

**A Relational Responsibilities Framework for Children’s Healthcare Law**  
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**Relational Responsibilities: a response to the current legal framework**

In the first cases concerned with the medical treatment of children, in the 1980s, medical paternalism and parental authority were challenged by the involvement of the court, which established its protective role through independent determination by a judge of the best interests of the child.<sup>1</sup> Judgments that followed expanded upon the scope of the protective best interests principle such that judgments now explain that it is considered ‘in the widest sense and to include every kind of consideration capable of impacting on the decision. These include, non-exhaustively, medical, emotional, sensory (pleasure, pain and suffering) and instinctive (the human instinct to survive) considerations’ (*An NHS Trust v A* (2007), [40]). The recent cases concerning the future medical treatment of Charlie Gard<sup>2</sup> and Alfie Evans<sup>3</sup> involved an unsuccessful challenge to the best interests principle through an assertion of parental rights grounded in their knowledge of their child and affirmation of the principle by the highest courts.

When disagreements about a child’s medical treatment are referred to court,<sup>4</sup> cases are decided by the judges of the Family Division of the High Court and, like cases concerning disputes between parents over their child’s upbringing and local authority applications for child protection, adjudication involves a particularistic, fact-based assessment of the best interests of the child. However, whilst the judge may feel that he or she has weighed up the available evidence to arrive at the best outcome for the child, parents often continue to object to the outcome and to the process which resulted in it. To give just one example, following a court order that C should be tested to determine her HIV status, her parents, who rejected mainstream medical explanations of HIV and hence its treatment, removed her from the UK and lived with her in Australia (*In re C (A Child) (HIV Testing)* (2000), 275; further examples are given in Bridgeman (2017)). The mother, who had herself tested HIV positive but chose to manage her health through a holistic lifestyle, objected to such state intervention into family life, expressing the view that parents should make decisions on behalf of their child until the child is old enough to make her own decisions (Levin (1999)). C and her father eventually returned to the UK, following her mother’s death, at which time she was made a ward of court which as a consequence had responsibility for future decisions about her medical treatment (Duckworth (2002)).

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<sup>1</sup> *Re D (a minor) (wardship: sterilisation)* (1976) concerned with the legality of sterilisation of a child with learning difficulties; *Re B (a minor) (wardship: medical treatment)* (1981) on the question whether it was in the best interests of a baby with Downs Syndrome to have surgery to remove an intestinal blockage.

<sup>2</sup> The declarations made by Francis J, in *GOSH v Yates & Gard* (April 2017), that it was in Charlie’s best interests and lawful for him not to be provided with a trial of nucleoside therapy and for ventilation to be withdrawn and palliative care provided were upheld through the appeal courts.

<sup>3</sup> The declarations made by Hayden J in *Alder Hey Children’s NHS Foundation Trust v Evans* (February 2018) that it was in Alfie’s best interests and lawful for ventilation to be withdrawn and palliative care provided were upheld by the appeal courts.

<sup>4</sup> This chapter focuses upon court determination of disagreements between parents and professionals with respect to the medical treatment of children who lack the capacity to make decisions about their own medical treatment, it does not consider disagreements between parents over medical treatment, cases which have been referred to court because the local authority also has parental responsibility of a child in care or cases concerning older children who may have capacity to decide for themselves.

In *Parental Responsibility, Young Children and Healthcare Law* (2007), I offered a critique of the legal framework for children's medical treatment decision-making and presented the case for a legal framework for determination of the best interests of the child underpinned by a moral framework of relational responsibilities. The critique of the law was that the particularistic analysis of best interests is being applied to a child who is legally constructed as a separate, isolated, vulnerable individual whose physical, emotional and personal boundaries are in need of protection from invasion by others including from his or her own parents who are pursuing their own self-interest and asserting their rights. As with vulnerability scholarship (For example, Fineman (2008), Mackenzie et al (eds.) (2014), Herring and Wallbank (eds.) (2013)), a relational responsibilities approach seeks to reveal the effects of liberal legalism's understanding of the legal subject. Rather than employing the concept of vulnerability, the relational responsibilities approach I developed drew upon the feminist ethic of care. To take one foundational example from Carol Gilligan's research on moral reasoning, Carol Gilligan contrasted the approach of 11 year-olds Amy and Jake to the Heinz dilemma - whether Heinz should steal from the chemist the drug needed to save his dying wife which he could not afford to buy (Gilligan (1982) 25-32). Jake approached the problem as a simple prioritisation of conflicting moral values of life and property and the assumption that there is societal consensus on prioritisation of the former. Amy, 'seeing a world comprised of relationships rather than of people standing alone, a world that coheres through human connection rather than through systems of rules, she finds the puzzle in the dilemma to lie in the failure of the druggist to respond to the wife', so that the solution lies in changing the terms of the dilemma by providing the chemist with more information about the wife's condition or identifying others who can help (Gilligan (1982) 29). As Carol Gilligan explains, Amy's approach is premised upon connections between people which gives rise to an awareness of responsibility for the other and the need for a response, with communication enabling a better understanding and leading to resolution. The particular relevance to the law is that if the legal process takes the people involved, their needs and relationships and re-constructs them as abstract ideals, it will not provide an adequate solution to the human issue which concerns them. Whilst of the opinion that best interests is the appropriate principle by which to determine disputes over a child's future medical treatment, given that all involved, parents, clinicians and judges are seeking to secure what is best for the child,<sup>5</sup> I argued that the approach to determination of the best interests of the child failed to recognise or support relational responsibilities in the provision of care to children.

