to the legal threshold for intervention from best interests to significant harm has received substantial attention, with strongly made arguments on both sides, but no clear consensus. Changes to the best interests test have also been advocated, along with alternative tests, and court structures.

Whilst there is recognition of the problematic aspects of court proceedings, the value of a transparent and robust legal process is also recognised.

1. Introduction – Background and Context

1. Decision-making about the care of critically ill children, and the disagreement¹ that sometimes arises between parents and healthcare professionals, presents one of the most challenging and sensitive areas of healthcare law, policy and practice. Important questions are evoked about roles and responsibilities; of what it is to be a “good parent” when faced with a critically ill child, how professionals should best exercise their duties, and who should be tasked with making decisions about care and treatment. Often assessments are made about the weight and importance of fundamental elements of human identity and flourishing – what is a good life (and a good death); the importance of religion, belief and values in healthcare decision-making; the merit of relational connections between children, families and those that care for them; the importance of the liberal standard in relation to family life and law;² and how and when as a society we believe that the State should intervene.³
2. The legal position in England (which is the geographical focus of this review) is that parents, as an aspect of their parental responsibility,⁴ are tasked with making decisions for their minor children who lack the competence to make such decisions for themselves.⁵ The liberal philosophical position to family life adopted in the UK, along with European Convention rights to private and family life,⁶ grant parents a large amount of discretion in day-to-day choices about how they bring up their children. Within the public law sphere, the State will only intervene once the “child protection threshold” is reached, in that the child is suffering, or likely to suffer significant harm.⁷
3. However, in the healthcare context when disagreements arise between families and healthcare professionals about the care and treatment of children, parental decisions may be challenged at a different, and lower, threshold - if they are deemed to be not in accordance with the child’s welfare (also often termed “best interests”). Ultimately, these disagreements may be adjudicated on by the courts, where the child’s welfare will be the court’s ‘paramount consideration’.⁸ The role of parents in decision-making and the threshold for State intervention when disagreements

¹ The terms ‘disagreement’, ‘tension’, ‘dispute’ and ‘conflict’ will be treated as referring to the same type of event and will be used interchangeably throughout this review.

² The liberal standard in relation to family law is a philosophical position, which holds that children are best brought up within their families, that parents are likely to have a strong interest in their child’s wellbeing and so should be tasked with making decisions for their child, and that diversity in upbringing and family life is a social good. The State should not intervene in family life unless certain conditions are met. For a discussion on how to achieve the balance between family privacy and state intervention, see for example, Jonathan Herring, Rebecca Probert and Stephen Gilmore, *Great Debates in Family Law* (2nd ed Macmillan 2015) 107.

³ This is a key current debate, particularly in relation to the proposed “Significant Harm” threshold, which will be discussed in detail below.

⁴ Children Act 1989 s3.

⁵ The basic presumption in the law is that children aged under 18 lack the competence to make decisions for themselves. However, children may demonstrate that they reach the threshold of ‘Gillick competence’ by having ‘sufficient understanding and intelligence to enable him or her to understand fully what is proposed’ within the context of a specific medical decision, as per *Gillick v West Norfolk & Wisbech Area Health Authority* [1986] AC 112. Once this threshold is reached, children may be able to consent to medical treatment in their own right, although whether they may refuse treatment is more controversial. Note – The focus of this review will be on children below the Gillick competence threshold.

⁶ Article 8 European Convention on Human Rights.

⁷ Children Act 1989 s 31.

⁸ Children Act 1989 s1(1).

arise were raised in the cases of *Charlie Gard*⁹ and *Alfie Evans*¹⁰ in 2017 and 2018 - cases which have proved to be a turning point in sparking public, professional and political debates about how such disagreements are handled.

4. In response to this debate, the Nuffield Council on Bioethics commissioned two literature reviews on the topic in 2018.¹¹ The review by Bhatia focused on disagreements in the care of critically ill children and concluded that the key challenges for the future were the role and impact of the internet and social media in treatment decisions, innovative treatments, and child medical tourism.¹² A second review by Austin on resolution mechanisms identified five possible processes; communication between families and healthcare professionals, expert second opinions, clinical ethics committees, mediation, and court proceedings.¹³ She found that whilst most disagreements were resolved through communication, there were difficulties with timings, a reluctance to bring in third-party help at an early stage, and a need for further research into why certain mechanisms were or were not effective.¹⁴ Following these, a briefing note was produced in 2019, which outlined some potential 'areas of action' for policy makers, health authorities, and researchers to consider. These included the development of processes and frameworks to help manage disagreements; recommended or mandatory training on ethics and communication for healthcare professionals and support for those involved in conflict; addressing the need for better information for parents on decision-making processes and the provision of independent legal advice and financial support; and further research on the effectiveness of various dispute resolution mechanisms and the impact of any changes to the law.¹⁵
5. An overview of contemporary literature for the purposes of the current review suggests that disagreements or 'tensions' in the care of ill children are not uncommon. Whilst there is little recent evidence on the prevalence of disagreements in the specific context of the *critically ill child in England*, a more broadly drawn study of children admitted for 5 days or more to a hospital in Newcastle upon Tyne found that there was 'as substantial level of tension in the paediatric in-patient setting', with 42% of the 153 patient cases studied having a source of tension and almost half of these with multiple sources of tension.¹⁶ An older Canadian study on the paediatric conflict experiences of a wide-range of healthcare professionals found that of those who had witnessed or participated in end-of-life discussions (466 out of 946 respondents), 73% had experienced at

⁹ *Great Ormond Street Hospital v Yates and Ors* [2017] EWHC 972 (Fam); *In the Matter of Charles Gard* [2017] EWCA Civ 410; *Charles Gard and Others v United Kingdom* [2017] Application no. 39793/17; *GOSH v Gard, Yates and Gard* [2017] EWHC 1909.

¹⁰ *Alder Hey Children's NHS Foundation Trust v Evans* [2018] EWHC 308; *In the Matter of E (A Child)* [2018] EWCA Civ 550; *Alder Hey Children's NHS Foundation Trust v Evans* [2018] EWHC 818; *Evans v Alder Hey Children's NHS Foundation Trust* [2018] EWCA Civ 805; *Alder Hey Children's NHS Foundation Trust v Evans* [2018] EWHC 953; *Evans v Alder Hey Children's NHS Foundation Trust* [2018] EWCA Civ 984.

¹¹ Neera Bhatia, *Disagreements in the Care of Critically Ill Children: Emerging Issues in a Changing Landscape* (2018) Nuffield Council on Bioethics; Louise Austin, *UK Processes for Resolution of Disagreements about the Care of Critically Ill Children* (2018) Nuffield Council on Bioethics.

¹² *ibid* Bhatia, The definition of child medical tourism used by Bhatia is 'bi-directional movement of children (<18 years of age) to and from a country to seek advice, diagnosis and treatments' 18.

¹³ Austin (n11) 3.

¹⁴ *ibid* 21.

¹⁵ Nuffield Council on Bioethics, *Bioethics Briefing Note – Disagreements in the Care of Critically Ill Children* (2019) 6-7.

¹⁶ Ceit Jesmont et al, 'Prevalence and Sources of Tension in Paediatric Inpatient Care' (2021) 106(12) *Arch Dis Child* 1238.

least one conflict in the preceding 5 years, with a 1/3rd of cases involving conflict between parents and professionals.¹⁷

6. A notable distinction in recent years is the growing number of cases coming before the courts, often involving entrenched positions and many months of legal dispute, with the attendant public interest such cases garner. Indeed, in the intervening years since *Charlie Gard*, there have been several further high-profile court cases, the most significant being the cases of *Tafida Raqeeb*,¹⁸ *Pippa Knight*,¹⁹ *Alta Fixsler*,²⁰ *William Verden*²¹ and *Archie Battersbee*.²² Much as in the 2018 literature reviews,²³ these cases will act as anchor points in this review in accessing and evaluating the related academic literature.
7. One of the most enduring academic and societal debates to emerge over the last 5 years has been over “Charlie’s Law” and “Alfie’s Law”.²⁴ First advanced by the Charlie Gard Foundation, these proposed amendments to the law aimed to strengthen parental rights in the care of critically ill children, including better provision of access to Clinical Ethics Committees (CECs), expert second opinion, mediation and medical records; legal and ethical advice and access to legal aid for parents; and a change to the law to “raise” the threshold for state intervention in parental decisions to those which caused, or risked, significant harm to the child.²⁵
8. There has been some support in Parliament for these proposals, and as Birchley notes, “Charlie’s Law” ‘retains significant momentum’.²⁶ The most recent iteration was in the form of proposed amendments to the Health and Social Care Bill 2021, sponsored by Baroness Finlay of Llandaff.²⁷ The Government ultimately rejected Baroness Finlay’s amendments, in favour of a further review of the evidence and a report to be delivered to Parliament, as enacted in s177 of the Health and Social Care Act 2022.
9. In response to this statutory provision, this current literature review has been commissioned by the Nuffield Council on Bioethics, as part of a larger independent review on disagreements in the

¹⁷ Marie-Anne Archambault-Grenier et al, ‘Survey highlights the need for specific interventions to reduce frequent conflicts between healthcare professionals providing paediatric end-of-life care’ (2017) 107 *Acta Paediatrica* 262, 264.

¹⁸ *Tafida Raqeeb v Barts NHS Foundation Trust* [2019] EWHC 2531 (admin); *Barts NHS Foundation Trust v Shalina Begum and Muhamed Raqeeb and Taifa Raqeeb* [2019] EWHC 2530 (fam).

¹⁹ *Guy’s and St Thomas’s Children’s NHS Foundation Trust v Knight* [2021] EWHC 25; *In the Matter of Pippa Knight (A Child)* [2021] EWCA Civ 362.

²⁰ *Manchester University NHS Foundation Trust v Fixsler* [2021] EWHC 1426; *In the Matter of Alta Fixsler* [2021] EWCA Civ 1018

²¹ *Manchester University NHS Foundation Trust v William Verden & Amy McLennan* [2022] EWCO 9.

²² *Barts Health NHS Trust v Dance* [2022] EWHC 1165 (Fam); *Barts Health NHS Trust v Hollie Dance & Paul Battersbee & Archie Battersbee* [2022] EWHC 1435 (Fam); *Barts Health NHS Trust v Hollie Dance & Paul Battersbee & Archie Battersbee* [2022] EWCA Civ 935;

²³ Bhatia (n11) 4.

²⁴ See for example, Rebecca Limb, ‘Alfie’s Law and Charlie’s Law: Are there alternatives to court battles between parents and hospitals?’ (29 November 2018) *Lacuna.org.uk* <<https://lacuna.org.uk/food-and-health/alfies-law-and-charlies-law-are-there-alternatives-to-court-battles-between-parents-and-hospitals/>> Last accessed 27 March 2023; David I Benbow, ‘An Analysis of Charlie’s Law and Alfie’s Law’ (2020) 28(2) *Medical Law Review* 223.

²⁵ Charlie Gard Foundation, ‘Charlie’s Law’ <<https://thecharliegardsfoundation.org/about/what-is-charlies-law/>> Last accessed 27 March 2023.

²⁶ Giles Birchley, ‘The Harm Threshold: A View from the Clinic’ in Imogen Goold, Jonathan Herring and Cressida Auckland (eds) *Parental Rights, Best Interests and Significant Harms* (Hart 2019) 107.

²⁷ Initially Amendment 172.

care of critically ill children commissioned by the Department of Health and Social Care. It builds upon the Council's earlier literature reviews and briefing note, and uses Barclay's definition of disagreement as '[a] breakdown in trust and/or communication between health professionals and a patient, parent/carer or family member which has an impact on any or all involved and/or affects the ability of a treating team to provide the care they deem optimal for the patient concerned'.²⁸ The remit of this literature review is to survey and assess the evidence base in relation to three questions:

1. What are the causes of disagreements in the care of critically ill children in England?
 2. What is the impact that these disagreements can have on the child, their family, the healthcare professionals, the NHS and wider society?
 3. What are the possible mechanisms for avoiding, recognising, managing and resolving disagreement?
10. The findings of this review will be used in conjunction with evidence gathered from the concurrent consultation and other research activities, to produce a final report to go before Parliament in October 2023. The aim of the independent review will be to 'inform national and regional learning and improvement and support the creation of good, collaborative relationships between parents and healthcare staff'.²⁹

2. Methodology

11. Given the tight timescales for the production and delivery of this literature review, it was not feasible to undertake a full systematic review of the literature. Nor would this have necessarily fit the research brief given that there were a number of questions to be addressed relating to the causes, impact and resolution of disagreements, and these needed to be examined from a range of disciplines and perspectives.³⁰ Instead a semi-systematic, or narrative review was undertaken, which proved especially useful in identifying key themes in the literature that have different disciplinary roots and conceptualisations.³¹ The semi-systematic method begins with an identification of all relevant disciplinary areas relating to the research questions, and then takes a qualitative approach to the review process. In this review, the relevant disciplines that were searched were law, bioethics, medicine, nursing, philosophy, psychology and theology. Results are synthesised by way of meta-narratives,³² seeking to uncover common themes, recent trends or developments, and shifts in thinking or practice.³³
12. The parameter for the search was literature published between 2017 (or since September 2018 for themes already explored in Bhatia's and Austin's literature reviews) and March 2023, with a

²⁸ Sarah Barclay, 'Recognizing and managing conflict between patients, parents and health professionals' (2016) 26(7) Paediatrics and Child Health 314.

²⁹ Nuffield Council on Bioethics, Independent Review: Disagreements in the care of critically ill children – project background, < [Project background - The Nuffield Council on Bioethics \(nuffieldbioethics.org\)](https://www.nuffieldbioethics.org/project-background)> Last accessed 26 March 2023.

³⁰ Hannah Snyder, 'Literature Review as a research methodology: An overview and guidelines' (2019) 104 Journal of Business Research 333; Giles Birchley and Jonathan Ives, 'Fallacious, misleading and unhelpful: The case for removing "systematic review" from bioethics nomenclature' (2022) 36(6) Bioethics 365.

³¹ Geoff Wong et al, 'RAMESES publication standards: meta-narrative reviews' (2013) 69(5) Journal of Advanced Nursing 985.

³² Trisha Greenhalgh et al, 'Storylines of research in diffusion of innovation: a meta-narrative approach to systematic review' (2005) 61 Social Science and Medicine 417; Katherine Footer et al, 'A meta-narrative literature synthesis and framework to guide future evaluation of legal empowerment intervention' (2018) 20(2) Health Human Rights 65.

³³ Virginia Braun and Victoria Clarke, 'Using thematic analysis in psychology' (2008) 3(2) Qualitative Research in Psychology 77.

focus on the most recent literature first. The initial search was confined to sources focusing on England, but this was supplemented by comparative literature from the USA and Europe and literature on resolution mechanisms from Australia and Canada, given their commonalities with England's medical and legal systems.

13. With a focus on peer-reviewed literature, UK legal databases Westlaw, Lexis, Lawtel and Bailii, along with HeinOnline were sought. For the sciences and humanities, ProQuest, Scopus, Web of Science and PubMed were used with Google Scholar as an additional resource. Google searches were undertaken to locate supplementary media reports, blogs and other contemporary commentary, with the obvious limitations in terms of quality being noted. Key words for the search were initially words and concepts related to the research questions for example, 'critically ill child/ren', as well as closely related terms such as 'end of life' 'medical complexity' 'palliative care'; 'medical decision-making'; 'disagreement/dispute in medical care'; 'parental responsibility and medical decisions'; 'family dispute resolution' etc. Additionally, the names of high-profile legal cases were used as key search terms.

3. Recent High-Profile Legal Cases

14. Before proceeding to discuss the findings of the literature review, it will be beneficial to briefly outline the facts and outcomes of the five recent high-profile legal cases noted in the introduction. Whilst as Birchley observes 'it is a well-known legal trope that difficult cases make a bad basis for policy'³⁴ and that the vast majority of disagreements are resolved "in the clinic", these cases reveal important themes around causes, impact and attempted resolution mechanisms. Additionally, they have acted as 'anchor points' around which the literature was searched.

Tafida Raqeeb³⁵

Tafida was a 5-year-old girl at the time of the case. She had suffered a life-threatening blood clot on the brain and underwent surgery. Post-surgery she was mechanically ventilated in the Paediatric Intensive Care Unit (PICU). A month after surgery her clinicians recommended palliative care, as they were of the view that the chances of Tafida regaining awareness were negligible. Tafida's parents are 'committed Muslims' and they viewed the active withdrawal of treatment as against their personal and religious beliefs. The parents located a hospital in Italy who were prepared to try weaning Tafida from the ventilator by use of tracheostomy, with a view to her being cared for at home. The parents wished to transfer Tafida's care to the Italian hospital, but the doctors felt that to move her would not be in her best interests. The parents sought judicial review of the hospital's decision, arguing that to prohibit the transfer would be an infringement of the right to receive services under EU law. The NHS Trust issued a concurrent application for a declaration that it was in Tafida's best interests for treatment to be withdrawn. The judicial review was not successful, but in the best interests hearing the court held that in the absence of pain and suffering, family and religious benefits could be considered – concluding that it was not satisfied that withdrawal was in Tafida's best interests. Tafida was transferred to the Italian hospital, where she currently resides.³⁶

Pippa Knight³⁷

³⁴ Birchley (n26) 107.

³⁵ *Tafida Raqeeb v Barts NHS Foundation Trust* [2019] EWHC 2531 (admin); *Barts NHS Foundation Trust v Shalina Begum and Muhamed Raqeeb and Taifa Raqeeb* [2019] EWHC 2530 (fam).

³⁶ Ayesha Buksh, 'Tafida Raqeeb: Mum hopes brain-damaged girl will return home' (22 March 2022) BBC News <<https://www.bbc.co.uk/news/uk-england-london-608399727>> Last accessed 24 April 2023.

³⁷ *Guy's and St Thomas's Children's NHS Foundation Trust v Knight* [2021] EWHC 25; *In the Matter of Pippa Knight (A Child)* [2021] EWCA Civ 362

Pippa was a 6-year-old girl who, when 20 months old, suffered acute necrotising encephalopathy and was left severely brain damaged in a persistent vegetative state. She was mechanically ventilated in the PICU. The position of the doctors was that treatment should be withdrawn as there was no prospect of recovery. Pippa's mother felt that she had made progress and wished for her to receive a tracheostomy and ultimately be cared for at home. The court tackled questions of what harm might constitute in the absence of pain and suffering. It held that continued treatment was burdensome to her person, with no corresponding benefits, and therefore harmful and not in her best interests. This finding was upheld on appeal, treatment was withdrawn, and Pippa died shortly after.