Inspired by the feminist ethic of care,<sup>6</sup> this approach recognises that the child is cared for within relevant relationships of responsibility. As I presented it, there were three elements to the moral orientation of relational responsibilities which I argued should underpin the legal framework for decision-making about a child's medical treatment.<sup>7</sup> The first, in contrast to the understanding of the child as an abstract ideal, was recognition of the child as an individual. The second, rather than seeing the child as endangered by parental pursuit of their own interests, was recognition of the knowledge and experience of parents gained as they cared for their child but who were in turn dependent upon the expertise of professionals. Third, rather than isolating the decision before the court, the treatment decision should be placed within the wider context of the provision of care recognising that there are external constraints upon the ability to care which cannot be ignored when reaching decisions about a child's best interests.

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<sup>5</sup> Others have argued for a threshold of significant harm, Diekema (2004), Gillam (2016), Auckland and Goold (2019).

<sup>6</sup> Key pieces included, Gilligan (1982), Tronto (1993), Urban Walker (1998), Smart and Neale (1999), Bartlett (1988), Lindeman Nelson (1999).

<sup>7</sup> Kirsty Moreton has developed this framework in relation to children in mid-childhood, between the years of 9-15 years, see Moreton (2019). I think it would work equally well with older children but their ability to state their own experiences, the range of relationships material to them and the contextual factors affecting their care are deserving of separate consideration.

Whilst I initially considered responsibilities as an alternative to rights, I have subsequently developed this framework to incorporate recognition of the rights of the child (Bridgeman (2008)). Appreciation of the individuality of the child as well as their rights, recognises that care and justice are complementary, not alternatives. Originally stressing the need for recognition of the different roles and expertise of parents and clinicians arising from their relationships with the child, I have subsequently also addressed the dependency of parents upon professionals for the care of their child and of the state upon parental care (Bridgeman (2008)). In this chapter, I develop this conceptual framework further in light of the body of case law concerned with the medical treatment of a child. Whilst some of the leading cases in the jurisprudence concerning children's medical law had been decided when I wrote in 2007, for example, *Re J* (1991),<sup>8</sup> *R v Cambridge Health Authority ex parte Bowen* (1995),<sup>9</sup> *Re T* (1997),<sup>10</sup> *Re A (Conjoined Twins)* (2000),<sup>11</sup> *Wyatt* (2003-2006),<sup>12</sup> despite the applicable law being clear, the courts have increasingly been asked to resolve disputes between parents and professionals, so this chapter is able to develop the elements of the framework in light of the increased body of case law. The framework developed here is informed by the extensive body of academic literature over the past decade on medical law, care, responsibilities and re-writing judgments. In particular, I have sought to draw out the complex web of relationships of care in the provision of medical treatment to a seriously ill child which need to be recognised in deciding these cases. Furthermore, decisions about a child's future medical treatment have to be embedded within social responsibilities of public services and institutions to support caring responsibilities and hence within the social, historical, cultural and political context for decisions about the provision of medical treatment. I conclude by applying this framework to a hypothetical case which draws upon the facts of a number of decided cases to demonstrate how it would work and, I argue, result in more care-full judgments which reflect the lived realities, inherent relationality and embedded lives of those directly affected.

### **The Child: an Individual Situated within Relationships**

A relational responsibilities framework for determination of the best interests of a child with respect to a child's medical treatment would recognise that the child is an individual with specific needs, experiences, preferences and interests and entitled to protection of his or her moral and legal rights. Rather than abstract ideas of a seriously ill child, it would ensure that the child as an individual is at the centre of decision-making. The focus would be upon the lived experience of the child, with a chronic or acute illness or life-limiting condition, resulting in embodied rather than disembodied decision-making. In many of the earlier judgments, the child appears as an abstract object of concern: a body upon which surgery needs to be performed; a potentially diseased body; or in terms of lack of capacities and, consequently, lacking the ordinary qualities of life (For example, *Re J* (1991), *Re J* (1992)). More recently, judgments have recognised to a greater extent the particular child, perhaps following a visit to hospital by the judge,<sup>13</sup> or evidence from the Guardian or parents. A recent example of a more situated judgment which gives some sense of the child about whose life the judge was making decisions, and which could be developed further, is the judgment of MacDonald J in the case

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<sup>8</sup> Whether it was lawful to withhold ventilation from J who had severe brain damage due to his premature birth.

<sup>9</sup> Judicial review of the decision of the health authority not to fund an extra-contractual referral for experimental treatment following relapse of cancer.

<sup>10</sup> Whether a liver transplant refused by T's parents was in his best interests.

<sup>11</sup> Whether surgical separation of conjoined twins resulting in immediate the death of one twin was lawful.

<sup>12</sup> There were a number of judgments given by Hedley J, concerning the legality of withholding of mechanical ventilation from Charlotte Wyatt who had mental and physical disabilities resulting from her premature birth, the first of which was *Portsmouth NHS Trust v Wyatt & Wyatt* (2004). The leading Court of Appeal judgment is *Re Wyatt (a child) (medical treatment: continuation of order)* (2005).

<sup>13</sup> For example, Hayden J visited Alfie Evans and his family in Alder Hey, *Alder Hey Children's NHS Foundation Trust v Evans*(February 2018) [54]-[56].

of five year-old Tafida Raqeeb. Tafida had suffered a bleed on her brain which caused catastrophic brain damage rendering her in a minimally conscious state. Her parents refused consent to the withdrawal of ventilation and wanted to transfer her to Italy for continued ventilation. MacDonald J observed that her parents had described, and provided videos which showed that she had been, a 'happy, joyful little girl':

'She was the helping hand monitor in her class, her favourite film was 'Frozen', she attended ballet lessons and she was always running everywhere. She was bilingual in English and Bengali, had learnt some verses from the Quran and was due to attend Arabic classes in September 2019. She had already, at her young age, travelled widely across the world' (*Tafida Raqeeb v Barts NHS Foundation Trust* (2019) [9]).