Alta Fixsler (2021)³⁸

Alta was a 2-year-old girl who, as a result of her premature birth, had suffered catastrophic brain injury. She had been mechanically ventilated and tube-fed in the PICU since birth, and her life expectancy was estimated at a further 6 months-2 years. All agreed that there was no prospect of recovery, and the clinicians' position was that Alta was experiencing consistent pain. The NHS Trust applied to the court for a declaration that it was not in Alta's best interests to continue treatment and that palliative care be instituted. Alta's parents are orthodox Chassidic Jews and Israeli citizens, and they objected to the NHS Trust's application due to their religious views on sanctity of life. They wished to take Alta to Israel for further treatment or to die in the Holy Land. The court declared that neither continued treatment nor transfer to Israel was in Alta's best interests and that palliative care should be instituted. This decision was upheld by the Court of Appeal and leave to appeal was refused by the Supreme Court and the European Court of Human Rights. Alta's case returned to the High Court five months after the original decision, regarding a dispute over the location in which Alta's treatment would be withdrawn. Whilst the parents argued that this should take place at home, the Court ruled that Alta should be transferred to a hospice for this purpose, and she died within hours of treatment being withdrawn.³⁹

William Verden (2022)⁴⁰

William was a 17-year-old boy at the time of the case, who lacked capacity due to learning disability, autism, Attention Deficit Hyperactivity Disorder (ADHD), and hypersensitivity. He had been undergoing dialysis as a result of kidney failure but did not tolerate invasive treatments well and had exhibited violence to his parents and the staff. He was in need of a kidney transplant, without which his venous access for dialysis would cease in approximately 12 months, and he would die. The NHS Trust felt that the harm from the transplant and post-operative treatment, including risks related to tolerance of necessary sedation and post-operative ventilation and the high potential for psychological damage, was greater than continuation of haemodialysis until venous access no longer possible. William's mother wished to consent to the transplant and argued that it was in his best interests despite the risks. The Trust sought a determination of William's best interests from the court, which declared that the transplant was not futile and was the 'least bad opinion' for William and was

³⁸ *Manchester University NHS Foundation Trust v Fixsler* [2021] EWHC 1426; *Manchester University NHS Foundation Trust v Alta Fixsler, Chaya Fixsler & Abraham Fixsler* [2021] EWHC 2664 (Fam); *In the Matter of Alta Fixsler* [2021] EWCA Civ 1018

³⁹ Harriet Sherwood, 'Alta Fixsler, toddler at centre of parents' legal battle dies in hospice' (19 October 2021) *The Guardian* <<https://amp.theguardian.com/uk-news/2021/oct/19/alta-fixsler-toddler-at-centre-of-parents-legal-battle-dies-in-hospice>> Last accessed 3 April 2023.

⁴⁰ *Manchester University NHS Foundation Trust v William Verden & Amy McLennan* [2022] EWCOP 9.

therefore in his best interests. William received a kidney transplant, spent weeks under post-operative sedation, and has since recovered at home.⁴¹

Archie Battersbee (2022)⁴²

Archie was a 12-year-old boy who suffered catastrophic brain damage after a hanging incident. For several weeks he had remained unconscious and mechanically ventilated in the PICU. The treating clinicians' view was that Archie was brain-stem dead, but his family believed there was a prospect for recovery and refused to consent to the confirmatory test. The court issued a declaration that it was in Archie's best interests to have the brain-stem death test. A series of court cases over the course of 4 months then ensued, with the clinical position being that either Archie was already dead, or that continued treatment was not in his best interests. The family refused to consent to withdrawal of treatment due to their views about the prognosis, the reliability of evidence and testing, and religious belief. The courts consistently held that it was not in Archie's best interests to continue treatment. Archie died shortly after his life support was withdrawn.

4. Findings

A: Causes of Disagreement

15. Evidence shows that due to advances in medicine and technology, some children with chronic conditions are living longer but with greater morbidity, and in acute cases children are now surviving that would otherwise have died. The ethical dilemmas arising from the tensions between what medical science *can* now do and what we *should* do, underlie many of the conflicts in the care of critically-ill children. Forbat and Barclay note that the clinical implications of greater survival rates 'include an increased frequency in difficult decision-making regarding the benefits versus the burden of intensive and invasive treatment, especially when curative treatment is no longer possible.'⁴³ One effect of technological improvements is a significant increase in the proportion and length of long-stays⁴⁴ in PICU as discovered in a 20-year retrospective analysis of PICU admissions in Birmingham Children's Hospital.⁴⁵ The authors suggest that reasons for the increase might include 'patient/public expectations of healthcare, increase in shared decision-making, a fear of litigation among physicians when considering end-of-life decisions for children'⁴⁶ - all factors identified in the literature as factors which may give rise to conflict.

16. Causes of disagreement can be complex and multi-faceted. In some cases, the reason can be clearly and quickly identified, but in others there are overlapping and cumulative factors, exemplified in *Battersbee*, which revealed at least eight possible reasons for relationship

⁴¹ Amy Sharpe, 'Right-to-life teen "in great spirits" as he leaves hospital after transplant, says mum' (24 September 2022) *The Mirror* <<https://www.mirror.co.uk/news/uk-news/right-to-life-teen-in-great-28073052.amp>> Last accessed 24 April 2023; Ami McLennan, 'After the kidney transplant: The view from "Team William"' (16 April 2023) *Open Justice: Court of Protection Project* <<https://openjusticecourtofprotection.org/2023/04/16/after-the-kidney-transplant-the-view-from-team-william>> Last Accessed 30 April 2023.

⁴² *Barts Health NHS Trust v Dance* [2022] EWHC 1165 (Fam); *Barts Health NHS Trust v Hollie Dance & Paul Battersbee & Archie Battersbee* [2022] EWHC 1435 (Fam); *Barts Health NHS Trust v Hollie Dance & Paul Battersbee & Archie Battersbee* [2022] EWCA Civ 935

⁴³ Liz Forbat and Sarah Barclay, 'Reducing Healthcare Conflict: Outcomes from using the Conflict Management Framework' (2019) 104(4) *Arch Dis Child* 328.

⁴⁴ In the study long stays were defined as 28 days or more.

⁴⁵ Hari K Kanthimathinathan et al, 'Trends in long-stay admissions to a UK paediatric intensive care unit' (2020) 105 *Arch Dis Child* 558. The study included admissions from 1 January 1998 to 31 December 2017.

⁴⁶ *ibid* 560.

breakdown between Archie's parents and the healthcare professionals. A typical trajectory of conflict according to Forbat is that:

[i]nitial conflict might include insensitive use of language, staff giving conflicting messages about a child's status, or a history of unresolved conflict in other services. Conflict then escalates to include repetitive arguments, staff or families avoiding contact with each other, and families micromanaging or documenting all care activities. At the most severe level of conflict, the relationship between staff and family disintegrates – the conflict takes on a life of its own and staff can experience physical and verbal threats and attacks.⁴⁷

17. In this section, the causes of disagreement as identified in the high-profile cases and the literature will be grouped into three categories: internal causes, relational causes and external causes. Internal causes may be the first to manifest in the trajectory of a dispute and include psychological responses; differences in views and judgments about religious beliefs and moral values; and expectations of medical treatment (and its potential limits). How these psychological factors then play out in interpersonal relationships will be explored in the relational causes section. Beginning with communication between healthcare professionals and families, along with understanding of roles and processes in the context of decision-making, leading to how relationship breakdown may manifest itself in behaviours and interactions. Finally, there are causes that are external to the individual parties or the clinical and care relationship, and often appear later in the course of disagreement, including the internet as a source of alternative information; the role of social media; involvement of third-parties; and requests for alternative treatments and care abroad. Each will be considered in turn.

INTERNAL CAUSES

i) Psychological responses

18. Beginning with parental psychological responses, the literature reveals that denial, distress and dread are very natural parental reactions to being faced with a critically ill child in the PICU.⁴⁸ Archambault-Grenier et al in their Canadian study of how paediatric healthcare professionals experienced conflict found that parents' fear of hastening death was a major contributing factor to disagreement.⁴⁹ This response was seen in the initial hearing in *Battersbee*, as Archie's family refused to consent to the final step in the brain stem death test, purportedly due to concerns that removing ventilation could lead to risks of further brain injury.⁵⁰ But in a later statement it was revealed that the family would not engage with mediation 'because they were not prepared to have the brain stem tests done.'⁵¹ This position, borne at least in part, out of denial or dread, was a cause of disagreement with the clinicians who believed Archie was already brain dead.⁵² The phenomenon was recognised by Arbuthnot J in both the first and second hearings where she concludes that, 'I understand on a human level, the family's deep anguish and concern for their young son (...) everyone can appreciate how much they must dread the results of this test',⁵³ and '(...)I have no doubt at all that their worst fear is that the clinicians are right, and that their much-loved son has lost his present and his future and that this period in which their lives have

⁴⁷ Liz Forbat, 'When doctors and parents disagree on how to treat a sick child the emotional and financial costs can be huge' (9 October 2019) *The Conversation*.

⁴⁸ Kim Mooney-Doyle and Connie M Ulrich, 'Parent moral distress in serious pediatric illness: A dimensional analysis' (2020) 27(3) *Nursing Ethics* 821.

⁴⁹ Archambault-Grenier (n17) 265.

⁵⁰ *Barts Health NHS Trust v Dance* [2022] EWHC 1165 (Fam) [82].

⁵¹ *Barts Health NHS Trust v Hollie Dance & Paul Battersbee & Archie Battersbee* [2022] EWHC 1435 (Fam) [101].

⁵² *Barts Health NHS Trust v Dance* [2022] EWHC 1165 (Fam) [6].

⁵³ *Barts Health NHS Trust v Dance* [2022] EWHC 1165 (Fam) [94].

been in suspension is coming to an end'.⁵⁴

19. These initial responses may morph into expressions of hope and the desire to wait for a miracle, often fuelled by “heroic narratives” of parental sacrifice and linked to conceptions of the “good parent” discussed in section iii) below. Again, in *Battersbee*, Archie’s mother ‘wished to care for Archie whatever the future held’,⁵⁵ and ‘hoped that he may make a recovery of some kind (...) but accepted he may be severely disabled or in a severely vegetative state but this was ‘better than nothing’.⁵⁶ She was ‘hoping and praying for a miracle’.⁵⁷ This can cause disagreement with healthcare professionals who may feel that parents are not accepting “reality” and so engage in concerted efforts to convince them of the “truth”.⁵⁸ Caruso Brown reports that clinicians fear both “taking away hope” as well as “false hope”.⁵⁹ Katz et al explore dissonance in understanding, wishes and plans between parents and clinicians. They suggest that this arises because clinicians do not appreciate the role that hope and “good parent” narratives have in helping parents find a ‘tolerable way of living’, and thus seek to continuously impose prognostic “reality” upon parents in order to prepare them and facilitate informed decision-making. They suggest one way to “bridge the gap” is for clinicians to recognise that prognostic awareness and hope for a cure are not mutually exclusive and can in fact co-exist and that parents may choose to live in hope for a cure as a ‘protective measure’, whilst periodically ‘visiting reality’ by confronting the medical “truth” of their child’s condition. In sum, they note that ‘this “duality” is possible for some parents who may hope until the end for their child to beat the odds and survive, and at the same time hope for a comfortable and dignified death’.⁶⁰
20. Dolan confirms that parents’ psychological distress may affect decision-making.⁶¹ Mooney-Doyle and Ulrich explain that parental distress can generate emotional responses such as anger at unjust circumstances, or worry about whether something important has been overlooked. Their view concurs with Katz’s concurrence of hope and “reality”, noting ‘emotions of grief in anticipation of the loss, uncertainty about how to be a “good parent” to one’s seriously ill child, gratitude for the time that is available to spend with the child, or sadness over the impending loss are commonplace emotions.’⁶²
21. The literature suggests that some of this disagreement relating to psychological factors is grounded in deeper-seated (and more difficult to address) cultural attitudes and taboos around talking about death, experienced by both families *and* healthcare professionals. Bioethicist Moore insightfully explores the ‘fraught notion’ of a “Good Death” in paediatrics and reveals cultural difficulties with conceiving of the death of a child as ever being “good”.⁶³ She contends that this may be a result of a generalised aversion to death, or a specific belief that ‘there is something uniquely bad about death in childhood’, due to lost potential for life and growth, a reaction to

⁵⁴ *Barts Health NHS Trust v Hollie Dance & Paul Battersbee & Archie Battersbee* [2022] EWHC 1435 (Fam) [9].

⁵⁵ *Barts Health NHS Trust v Dance* [2022] EWHC 1165 (Fam) [10].

⁵⁶ *Barts Health NHS Trust v Hollie Dance & Paul Battersbee & Archie Battersbee* [2022] EWHC 1435 (Fam) [98].

⁵⁷ *Barts Health NHS Trust v Hollie Dance & Paul Battersbee & Archie Battersbee* [2022] EWHC 1435 (Fam) [98].

⁵⁸ Naomi T Katz, Jenny L Hynson and Lynn Gillam, ‘Dissonance in views between parents and clinicians of children with serious illness: How can we bridge the gap?’ (2021) 57 *Journal of Paediatrics and Child Health* 1370.

⁵⁹ Amy E Caruso Brown, ‘Reconceiving Decisions at the End of Life in Pediatrics: Decision-Making as a Form of Ritual’ (2019) 62(2) *Perspectives in Biology and Medicine* 301, 309.

⁶⁰ Katz (n58) 1371 -1373.

⁶¹ J Gregory Dolan et al, ‘Association of psychological distress and religious coping tendencies in parents of children recently diagnosed with cancer: A cross-sectional study’ (2021) 68 *Pediatr Blood Cancer* e28991, 2.

⁶² Mooney-Doyle (n48) 823.

⁶³ Bryanna Moore, ‘The Fraught Notion of a “Good Death” in Pediatrics’ (2023) 48 *The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine* 60, 61.

the rarity of child death, and a sorrow that children lack time or a sense of self to help prepare them for death⁶⁴ - essentially that a 'child's status as child therein precludes them from dying a good death'.⁶⁵ These attitudes may manifest themselves as a reluctance to acknowledge the possibility of child death and a discomfort on the part of both families and professionals in having needed conversations. As a result, parties may find themselves talking at cross-purposes, with the parents often continuing to adopt the typical future-orientated understanding of the child's interests, and perhaps push for "everything to be done", whilst the clinicians view is present-orientated.⁶⁶ Moore sums up the dilemma:

If parents reject that their child is dying, then continuing to push for goals connected to the interests of dying children, when parents' goals are based on a different set of interests, may exacerbate miscommunication and conflict, and stonewall decision-making for the child. Such situations require either deference to the parent's future-oriented goals (i.e., professional acceptance that, sometimes, patient care does not meaningfully connect with the patient's interests), or a sustained investment in shifting parents' understanding of their child's clinical reality.⁶⁷

ii) Differences relating to religious beliefs and moral values

22. Whilst some disagreements may turn on interpretations of "factual" issues, such as medical prognosis or treatment, in other cases religious and value-based differences can be a major factor in disagreement.⁶⁸ Religious beliefs may vary in their depth and impact on the life of the individual and their family. For some they are a core part of the parents' identity and central to the vision with which they raise their family. For example, in *Fixsler* the parents stressed that 'their faith is not simply a religion but is also a way of life',⁶⁹ and argued that their firm stance on the sanctity of life and religious ritual around death meant that 'the best interests decision-making process can and must be framed within the Jewish belief system in this case' – a stance rejected by MacDonald J.⁷⁰ In response, Pruski contends that 'it seems sensible for the role of religion in such judgments to be proportionate to the role religion played in the patient's life-in the case of a child of Orthodox Jewish parents, the role of religion is rather substantial.'⁷¹ For others, such as the *Battersbee* family who had been 'vaguely Christian' but never regular churchgoers,⁷² in the face of critical illness 'growing religious views' were evident.⁷³ Family baptisms were performed at Archie's bedside⁷⁴ and they drew on religious positions, exemplified in statements such as 'they would like him to die naturally in hospital as that accords with their Christian faith'⁷⁵ to support their objections.
23. Disagreement can arise when healthcare professionals have 'limited cultural understanding' of religious belief, with the evidence suggesting that 'parents described feeling increasingly judged

⁶⁴ *ibid*

⁶⁵ *ibid* 62.

⁶⁶ *ibid* 67.

⁶⁷ *ibid* 70.

⁶⁸ Archambault-Grenier (n17) 268.

⁶⁹ *Manchester University NHS Foundation Trust v Fixsler* [2021] EWHC 1426 [3].

⁷⁰ *Manchester University NHS Foundation Trust v Fixsler* [2021] EWHC 1426 [72].

⁷¹ Michal Pruski, 'Alta Fixsler: Medico-Legal Paternalism in UK Paediatric Best Interest Decisions' (2022) 37(1) *Issues in Law & Medicine* 81, 85.

⁷² *Barts Health NHS Trust v Hollie Dance & Paul Battersbee & Archie Battersbee* [2022] EWHC 1435 (Fam) [102].

⁷³ *Barts Health NHS Trust v Hollie Dance & Paul Battersbee & Archie Battersbee* [2022] EWHC 1435 (Fam) [107].

⁷⁴ *Barts Health NHS Trust v Hollie Dance & Paul Battersbee & Archie Battersbee* [2022] EWHC 1435 (Fam) [104].