In her evidence as to Tafida's wishes and feelings, her mother said that,

'Tafida demonstrated herself to greatly value all life, reiterating a story of Tafida becoming upset at the death of a ladybird and of a goldfish, and of Tafida's gentle, accepting and non-judgmental approach to another child with serious disabilities' (*Tafida Raqeeb v Barts NHS Foundation Trust* (2019) [41]).

Although she was too young to have a developed understanding of the issues before the court, Tafida had begun to follow Islamic practices, such as prayer, had understood that "if you kill or do harm you will be in trouble with Allah" and her mother's view was that Tafida would wish to live whatever life is left to her notwithstanding her current condition' (*Tafida Raqeeb v Barts NHS Foundation Trust* (2019) [42]).

MacDonald J had also recognised personhood, the pleasure of human interaction and the development of the self through relationships with others, although in the context of their absence, in his conclusions in the case of Isaiah Haastrup capturing something of the human life that Isaiah's condition had deprived him of. The evidence was that Isaiah's condition meant that he would never be able to engage in meaningful interaction, to see, to move independently, he may have some hearing but there was no evidence that he could make sense of anything he might hear, no evidence that he was aware of what was going on around him, or of an ability to experience enjoyment or comfort or to experience pleasure from interaction with his family or to develop emotional attachment to them, to benefit from the experiences of love, human connection, or a sense of identity and belonging (*King's College NHS Trust v Thomas & Haastrup* (2018) [107]). In comparison the possibility of awareness of connected others, albeit minimal, and the provision of loving care at home as experienced by children in similar conditions, recognising the importance of caring relationships to the development of the self and to the maximisation of capacities, led MacDonald J to the conclusion that it was not in Tafida's best interests for ventilation to be withdrawn (*Tafida Raqeeb v Barts NHS Foundation Trust* (2019) [168] [173]).

It could be argued that Tafida had years to develop her personality whereas children in other cases, such as Isasiah Hastrup who was born with his life-limiting condition and had never left hospital or Charlie Gard and Alfie Evans, hospitalised at six weeks-old and seven months-old respectively had not formed their individual personalities. However, the study by Priscilla Alderson et al clearly demonstrated, what anyone who has spent any time with children knows, that even very young children (in their study premature newborn babies in the neonatal intensive care unit) demonstrate character and express themselves through sounds, facial expressions and movements to which those caring for them can attend, interpret and respond (Alderson, Hawthorn and Killen (2005)). As Joan Tronto has argued, rather than drawing upon adult impressions of life for a child in a given situation, attentiveness to the individual child is required in order to recognise the child's specific needs, experiences, preferences and

interests and identify what, at the current time, is best for the child.<sup>14</sup> Even if the child's capacities have now been diminished by their condition, what is required to respect their personal integrity is consideration of the personality, the character, the spirit of the child and attentiveness to their ability to cope with their condition and with the pain caused by it and its treatment in order.

Within the current legal framework, the independent interests of the child are, in cases concerning future medical treatment, represented by the Guardian. Appointed by the state to represent the 'voice of the child', the Guardian will form an independent view of best interests by visiting the child in hospital, speaking to his or her parents, doctors and nurses, and considering the oral evidence presented at the hearing. Where the Guardian, whose relationship with the child cannot be as intimate as that with his or her parents, reaches the same conclusion as to best interests as the child's clinicians, the parents are then positioned in opposition to their child's interests. For example, the parents of Charlie Gard, diagnosed with an extremely rare, inherited, progressive, condition, mitochondrial depletion syndrome, RRM2B, which affected his ability to move, breathe, neurological functioning, and hearing, wanted him to have a trial of nucleoside therapy which they believed offered him the chance of an improved quality of life. When they appealed the decision of Francis J that it was lawful for ventilation to be withdrawn and palliative care provided, they appeared in court as appellants against Great Ormond Street Hospital and Charlie, represented by his Guardian, as respondents (*In the Matter of Charles Gard* (2017)). Baroness Hale, in her speech rejecting the parents' application for permission to appeal to the Supreme Court, stated that in significant disputes over a child's best interests the child 'must have an independent voice in that dispute' but that this was provided through representation by his Guardian not by his parents (*In the matter of Charlie Gard (Permission to Appeal Hearing)* (2017)). Baroness Hale further observed that there were questions, which the Supreme Court did not need to resolve, about the ability of his parents to apply to the ECtHR, in their attempt to protect his interests, on the grounds that the interests of Charlie and his parents conflicted.<sup>15</sup> Whilst, as both the Supreme Court and European Court of Human Rights stressed, it is important that the child is independently represented, as the Guardian had reached the same conclusion as his doctors as to Charlie's best interests (*GOSH v Yates & Gard* (April 2017) [116]-[122]). it is understandable that Charlie's parents felt that the Guardian was supporting the position of his doctors leaving them to defend their child's right to life. Rather than independently representing the voice of the child ensuring the interests of the child are separately identified, the Guardian appeared as a distanced adult making an independent assessment of the available evidence and deciding which of the two opposed positions to support. Instead, we could expect the Guardian to bring independent evidence to the court of the child as an individual. Appointed by the state, fulfilment by the Guardian of the responsibility to give a voice to the child in this way would serve to address concerns that Marie Fox and Michael Thomson have raised that relational approaches risk doing nothing more than recognising the importance of family relationships and '[i]n so doing, they risk continuing to prioritize family integrity over the child's interests and rights, thus reinforcing the parental power'.<sup>16</sup>

Dominated by the welfare principle, judgments concerning a child's future medical treatment may reference the rights of the child under Articles 2 or 8 of the ECHR,<sup>17</sup> or Articles 5, 6 or 24

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<sup>14</sup> Joan Tronto (1993) identified the values of the ethic of care as attentiveness, responsibility, competence and responsiveness, 127-36.