⁷⁵ *Barts Health NHS Trust v Hollie Dance & Paul Battersbee & Archie Battersbee* [2022] EWHC 1435 (Fam) [3].

when religion plays an important part in their decision-making'.⁷⁶ Conflict may also arise in relation to the child's beliefs, and perceptions that the parents are "imposing" their beliefs on a child unable to develop their own faith. Reflecting on *Fixsler*, Pruski notes however that due to the influence of family life on a child's values, assumed parent-child congruence in religious belief is warranted, and that statistically it is most likely that children like Alta would retain their Jewish faith.⁷⁷ This issue was tackled by the courts in both *Raqeeb* and *Fixsler*, with judicial positions tied to an assertion of the secular nature of best interests determinations. Pruski views the judicial rejection of the religious in favour of the secular in *Fixsler* as 'paternalism',⁷⁸ and contends that a secular state is only compelled not to enforce a particular religious view, not to deem that religious convictions are irrelevant.⁷⁹ This is a position also taken by Auckland and Goold who, drawing on Heywood's work,⁸⁰ claim that 'if the law is to take seriously views about freedom of religion, expression, and the right to respect for private and family life, it must attach genuine significance to medical decisions which are underpinned by those values, values which the English courts have only ever tipped their hats to in the evolving case law'.⁸¹

24. Dolan et al have undertaken a study to determine links between parental psychological distress and "religious coping", which they define as 'an individual's effort to understand adversity in ways related to the sacred'.⁸² Religious coping is a dynamic process that encompasses behaviours, emotions, relationships, and cognition. The process manifests in two different forms: positive and negative religious coping. Whilst surprisingly, they found that positive religious coping had no direct impact on distress, there was a subset of parents, usually those with the highest level of religiosity, who demonstrate negative or 'maladaptive' spiritual coping tendencies and thus had heightened distress. The authors suggest this may be linked to increasing anxiety due to fear of punishment by God.⁸³ Mooney-Doyle and Ulrich also describe spiritual distress as a possible antecedent to moral distress, for example when families struggle to understand why their child should be ill or die.⁸⁴
25. In contrast, moral-values are not dictated by doctrine as religious beliefs are, but are grounded in subjective assessments about what makes life worth living and which risks are worth taking.⁸⁵ Zimmerman argues that such values are deeply held, the violation of which can have personal effect.⁸⁶ Yet, Auckland and Goold contend that given the diversity of views on these matters, they may be more amenable to discussion than religious belief.⁸⁷ They also claim that differences may derive not just from a person's origin but also their "culture" including professional and societal cultures,⁸⁸ – exemplified in a professional sub-culture in certain medical specialities of pursuing

⁷⁶ Mooney-Doyle (n48) 828.

⁷⁷ Pruski (n71) 83.

⁷⁸ *ibid* 83.

⁷⁹ *ibid* 84.

⁸⁰ Rob Heywood, 'Parents and Medical Professionals: Conflict, Cooperation, and Best Interests' (2012) 20 (1) *Medical Law Review* 29, 33.

⁸¹ Cressida Auckland and Imogen Goold, 'Parental Rights, Best Interests and Significant Harms: Who should have the final say over a child's medical care?' (2019) 78(2) *Cambridge Law Journal* 287.

⁸² Dolan (n61) 2.

⁸³ *ibid* 7.

⁸⁴ Mooney-Doyle (n48) 832.

⁸⁵ Dominic Wilkinson, 'In Defence of a Conditional Harm Threshold Test for Paediatric Decision-Making' in Goold I, Herring J and Auckland C (eds) *Parental Rights, Best Interests and Significant Harms* (Hart 2019) 85,88.

⁸⁶ Anne Zimmerman, 'The trauma of disregard: Doing justice to parental healthcare values in conflicts in pediatric medical care' (2021) 7 *Voices in Bioethics* 1,2.

⁸⁷ Auckland (n81) 306.

⁸⁸ Cressida Auckland and Imogen Goold, 'Resolving Disagreement: A Multi-Jurisdictional Comparative Analysis of Disputes about Children's Medical Care' (2020) 28(4) *Medical Law Review* 643, 658.

“heroic measures” at the end-of-life.⁸⁹ This may also explain the evidence that doctors assess quality of life differently to parents.⁹⁰ For example, in *Battersbee* the family contended that Archie would want to remain on life support because he had told his Mother that he would not want to leave her’.⁹¹

26. In response to media narratives that the public are opposed to the withdrawal of treatment in high profile cases such *Battersbee*, Brick et al undertook an online survey of UK public views on when life is worth living and found that 94% of the 130 participants agreed that there was a threshold below which life was no longer worth living and that below this threshold treatment must be withdrawn.⁹² In *Verden*, the disagreement was essentially about which risks were worth taking and about the quality of life that potentially awaited William, versus the certainty of death within months, without the transplant.⁹³
27. A key recent values debate seen in the case law and literature is over the nature and role of pain and suffering. The question of whether Alta was capable of experiencing pain and if so, whether she was suffering, was central to *Fixsler*. For the healthcare professionals in the case the driving force behind the withdrawal argument was that Alta was suffering. In contrast, the parental position was that suffering was uncertain and therefore the religious imperative to maintain life was overriding. Pruski contends that the law should acknowledge ‘that suffering is not always the overriding factor in any decision/problem - with the plurality of goods present in life (...) we cannot simply dismiss all of these goods for the sake of abbreviating suffering, especially in a pluralistic state.’⁹⁴ He asserts that the courts’ finding that Alta was at risk of experiencing suffering is a conclusion ‘not purely based on the facts of medical science but required philosophical assumptions as to the nature of suffering’ and he fears the situation where the ‘presence of suffering becomes the default assumption.’⁹⁵
28. In the absence of clear evidence of pain and suffering that might justify the withdrawal of treatment, clinicians and judges sometimes turn to the concept of harm to dignity.⁹⁶ In *Raqeeb*, the Trust argued that further invasive treatment imposed ‘an unacceptable burden on her human dignity’, but MacDonald J noted that the concept is ‘not without difficulty’ given its absence of precise definition and the inevitable cultural or religious framing of its meaning.⁹⁷ Likewise the Poole J in *Knight* found the concept of dignity unhelpful in assessing Pippa’s best interests given its high degree of subjectivity.⁹⁸ In contrast in *Battersbee*, the family drew on notions of dignity cited in *Raqeeb*, to support continued treatment when they contended that ‘the fact that Archie feels no pain does not mean that his life has no value...’.⁹⁹ Wheeler commenting on *Knight* claims that attributes of dignity are not about ‘doing life’ as much as being alive – ‘[t]hose who are participating in the human adventure flourish on that journey (...) It all turns on ‘being’. Judicial evaluation of how respect for dignity *would* apply when assessing best interests would be welcomed.¹⁰⁰

⁸⁹ Moore (n63) 70.

⁹⁰ Auckland (n88) 658.

⁹¹ *Barts Health NHS Trust v Hollie Dance & Paul Battersbee & Archie Battersbee* [2022] EWHC 1435 (Fam).

⁹² Claudia Brick et al, ‘Worth Living or Worth Dying?: The views of the general public about allowing disabled children to die’ (2020) 46 J Med Ethics 7.

⁹³ *Manchester University NHS Foundation Trust v William Verden & Amy McLennan* [2022] EWCOP 9 [125].

⁹⁴ Pruski (n71) 85.

⁹⁵ *ibid* 86.

⁹⁶ Wilkinson (n85) 100.

⁹⁷ *Tafida Raqeeb v Barts NHS Foundation Trust* [2019] EWHC 2531 (admin) [176].

⁹⁸ *Guy’s and St Thomas’s Children’s NHS Foundation Trust v Knight* [2021] EWHC 25 [86].

⁹⁹ *Barts Health NHS Trust v Hollie Dance & Paul Battersbee & Archie Battersbee* [2022] EWHC 1435 (Fam) [167].

¹⁰⁰ Robert Wheeler, ‘Pippa Knight: Opening a Door to Dignity?’ (2021) 98 RCS Bulletin 268.

iii) Expectations of medical treatment

29. Studies in both the UK¹⁰¹ and Australia¹⁰² indicate that ‘unrealistic’ parental expectations and demands are a major factor in disagreements. As Sokol notes, ‘it is understandable that parents would fight mightily to keep their child alive. It is a natural instinct, even if it no longer makes sense logically and ethically.’¹⁰³ This may be manifest in a variety of ways, including parents who have unrealistic expectations about the power of medical science, or their child’s ability to recover. In *Battersbee* where the families position was that ‘the clinicians are wrong in taking their decision not to operate on Archie to relieve the pressure from the swelling of his brain’ Arthbutnot J notes that ‘the implication is that that might make a difference to his condition’.¹⁰⁴ As Wallis observes, the root of these expectations may lie in the use of life sustaining technology at a time of crisis and then ‘[o]nly after a period of time do we realise that death is inevitable but disallowed by the very technology that we have introduced. Unforeseeably one gets stuck on a piece of machinery or treatment that prevents a child from growing up, developing and interacting with their environment and leaves them to a life in a high dependency hospital bed (...)’.¹⁰⁵
30. However, an emerging issue in terms of parental expectation is the rising numbers of children with medical complexity.¹⁰⁶ A recently reported observational study by Fraser et al found that over an 18-year period from 2000-2018, the prevalence of this population had risen almost three-fold.¹⁰⁷ Birchley et al explain that complex care needs ‘can be both materially and logistically difficult to manage, causing friction with parents’, such as ‘incoordinate decision-making, increased incidence of disagreements with families and a loss of focus on the child’s best interests.’¹⁰⁸
31. There is little in the academic literature about the ethical and legal challenges raised in the care of children with medical complexity, although Moreton and Brierley contend that it is likely to be a growing area of difficulty.¹⁰⁹ They claim that tension inevitably arises when clinicians seek legal determination of ‘ceilings of treatment’ for very ill children who are likely to significantly deteriorate in the near future, but parents who have advocated for their children for possibly decades, and seen them recover through countless health crises, struggle to understand “what has changed”. This source of disagreement has been exemplified in a series of recent cases,¹¹⁰ such as *Re Z* which involved a 16-year old boy with cerebral palsy and multiple other severe disabilities, whose home care was described as ‘akin to a High Dependency Unit’ and who had experienced an increasing number of hospital stays in PICU.¹¹¹ The NHS Trust applied to court for a determination of the ‘ceiling of treatment’ – in other words, at what point they should cease

¹⁰¹ Jesmont (n16) 1238.

¹⁰² Katz (n58) 1370.

¹⁰³ Daniel Sokel, ‘An ethicist’s view on the Archie Battersbee case: a bad situation made worse’ (2022) 378 *BMJ* o1980.

¹⁰⁴ *Barts Health NHS Trust v Dance* [2022] EWHC 1165 (Fam) [86].

¹⁰⁵ Colin Wallis, ‘When Paediatricians and families can’t agree’ (2018) 103(5) *Arch Dis Child* 413.

¹⁰⁶ Jesmont (n16) 1238.

¹⁰⁷ Lorna K Fraser et al, ‘Estimating the current and future prevalence of life-limiting conditions in children in England’ (2021) 35 *Palliative Medicine* 1641, 1645.

¹⁰⁸ Giles Birchley et al, ‘Factors affecting decision-making in children with complex care needs: a consensus approach to develop best practice in a UK children’s hospital’ (2022) 6(1) *BMJ Paediatrics Open* [e001589] 1.

¹⁰⁹ Kirsty Moreton and Joe Brierley, ‘The Ethical and Legal Challenges of Caring for Children with Medical Complexity’ (September 2022) Presented at the Annual Scientific Meeting of the Paediatric Critical Care Society, Leicester.

¹¹⁰ See for example, *Birmingham Women’s and Children’s NHS Foundation Trust v J & M & F* [2022] EWHC 2229; *Great Ormond Street Hospital for Children NHS Foundation Trust v A Local Authority & M & J* [2022] EWHC 2596.

¹¹¹ *Re Z (Medical Treatment: Invasive Ventilation)*[2021] EWHC 2613 (fam).

active treatment such as short-term ventilation. This was in order to gain clarity in the course of action in anticipation of severe deterioration of Z's condition and to avoid legal action at a critical time when he is in the PICU. However, the parents having cared for Z for 16 years and being driven by their Muslim faith in the sanctity of life, could not be reconciled to any steps which they felt would have the effect of shortening life and viewed even a 10% chance of success in ventilation as representing 'good odds'.¹¹²

RELATIONAL CAUSES

iv) Communication, roles and processes

32. Relationships with healthcare professionals can be significant to families, both as a source of relief, but also as one of conflict.¹¹³ As Katz et al note, '[c]linicians are tasked, often in a brief window of time, with understanding how individual parents get through each day, and how they think about their child's illness in the context of their broader values, culture and psychosocial background. The relationship between clinicians and families is paramount and is at risk of being fractured when parents and/or clinicians feel misunderstood or unheard.'¹¹⁴ Poor communication can be a key contributor to disagreement, with Bateman et al finding that 'communication with providers has been historically ranked at the bottom of the list in terms of patient satisfaction', and that doctors personal characteristics, such as gender and parental status, and communication style can influence patient care decisions.¹¹⁵
33. In *Battersbee*, the initial trigger for the disagreement that followed appeared to be related to the *timing* of a conversation, as Arthbutnot J recounted, 'the family objected to the position taken by the hospital within three days of their arrival that he was not going to make it through. The family were very upset that a Consultant had raised the question of organ donation at this very early stage of Archie's admission'.¹¹⁶ However at this stage, the negative impact on doctor-family communication was distinct from the relationship between the nurses and the family, who had 'nothing but good to say about each other.'¹¹⁷
34. Parents' sense of powerlessness and desire to take back some control,¹¹⁸ can manifest itself in disputes over who the prime decision-maker should be. Whilst shared decision-making is generally the goal, Richards et al's study discussed that PICU doctors varied in the extent they engaged parents in decision-making.¹¹⁹ This can lead to a sense of exclusion as Mooney-Doyle and Ulrich recount: 'parents experienced lingering negative emotions when healthcare providers were insensitive (...) toward their desire to fulfil parental roles (...) parents in this study described "choice as a freedom" because they did not feel in control of decision making'.¹²⁰ As Archard discusses, this response was also seen in *Gard*, in the adoption of the slogan 'My Child, My Choice'.¹²¹ The justifications given for parents being the prime decision-makers often turn on sacrificial narratives, as Wilkinson notes 'optimal choices for children may require very substantial

¹¹² *ibid.*

¹¹³ Mooney-Doyle (n48) 826.

¹¹⁴ Katz (n58) 1370.

¹¹⁵ Lori B Bateman et al, 'A Qualitative Examination of Physician Gender and Parental Status in Pediatric End-of-Life Communication' (2017) 32(7) *Health Communication* 903.

¹¹⁶ *Barts Health NHS Trust v Hollie Dance & Paul Battersbee & Archie Battersbee* [2022] EWHC 1435 (Fam)[100]

¹¹⁷ *Barts Health NHS Trust v Dance* [2022] EWHC 1165 (Fam) [18].

¹¹⁸ Claire Richards et al, 'Physicians perceptions of shared decision-making in neonatal and pediatric critical care' (2018) 35(4) *American Journal of Hospice and Palliative Medicine* 669,671.

¹¹⁹ *ibid* 670.

¹²⁰ Mooney-Doyle (n48) 822.

¹²¹ Dave Archard, "'My Child, my choice": Parents, doctors and the ethical standards for resolving their disagreement' (2019) 70(1) *NILQ* 93,94.

sacrifice of the parents' own wellbeing.¹²² This was identified by the Guardian in *Battersbee*, who reported that Archie's 'mother had placed his needs above her own as their family life had ground to a halt'.¹²³ Another claim to support parents as best placed to be decision-makers is their privileged knowledge of the child due to their relationship.¹²⁴

35. Much of this stems from what the literature terms the "good parent" narrative, with studies showing variation in its characterisation, but including making decisions for their child or ensuring they feel loved. It may also include advocating for the child, as was seen in *Verden*, with William's mother characterised as 'a "doer" who fights for her child'.¹²⁵ This role is extra challenging when the parent is seeking to advocate for a refusal or withdrawal of treatment, as it can carry with it accusations of poor parenting or neglect. Moreton's narrative analysis of the case of Hannah Jones, a 12-year old who refused a life-saving heart transplant, explores the position of Hannah's mother Kirsty as she seeks to support her daughter's choice and found the scrutiny of the quality of her care and of her motivations particularly difficult.¹²⁶ Similarly in the case of *R(A Child)*,¹²⁷ as discussed by Gollop and Pope,¹²⁸ a mother who advocated against active resuscitation and questioned continuation of artificial nutrition and hydration for her disabled daughter was subject to Social Services intervention. Yet, Katz et al stress the benefits of such advocacy, observing that parents are comforted and receive strength from striving to achieve their personal definition of what it is to be a "good parent", and bereavement outcomes are affected by the extent to which parents feel this was achieved.¹²⁹
36. Parents juggling multiple and sometimes competing commitments can also be a source of moral distress than can feed into conflict with healthcare professionals.¹³⁰ Mooney-Doyle and Ulrich highlight parental distress caused by concerns about finances, employment and the wellbeing of the family, with parents 'trading-off the needs of one family member in order to meet the needs of another while caring for a seriously ill child'.¹³¹ Brownes observes that because the law requires that the child's welfare is paramount, family interests cannot impinge the interests of the child, and 'this can have devastating effects on the family. It may mean the end of a marriage, changing professional or personal goals, and depriving other children of attention or social and educational opportunities.'¹³²
37. Finally, doctors' sense of their duty to involve parents in decision-making¹³³ may feel in conflict with their perceived responsibilities to the child, especially if there is a value-based disagreement

¹²² Wilkinson (n85) 91.

¹²³ *Barts Health NHS Trust v Dance* [2022] EWHC 1165 (Fam) [70].

¹²⁴ Archard (n120) 105; Brick (n92) 8.

¹²⁵ *Manchester University NHS Foundation Trust v William Verden & Amy McLennan* [2022] EWCOP 9, [16].

¹²⁶ Kirsty L Moreton, 'Reflecting on "Hannah's Choice": Using the Ethics of Care to justify child participation in end-of-life decision-making' (2020) 28(1) *Medical Law Review* 124, 152.

¹²⁷ *R (A Child)* [2018] EWFC 28.

¹²⁸ Katie Gollop and Sarah Pope, 'Charlie Gard, Alfie Evans and R (A Child): Why a medical treatment Significant Harm test would hinder not help' (22 May 2018) The Transparency Project <<https://transparencyproject.org.uk/charlie-gard-alfie-evans-and-r-a-child-why-a-medical-treatment-significant-harm-test-would-hinder-not-help>> Last accessed 27 March 2023.

¹²⁹ Katz (n58) 1372.

¹³⁰ Karla Abela et al, 'Impact of Pediatric Critical Illness and Injury on Families: An Updated Systematic Review' (2020) 51 *Journal of Pediatric Nursing* 21, 28.

¹³¹ Mooney-Doyle (n48) 822.

¹³² Alistair Browne, 'Physician Authority, Family Choice and the Best Interests of the Child' (2022) 31(1) *Cambridge Quarterly of Healthcare Ethics* 34, 38.