<sup>15</sup> These questions were left unresolved as the ECHR considered it sufficient to address the parents' complaints under Article 2 and 5.

<sup>16</sup> Fox and Thomson (2017) 531, in which they developed the concept of embodied integrity as a 'useful supplement to the current vogue for relational approaches', 31.

<sup>17</sup> For example, *In the Matter of Ashya King (a Child)* (2014) [30] .in which Baker J in wardship proceedings authorised the administration of Proton Beam Therapy in a Prague clinic as post-operative treatment following the removal of a malignant brain tumour.

of the UNCRC (For example, *In Re C (A Child) (HIV Testing)* (2000) 282), understood within the current legal framework to confirm rather than 'alter or add to established principles of English domestic law' (*In Re A (Children) (Conjoined Twins: Surgical Separation)* (2001) 257, *An NHS Trust v A* (2007) [44], *Portsmouth NHS Trust v Wyatt* (2004) [25]). Whilst this is one view of the judgments of the ECtHR in *Glass v United Kingdom* (2004)<sup>18</sup> and, more recently, *Gard (Charles Gard and Others v United Kingdom)* (2017)), these cases themselves merely served to confirm the established domestic legal framework which fails to engage with the rights of the child. The feminist judgment in *Glass* sought to demonstrate the potential for a more rigorous engagement with the rights of the child to recognise the child as an individual situated in caring relationships (Bridgeman (2010)). The children's rights judgment in *Re A* examined the rights of the children and those of the parents in depth and viewed the welfare of the twins from the perspective of their connectedness (Alghrani (2017)) and Jonathan Herring's commentary upon it reflected further on a relational understanding of rights (Herring (2017)). Warning against the dangers of conflating the interests of the child and his or her parents, in his children's rights judgment on *Re T*, Michael Freeman respected the participation rights of young children, with reference to the research of Priscilla Alderson et al noted above, emphasising the ability of even the youngest child to express their feelings which can be understood by attentive adults in caring relationships (Freeman (2017)).

### **Caring Relationships**

Despite the concern of both parents and clinicians to ensure that the child receives the treatment that is in his or her best interests, it is the differences between the adult decision-makers, rather than their common purpose or common ground, that becomes the focus in court proceedings, formulated as a dispute through which opposing positions become entrenched. As Carrie Menkel-Meadow has observed, whilst as people they have empathy for the position of the other, the legal process discourages expression of concern for those positioned on the other side (Menkel-Meadow (1985) 52). The legal process creates or cements separation between those previously working in partnership and widens the distance between them when they most need to come together, depending as they do upon the other to secure what each considers to be in the child's best interests. Rather than understanding persons to be primarily separate, self-interested, rational individuals whose principal concern is to protect themselves from invasion by others but who form relations by agreement, feminist theories of care and responsibility understand individuals to be primarily connected through relationships. The self is conceived of as relational with interests which are inevitably tied to those of others. Dependency and vulnerability are universal experiences not the exception to the liberal male ideal. If the law chooses to ignore the relationality of persons it ignores a crucial aspect of the reality of the persons it is regulating. As Jonathan Herring has argued legal norms are required which understand and respond to people in interdependent relationships, with entwined interests and responsibilities to each other (Herring (2010) 254). A relational responsibilities approach would place the individual child at the centre of care and the provision of his or her medical treatment within the context of caring relationships and recognise both the experience of parents and the expertise of professionals. Its application requires consideration to the attentiveness to the cared-for and, in the context of medical treatment where both parents and professionals have responsibilities to the child, consideration of the care taken of the other in these relationships.

As Joan Tronto has argued, whilst parents have obligations to their children simply by virtue of having them, responsibilities arise out of relationships, shaped by the particular needs of the child, rather than choices or promises (Tronto, (1993) 133). Parents generally take responsibility for meeting the needs of their dependent child in order to preserve this valued relationship. The feminist judgment in *Re A* observed that the parental objection to separation surgery of their conjoined twins was reinforced by their growing relationship of love and

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<sup>18</sup> Provision of diamorphine to 12 year-old David Glass contrary to the refusal of his mother was a breach of Article 8 ECHR.

protection for both girls (Hastings (2010)). The responsibilities of parenthood are both general, those which arise from the relationship of parent and child, and specific, shaped by the particular needs of the child. Working out what ought to be done in the provision of care requires attentiveness to the requirements of institutions such as the law and to societal expectations and to the specific context and individual needs. Upon diagnosis of a child's serious illness, parents are immediately required to make important decisions about their child's medical treatment often to subject the child to invasive and painful interventions with unpleasant side effects and risks to future quality of life in the attempt to save life and improve health. Whilst the ordinary rhythms of family life will be disrupted by a child's minor illness, everything changes with the diagnosis of a child's serious illness: family life is disrupted; careers put on hold; responsibilities to other family members – parents, other children, siblings, - accommodate to focus upon the needs and interests of the seriously ill child.<sup>19</sup> Not only do parents have specific knowledge of their own child as an individual material to the child's medical treatment (Anderzen-Carlsson, Kihlgren, Svantesson, Sorlie (2007) 243), they are usually focused upon their child's needs and consequently develop expertise in the individual child's ability to cope with their condition and the pain and distress which results from it and its treatment, necessary to respect the child's personal integrity. As Carol Glass said of her relationship with her son David,

'I have known David all his life. I know when he is happy, when he is sad or when he is in pain. ... I was angry for David because I knew him best and I needed to stick up for him. I needed to give him a voice.'(Day (2004) quoting Carol Glass)