¹³³ Chiara Baiocchi and Edmund Horowicz, 'Children, Futility and Parental Disagreement: The importance of ethical reasoning for clinicians in the pediatric intensive care setting' (2023) 18(1) *Clinical Ethics* 26, 28.

with the parents. Bridgeman explains that there is a legal duty on the State (usually in the form of NHS Trusts) to intervene to uphold the best interests of the child.¹³⁴ Sometimes ‘medical-legal paternalism’ that Pruski argues is present in court best interests decisions,¹³⁵ can be apparent in the clinic as doctors decide to limit parental involvement and decision-making as a way to “lift the burden’ on the parents, in a bid to reduce their guilt or regret.¹³⁶

v) Interactions between professionals and families

38. There has been scant mention in the literature of how the nature and quality of interactions between professionals and families may cause or exacerbate disagreement. Archambault-Grenier et al list parental ‘behaviour or temperament’ as a moderately frequent cause of disagreement, with nurses flagging this up more often than doctors.¹³⁷ However, they give no further detail as to its nature. Basu and Preisz have recently considered Australian healthcare professionals’ experiences of conflict and aggression in the PICU and identify a range of ‘challenging’ parental behaviours, from overly emotive communication, to physical and verbal abuse and threats.¹³⁸ They note that the most damaging behaviour for healthcare professionals are passive-aggressive behaviours, which include ‘parent/carer hypervigilance, microaggression, repeated impedance of standard care (...) target and criticise certain staff at the bedside, make derogatory comments about care to other families, or overtly favour some staff over others’, often tolerated in a bid to foster family centred care.¹³⁹
39. The behaviour of healthcare professionals has also been identified as a factor contributing to conflict, albeit with less frequency than parental behaviour. In their study Archambault-Grenier et al found that ‘healthcare professional behaviour of temperament’ was identified as a factor by 14% of 281 respondents, ‘staff avoidance’ by 17% of 279 respondents and ‘potential prejudice toward the patient’ by 15% of 247 respondents.¹⁴⁰ Basu and Preisz conclude that ‘[f]or all parties, constantly experiencing challenging communication and behavioural styles can perfuse the unit with malaise, and pervasive interpersonal tension can tacitly lead to avoidance between parents and healthcare professionals’,¹⁴¹ thus fuelling disagreement.

EXTERNAL CAUSES

vi) Alternative sources of information, distrust of doctors, and the role of social media

40. The evidence suggests that parents of critically ill children are increasingly turning their attention to, and putting their trust in, the internet and social media. A USA study by Foot et al, which surveyed 90 parents of children with cancer, found that families frequently turned to social media to fill information gaps about prognosis or symptoms. 50% of respondents used it to find new treatment options and 40% to confirm information provided by their child’s doctor.¹⁴² Foot et al’s results showed that parents assessed the credibility and trustworthiness of information online, by seeking to verify it with doctors, with friends and relatives, with other families experiencing child

¹³⁴ Jo Bridgeman, ‘“Our Legal Responsibility...to intervene on behalf of the child”: Recognising public responsibilities for the medical treatment of children’ (2021) 21(1) *Medical Law International* 19.

¹³⁵ Pruski (n71) 82.

¹³⁶ Richards (n118) 670.

¹³⁷ Archambault-Grenier (n17) 265.

¹³⁸ Shreerupa Basu and Anne Preisz, ‘Family Conflict and Aggression in the Paediatric Intensive Care Unit: Responding to Challenges in Practice’ (2022) (Apr) *Clinical Ethics* 12, 15.

¹³⁹ *ibid.*

¹⁴⁰ Archambault-Grenier (n17) 265.

¹⁴¹ Basu (n138) 13.

¹⁴² Elizabeth Foot et al, ‘“The stakes could not be higher”: A mixed methods study of parental social media use in pediatric oncology’ (2021) 68 *Pediatr Blood Cancer* e29176, 1, 5.

cancer, or with “credible” sources, such as hospital websites and online medical journals.¹⁴³ Yet Wallis identifies that this is sometimes challenging given that ‘[t]hey find the internet alive with solutions from well-meaning families and untried miracle cures from salesmen some of whom are doctors too. They will promise help and cure in exchange for money or fame. Desperate parents will cling to these hopes.’¹⁴⁴

41. Another driving factor was identified in Mooney-Doyle and Ulrich’s study, where they observed ‘ineffective or insensitive communication and insults to the parent–child relationship’ that led to distrust between parents and healthcare professionals’.¹⁴⁵ This loss of trust may result in parents no longer accepting what the doctors tell them,¹⁴⁶ and thus turning to the internet and social media as an alternative source of information.¹⁴⁷ However, as Das found in her study of online support group “Charlie’s Army”, the evidence also reveals increasing populist rejection of expert opinion in general, in favour of anecdote and personal experience.¹⁴⁸ Whilst Auckland and Goold’s view is that a ‘culture of deference to doctors which results in parents feeling unable to voice discontent at the way their child is being treated would clearly be undesirable,¹⁴⁹ Wallis contends that there has been a shift where ‘[a] section of modern society has turned against experts and gives equal weight to a 120-character tweeted opinion.’¹⁵⁰
42. In *Battersbee* the family turned to online sources of information to support their position in the first court case, by citing American journal articles to suggest the brain stem death test was unreliable and drawing on press reports of recovery of consciousness after declaration of brain death, to argue against testing.¹⁵¹ When considering this evidence Arbuthnot J held that placing reliance on it was unhelpful given that the information in the American journals was outdated and contextually inapplicable and the press reports had no clear relevance a case like Archie’s.¹⁵² In the second case, when the relationship between the professionals had broken down further, Arbuthnot J noted that whilst Archie’s medical records contained a nursing note that ‘Archie’s mother preferred to search for answers on the internet or from people who had contacted her rather than accepting what the specialist doctors treating Archie and who have care of him on a daily basis were saying’, she did not accept that ‘these experienced doctors were not worthy of her [Archie’s mother’s] trust’.¹⁵³
43. It is undeniable that access to online information has altered the balance of power in healthcare.¹⁵⁴ Often healthcare professionals are concerned about misinformation, with Nottingham noting that during the *Gard* and *Evans* cases ‘much misinformation was spread (...) partly because the ease with which misinformed members of the public could post their views on

¹⁴³ *ibid.*

¹⁴⁴ Colin Wallis, ‘When Paediatricians and families can’t agree’ (2018) 103(5) *Arch Dis Child* 413.

¹⁴⁵ Mooney-Doyle (n48) 827.

¹⁴⁶ Auckland (n81) 302.

¹⁴⁷ *ibid.*

¹⁴⁸ Ranjana Das, ‘Populist discourse on a British social media patient-support community: The case of the Charlie Gard support campaign on Facebook’ (2018) 24 *Discourse, Context and Media* 76, 80.

¹⁴⁹ Auckland (n88) 661.

¹⁵⁰ Wallis (n144) 413.

¹⁵¹ *Barts Health NHS Trust v Dance* [2022] EWHC 1165 (Fam) [82].

¹⁵² *Barts Health NHS Trust v Dance* [2022] EWHC 1165 (Fam) [83] –[85].

¹⁵³ *Barts Health NHS Trust v Hollie Dance & Paul Battersbee & Archie Battersbee* [2022] EWHC 1435 (Fam) [47] –[48].

¹⁵⁴ Foot (n142) 2.

social media, and the ease with which these posts could be shared or retweeted extensively'.¹⁵⁵ However Foot et al found that it was 'less pervasive a theme than we expected'.¹⁵⁶ In this respect they point to a 'potential mismatch between professional and parental priorities in discussions of social media-related concerns', with professionals aiming to counter perceived misinformation, whilst parents wanted to know how to navigate social media effectively, as 'part of retaining agency in difficult circumstances, (...) while also protecting their own mental health and well-being'.¹⁵⁷ Foot et al referred to studies that showed that doctors felt 'obliged to reallocate time' to better help parents understand the 'concept of "evidence" in medicine and to respond to perceived critiques of their practices'.¹⁵⁸ 70% of the 90 respondents in their study who had spoken to their doctors about conflicting evidence felt listened to, with doctors willingly answering questions, offering to do further research and affirming parent education. However, some described negative reactions, including healthcare professional avoidance and anger, which in the most extreme cases led the parents to transfer care.¹⁵⁹

vii) Third-party involvement

44. Aside from the purpose of information gathering described in section vi), social media has continued to play a further part in the recent high-profile cases – in *Raqeeb* there was a social media awareness and fundraising campaign,¹⁶⁰ whilst in *Verden* Ami McLennan had taken to social media in an attempt to secure a kidney donor for her son William. In *Battersbee* the parents organised a weekly online prayer vigil,¹⁶¹ whilst in *Fixsler*, the publicity sought by the parents in order to highlight Alta's "plight", 'attracted a significant amount of coverage and comment in the press and on social media, both domestically and in other jurisdictions.'¹⁶² This included revealing the proposed home location for the withdrawal of Alta's treatment. Consequently, the Trust expressed concern that Alta's safety and security had been compromised,¹⁶³ leading the Court to reject "home" as a possible location for Alta's death.
45. The use of social media can also have an impact on healthcare professionals and further exacerbate disagreement. Wallis notes that '[i]n today's connected world, individual cases and their families can capture and dictate the social and established media news cycle in unpredictable ways. Opinion from the uninformed can be forcefully promulgated and fuel a maelstrom of anger, death threats and unreasonableness'.¹⁶⁴ Pearce reports that not only can healthcare professionals be subject to online abuse from members of the public, but also from within their profession, with

¹⁵⁵ Emma Nottingham, 'Experience as a legal blogger at Tafida Raqeeb case' (23 December 2019) The Transparency Project <<https://transparencyproject.org.uk/experience-as-a-legal-blogger-at-the-tafida-raqeeb-case>> Last accessed 2 April 2023.

¹⁵⁶ Foot (n142) 9.

¹⁵⁷ *ibid*

¹⁵⁸ *ibid* 2.

¹⁵⁹ *Ibid* 6.

¹⁶⁰ David Benbow, '*Tafida Raqeeb v Barts NHS Foundation Trust and Others* [2019]: Bolstering the Argument for Mediation' (2019) 19(4) *Medical Law international* 298, 301.

¹⁶¹ Jordan King, 'Mum of boy, 12, in a coma "praying for a miracle" with life support decision looming' (14 May 2022) *Metro News* <<https://metro.co.uk/2022/05/14/archie-battersbee-mum-is-praying-for-miracle-over-sons-life-support-16643810/amp>> Last accessed 2 April 2023.

¹⁶² *Manchester University NHS Foundation Trust v Alta Fixsler, Chaya Fixsler & Abraham Fixsler* [2021] EWHA 2664 (Fam) [34]

¹⁶³ *Manchester University NHS Foundation Trust v Alta Fixsler, Chaya Fixsler & Abraham Fixsler* [2021] EWHA 2664 (Fam) [35]

¹⁶⁴ Wallis (n144) 413.

accounts of nurses sharing social media stories or online petitions calling for other nurses to be 'held to account' for their perceived role in high-profile cases.¹⁶⁵

46. Third-party intervention also continues to play a part in disagreement. In *Fixsler*, the parents sought 'the intercession of politicians, religious leaders and Heads of State'.¹⁶⁶ The literature has also drawn attention to the involvement of religious groups to provide legal advice and representation, such as the involvement of the Christian Legal Centre (CLC) in *Battersbee*. Mir characterises such involvement as a 'discomforting facet', noting while such groups 'undeniably provide support to families, (...) may also serve to ferment division and mistrust in an already fragile and fraught situation.'¹⁶⁷ Woolley expands on this 'discomfort', citing Wilkinson's concerns that advice given by such organisations may not be accurate and that there is doubt that the CLC would have given Archie's parents 'a fair assessment of their chances'. Additionally, Woolley draws attention to the vulnerability of parents and questions whether such organisations 'prey' on this, and seek to break down trust between families and healthcare professionals in order to further their own agendas.¹⁶⁸ Some of the driving force behind parents making such connections is likely to be the absence of legal aid funding for these court cases, and so the need to seek out pro-bono representation. Mir concludes that '[s]erious consideration has to be given to what role, if any, third parties should play in discussions between families and clinicians going forward.'¹⁶⁹

viii) Alternative treatment and medical tourism

47. In the 2018 review Bhatia examined the crucial role in the high-profile cases, such as *Gard* and *Evans*, of disagreements stemming from parents wishing to take their child abroad for alternative/experimental treatments, and noted that such opportunities may both amplify the hope, but also vulnerability, of parents seeking them.¹⁷⁰ Fovargue has examined requests for experimental treatment and deems it right that the court be the arbiter in such cases. In disputes about "viable alternatives" she contends that such a request should not automatically be seen as a 'fair request', but that the court must weigh up the benefits, burdens and risks, before considering if the proposal is in the best interests of the child.¹⁷¹ Some of the recent cases have also featured disagreement about whether a child should be permitted to travel abroad for continuation of treatment that UK doctors do not think is in her best interests.¹⁷² In *Raqeeb* and *Fixsler*, the parents wanted to take their child abroad (to Italy and Israel respectively), albeit for continuation of life support rather than novel treatment. In *Raqeeb* the court held that it was in Tafida's best interests to be transferred to Italy,¹⁷³ whereas the court in *Fixsler* distinguished the parents' application from that of *Raqeeb* given that the details of the proposed plan were

¹⁶⁵ Lynne Pearce, 'Social Media: When mob mentality takes over and nurses turn on nurses' (2019) 34(10) *Nursing Standard* 42, 43.

¹⁶⁶ *Manchester University NHS Foundation Trust v Alta Fixsler, Chaya Fixsler & Abraham Fixsler* [2021] EWHa 2664 (Fam) [33].

¹⁶⁷ Fraz Mir, 'Reflecting on conflict between healthcare professionals and families of critically ill children' (2022) 379 *BMJ*(Online) 2735.

¹⁶⁸ Sarah Woolley, 'Religious fundamentalist lawyers "preyed on" Archie Battersbee's family' (8 August 2022) *OpenDemocracy* < <https://www.opendemocracy.net/en/archie-battersbee-christian-legal-centre-preying-whitewash/>> Last accessed 23 April 2023.

¹⁶⁹ Mir (n167) 2735.

¹⁷⁰ Bhatia (n11) 18.

¹⁷¹ Sara Fovargue, 'Preserving the therapeutic alliance: Court intervention and experimental treatment requests' in Imogen Goold, Jonathan Herring and Cressida Auckland (eds) *Parental Rights, Best Interests and Significant Harms* (Hart 2019) 153, 167.

¹⁷² Cressida Auckland and Imogen Goold, 'Re-evaluating "Best Interests" in the wake of *Raqeeb v Barts NHS Foundation Trust and Anor*' (2020) 83(6) *Modern Law Review* 1328.

¹⁷³ Benbow (n160) 301.

‘unhelpfully sparse’.¹⁷⁴ Yet the legal and ethical challenges of determining when such requests will be deemed to be in the child’s best interests has received little recent focus in the literature.

Summary

48. In summary, eight causes or factors in disagreement have been identified in the literature, matching appropriate resolution mechanisms with the severity of the dispute. Internal approaches are suitable for mild conflicts, with the literature outlining the merits of sensitive, well-timed communication and shared decision-making, situated within Conflict Management Frameworks including elements such as structured communication tools, managerial processes and psychologist involvement. Escalation to moderate disagreement may call for third-party intervention, but doubts are expressed in the literature of the effectiveness of the common approach of seeking expert second opinion. The use of Clinical Ethics Committees is seen as more promising in bringing parties together, with even the potential for determinative decision-making, but a major re-orientation of its role and remit would be required. Mediation has received sustained attention, with suggestions that its early use can be effective, although success may be limited where disagreements turn on religious beliefs or moral values. The strength of its voluntary nature is stressed, urging the avoidance of mandated participation. Legal resolution is generally needed in severe dispute and changes to the legal threshold for intervention from best interests to significant harm has received substantial attention, with strongly made arguments on both sides, but no clear consensus. Changes to the best interests test have also been advocated, along with alternative tests and court structures. Whilst there is recognition of the problematic aspects of court proceedings, the value of a transparent and robust legal process is also recognised.

B: The Impact of Disagreement

i) On the child

49. There is a noticeable lack of research on the impact of disagreement upon the child. This may be because in the high-profile cases in particular, either the child does not survive far beyond the end of the court proceedings, or they are not in a position of competence to form or share their views – as Macintosh and McConnell note, they are ‘beyond experience’.¹⁷⁵ There are also significant ethical and practical difficulties with undertaking research with critically-ill children, with Moore detailing the ‘enduring practical and methodological difficulties associated with filling this important gap in existing knowledge about what children value at the end of life.’¹⁷⁶

50. Where literature does exist about the impact on the child, there are two main themes that can be seen. The most common theme is the assumption that disagreements are damaging for the child,¹⁷⁷ largely due to the child being exposed to lengthy and potentially burdensome treatment whilst the court case on-going. Bridgeman’s commentary on the *Gard* case observed that despite fast-tracking, it still lasted for five months,¹⁷⁸ and Auckland and Goold posit that there is a contingent effect on the child of continued treatment that might not just be contrary to his best interests but may be also harmful.¹⁷⁹ This assumption is exemplified in Sokol’s commentary of *Battersbee* when he claims that ‘(...)Archie’s death was drawn out by weeks. Surely no one would want to survive in that condition, awkwardly balancing between the world of the living and the

¹⁷⁴ *Manchester University NHS Foundation Trust v Fixsler* [2021] EWHC 1426 [39].

¹⁷⁵ Karen Macintosh and Paul McConnell, ‘Parent and medical team disagreements in the UK: universal lessons in the origins and resolution of conflict’ (2022) 2(47) *J Anesth Analg Crit Care* 1, 5.

¹⁷⁶ Moore (n63) 60.

¹⁷⁷ Forbat (n43) 328; Katz (n58) 1370.

¹⁷⁸ Jo Bridgeman, ‘*Gard & Yates v GOSH*, the Guardian and the United Kingdom: Reflections on the Legal Process and the Legal Principles’ (2017) 17 *Medical Law International* 285, 292.