In their judgments, it is usual for judges to note the weight they give to parental views of the child's best interests as the persons who know the child 'immeasurably better than anybody else does, professional or otherwise' (*GOSH v Yates & Gard* (April 2017) [107]). Yet, decisions are explained largely in terms of the benefits and burdens of treatment and its effect upon quality of life, rather than the interests of the child as a person in relationship. The short paragraphs detailing parental views are set alongside the much more lengthy account of the medical evidence of the child's treating clinicians and second opinions. For example, in the case of Charlie Gard, the parental evidence is set out in 6 paragraphs noting the number of hours they had spent with their son, how they thought he reacted to their presence, toys and to medical interventions, that he liked to be stroked on his head and to be tickled but not on his feet and the parental belief that, contrary to the views of his clinicians, he did have a wake/sleep cycle indicating that his brain damage was not as bad as his doctors thought. Their wishes for him to be given the chance to improve his quality of life which they believed nucleoside therapy offered were noted (*GOSH v Yates & Gard* (April 2017) [107]-[112]). Of course, these are decisions about the provision of medical treatment to a child but whilst the parental experiences of their son's reactions were noted, as evidence relevant to determination of whether continued ventilation for the trial of a therapy administered via his feed, they were not tested. Neither were the views of the parents of eighteen month-old T who had decided to refuse further surgery given the pain and distress caused to him by surgery he had undergone when a few weeks old (*Re T (a minor) (wardship: medical treatment)* (1997)). Neither was the expertise recognised of the mother of 12 year-old David Glass, a child with mental and physical disabilities, who had cared for him at home with the help of family and community professionals with occasional periods of hospitalisation and who, contrary to the views of the clinicians caring for him, was adamant that he was not dying. As Judge Casadevall observed, giving a separate opinion in the ECtHR six years later when David was still alive,

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<sup>19</sup> This is quite a big claim and, of course, as is recognised below, the circumstances of individual families and how they respond will be different. However, this view is supported by the accounts of parents of children who underwent heart surgery at Bristol Royal Infirmary considered in Bridgeman (2003); of studies of parents caring for a child with cancer, explored in Bridgeman (2017); and, of personal accounts of parents whose child is born with severe disabilities, for example, Raca (2012), Wright (2015), Melville-Ross (2016).

the facts showed that ‘in the particular circumstances of the present case, maternal instinct has had more weight than medical opinion.’ (*Glass v United Kingdom* (2004)). Whilst parental knowledge and expertise needs to be taken into consideration in determination of a child’s best interests so too must the experience of other carers where it is they rather than the child’s parents who have gained knowledge and expertise of the individual child through their day to day care of the child. For example, where parents have removed themselves from involvement in their child’s care (for example, *Bolton NHS Foundation Trust v C and LB and PT* (2015)) or been unable to meet their child’s needs (for example, *Re B* (2008)) so that the child has been taken into the care of the state and the day to day care of the child is provided by foster carers, it is they who will have gained the knowledge and expertise relevant to determination of the child’s best interests.

The parent/child relationship is ‘generally but one configuration in a cluster of overlapping relationships of partiality, each of which gives rise to its own set of responsibilities.’ (Lindeman Nelson (1999)). Children with serious illnesses or complex health needs usually receive care from a range of professionals who will as a consequence gain particular knowledge of the child which needs to be given full recognition in the legal process. Nineteen month-old ID, who had severe, chronic and irreversible lung disease, was cared for at home by his parents with the assistance of community healthcare professionals and occasional hospital treatment. The parental view of his best interests was supported by the evidence of his paediatric therapist, occupational therapist, home visitor, lead nurse in neo-natal home care and speech and language therapist on the developmental progress ID had made and his current state of health. His speech and language therapist gave evidence of

‘ID becoming more alert and responsive to the environment around him and that he greeted familiar people with recognition. He follows with his eyes people and toys which interest him. He is beginning to show signs of some vocabulary with a hand and arm movement to indicate “bye bye”. He has a delightful smile and can indicate pleasure and displeasure.’ (*A National Health Service Trust v D* (2000) 684)

Yet Cazalet J, who authorised clinicians to withhold mechanical ventilation in the event of a respiratory or cardiac failure or arrest, seemed to give more weight to the medical evidence of Dr P, consultant in paediatric intensive care, based upon a review of the hospital records and clinical notes and a clinical examination of ID conducted four days after he was admitted to hospital with a fever. Dr P noted that the

‘family’s description of ID’s development appears at odds with what has been documented by the medical staff, saying that he could find no record of DI having head control, visual fixation and following, sitting, speaking words or reaching for an object’ (*A National Health Service Trust v D* (2000) 683).

Judgments sometimes, but not always, consider evidence from the nursing staff but if they do so it is only brief. Yet, it is the nurses rather than clinicians who will spend a lot of time with the child providing nursing care and thus have views material to the evidence as to child’s interests in the wider sense beyond medical interests. As Jonathan Herring has observed, after quoting from an anonymous healthcare professional who had cared for Charlie Gard, ‘the mask of professional detachment ... means that arguments based on their emotional attachment and the dedication of their care work get underplayed in the legal system.’ As Jonathan Herring argued, ‘the depth of their caring relationship with the children gives them a legitimate voice in the legal decision-making process’ (Jonathan Herring (2019) 204). Relational perspectives, as Marie Fox and Thérèse Murphy have suggested, challenge ‘traditional legal understandings of authority, status and power’. However, they expressed concern that they can also ‘valorize’ the views of parents when they differ from healthcare professionals (Fox and Murphy (2013) 254). This can be avoided by ensuring that an approach which gives insufficient consideration to parental experience is not replaced by one which



uncritically accepts their views. What is required is a critical assessment of and appropriate weight given to the evidence all in the web of caring relationships who gain experience and knowledge through the provision of care to a seriously ill child.