¹⁷⁹ Auckland (n88) 649.

dead with no chance of survival? It was a tragic situation made worse.’¹⁸⁰

51. In the same vein, but framed in a more nuanced and potentially more ethically challenging way given the taboos around child death, the second theme is Moore’s claim that there is little consideration of the fact that the child might actually welcome death. This may be particularly so if the child is sentient or conscious, – either as a form of relief from suffering, or in terms of a reconciliation with the reality that their life is coming to an end and death is preferable to continued life.¹⁸¹ This is emblematic of the avoidance of the notion of the “good death” for a child, as discussed in the Causes section above.

ii) On the family

52. Having a child that is critically ill is extremely stressful for the child’s family and is compounded by the “moral distress” that parents experience. This type of distress arises from having decision-making challenged and being prevented from pursuing what parents feel is the ethically right course of action for their child and family.¹⁸² Abela et al’s US Systematic Review, observed that whilst the 24-hour presence of families at the child’s bedside with attendant participation in the child’s care, may ‘promote coping and healing’, there is little evidence of the adverse implications on families of this increased involvement.¹⁸³ Zimmerman has explored the place of parental values in healthcare decision-making and asserts that these values are much deeper than mere preferences. She claims that inattention to them ‘results in the sense of invisibility, disregard, and even abandonment as a decision maker’- something which she equates to a ‘trauma’.¹⁸⁴ Both Zimmerman, and Mooney-Doyle and Ulrich claim that there is little discussion, and no real data or mechanisms for assessing the meaning and impact of conflict and the undermining of values on parents.¹⁸⁵ Furthermore, Zimmerman’s view is that, whether due to lack of data or paternalistic attitudes, clinicians underestimate the ‘trauma caused when parents are forced to deviate from values dear to them.’¹⁸⁶
53. Being the parent of a child who has received care in the PICU can have both short and long-term psychological implications. Abela et al’s review reveals that parents suffered a ‘significant psychological impact’, with the findings from the 19 studies reviewed showing up to 60% of parents experiencing anxiety and 50% suffering depression within a day of admission and for up to 3 months after discharge.¹⁸⁷ This was also borne out in a Canadian empirical study looking at the prevalence and factors associated with psychological impact and decisional conflict for parents with children in the PICU.¹⁸⁸ Additionally, parents may be diagnosed with Post Traumatic Stress Disorder (PTSD), often triggered by stress reactions to sights and sounds. As Abela et al note that ‘[w]hen a child is admitted to the PICU, the family is immersed in an unfamiliar environment filled with unique sounds, equipment, and routines that can become frightening and overwhelming’.¹⁸⁹ This is an effect which can possibly last for years,¹⁹⁰ and tellingly, Stremmer et al’s study found that the extent of later PTSD had a positive correlation to the parents’ level of distress at PICU

¹⁸⁰ Sokel (n103) o1980.

¹⁸¹ Moore (n63) 64.

¹⁸² Auckland (n172) 1341.

¹⁸³ Abela (n130) 21.

¹⁸⁴ Zimmerman (n86) 2.

¹⁸⁵ Zimmerman (n86) 4; Mooney-Doyle (n48) 822.

¹⁸⁶ Zimmerman (n86) 8.

¹⁸⁷ Abela (n130) 26.

¹⁸⁸ Robyn Stremmer et al, ‘Psychological outcomes in parents of critically ill hospitalized children’ (2017) 34 *Pediatric Nursing* 36.

¹⁸⁹ Abela (n130) 28.

¹⁹⁰ *ibid.*

admission, and not on the child's illness severity'.¹⁹¹

54. The addition of protracted legal action adds to parental distress.¹⁹² Mir, claims it was 'an enormously harrowing and traumatic experience for the parents' in the *Battersbee* case.¹⁹³ There is little evidence on the long-term impact of court proceedings on families, just an assumption in the literature that court proceedings have a negative impact on the family and are best avoided. Such a view is borne out in a recent interview with the parents of Charlie Gard for ITV, in which they say that 5 years on from their experiences, 'no time or distance has been able to erase the pain they feel every day. And the trauma of the court battle, is still very much with them'.¹⁹⁴ Yet for some families, the picture may be more complex. Also writing on the *Battersbee* case, Sokol opines the 'further ordeals' of multiple legal challenges, which he assumes will have taken their toll on Archie's parents as they would rather have been with their child than in court or instructing legal teams.¹⁹⁵ However, media interviews with Hollie Dance, Archie's mother, reveal a more nuanced account. On one hand she recounts that 'I feel we were stripped of all our rights and backed into a corner by the system and, I've explained before, it felt like we were on trial'.¹⁹⁶ Yet she also recognised the benefits of legal action, saying she had 'no regrets about exploring every avenue with her legal case' and noting that the opportunity to utilise the legal process 'bought us five extra months with my child'.¹⁹⁷
55. Despite the role that healthcare professionals, and sometimes the courts, play in decision-making, several commentators point out that it is the family that have to live with the consequences of the decision.¹⁹⁸ Macintosh and McConnell highlight the disparity between professionals and parents in the courtroom – they note that for doctors there can be no judicial compulsion to treat, so clinical teams can use the courts 'to green light their medical decisions or offer a judicial absolution for their consciences'. In contrast, parents are bound by court decisions, with no opportunity to argue the reasonableness or safety of their choices and '[t]hey are the individuals who bear the long-term consequences and deal with the direct impact on their family. Clinicians and courts move on to the next patient or case'.¹⁹⁹ Medical anthropologist Coruso Brown explores paediatric end-of-life decision-making as a form of ritual, contending that '[r]egret, or feeling that one might have done more for one's child, is likely to cause harm that persists far beyond the child's death, while the opposite—feeling that one has done "everything," in the sense held by that particular parent, and been a "good" parent to that child—can facilitate long-term healing for the parent and family'.²⁰⁰ American clinicians Barlet et al's prospective cohort study found that although there were high levels of decisional conflict, there were also high rates of satisfaction with the decision-making process and low rates of decision regret amongst parents with children

¹⁹¹ Stremler (n188) 36.

¹⁹² Dominic Wilkinson, 'Resolving conflict about treatment for seriously ill children' (2022) 378 *BMJ* o2000

¹⁹³ Mir (n167) 2735.

¹⁹⁴ Louise Scott, 'Charlie Gard's parents wouldn't wish court battle to save child "on worst enemy"' (20 July 2022) *itvNEWS* <<https://www.itv.com/news/2022-07-20/charle-gards-parents-wouldt-wish-court-battle-to-save-child-on-worst-enemy>> Last accessed 20 March 2023.

¹⁹⁵ Sokel (n103) o1980.

¹⁹⁶ Neil Shaw, 'Archie Battersbee's mum Hollie says his final moments were "awful"' (19 August 2022) *North Wales Live* <<https://www.dailypost.co.uk/news/north-wales-news/archie-battersbees-mum-hollie-says-24796995>> Last accessed 27 March 2023.

¹⁹⁷ Olivia Burke, 'Heartbreaking End: My beloved son Archie Battersbee died in 15 minutes with no dignity – the image will never leave me' (19 August 2022) *The Scottish Sun* <<https://www.thescottishsun.co.uk/news/9332251/archie-battersbee-died-15-minutes-no-dignity-mum/amp/>> Last accessed 27 March 2023.

¹⁹⁸ Mooney-Doyle (n48) 822; Auckland (n81) 299.

¹⁹⁹ Macintosh (n175) 2.

²⁰⁰ Caruso Brown (n59) 309.

in the PICU.²⁰¹ We may need to treat these results with caution given it is a US study with potential jurisdictional differences in approach to decision-making and conflict resolution, plus the very specific patient context of children with neurologic conditions. However, if transferable, these results would suggest that conflict itself is not a barrier to high decision-making satisfaction or low decisional regret, rather this largely depends on the support and clarity of thinking offered to the parents.²⁰²

56. The literature has also considered the impact of the quality of the relationship between healthcare professionals and families. On the positive side, Mooney-Doyle and Ulrich share Brosig's research on how bereaved parents felt 'supported by healthcare providers who communicated with honesty, who supported their parental role by creating an environment in which they could hold and be near their infant, and who helped them make meaning of the situation.'²⁰³ Bateman et al also confirm that good communication resulted in 'less suffering in parents whose child has died'.²⁰⁴ Moore's work on the notion of a "good death" for children, discussed in the Causes section above, acknowledges that the focus on "good", whilst sometimes for the child, is more often for the carers because of the lasting impact on them of the end-of-life decisions.²⁰⁵ Conversely, evidence on the impact of disagreement drew attention to 'breakdowns in therapeutic relationships',²⁰⁶ 'families feeling uncared for'²⁰⁷ and loss of trust,²⁰⁸ which for families feeling 'ignored (...) may include an irreconcilable distrust for the doctor, hospital, medical profession, public health profession, and even the government.'²⁰⁹
57. Finally, there are the emotional, relational and financial impacts on the family.²¹⁰ As Auckland and Goold point out, in the absence of legal aid, there are substantial financial costs for families to bear in going to court. As noted in the Causes section above, this may drive the family to seek other avenues of financial support, such as crowd funding, with the increased public exposure that entails.²¹¹ Whilst such "visibility" is sometimes sought by families and portrayed as a benefit, Auckland and Goold contend that it may also have negative impacts on the family, such as the inability to change their stated position in the face of social media pressure, and the cost of being 'forced to watch their personal tragedy played out on the world's stage'.²¹² In relation to family life, Katz et al point out in their Australian study that parents 'must find a tolerable way of living' and are tasked with making decisions that have implications for wider family life such as schooling, finances and employment.²¹³ Abela argues that siblings are often overlooked and that as '[s]iblings bear witness to not only the ill child's suffering but also their parents' fear and sorrow', further research is needed on the impact on them of parental absence or experiences of visiting the PICU.²¹⁴ Lastly, Mooney-Doyle and Ulrich explore the wider relational impact of

²⁰¹ Margaret H Barlet et al, 'Decisional Satisfaction, Regret and Conflict among Parents of Infants with Neurologic Conditions' (2022) 245 *The Journal of Pediatrics* 81, 85.

²⁰² *ibid* 87.

²⁰³ CL Brosig et al, 'Infant end-of-life care: The Parents Perspective' (2007) 27(8) *J Perinatol* 510 as cited in Mooney-Doyle (n48) 827.

²⁰⁴ Bateman (n110) 903.

²⁰⁵ Moore (n63) 60.

²⁰⁶ HK Johal et al, 'Conflict before the Courtroom: Challenging Cognitive Biases in Critical Decision-Making' [2020] *J Med Ethics: medethics-2020-106177*.

²⁰⁷ Katz (n58) 1370.

²⁰⁸ Sokel (n103) o1980; Mir (n167) 2735.

²⁰⁹ Zimmerman (n86) 5.

²¹⁰ Forbat (n47).

²¹¹ Auckland (n88) 649.

²¹² *ibid*.

²¹³ Katz (n58) 1370.

²¹⁴ Abela (n130) 29.

disagreements, drawing our attention to individual reactions of grandparents and siblings and how these play out across the family dynamic, for example in terms of regret or criticism of each other.²¹⁵

iii) On health care professionals

58. A large proportion of the focus in the literature on impact is on the experience of healthcare professionals. This may be due, at least in part, to the relative ease of access to and lesser ethical challenges for researchers in surveying this population, as compared with children and families. For Mooney-Doyle and Ulrich the question of moral distress is as pertinent for healthcare professionals as it is for families.²¹⁶ Moral distress as defined by the British Medical Association is 'the psychological unease generated where professionals identify an ethically correct course of action to take but are constrained in their ability to take that action' with constraints largely coming from 'institutionally required behaviour'.²¹⁷ Mooney-Doyle and Ulrich observe that the phenomenon 'has gained increased attention across disciplines, with growing recognition that clinical encounters can promote feelings of helplessness, hopelessness, distress, and secondary trauma in healthcare providers'; highlighting that the most prominent causes are 'challenging families and those requesting aggressive treatments'.²¹⁸ Additionally, a shift to the legal process in intractable disputes, means that professionals 'move from our traditional paediatric platform, based on consensus and mediation, to an arena of adversarial argument'.²¹⁹ Arbuthnot J in *Battersbee* noted the particular impact on nurses 'who have 24-hour care of Archie who have found in recent weeks an ethical strain that they have struggled with'.²²⁰ Gollop and Pope also explore the acute impact on PICU nurses, who they claim suffer the most of all healthcare professionals:

What nurses do feel, like doctors, is an innate and powerful drive to first, do no harm. A nurse required to provide life sustaining care to a child when experience tells her that care is harming not helping the patient, whilst simultaneously sharing the PICU bed space with exhausted, angry, desperate parents who know the nurse is conflicted and believe that she is "not on their side", is under enormous psychological pressure.²²¹

59. These psychological implications are recounted in the literature, with staff 'left anxious and bruised' after conflict.²²² Birchley et al claim that professionals 'intrinsic desire to "do the right thing" through leading in complex cases may override their regard for their personal well-being, and increase their vulnerability to experiencing moral distress, compassion fatigue and burnout'.²²³ Wallis describes the impact of court proceedings on healthcare professionals:

Paediatricians, who are not innately confrontational and are trained to seek compromise and consensus, are thrust into a world of adversary. Although we are witnesses to the facts, we enter the courts with an opinion which is of course challenged. It is inevitable. That is how the judicial system works. It is the role of the

²¹⁵ Mooney-Doyle (n48) 822; Auckland (n81) 299.

²¹⁶ Mooney-Doyle (n48) 822.

²¹⁷ British Medical Association, *Moral Distress and Moral Injury: Recognising and Tackling it for UK Doctors* (2021, BMA) 3.

²¹⁸ Mooney-Doyle (n48) 822.

²¹⁹ Wallis (n144) 413.

²²⁰ [187].

²²¹ Gollop (n128).

²²² Forbat (n47).

²²³ Birchley (n108) 1.

courts to consider a declaration of lawfulness, but inevitably the previous dilemma between the paediatrician and the family is now converted into a 'if you win/I lose' situation.²²⁴

60. The impact of public exposure through media and online commentary can be particularly severe. Mir opines that 'an equally worrying aspect has been the public criticism of the medical "establishment" in the mainstream media (...). It is understandable that a disagreement of this nature will inevitably lead to emotions running sky-high, but vilifying healthcare professionals in public will undoubtedly serve to undermine clinical medicine in general'.²²⁵ As reported in the 2018 literature review, Forbat highlights the additional distress caused by staff's lack of opportunity to reply to news stories – '[b]ound by patient confidentiality they have no voice to express the profound and lasting impact such conflicts and court cases have on them and they are unable to publicly talk about being threatened or attacked at work'.²²⁶
61. Finally, a small but useful recent study by Bell and Brierley on the impact of high-profile cases on PICU trainees revealed that they were concerned about the impact on their future careers, particularly in relation to lack of preparation and legal and ethical training needed to handle such cases. They note that '[all] had purposefully minimised their social media presence, being concerned about press and social media in these cases (...). All felt these issues had made them re-consider training in PIC medicine'.²²⁷

iv) On the National Health Service and wider society

62. There is little in the literature on the impact of disagreements on the health service. Sokol draws attention to the implications for practice and policy, with Trusts 'treading on eggshells while trying to avoid offence and reputational damage'²²⁸ and Jesmont et al note that medico-legal involvement is an 'ever-present risk.'²²⁹ Additionally, Sokol surmises that the dread of possible future litigation might cause Trusts to make a 'tactical decision' to accede to the views of the family, even when harmful, rather than risk another legal battle.²³⁰ Mir concurs, noting that '[m]any doctors would admit that they occasionally over-treat or over investigate patients to avoid a complaint or patient dissatisfaction'.²³¹
63. Some commentators reflect on the financial implications, such as Sokol's claim that in the *Battersbee* case '[t]he legal costs alone must have reached hundreds of thousands of pounds. The increased levels of security have added to the bill: at one point there were reportedly eight security guards around Archie's room'.²³² Forbat considers the staffing implications of disagreement, noting that '[i]n one study it was estimated that 448 hours of staff time was used in managing conflict in one children's hospital over a period of 24 weeks (...).²³³
64. Brief mention is made by Auckland and Goold of the public debate ignited by the high-profile cases, which they claim has done more than just 'stir up public sentiment' but has also revealed

²²⁴ Wallis (n144) 414.

²²⁵ Mir (n167) 2735.

²²⁶ Forbat (n47).

²²⁷ Clare Bell and Joe Brierley, 'What is the impact of high-profile end-of-life disputes on Paediatric Intensive Care (PIC) trainees?' (2022) 107(Suppl 2) Arch Dis Child A1-A537, A366.

²²⁸ Sokel (n103).

²²⁹ Jesmont (n16) 1238.

²³⁰ Sokel (n103) o1980.

²³¹ Mir (n167) 2735.

²³² Sokel (n103) o1980.

²³³ Forbat (n47).

‘not hitherto apparent powers’ of the courts.²³⁴ Das’ analysis of the populist discourse of “Charlie’s Army” in connection with the *Gard* case, sheds light on the societal impact of social media involvement in these disagreements, and the resulting ‘public perceptions and expectations of healthcare systems and professionals’.²³⁵ She also connects this to impacts on the NHS, observing that ‘[u]nderlying populist rhetoric in the UK, is an ongoing climate of critical opinion against the public services including the National Health Service.’²³⁶

Summary

65. In summary, the effect of disagreement on healthcare professionals is the overwhelming focus of the literature, with moral distress, compassion fatigue, staff burnout and fears for career prospects documented. The literature highlights the stress caused to healthcare professionals when switching from seeking consensus with families to the adversarial nature of court proceedings, and the negative impact that media exposure of these court cases can generate. In contrast, there is a significant gap in the literature relating to the impact on the child, which may be attributed to the legal and ethical difficulties of undertaking research with child patients, or the practical reality that child patients may not survive far beyond the decision, or ever have sufficient capacity to be able to share their experiences. Nonetheless, there is an assumption in the literature that disagreement and court proceedings are detrimental to the child. The literature on the impact on families paints a more nuanced picture, with the majority focus given to accounts of psychological trauma, moral distress, relationship deterioration and financial implications arising from experiences both within the hospital and the courtroom - the impact of which can be underestimated by healthcare professionals. Poor experiences can have wide-ranging implications in undermining trust in doctors, the health service, the legal system and even the government. Yet, there may be a disconnect between findings in the academic literature and the lived reality of families, as for some parents the opportunity to have their voice heard and views examined by the courts is highly valued. Literature on the impact on the NHS and wider society is scarce, but changes in policy and adoption of defensive practice, financial and staffing implications, reputational damage, and an increasing climate of public critical opinion against the health service, are documented.