In her commentary, reflecting upon the ethical judgment of Richard Huxtable in *Re A*, (Huxtable 2017), Jackie Leach Scully argued that his conclusion that the finely balanced welfare arguments meant that the decision should be left to the parents reached in good conscience, was 'pragmatic and compassionate', it was 'theoretically rather thin'. In her view an 'ethically satisfying basis may be found in a *relationally grounded ethics of care*' (Leach Scully (2017) 32). In addition to the twins' dependency on each other which would be recognised in any ethical analysis, she argued that an ethic of care approach would ensure fuller consideration of the importance to the parents of providing the best kind of care to that dependency through consideration of existing and future relationships amongst all involved, the children, their parents and the healthcare professionals Leach Scully (2017) 33). To examine critically the evidence provided by those in the wider web of care is not to suggest that clinical evidence and professional judgement are not important. To the contrary, in the context of a seriously ill child, relationships with healthcare professionals take on particular significance for the child's future but it must be emphasised that these are *professional relationships of care*. The provision of medical treatment to a seriously ill child is a process of judgement-making in the delivery of individualised medicine involving complex judgements of diagnosis, identification of treatment options and modification of treatment in response to the reaction of the individual child (Downie and Macnaughton (2013)). It involves the interaction of a team of experts, exercising professional judgement, responding to uncertainty and changing information with regard to the child. As professionals subjecting a seriously ill child to tests, monitoring, medication and invasive procedures, they have, as Hilde Lindemann and Alisa Carse have argued, to be true to their conscience<sup>20</sup> and to accept responsibility for their moral judgements (Lindemann and Carse (1996) 25). Where professionals and parents disagree about the future medical treatment of a child, professional judgement has to be supported by second opinions and reached in accordance with professional guidance.

As Tove Pettersen has identified, an ethic of care seeks to avoid moral conflicts, prevent harm and promote flourishing by reconciling different interests (Pettersen (2008) 76). This requires attentiveness also to the relationship between those with responsibility to care. To counter the tendency in medical ethics to focus upon the responsibilities of doctors, Heather Draper and Tom Sorrell have examined the responsibilities which adult patients owe to their doctors. The first obligations they identify owed by adult patients to their doctors, but equally applicable to the relationship between parents and their child's clinicians, are grounded in the general responsibility to treat others with the respect that is owed to anyone, that is not to be abusive or disrespectful (Draper and Sorrell (2002) 341). But further, the responsibilities which parents have towards their child's doctors, parallel to those owed by the autonomous individual arising from duties to take care of the self, arise from the legal and moral responsibilities that parents owe to their child. The law imposes the legal duty upon parents, as those with primary responsibility for care of the child, to seek medical advice but once they have done so they have a duty to listen to that advice even if there may be circumstances, such as when different values are placed upon quality and quantity of life, when they are justified in not following that advice (Draper and Sorrell (2002) 343).

The clinical duty of care to the child and parental responsibilities to their child require both to take care to maintain an effective partnership of care each respectful of the interests, expertise, views and concerns of the other. The question to consider is whether the parties have worked to achieve what Tove Pettersen refers to as mature care (Pettersen (2008) 4), balancing the respective interests of the self and others. In the provision of medical treatment

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<sup>20</sup> Lindemann and Carse (1996) 25. For consideration of professional conscience in relation to the provision of medical treatment to children see Bridgeman (2019).

to a child this requires both parents and professionals to seek to respond to needs, to be concerned to maintain trust, to be concerned for the emotional and physical wellbeing of all others. Mature care, Tove Pettersen has argued, requires reflection on well-being, on the relationship, on the social, moral and intellectual issues (Pettersen (2008) 57). It requires those in the relationship to attend to the relationship, not only reflecting upon how to understand and respond to the other but also upon the way in which, and how well, one responds to the other (Pettersen (2008) 73-4). It requires all to be true to their conscience without, as Hilde Lindemann and Alisa Carse have argued, becoming self-interested, by 'being responsible for one's own moral judgements' (Lindemann and Carse (1996)). Where interests of self and other diverge and seem incompatible, rather than follow the conflict pathway (Forbat, Teuten and Barclay (2015)), what is required is careful listening to the different perspective to attempt better to understand and to respond to the other (Pettersen (2008) 94). As Tove Pettersen has suggested, solutions will not be found through entrenched positions but more contextualised knowledge may present a way forward (Pettersen (2008) 94).

### **The Context for Care**

A relational autonomy approach challenges the isolated individualism of traditional approaches to autonomy, as Jennifer Nedelsky has argued, understanding our autonomous decisions or actions, our 'own laws' as constituted and nurtured by our relationships with others and by the 'shared social norms, values, and concepts' of the societies in which we live.<sup>21</sup> A relational responsibilities approach, in contrast, recognises that the ability of parents and professionals to care for a seriously ill child are not matters of individual choice, however constituted, but that in addition to informing choices, the social, cultural, and political context affects abilities to ensure the best possible care is provided.

With respect to the medical treatment of children, the obvious contextual factor are advancements in medicine and medical technology which now mean that diseases once invariably fatal, such as leukaemia,<sup>22</sup> are more often survived so that children live with their experiences and effects of illness and its treatment. Advances in medical technology enable lives to be sustained even when there are no further treatment options to try. Children who are, for example, reliant upon ventilation, can be assisted to live with life-sustaining technology at home in the care of their parents, as was the hope with both Alfie Evans and Tafida Raqeeb.

Decisions about NHS funding are political decisions. Provision of facilities, equipment, resources, medicines and services - locally and nationally - affect the ability to care. There are examples in the case law from early in the jurisprudence of parents undertaking research to find innovative treatment, beyond that offered by the child's clinicians through the NHS, for their child with the aim of saving his or her life (*R v Cambridge District Health Authority, ex parte B* (1995)) or improving his or her condition (*Donald Simms and Jonathan Simms v An NHS Trust and Secretary of State for Health; PA and JA v An NHS Trust and Secretary of State for Health* (2002)).<sup>23</sup> But, parents no longer have to use the library of the Royal Society of Medicine as did the father of Jaymee Bowen in his search for treatment options for his daughter, who relapsed after a period in remission from acute myeloid leukaemia. Information is now easily accessible via the internet, if no easier to assess. Where the treatment is not currently available in the UK, parents are confronted with examples of parents of other children

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<sup>21</sup> Nedelsky (1989) 10, 11. However, what relational autonomy shares with traditional accounts is the starting point of a separated, isolated individual.

<sup>22</sup> In the 1960's the most common form of childhood cancer, acute lymphoblastic leukaemia, was invariably fatal, Dixon-Woods, Wilson, Jackson, Cavers and Pritchard-Jones (2008) 62. Treatment now offers a five year survival rate of about 80%, <http://www.cancerresearchuk.org/about-cancer/type/rare-cancers/rare-cancers-name/childrens-cancers#cure> .

<sup>23</sup> In which Butler-Sloss P determined that the administration of experimental treatment was in the best interests of two teenagers both of whom had vCJD.

raising money through crowdfunding,<sup>24</sup> or selling their most valuable asset, their home (Strange (2014)), to raise money to travel abroad, framing societal norms of parenting expectations in the context of the care of a seriously ill child. The responsibilities of parents are in part constituted by the minimum expectations set by the law but also by social norms, given individual interpretation. This was part of the context to the court determination of the future medical treatment of Ashya King whose parents removed him from hospital to take him to Spain with the intention of selling their house there to pay for his treatment in Prague (*In the Matter of Ashya King* (2014)). Concerned about the effects upon Ashya of the surgery to remove the malignant brain tumour which left him unable to move his limbs, head, or eyes and with difficulties swallowing so that he required nasogastric feeding, his parents were concerned about the effects of radiotherapy the risks of which include intellectual and cognitive impairment, effects upon growth, thyroid (which may cause lethargy or weight gain] and sub-, or in-, fertility, and risks secondary cancers in later life. His parents thought that Proton Beam Therapy, which they had discovered from a search of the internet, presented risks of fewer side-effects. As Baker J observed in his judgment, '[a]ny parents in the position of Mr and Mrs King would do whatever they could to explore all options, some would follow the advice of the responsible clinicians, others the 'relatively untested option of proton therapy... in the hope that the toxic effects of radiation will be reduced' (*In the Matter of Ashya King* (2014) [34]). The concern of parents to do all they can to secure the best possible treatment for their child, 'leaving no stone unturned' (Bridgeman (2017)), is framed by searching out alternative treatment options offered outside the NHS, finding facilities for privately funded treatment abroad, raising funds, leaving home and travelling overseas. Ashya King's parents are not alone in risking prosecution and imprisonment in their efforts to secure what they believe to be the best possible treatment for their child. For example, Charlotte Caldwell brought cannabis oil from abroad where its use is legal to administer to her son, Billy, with the aim of stopping his life-threatening and damaging epileptic fits.<sup>25</sup> This is not to suggest that all parents would, or should, take these steps, but that these examples form part of understandings of the expected norms.

But the ability of parents of a seriously ill child to be involved in their child's care will be affected by their financial situation, such as the need to work to provide for themselves and other children. Decisions about care will be affected by their family situation, for example having other children to care for whilst, because families no longer live in close proximity, they may lack support with childcare. Although made within the context of their study of families caring for a child with disabilities, the argument made by Janice McLaughlin et al that where the provision of care is perceived as primarily a private and individualised responsibility which parents, and more specifically mothers, are expected to fulfil questions about rights to care, state responsibility and the requirement for a caring society are avoided (McLaughlin, Goodley, Clavering and Fisher (2008) 182), is of wider significance. Decisions about the provision of treatment have to be approached within the context of societal decisions about the provision of institutional and public support for parents caring for children with additional needs, including those which result from life-saving treatment. As a society we need to recognise caring responsibilities and ensure they are properly supported by communities, public institutions and services so that once children are discharged from hospital, families are not abandoned to their caring responsibilities. Caring needs to be fully understood not solely as a private, individualised, responsibility but that the care provided within families is embedded within the care and support of a range of public services and institutions.

I now turn to consider a hypothetical example the facts of which are drawn from a number of recent cases. Although I am not seeking to re-write the judgment in a specific case, the methodology is inspired by the turn in academic work to re-writing judgments. The primary

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<sup>24</sup> Dressler and Kelly (2018) noted that health related issues are GoFundMe's largest category of fundraising for personal use.

<sup>25</sup> Gilligan (2018). The home secretary subsequently issued a licence permitting its administration.

goal of the academic practice of re-writing judgments is to explore the extent to which the critical perspectives employed in academic critique of judgments, whether that be from a feminist, ethical or children's rights perspective, can be applied in the writing of judgments which remain faithful to judicial conventions. The purpose of applying the relational responsibilities framework to a hypothetical constructed from the facts of recent cases is to demonstrate that a relational responsibilities perspective for the resolution of children's medical treatment decisions is not a purely theoretical academic enterprise but one of practical application.