C: Possible Means of Avoiding Disagreement or Resolving Disputes

66. In this third section, suggestions for avoiding disagreement, or recognising it in its early stages will be explored, along with a review of the evidence on mechanisms to help resolve dispute. More than ten years ago Teuten, Forbat and Barclay undertook a project seeking to discover if conflict follows an identifiable path and found that there were triggers for conflict and warning signs of its escalation.²³⁷ They posed a helpful “traffic lights” model as a way of categorising severity of disagreement and matching it with the appropriate responses – the “green zone” for mild conflict which can be addressed with internal strategies; the “amber zone” for moderate level conflict, which may need some third-party intervention; and finally the “red zone” for the most severe conflicts, which will often need legal resolution. Their model will be used to guide the examination of the literature in this section.

a) Green Zone: Mild Conflict – Internal Mechanisms

i) Good communication

67. There is much made in the literature of the merits of good communication in both avoiding

²³⁴ Auckland (n81) 291.

²³⁵ Das (n148) 76.

²³⁶ *ibid* 83.

²³⁷ BJ Teuten, E Forbat & SF Barclay, ‘The Conflict Pathway: A model to address conflict in paediatric practice’ (2012) 97 (Supp 1) Arch Dis Child A5.

disagreements, or in their early resolution. Forbat and Barclay claim it is a ‘core skill’ in paediatric specialities where there is complex case management of critically-ill children.²³⁸ Wilkinson and Savulescu outline the general approach in professional guidelines of seeking consensus between professionals before proceeding to limit or withdraw treatment, although they question whether consensus means unanimity or a majority view.²³⁹ They claim that the utility of a consensus approach is that it acts as recognition of the seriousness of the decision, can be psychologically beneficial to families, and can provide confidence to professionals and reduce their ‘legal vulnerability’.²⁴⁰ Communication between parents and professionals in the form of discussion was examined in Austin’s 2018 review and characterised as a means of seeking consensus through “shared-decision making”.²⁴¹ She drew on Brierley et al’s 2013 Great Ormond Street Hospital (GOSH) study as evidence that it was largely effective at doing so, with only 17 out of the 203 cases he reviewed not being resolved by discussion.²⁴² More recently, Archambault-Grenier et al’s large-scale Canadian study focusing on the 341 respondents who had experienced end-of-life conflict in the last 5 years, demonstrated that ‘negotiating with parents’ was the most commonly used strategy by healthcare professionals to deal with conflict (74% of the 291 respondents who answered the question), but with less conciliatory methods such as ‘attempting to convince the family’ or ‘informing and educating the parents’ being used by over 40%.²⁴³ Mooney-Doyle and Ulrich examine studies that show that parents want ‘honest and compassionate communication’ and value access to information and positive relationships with healthcare professionals.²⁴⁴

68. Recent thinking has questioned the avoidance of disagreement as the aim of discussion. Given, that many of the most challenging decisions about critically-ill children involve differences about values, and not just medical facts, Auckland and Goold point out that that ‘in a liberal democracy committed to religious freedom and tolerance, it is crucial that we leave space for people to disagree.’²⁴⁵ Wilkinson and Savulescu go further in claiming that disagreement should not just be tolerated, but celebrated; ‘ (...) in a sense, disagreement is a good thing – it is a sign of a pluralistic and tolerant society’.²⁴⁶ They also question the consensus model for professionals, asserting that if unanimity, or even a majority view, is needed that ‘end-of-life decisions could be held hostage by the most conservative or cautious decision-maker’, and that instead professionals should acknowledge and accept disagreement.²⁴⁷ They propose an alternative “reasonable dissensus” approach. Adopting this approach would permit initiating discussion with families, which could subsequently lead to action to limit or withdraw treatment, if at least one member of a treating team who is aware of the clinical facts, would endorse the course of action and be prepared to take over the patient care.²⁴⁸ They suggest that a mitigating safeguard against vesting such power in only one professional would be the requirement that before any endorsement of the course of action, there must be ‘adequate reflection and discussion’.²⁴⁹

69. Some of the literature has broached the need for healthcare professionals to reflect on their own

²³⁸ Forbat (n43) 331.

²³⁹ Dominic Wilkinson and Julian Savulescu, *Ethics, Conflict and Medical Treatment for Children* (Elsevier 2019) 103-104.

²⁴⁰ *ibid* 104.

²⁴¹ Austin (n11) paras 9-10.

²⁴² J Brierley, L Linthicum and A Petros, ‘Should religious beliefs be allowed to stonewall a secular approach to withdrawing and withholding treatment in children?’ (2013) 39(9) *J Med Ethics* 573.

²⁴³ Archambault-Grenier (n17) 266.

²⁴⁴ Mooney-Doyle (n48) 827.

²⁴⁵ Auckland (n88) 663.

²⁴⁶ Wilkinson (n239) 146.

²⁴⁷ *ibid* 106.

²⁴⁸ *ibid*.

²⁴⁹ *ibid*.

characteristics, values and perceptions, as well as seek a more nuanced understanding of the context of parental decision-making. Birchely et al's study found a high degree of consensus for the use of a 'traffic light system' to grade parents' behaviour, but they are keen to point out that this should not 'be misinterpreted as a judgemental critique of a family's behaviour but rather as an opportunity for professionals to think about their own assumptions and approaches'.²⁵⁰ In the USA, Bateman et al undertook narrative interviews with paediatric doctors to assess what impact their gender and parental status had on their practice of patient-centred communication.²⁵¹ They found that female doctors believed they were more empathetic, spent longer with patients, formed deeper emotional attachments and experienced more emotional pain as a result, as compared to male doctors who could more easily detach.²⁵² The male doctors refuted the gender stereotype, believing that personality and life experience played a greater part in communication styles. However, both groups agreed that parental status had the biggest impact on interactions with families, which had a complex effect overall. This was described by one male doctor who explained 'it became a lot more difficult once I had children ...it became easier to empathize with families once I had children too. The pain was bigger because you feel like "whoa, that could have been my child". But... at the same time it prepares you better because you understand the love they have for their children.'²⁵³ Bateman et al contend that recognising the vulnerabilities that these factors give rise to and how they might impact communication, will help doctors to better form a 'therapeutic alliance' with patients, and provide avenues for training and emotional support.²⁵⁴

70. Mooney-Doyle and Ulrich suggest that a deeper understanding by healthcare professionals of parental moral distress at 'intrapersonal, interpersonal, and existential/spiritual dimensions' is needed. Understanding the intrapersonal aspects could then prompt them to ask, for example, about the 'multiple stressors parents face in caring for their family'.²⁵⁵ Caruso Brown offers a fresh perspective in viewing parental decision-making as a form of healing ritual for the family and that an understanding of this can help 'to attenuate moral distress surrounding end-of-life care choices that seem inappropriate or even unethical to health-care providers and thus facilitate better communication and collaboration between parents and clinicians'.²⁵⁶ Relating back to the discussion in the Causes section above, on parental understandings of hope and "visiting reality" as a factor in disagreement, Katz et al suggest that whilst the hope and "good parent" literature can help to fill in knowledge gaps:

The missing piece of the puzzle may be the extent to which parents contemplate what clinicians perceive to be the 'reality' of their child's illness, including the potential or likely death of their child. Some parents seem to spend a lot of time thinking about these concepts, some can only 'visit' them from time to time, and others cannot think about them at all. Clinicians' motivation for parents to 'visit' such 'reality' stems from the desire to emotionally and intellectually prepare them for the future, and facilitate informed decision-making. However, this may be at odds with some families' avoidance of 'reality' as a protective measure. Clinicians may find themselves talking at cross purposes with parents who are not able to contemplate 'reality' in that moment but on another day, the conversation may be

²⁵⁰ Birchley (n108) 3.

²⁵¹ Bateman (n110) 903. Note - the authors do not provide a definition of gender, nor do they say how they determined the gender of the participants. There is no reference to non-binary gender.

²⁵² *ibid* 905.

²⁵³ *ibid* 906.

²⁵⁴ *ibid* 908.

²⁵⁵ Mooney-Doyle (n48) 833.

²⁵⁶ Caruso Brown (n59) 315.

very different.²⁵⁷

71. On a practical level, there is agreement in the literature on the benefits of improving communication and ethics training, for the latter particularly in the difference between facts and values and the nature of value-based disagreement.²⁵⁸ Archambault-Grenier et al's study showed that more than 85% of the 663 respondents who had witnessed or cared for dying children would find education on paediatric palliative care, ethics, conflict resolution, communication and cultural differences useful.²⁵⁹ Bell and Brierley focus on the needs of trainee doctors in urging the adaption of PIC training to include trainees 'observing difficult conversations, legal discussions and ethics meetings during their training.'²⁶⁰ Forbat and Barclay's study found that staff reported that training provided them with a 'marked advantage' notably in the 'frequently neglected skills' of listening and -taking'.²⁶¹ Various practical communication models have been proposed, such as the 'standardised approach' as discussed by Birchley et al, which provides for uniform practices in communicating with families in relation to consistent messaging, assessing concerns, noting discussions, and utilising 'family held records' to permit families to document meetings and note their reflections and understandings.²⁶² The authors are also quick to point out that 'this is not intended to imply a 'one size fits all' solution. Each family is unique (...). There is a delicate balance between structure and intimate spontaneity that must be achieved in practice'.²⁶³ Macintosh and McConnell suggest 'content-oriented strategies' as being effective as they include 'acknowledging opposing views on treatment, clarifying by providing factual information or reformulating such as reiterating what the medical team has previously said.'²⁶⁴ Ultimately, Wilkinson and Savulescu conclude that '[w]here families feel that they are being listened to, and where they can understand a patient's medical situation, it seems likely that families would maintain trust in the professionals and be less inclined to seek alternative views or treatments'.²⁶⁵

ii) Managerial processes and Conflict Management Frameworks

72. Good communication can form a part of larger "Conflict Management Frameworks"(CMF), which Macintosh and McConnell define as 'a tool, which can be tailored to individual institutions with the aim to resolve difficulties at ward level.'²⁶⁶ They urge healthcare professionals to recognise the early warning signs of conflict, such as avoidance, or families trying to micromanage or play professionals off against each other, and to respond quickly, using frameworks to help resolve conflict and reduce staff burnout.²⁶⁷ Elements of the framework may also include provision of a liaison or key worker, a single clinical lead,²⁶⁸ and earlier involvement of palliative care teams.²⁶⁹ Additionally, Gamble and Pruski suggest structured de-briefing sessions for staff, and psychological support for both staff and patients to help handle distress.²⁷⁰ These are all concepts that Birchley et al note are not new, but require 'some committed resource and intent' to

²⁵⁷ Katz (n58) 1373.

²⁵⁸ Wilkinson (n239) 127.

²⁵⁹ Archambault-Grenier (n17) 266.

²⁶⁰ Bell (n227) A1-A537.

²⁶¹ Forbat (n43) 331.

²⁶² Birchley (n108) [e001589]

²⁶³ *ibid.*

²⁶⁴ Macintosh (n175) 3.

²⁶⁵ Wilkinson (n239) 127.

²⁶⁶ Macintosh (n175) 3.

²⁶⁷ *ibid.*

²⁶⁸ Wilkinson (n192) o2000.

²⁶⁹ Macintosh (n175) 3.

²⁷⁰ Nathan Gamble and Michal Pruski, 'Should Parents be asked to consent for life-saving paediatric interventions?' (2021) 22(4) J Intensive Care Soc 335, 338.

succeed.²⁷¹

73. One such model forms part of the Evelina Resolution Project, first launched in 2013 and later adopted by the Medical Mediation Foundation. Its conflict management framework provides training and tools to utilise a two-stage 'structured approach to talking with families about disagreements, documenting discussions and escalating concerns'.²⁷² The first stage focuses on prompts to awareness and avoidance of conflict triggers which are used in daily huddles/handovers and urges timely engagement with the family to explore their concerns. Stage 2 has a four-step process to be used in the event of escalation and communication breakdown, where 'conflict is recognised as serious, so senior hospital managers are informed of the case, and if necessary so too are child protection teams, legal services and hospital security.'²⁷³ Forbat and Barclay have reported that early trials of the framework in a paediatric oncology ward in an Australian hospital, showed a 64% decrease in conflict incidents between the baseline and follow-up 6 months later, along with increased staff confidence in discussing and positively managing difficult situation, and a resultant statistically significant decrease in staff burnout.²⁷⁴ The authors note however that '[f]or continued use of the framework, senior leadership is required at the ward and hospital levels, including buy-in from medical colleagues.'²⁷⁵
74. In the context of children with medical complexity, Birchley et al have undertaken a very recent Delphi study surveying 99 healthcare professionals at a tertiary children's hospital in England, in order to develop a consensus approach to case management.²⁷⁶ The study identified 69 normative statements that Birchley et al grouped into seven key themes: standardised approaches to communicating with families; processes for interprofessional communication; processes for shared decision-making in the child's best interests; role of the multidisciplinary team (MDT); managing professional-parental disagreement and conflict; the role of clinical psychologists; and processes to support staff.²⁷⁷ They note that the study is inevitably limited by its exclusion of the views of families and the child patient and observe that this is an area in need of further research.

b) Amber – Moderate Dispute: Third-party Involvement

iii) Expert second opinion

75. As already discussed in Austin's earlier review, seeking an expert second opinion is a usual next step if discussions have been unsuccessful.²⁷⁸ Yet despite Birchley noting that '[r]eferral for external second opinions has been a consistent recommendation for reducing conflict (...)',²⁷⁹ there remains the same lack of evidence on their effectiveness or their frequency of use as was identified by Austin in 2018.²⁸⁰ What mention that there *is* in the literature of expert second opinions draws attention to the difficulties and possible exacerbation of conflict that their usage may provoke. Wallis asks 'Who decides on that opinion? Is it the parents? Parents often do not have access to professionals they trust and turn to social media and the web. If the doctors decide on the choice of a professional second opinion, they need to remain neutral in their choice to ensure they do not subconsciously or consciously invite someone they know will support their

²⁷¹ Birchley (n108) [e001589].

²⁷² Forbat (n47).

²⁷³ Forbat (n43) 329.

²⁷⁴ *ibid* 329-330.

²⁷⁵ *ibid* 331.

²⁷⁶ Birchley (n108) [e001589].

²⁷⁷ *ibid* 3.

²⁷⁸ Austin (n11) para 20.

²⁷⁹ Birchley (n108) 7.

²⁸⁰ Austin (n11) paras 23-24.

position.’²⁸¹ In Birchley et al’s recent study they report a strong consensus in healthcare professionals on the need to nationally standardise processes for seeking second opinion, but less enthusiasm for their use as an element of an automatic conflict resolution pathway at a local level.²⁸²

76. That said, Expert Second Opinion *can* be a component of the type of Conflict Management Framework outlined in ii) above, and might be particularly appropriate where there is a dispute between parents and clinicians over the interpretation of medical fact.²⁸³ Such was the case in *Verden*, where the focal point of disagreement was on what risks were posed by, and could justifiably be taken, in relation to the proposed transplant and post-operative care. Two expert second opinions were sought. However, the kinds of difficulties identified by Wallis were apparent, with the family not persuaded by either the first expert opinion, recommending William meet the palliative care team, nor the second stating that a transplant was not in William’s best interests unless active treatment was pursued.²⁸⁴ The use of expert second opinion was therefore ineffective at resolving disagreement. As Wallis contends, even when the parents chose the expert, when the opinion is delivered, it is often rejected²⁸⁵ – particularly if it does not accord with the parents’ position.

iv) Clinical Ethics Committees and other resolution forums

77. There has been increased interest in the recent literature on Clinical Ethics Committees (CECs) as an effective mechanism for dispute resolution.²⁸⁶ Wallis claims CECs can be useful ‘in shining a new light on the problem’ revealing ‘issues of the care and treatment that have been missed by simply being up too close to the problem for too long’.²⁸⁷ Intended as a way of bringing a diverse range of people and experience together to consider the ethical as well as medical aspects of a particular decision, CECs can be especially useful where parents are struggling with ‘decisional conflict related to values clarity’ that spills over into disagreement.²⁸⁸ Auckland and Goold find committee deliberation can avoid excessive influence of one set of values and if specific value-commitment *is* involved, these values can be openly scrutinised by committee members.²⁸⁹ Huxtable suggests that specialist ethics services focusing on particular clinical areas or patient populations have promise, with their benefits including the provision of practical advice, being supportive to both professionals and parents, expertise in ethical matters (amplified for specialist committees), and are quicker, cheaper and less adversarial than the courts.²⁹⁰

78. Yet CECs are not without problems. As Johal et al’s study notes, their remit, the weight given to their advice, and overall perceptions of their utility in the decision-making process by stakeholders, is unclear.²⁹¹ Lack of clear processes in determining membership and expertise of

²⁸¹ Wallis (n144) 413.

²⁸² Birchley (n108) 1.

²⁸³ Austin (n11) para 21.

²⁸⁴ *Manchester University NHS Foundation Trust v William Verden & Amy McLennan* [2022] EW COP 9 [101]-[102].

²⁸⁵ Wallis (n144) 413.

²⁸⁶ Mir (n167) 2735.

²⁸⁷ Wallis (n144) 413.

²⁸⁸ Barlet (n201) 86.

²⁸⁹ Auckland (n88) 668.

²⁹⁰ Richard Huxtable, ‘Clinic, Courtroom or (Specialist) Committee: In the Best Interests of the Critically Ill Child’ (2018) 44 J Med Ethics 471, 473.

²⁹¹ Harleen K Johal, Giles Birchley and Richard Huxtable, ‘Exploring physician approaches to conflict resolution in end-of-life decisions in the adult intensive care unit: protocol for a systematic review of qualitative research’ (2022) 12(7) BMJ Open e057387, 2.

CECs, along with the deliberative frameworks they use, have been raised as a problem, but Huxtable contends that a more specialist focus would lend itself to greater transparency.²⁹² In Jesmont et al's hospital study the value of CEC's was recognised, despite an absence of CEC referrals during the 4-week duration of the study. However, it also identified shortcomings in the use of CECs that lay in the difficulties of advice implementation, which largely fell to clinicians.²⁹³ Exclusion of the family from the CEC is also a concern. In *Verden*, the CEC appears to have met at a time when William was unsettled and when options for post-operative measures had not been fully explored.²⁹⁴ The parents' views were excluded from consideration; critical of this the Arbuthnot J claimed it would have been better to hold a two-part meeting, one for the parents and one for the doctors and '[t]he Ethics Committee would then have a better idea of William's quality of life, his wishes and the position of the family'.²⁹⁵

79. In *Battersbee*, Archie's case was only looked at by a "rapid case review group," rather than a full CEC and again, absent any parental involvement.²⁹⁶ Sokol surmises that '[m]aybe a full ethics committee, well constituted and considering the views and values of the parents, would have altered the course of events. Maybe a skilled clinical ethicist, rather than a more daunting institutional committee, could have gained the trust of the family early on, managed expectations, and avoided the subsequent conflict between the healthcare team and the parents'.²⁹⁷
80. One suggestion explored in the literature is to give the views of CECs legally-binding authority, so they could make decisions in the place of the courts. This idea is rejected by Wallis, claiming '(...) ethics committees will not make a decision. That is not their role. They thrive on the various ways that a problem can be viewed.'²⁹⁸ Auckland and Goold, however are more open to the proposal, looking to models in Chile, Argentina and Israel where CECs can make binding best-interests decisions. In Texas doctors who wish to refuse a treatment request can refer it to the CEC and if the committee deems treatment 'medically inappropriate', the clinicians are legally permitted to withdraw or withhold treatment after 10 days, unless the family can find another doctor who is willing to offer the treatment sought.²⁹⁹ Auckland and Goold recognise that CECs in England are currently tasked with providing ethics advice to doctors, not mediating disputes between professionals and patients, so it would take a significant reorientation and restructuring to fulfil such a role.³⁰⁰ The power imbalance between clinician and patients may also be an obstacle to persuading parents as to the neutrality of CECs. Additionally, the very benefits of the informality and diversity of CECs may act against them having legally-binding authority, given the lack of transparent procedural and evidential processes, duty to provide a reason for the decision, public scrutiny, and appeal opportunities that accompany the court process.³⁰¹ Auckland and Goold conclude that '[i]ndeed, it may be something of a paradox that in order to supplant courts, committees would need to introduce a degree of formality that would in turn undermine the flexibility that makes them so effective at resolving disputes'.³⁰²

²⁹² Huxtable (n290) 473.

²⁹³ Jesmont (n16) 1238.

²⁹⁴ *Manchester University NHS Foundation Trust v William Verden & Amy McLennan* [2022] EWCOP 9 [105].

²⁹⁵ *Manchester University NHS Foundation Trust v William Verden & Amy McLennan* [2022] EWCOP 9 [106].

²⁹⁶ *Barts Health NHS Trust v Hollie Dance & Paul Battersbee & Archie Battersbee* [2022] EWHC 1435 (Fam) [136]

²⁹⁷ Sokel (n103) o1980.

²⁹⁸ Wallis (n144) 413.

²⁹⁹ Auckland (n88) 667.

³⁰⁰ *ibid* 668.

³⁰¹ *ibid* 669.

³⁰² *ibid* 670.

v) Mediation

81. A final suggested resolution mechanism for moderate level disagreement is mediation. There has been significant interest in both the academic literature and public debate about the value of mediation, not least driven by advocacy for “Charlie’s Law” and the proposed parliamentary amendments seeking to mandate mediation.
82. Benbow argues that the *Raqeeb* case ‘demonstrates the need for legal reform to ensure that mediation is offered where such disputes arise’.³⁰³ He feels that mediation could facilitate an understanding between parties that could prevent otherwise stressful and costly litigation.³⁰⁴ Preisz et al’s work on the use of mediation in the Australian context suggests that it is most effective when used early on at the first signs of disagreement, as ‘opposed to a “last-resort” strategy’.³⁰⁵ They lists strengths of mediation as ‘concentrating on the mutual ‘interests’ of the involved parties as opposed to polarised positions, aiming to shift perspectives and achieve stable, lasting solutions’ and highlight that it may be preferable to CECs in terms of inclusion of parental view and voice.³⁰⁶
83. Yet Choong questions mediations’ ability to resolve disputes that turn on questions of medical futility. She contends that the lack of a middle-ground, given the stark choices or entrenched religious positions that these cases involve, can be a barrier.³⁰⁷ As Auckland and Goold observe:

Achieving compromise in this context is hard: for the parent who regards their child’s life as inherently valuable, anything short of further treatment would be unacceptable. For the doctor meanwhile, agreeing to act in a way that they strongly believe to be contrary to the child’s interests (and potentially harmful), would require them to compromise on their core ethical duty to do good for their patient (...). Anticipating this, one or other party may fail to engage fully in the process, which will further undermine its likelihood of success. Mediation in these cases may then have done little more than to delay access to court proceedings and entrench the parties’ positions further.³⁰⁸

Conversely, where dispute is driven by a medical factual error of understanding by the parents, and where if permitted could cause harm to the child, Auckland and Goold would welcome some form of pre-court mediation to help address such errors.³⁰⁹ The second obstacle that Choong identifies is that negotiations happen in the “shadow of the law” – in that doctors know that should mediation fail they can always take the case to court. She contends that because doctors know that the courts almost always find in favour of doctors in futility cases, this therefore creates an unequal bargaining power in the mediation process.³¹⁰

84. Another important point against mandating mediation is that it works on the premise of voluntary involvement. Barclay, founder of the Medical Mediation Foundation has stated in an

³⁰³ Benbow (n160) 300.

³⁰⁴ *ibid* 306-307.

³⁰⁵ Anne Preisz et al, ‘Defining the role of facilitated mediation in medical treatment decision-making for critically-ill children in the Australian clinical context’ (25 September 2022) *Clinical Ethics* doi.org/10.1177/14777509221125340, 2.

³⁰⁶ *ibid*

³⁰⁷ Kartina Choong, ‘Can “Medical Futility” conflicts be mediated?’ (2018) 6 *Journal of Medical Law and Ethics* 41, 48.

³⁰⁸ Auckland (n88) 665.

³⁰⁹ Auckland (n81) 303.

³¹⁰ Choong (n307) 49.

interview with Radio Ombudsman, 'I know there's a discussion at the moment about whether in medical mediation it should be compulsory. I understand that, but I think the value of mediation is in its voluntariness. It should never be a tick-box exercise.'³¹¹ The impact of this voluntariness was seen in the *Battersbee* case, where mediation was initially refused, but after receiving legal advice the family had reconsidered.³¹² However, this new position on mediation had apparently not been communicated back to the treating team or NHS Trust, so no further opportunities for mediation were taken.³¹³

c) Red – Severe Conflict: Legal Resolution

vi) Legal reform – Significant Harm

85. The most prominent debate in the literature in the last 5 years has been whether there should be a change to the legal threshold for intervention in parental decision-making,³¹⁴ so that court proceedings can only be instituted if the child is suffering or at risk of suffering significant harm.³¹⁵ The courts have already considered this argument in both *Gard* and *Evans* and rejected it both times³¹⁶, but the idea has substantial academic and popular interest (although by no means consensus),³¹⁷ and as noted in the introduction, various proposals relating to it have been put before Parliament.
86. The first argument advanced by proponents is one of consistency. In the public law context, in order for the State to intervene in relation to child protection concerns, the "significant harm" threshold must be crossed.³¹⁸ Birchley explains that in this context the law refrains from intervening when parenting is merely mediocre or unusual, as to do otherwise 'would amount to social engineering'.³¹⁹ However, Pruski points out there is a disconnect when it comes to healthcare, with intervention happening at a lower point - where parental decision-making is deemed contrary to the child's best interests. He laments this apparent inconsistency in the law, noting that 'we accept such a competent (or good enough) parent standard in other areas of the child's life, such as education or nutrition, so it is an oddity that we do not accept it in cases of conflict with the clinical treating team'.³²⁰
87. In response, Birchley questions whether consistency is always desirable.³²¹ Gollop and Pope point to the fact that medical decision-making and care proceedings are entirely different and that therefore different thresholds are justified.³²² The first addresses a single issue decision that requires 'targeted intervention',³²³ which the state is well resourced to deliver and the outcome

³¹¹ Sarah Barclay, 'Approaches to Mediation and Dispute Resolution' Radio Ombudsman (13 April 2018) <<https://gate.sc/?url=https%3A%2F%2Fwww.ombudsman.org.uk%2Fnews-and-blog%2Fpodcast%2Ftranscript-radio-ombudsman-3-approaches-mediation-and-dispute-resolution&token=7dc1cf-1-1680394247751>>

³¹² *Barts Health NHS Trust v Hollie Dance & Paul Battersbee & Archie Battersbee* [2022] EWHC 1435 (Fam) [101].

³¹³ *Barts Health NHS Trust v Hollie Dance & Paul Battersbee & Archie Battersbee* [2022] EWFC 80.

³¹⁴ There is some debate as to whether this would require a change to the Children Act 1989, in terms of the Welfare Principle under s1.

³¹⁵ Rob George, 'The legal basis of the Court's jurisdiction to authorise medical treatment of children' in Imogen Goold, Jonathan Herring and Cressida Auckland (eds) *Parental Rights, Best Interests and Significant Harms* (Hart 2019) 67, 68.

³¹⁶ Wilkinson (n85) 86.

³¹⁷ For example, see Auckland (n81) 287.

³¹⁸ Children Act 1989 s31.

³¹⁹ Birchley (n26) 110.

³²⁰ Pruski (n71) 88.

³²¹ Birchley (n26) 128.

³²² Katie Gollop (n128).

³²³ *ibid.*

is reasonably predictable, whereas the latter is an intervention due to an assessment of overall poor parenting;³²⁴ ‘a last-ditch activity, poorly resourced and that we are unsure will produce significant benefit’.³²⁵ Cave and Nottingham argue that clinical decision-making is different to legal decision-making – clinical is within a constantly changing dynamic and failures can result in increased patient burden, scrutiny of decision-makers and additional resources.³²⁶ To counter this, Wilkinson contends that whatever the legal differences might be, there is an *ethical* case to support consistency, which links to the parents’ role as decision-makers.³²⁷

88. This is the second reason given to support the change; that a shift to a “higher” threshold for intervention would better recognise and protect ‘parental autonomy’, which could be seen as ‘the extension of liberal democratic principles to confer a limited privacy right for parents’.³²⁸ Giving parents determinative decisional rights below that threshold is justified by the premise that parents are best placed to make decisions for their children due to their intimate knowledge of the child, that they generally act in love, and that they will bear the long-term consequences of the decision.³²⁹
89. Yet there are concerns that the harm threshold ‘seems to break the link with the necessity to act with a child’s welfare in mind’,³³⁰ with Archard contending that ‘[b]eing motivated to do what is best for someone does not make one the best or even a better judge of what is in fact best. Love can indeed be blind’.³³¹ Opponents claim that best interests already recognises the parents role in decision-making. Birchley recounts that there is sometimes a degree of sub-optimisation of the clinical goals to maintain dialogue with the parents, yet this should not amount to ‘simple capitulation to obviously poor parental judgments’.³³² According to Taylor, the law works by emphasising the parents primary decision-making role, not by ‘carving out decisions in which parents are immune from challenge’.³³³
90. Proponents claim that the concept of best interests is too vague, especially when decisions are complex, value laden and medically uncertain.³³⁴ Diekema argues that harm is much better understood by clinicians than best interests,³³⁵ offering ‘a clearer line for clinicians to engage with about when to request judicial input’,³³⁶ as well as ‘more overtly’ protecting parents decision-making authority and presenting a threshold which is ‘clear and more intelligible’ to them.³³⁷ A

³²⁴ Archard (n121) 99.

³²⁵ Birchley (n26) 128.

³²⁶ Emma Cave and Emma Nottingham, ‘Who knows Best (interests)? The case of Charlie Gard’ (2017) 26 *Medical Law Review* 500.

³²⁷ Wilkinson (n85) 92-93.

³²⁸ Birchley (n26) 113.

³²⁹ Imogen Goold, ‘Evaluating Best Interests as a Threshold for Judicial Intervention in Medical-Decision Making on behalf of Children’ in Imogen Goold, Jonathan Herring and Cressida Auckland (eds) *Parental Rights, Best Interests and Significant Harms* (Hart 2019) 29, 44.

³³⁰ Birchley (n26) 127.

³³¹ Archard (n121) 105.

³³² Birchley (n26) 129.

³³³ Rachel Taylor, ‘Parental Decisions and Court Jurisdiction: Best Interests or Significant Harm’ in Imogen Goold, Jonathan Herring and Cressida Auckland (eds) *Parental Rights, Best Interests and Significant Harms* (Hart 2019) 49, 65.

³³⁴ Dominic Wilkinson and Tara Nair, ‘Harm isn’t all you need: parental discretion and medical decisions for a child’ (2016) 42(2) *Journal of Medical Ethics* 116.

³³⁵ Douglas Diekema, ‘Parental Refusals of Medical Treatment: The Harm Principle as Threshold for State Intervention’ (2004) 25(4) *Philosophy of Medical Research and Practice* 243, 249.

³³⁶ Goold (n328) 43.

³³⁷ *ibid.*

study by Nair et al, bore this out, finding that the intuitions of members of the public surveyed were most consistent with a harm or parental discretion model and inconsistent with best interests.³³⁸

91. However, the literature contends that the concept of harm is not without its difficulties,³³⁹ and Bester argues that indeterminacy in what “harm” actually entails and how to measure if it is “significant”, might make it more difficult, not less for parents to uphold their views.³⁴⁰ Birchley notes that often harm is equated to physical suffering, but with many interventions in the PICU entailing some degree of pain or suffering in ‘a trade-off between short-term pain and long-term recovery’, it is problematic to necessarily equate pain with harm.³⁴¹ Even if not suffering pain, it is possible to argue that the continuation of futile treatment could be deemed to be a ‘harm’ – a harm to dignity,³⁴² but equally to withdraw treatment and end a life may also be a significant harm.³⁴³ Parents suffer significant harm if treatment is withdrawn when they are not reconciled to it and want their child to go on living,³⁴⁴ and Moore draws attention to claims of ‘spiritual wrongs’ which parents could claim result in ‘grievous metaphysical harm to the child, which cannot be proved nor disproved’.³⁴⁵ Wilkinson responds by acknowledging that whilst notions of harm may be vague, they are no *more* vague than best interests.³⁴⁶
92. Gollop and Pope are concerned about the language of “harm”, contending that it is bad enough for parents to be told by a court that what they wanted for their child was not ‘best’ let alone that it was ‘significantly harmful’.³⁴⁷ A change to harm could have a ‘chilling effect’ on parental autonomy, and they warn that a court-finding of significant harm has the potential to put the parents on the Local Authority’s radar as a safeguarding concern. This would shift a hospital’s duty from care to child protection, entailing them building a case of “harm” against the parents and as a result ‘positions would harden, dialogue would be more difficult and mediation would have less chance of success.’³⁴⁸ Goold responds that we should be concerned about an ‘unnecessarily harsh’ impact, but that there is no evidence that parents would find the language of “harm” any more stigmatising than having their wishes overridden in the name of best interest – the problem comes from the thwarting of choice, not the language used to achieve it.³⁴⁹
93. The final reason given in support of change, is that the harm threshold more accurately reflects what is actually used in practice in both the clinic and the courtroom, given that intervention does not occur until there are concerns about harm,³⁵⁰ or as Bridgeman contends there is a ‘conflict of professional conscience’.³⁵¹ Birchley draws on an empirical study of parental and professional understandings of approaches used in the clinic when making decisions about children. The results

³³⁸ Tara Nair et al, ‘Settling for second best: When should doctors agree to parental demands for suboptimal medical treatment?’ (2017) 43(12) J Med Ethics 831, 839.

³³⁹ Auckland (n81) 315.

³⁴⁰ Johan C Bester, ‘The Harm Principle cannot replace the Best Interests standard: Problems with using the Harm Principle for medical decisions for children’ (2018) 18 American Journal of Bioethics 9.

³⁴¹ Birchley (n26) 119.

³⁴² Gollop (n128).

³⁴³ Bester (n340) 15.

³⁴⁴ Gollop (n128).

³⁴⁵ Moore (n63) 70.

³⁴⁶ Wilkinson (n85) 94.

³⁴⁷ Gollop (n128).

³⁴⁸ *ibid.*

³⁴⁹ Goold (n329) 43.

³⁵⁰ *ibid.* 42.

³⁵¹ Jo Bridgeman, ‘Beyond Best Interests: A Question of Professional Conscience’ in Imogen Goold, Jonathan Herring and Cressida Auckland (eds) *Parental Rights, Best Interests and Significant Harms* (Hart 2019) 137.

surprisingly found that the term ‘harm’ is rarely used by either parents or professionals, however, the minimising of pain and suffering was a reasonably common threshold, which may equate to the avoidance of harm.³⁵² Yet what was ‘best for the child’ was found to be the overriding imperative for parents, whilst for doctors and nurses it was what was ‘best for the family’.³⁵³ Birchley notes that this latter result ‘potentially bears out the assertion by advocates of the harm threshold that clinicians use a family-facing approach that ill matches the best interests test’, because it allowed ‘limited trades against a child’s well-being to secure a parental benefit’.³⁵⁴ Birchley suggests that ‘best for the family’ can also be conceptualised as a threshold focused on advancing parental autonomy, and the fact that support for this threshold was concentrated amongst clinicians ‘could be read to offer empirical support for the claim that the harm threshold is commonly used by clinicians in practice’.³⁵⁵

94. Opponents claim that a change will amount to ‘no practical difference’³⁵⁶ and any change will be merely semantic - ‘the harm threshold might essentially mean that business is carried on as usual’.³⁵⁷ Yet those in favour claim that language is important in ‘law’s role of signalling the boundaries of acceptable behaviour to the wider public. It would signal that society values and, except in exceptional cases, protects parental autonomy as a means to advance the welfare of children.’³⁵⁸

vii) Reinterpreting Best Interests or other possible thresholds

95. The most recent discussion has centred on the retention of best interests both as a threshold for intervention and as a measure to guide what is to be done once the threshold is crossed,³⁵⁹ although Bridgeman contends that best interests is a ‘titanic principle that is inured to erosion in either courtroom or practice’.³⁶⁰ In the past, it has been argued that use of best interests by the courts has been too rigid with its aim of finding the single objective “best” option, and in doing so was too focused on medical considerations³⁶¹ and inattentive to relational interests.³⁶² Critics such as Wilkinson characterise a binary approach as ‘hopelessly simplistic’ when it comes to disputes about medical care.³⁶³ However, Bester claims that best interests is a flexible test,³⁶⁴ whilst Benbow states that it is not designed merely to override the wishes of the parents, and in cases like *Raqeeb* where there is no clear evidence of pain and suffering, the test gives more weight to ‘subjective interests’.³⁶⁵ Auckland and Goold agree, noting that in *Raqeeb* MacDonald J displayed sensitivity and transparency in his detailed balancing of the relevant factors, including the cultural and religious values of the parents and the concerns of the hospital and the medical views of the Italian clinicians. But they fear that this kind of approach is the exception not the rule.³⁶⁶ They observe that ‘[t]he decision in *Raqeeb* thus places substantial weight on the way in

³⁵² Birchley (n26) 115. The data was drawn from the ‘Best Interests in Paediatric Intensive Care’ Project. The data was collected in 2014, but a portion was reanalysed in 2017.

³⁵³ *ibid* 118-122.

³⁵⁴ *ibid* 121.

³⁵⁵ *ibid* 122.

³⁵⁶ Benbow (n160) 307.

³⁵⁷ Birchley (n26) 129.

³⁵⁸ *ibid*.

³⁵⁹ Auckland (n81) 297.

³⁶⁰ Bridgeman (n351) 151.

³⁶¹ Macintosh (n175) 2.

³⁶² Moore (n63) 68.

³⁶³ Wilkinson (n85) 88.

³⁶⁴ JC Bester, ‘The Best Interests standard and children: Clarifying a concept and responding to its critics’ (2019) 45 *Journal of Medical Ethics* 117.

³⁶⁵ Benbow (n160) 299.

³⁶⁶ Auckland (n88) 672.

which the decision-maker applies the 'objective' best interests test, and the extent to which they accept (and attempt to capture within it) the validity of different medical, ethical and legal systems. The difficulties in doing so were recognised by MacDonald J, who concluded that (...)the 'objective best interests test' can be put "under some stress".³⁶⁷

96. In contrast, the finding in Birchley's study that in practice clinicians most commonly use what is 'best for the family' as their standard³⁶⁸ rather than the welfare of the individual child, meant that good care might accordingly entail a re-calibration to 'consider the child in isolation as well as within a family unit, and that one should not automatically assume that children will share their parents' values.'³⁶⁹ This finding supports Benbow's contention that there should be no 'right to try' as proposed under the significant harm threshold, which would largely cater to the parents interests and might prolong the child's pain or suffering.³⁷⁰ In sum, Birchley argues that '(...) given the very amorphous nature of welfare when facts are in short supply, any approach that concentrates power with a parent, a doctor or any other party risks failing to take account of important perspectives...Shared decision-making is a good start, yet risks excluding consideration of the child'.³⁷¹
97. Various alternative thresholds to significant harm and best interests have been proposed over the years. Recent incarnations include Bester's 'Reasonable Argument' test, which uses factual premises and values to make a reasonable argument that the decision is in the best interests of the child.³⁷² In *Fixsler*, although MacDonald J rejects assessing reasonableness of the parents' view,³⁷³ Pruski argues it is 'the most appropriate thing to do in a secular and liberal state - to assume a reasonable parent standard before transferring the responsibility for the best interest decision to the judge if the parents do not meet the reasonable parent standard'.³⁷⁴ Gamble and Pruski propose that three criteria need to be met in order for parental views to be deemed 'reasonable' and therefore be decisive; 1. Prima facie caring, 2. Can meaningfully engage with the medical evidence for benefit and harm (implicit here is that there is a competent body of medical opinion to support the claim), and 3. "Intend the child's health", which they define to a minimal standard as not intending the child's death, even if they recognise it as a foreseeable consequence of the decision.³⁷⁵ Pruski argues that accepting parental views that meet these criteria is logical and similar to how doctors' views are accepted when they conform to a reasonable body of medical opinion.³⁷⁶
98. Another alternative approach is Wilkinson's "Conditional Harm" threshold.³⁷⁷ Whilst as seen above, he advocates for the significant harm threshold on a normative ethical basis, he acknowledges that 'it may be appropriate for the default *legal* test to remain best interests'.³⁷⁸ He claims this is due to the difficulties of applying "harm" to situations where there is for example an absent decision-maker, or where there is disagreement between the parents or between the professionals, and that it is ethically problematic to compel doctors to continue with treatment

³⁶⁷ Auckland (n172) 1337.

³⁶⁸ Birchley (n26) 118.

³⁶⁹ Birchley (n108) 3.

³⁷⁰ Benbow (n160) 300.

³⁷¹ Birchley (n26) 131.

³⁷² Bester (n340) 16-17.

³⁷³ *Manchester University NHS Foundation Trust v Fixsler* [2021] EWHC 1426 [105].

³⁷⁴ Pruski (n71) 86.

³⁷⁵ Gamble (n270) 336-337.

³⁷⁶ Pruski (n71) 88.

³⁷⁷ Wilkinson (n85) 85.

³⁷⁸ *ibid* 98. (Emphasis added).

that the court does not find to be significantly harmful but that they deem to be not in the child's best interests.³⁷⁹ In light of this, he proposes a compromise position – the “conditional harm” threshold, to apply in cases akin to *Gard* or *Raqeeb* where; 1. Parents are requesting the provision or continuation of treatment; 2. The child's healthcare professionals do not support the treatment; and 3. Other suitably qualified healthcare professionals are prepared to provide treatments and ongoing care, including transfer to their facility. If all three of these conditions are met, the parental request should ‘ordinarily be respected’ unless it will cause or risk causing significant harm to the child.³⁸⁰ He does however concede that the application of the conditional harm threshold will very much turn on how “harm” is defined by the courts, and as discussed above, whether it would turn solely on pain/suffering or whether it would include more “intangible” harms, such as the indignity caused by prolonging death through continued treatment.³⁸¹

99. Bridgeman offers a new perspective and reconceives many of the recent high-profile cases turning on an issue “beyond best interests” - the limits of “professional conscience”.³⁸² Smith's definition of professional conscience as being distinct from moral conscience, but including moral values, being owned by the individual and relating to their conduct.³⁸³ Her contention is that in practice disputes over the continuation of life-sustaining treatment are only referred to court when doctors drawing on technical expertise, professional guidance and supported by the opinions of other colleagues, ‘have reached the limits of what is professionally conscionable’.³⁸⁴ Adopting this different perspective of decision-making would be significant in better helping parents understand why judges more often agree with doctors rather than parents. It would offer an explanation as to why treatment cannot continue, that may help parents understand the limits of what is possible and therefore avert court action, and better frame inevitably distressing consequences of court decisions, as ones of professional impossibility, rather than what is “best”.³⁸⁵
100. Birchley highlights the need for more research on the interaction between policy and practice on best interests, pointing to the ‘dearth of empirical research into practice and in a range of settings to capture everyday experience’.³⁸⁶ Pruski's answer would be that ‘from the perspective of a liberal and secular state’ the reasonable parent view supported by a competent body of medical opinion ‘would protect children from malevolent harm while respecting the plurality of views that permeate society on important life issues’.³⁸⁷ Yet Birchley, whilst conceding that new approaches may be needed, warns that ‘liberal welfare should be based on pluralised decisions, rather than concentrating power in one group or another’.³⁸⁸

viii) Problem Solving Courts and other alternatives

101. There is a small amount of attention in the literature towards other types of legal resolution mechanisms. For example, Wallis suggests a model consisting of a hospital-based group of lawyers, clinicians and lay members, peripatetic within the NHS and who are trained in mediation, that would hear in the presence of an arbitrator, from the parties ‘during an inquisitorial and non-

³⁷⁹ *ibid.*

³⁸⁰ *ibid* 101.

³⁸¹ *ibid* 103-104.

³⁸² Bridgeman (n351) 137.

³⁸³ Stephen Smith, ‘Individualised claims of Conscience, Clinical Judgement and Best Interests’ (2018) 26 Health Care Analysis 81, 84.

³⁸⁴ Bridgeman (n351) 138-140.

³⁸⁵ *ibid* 152.

³⁸⁶ Birchley (n26) 133.

³⁸⁷ Pruski (n71) 91.

³⁸⁸ Birchley (n26) 133.

confrontational hearing'.³⁸⁹ The decision of the arbitrator is then bound to agreement with a pre-hearing buy-in from all the parties. He notes however that '[o]f course this relies on the reasonableness of the parties, the skills of mediation and the authority of the arbitrator (...)'.³⁹⁰

102. Another novel option is to utilise a type of 'problem-solving court', first seen in the USA and developed as an alternative within the criminal justice system, where substance abuse or mental health was an element in the crime.³⁹¹ These courts move away from the traditional adversarial model seen in the US or UK, and have been adapted to tackle issues within family law – a notable example being the UK Family Drug and Alcohol Courts, used in cases where children are at risk of being taken in to care due to parental substance misuse and addiction.³⁹² Harwin et al explain that these courts operate on a model based on active involvement of parents in the legal process, and is founded on ideas of "therapeutic jurisprudence", drawing motivational psychology and solution-focused approaches.³⁹³ The review-hearings are judge-led, without the involvement of lawyers, and aim to problem-solve and motivate parents - a process which continues outside of the court room with the help of specialist teams.³⁹⁴ Their results from 2018 suggest that this is 'providing an entirely new way of supporting parents to meet their children's developmental needs (...) and that 'given the experiences of honesty and clarity' there is much less conflict and antagonism and even if the outcome is not as the parents wished, 'the court experience is held to be more humane and compassionate than ordinary court'.³⁹⁵

103. There has been some discussion about whether this model can be extended to other types of problems and Harwin et al consider that it might work in cases of parental neglect, domestic violence or mental health.³⁹⁶ Its utility in the context of medical decision-making is unclear though, as whilst the less adversarial forum and external support may be beneficial in seeking resolution, the underlying aim to produce responsibility for and change in parental behaviour is less likely to be applicable to disagreements about what is "best" in terms of medical care.

ix) Court

104. Finally, we come to the traditional recourse to court, often after some (or all) of the mechanisms outlined in the green and amber zones have failed. For some, such as Benbow, court is seen as having a necessary role for those cases that cannot be successfully mediated.³⁹⁷ Reflecting on her experiences, William Verden's mother Ami McLennan feels it is 'worth going to court' and urges other parents of children with autism or learning disabilities who disagree with doctors' assessments of their child's best interests to do the same, as '[j]udges can be fair and you can get the right outcome'.³⁹⁸ Yet for others, such as Forbat '[k]eeping these cases out of the courts has to be a core objective'.³⁹⁹ Jesmont et al recognise that legal measures 'provide finality to disagreements' but 'they do not necessarily result in resolution of broken-down relationships and trust'.⁴⁰⁰

³⁸⁹ Colin Wallis (n144) 414.

³⁹⁰ *ibid.*

³⁹¹ Judith Harwin, Mary Ryan and Sophie Kershaw, 'A problem-solving approach to family justice' in *Justice for Children and Families: A Developmental Perspective* (Royal College of Psychiatrists, Cambridge 2018) 68.

³⁹² *ibid* 69.

³⁹³ *ibid.*

³⁹⁴ *ibid* 70.

³⁹⁵ *ibid* 71-73.

³⁹⁶ *ibid* 74.

³⁹⁷ Benbow (n160) 307.

³⁹⁸ McLennan (n41).

³⁹⁹ Forbat (n47).

⁴⁰⁰ Jesmont (n16) 1238.

105. This is compounded by concerns about the financial implications for families of defending legal action in the absence of Legal Aid provision. As discussed in the Causes section, this may lead to online crowdfunding or involvement of third-party organisations for pro-bono legal advice and representation.⁴⁰¹ Use of the latter can exacerbate conflict, particularly if this third-party advice is provided by campaign groups driven by an ideology or agenda that may not accurately align with the authentic views of the family, or their best interests.⁴⁰² The Ministry of Justice have signalled that they propose to offer non-means tested legal aid to parents for cases involving the withdrawal or withholding of life-sustaining treatment for children,⁴⁰³ - this should go some way in ameliorating such vulnerabilities. However, concerns over significant power imbalances remain that will not be resolved simply by providing Legal Aid to families, given the comparably vast resources and expertise that NHS Trusts can draw upon.
106. Yet whilst Wilkinson recognises that court-action poses problems, he declares ‘the UK is commendable in having a clear, transparent, and generally consistent legal process that strictly focuses on the interests of the child.’⁴⁰⁴ Indeed, Auckland and Goold in their multi-jurisdictional comparative analysis find that England is an outlier - across almost thirty jurisdictions examined, judicial resolution was much more frequent in England than most other countries (with some countries having none, including Scotland, and with only Australia and USA having similar numbers).⁴⁰⁵ Rarity of litigation elsewhere may be due to an absence of any legal mechanism to permit health providers to intervene in parental decision-making such as in Sweden, Botswana, China or Thailand;⁴⁰⁶ adoption of a “higher” threshold for intervention, such as in Chile, Mexico or Switzerland, which all require some risk of harm or death;⁴⁰⁷ or cultural practices that accord one decision-maker greater weight than the other, whether that be the family-centric practices of China, or the medical deference seen in Malaysia.⁴⁰⁸
107. Given that many disagreements turn on value-judgments, Auckland and Goold observe that ‘it would be hard to extrapolate the cultural tendency towards consensus-building and avoidance of conflict seen in some countries, to a country such as England’ which has greater cultural and religious diversity and therefore more scope for values disagreement and inability to find resolution without judicial intervention.⁴⁰⁹ They conclude that ‘[w]hile avoiding disagreements escalating has undoubted advantages, where an intractable dispute arises which cannot be resolved except by the use of an independent arbiter, courts, with their commitment to due process and robust reasoning, offer the most legitimate option’.⁴¹⁰ They list three distinguishing features of the court process lacking in all other resolution mechanisms: first, allowing each party to present their case ‘avoids concerns that one voice may be presumptively silenced by the other’; second, a Guardian is appointed for the child, which keeps advocacy of the child’s welfare at its heart; and third, transparency of court processes and judgments allows for public scrutiny and challenge through democratic processes.⁴¹¹

⁴⁰¹ Auckland (n88) 649.

⁴⁰² Woolley (n168).

⁴⁰³ As published on 15 March 2022 as part of the Ministry of Justice, *Legal Aid Means Test Review* (15 March 2022) [328]-[333].

⁴⁰⁴ Wilkinson (n200) o2000.

⁴⁰⁵ Auckland (n88) 644.

⁴⁰⁶ *ibid* 647-648.

⁴⁰⁷ *ibid* 651.

⁴⁰⁸ *ibid* 655.

⁴⁰⁹ *ibid* 660.

⁴¹⁰ *ibid* 671.

⁴¹¹ *ibid*.

Summary

108. In summary, disagreement can be categorised by severity and matched with appropriate responses. For mild conflict, mechanisms internal to the clinical setting have been suggested, with significant attention paid to good communication as a key strategy. There is much in the literature outlining the merits of sensitive, well-timed communication and shared decision-making, with healthcare professionals examining their own perceptions and seeking to understand parental experiences of hope and “reality”. The literature outlines the value of specific training for professionals in communication skills and legal and ethical concepts. Managerial strategies and Conflict Management Frameworks have been shown to be beneficial in handling conflict, and include elements such as guides for conversation, involvement of psychologists and provision of key workers and single clinical leads. When conflict escalates to moderate disagreement, the literature suggests that third-party intervention may be needed. The use of expert second opinion is a common approach but its effectiveness in resolving dispute is cast in doubt and it may even exacerbate conflict, given the potential for selection bias of experts or the likelihood that the family will reject the expert opinion if it concurs with that of the treating team. There is more promise seen in the use of Clinical Ethics Committees which provide for examination of a range of views and whose conclusions could even potentially have a determinative role, but in order to be useful in resolving dispute they would require a significant restructuring of form and remit, away from their current role in advising clinicians about ethics. Mediation as a resolution tool has received significant attention in the academic literature and public and political debate. It is suggested that early use of mediation can be effective, and it may better allow for the sharing of parental perspectives than the current CEC structure permits. However, mediation has less success in resolving disputes about religious beliefs or moral values, than disagreements over medical facts, and the literature is clear that its strength lies in its voluntary nature and therefore mandated participation should be avoided. Finally, when dispute becomes severe, legal intervention is often needed. Possible changes to the law have received substantial attention, in particular whether the threshold for intervention in parental decision-making should be raised from best interests to significant harm. Whilst there are strongly made arguments on both sides, there is no clear consensus in the academic literature. Changes to the best interests test have also been advocated, along with alternative tests, and court structures. Whilst there is recognition of the problematic aspects of court proceedings, the value of a transparent and robust legal process is also recognised.

Conclusion

109. This review has examined the literature and evidence base relating to the causes, impact and possible resolution mechanisms in disagreements between parents and healthcare professionals about the care of critically ill children. Eight possible causes of conflict, grouped into internal, relational and external factors, have been identified, many of which may overlap and several may be present within an individual case. Whilst much popular focus has been on the external factors, such as the role of social media and parental “rights” to choose alternative treatments, the literature has revealed that many disputes find their roots in internal or relational factors. Characteristics and views of either the parents or the professionals, such as attitudes towards death, religious and value-based views about sanctity and quality of life and risks worth taking, and narratives about the “good parent” and the clinicians “duty” all play a part. These may then spill over into fractures in the relational connections between the parties, manifested in communication difficulties or wrangles about the power balance in terms of decision-making.

110. The impact of disagreement, and of court proceedings in particular, are clearly detailed in the literature. The evidence suggests that for parents, whilst disagreement is distressing and can have long-lasting implications, the opportunity to be able to ‘say their piece’ and be heard, is also

valued. There is much less evidence on the impact on the child, aside from an assumption that disagreement (and possibly continued treatment during it) is burdensome. For healthcare professionals, the NHS and society at large, the effects are moral distress and burnout, doubts about career prospects, financial implications and loss of trust in doctors and the health service.

111. Eight potential mechanisms for resolution have been discussed, with the appropriate resolution being matched with the severity of the disagreement. For initial or low-level disputes, there is considerable evidence that better communication and conflict management frameworks have much success in avoiding dispute altogether or ameliorating it when it first arises. In the 'moderate zone' of disagreement, the literature suggests third-party intervention may be helpful. Much attention has been paid to the role of CEC's and mediation, and whilst the evidence suggests that more consistent, and earlier, use of these may be beneficial in some circumstances, it appears limited or ineffective in others. Finally, sustained attention has been given to the use of law in severe disagreement and whether the legal threshold for intervention needs to be changed in an attempt to "re-dress the balance of power" between parents and professionals. The 'Significant Harm' debate has provoked strong arguments on either side, but has produced little consensus. In the final assessment, and despite the clear disbenefits of litigation, the literature concedes that the opportunity to use the courts in disagreements of this kind is a testament to this jurisdiction's commitment to transparency, fairness and a reflection of a pluralist society.

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