### **Application of a Relational Responsibilities Approach: A Hypothetical Case**

Seven year-old Samuel James first underwent surgery, radiotherapy and chemotherapy in the treatment of a malignant brain tumour when he was eighteen months-old. After a period in remission, Samuel relapsed. After further invasive treatment, his treating doctors formed the view that all medical and surgical options had been exhausted. The position of the tumour meant that further surgery was not possible and the radiotherapy and chemotherapy which had been administered had not stopped the tumour from growing. His clinicians considered that his condition was now deteriorating quickly. His parents, whose religious beliefs meant that they believed in the sanctity of life and that life should be sustained through all means possible, had searched the internet, identified a novel therapy which had been used by an expert abroad in the treatment of adults with a similar form of brain cancer and who had advised them that he considered that there was a theoretical chance it could work in Samuel's case. His parents claimed that Samuel was a brave fighter who had a right to be given this chance of life. They had raised half of the costs of treatment abroad by cashing in life insurance policies and re-mortgaging the family home. A children's cancer charity had offered to pay the balance. The Trust applied to court for authority to withhold further invasive treatment and to provide palliative care to ease the pain and suffering in the remainder of Samuel's life. His parents considered that it was in his best interests to travel abroad for a trial of the innovative therapy and that the risks involved in doing so were not the same as in other cases, such as that of Charlie Gard, given that he was not dependent upon a ventilator.

A relational responsibilities approach to determination of Samuel's best interests would ensure that the child was at the centre of decision-making. To ensure that the focus is upon him as an individual, the court would require evidence from his parents, family members and others who know him well about his interests, his character and his developing views on relevant issues such as quality and sanctity of life. In contrast to the similar aged boys, Ashya King (*In the Matter of Ashya King* (2014)) and Neon Roberts (*An NHS Trust v SR* (2012)), both of whom were shadowy presences in the background to the disputes between adults, videos could also be used to bring the child to life for the judge. In the same way that Samuel would have received support, such as play therapy, in preparation for his treatment, the same kind of support could be made available to gain a better understanding of how he is currently feeling, to inform the Guardian's independent representation of him and give effect to his participation rights to ascertain as far as possible his attitude to further treatment aimed at giving him a chance of life.

In addition to the clinical judgement of those responsible for his treatment and their professional judgement informed by second opinions and professional guidance, a relational responsibilities approach would require evidence from Samuel's parents, other family members and those involved in his daily life of how he had coped with the previous treatment he had received, the attitude he demonstrated to the pain of medical intervention and the side-effects of treatment and how the treatment he had received had affected him in the years he was in remission. As the question for the judge to determine relates to the future medical treatment of Samuel, evidence should be secured from a range of health professionals such as his GP and nurses and other community health professionals as to the effect of the treatment he has received upon his quality of life. The court would seek substance to the

claims that he was a 'brave fighter' in his experience of his illness and its treatment and how that bears upon decisions about his future treatment.

The judge would need to be satisfied as to the nature of the professional relationship of care between Samuel and the doctor who was offering the innovative therapy abroad. The judge would need evidence that the doctor had examined Samuel, his medical records and consulted with his clinicians and been informed of the second opinions (As Francis J stated in *Re Gard* (2017) [12]). Whilst, as Butler-Sloss P observed in *Simms*, the *Bolam* test (*Bolam v Friern Hospital Management Committee* (1957)) should not 'inhibit medical progress' (*Donald Simms and Jonathan Simms v An NHS Trust and Secretary of State for Health; PA and JA v An NHS Trust and Secretary of State for Health* (2002) [48]), but before the administration of the therapy could be considered in Samuel's best interests, the judge would have to be satisfied that there was a responsible body of professional opinion capable of withstanding logical analysis supporting its administration. It would not be in Samuel's best interests to be subjected to further treatment which had no reasonable prospect and an assessment would have to be made of the side effects and short-, medium- and long-term risks of the therapy. Samuel and his parents would depend upon the doctor offering treatment fulfilling his legal and moral duties to take care, including consideration of why the therapy was not available to him. There would need to be evidence as to why it had not been approved for use in children, whether that was due to resources or to judgements about its efficacy or failure to meet standards of care to protect children from being subjected to experimental treatment. The social, political and cultural context for decisions about the care being offered would have to be understood.

As is apparent, a relational responsibilities approach, more attentive to the particular and contextual, seeks to identify a way forward either through gaining more information to bring greater clarity to the best interests determination, or through a more detailed exploration of the relevant issues to find an alternative solution to the two separate routes currently favoured by those primarily responsible for the care of the child. For example, the additional information may lead the caring professionals to the conclusion that they should try the medication, lead the parents to understand why this is not a possibility or enable them to arrive at a different solution. By responding to each other they may find 'shareable interpretations of their responsibilities, and/or bearable resolutions to their moral binds' (Urban Walker (1989) 20).

### **Judging with Care**

The current legal framework polarises the positions of those confronted with making decisions about the medical treatment of children in their care, condensing the views of parent and professional as oppositional, one of which must prevail. It creates a clash of conflicting assessments of what is best, a conflict in which there is a winner and a loser and in doing so contributes further to the breakdown in trust between those seeking to do the best for the child. As Katherine Bartlett has identified, when disputes arise, the law forces the parties to present their positions and the court to decide through individualised, abstract, conflicting claims when the reality is of connections and interdependencies (Bartlett (1988) 295).

As Leslie Bender has observed, the ethic of justice,

'closely parallels the dominant rationality and methodology of Anglo-American law. This justice ethic is based on a rights model, where problem-solving consists of the application of abstract, generalized principles to arbitrate rights disputes between separate individuals (conflicting rights-holders) and to privilege one over another. The justice-oriented problem-solver seeks a distanced stance from which to make objective decisions by applying formal rules of equality and other general principles of justice' (Bender (1990-1991) 37).

Once the decisions of parents and professionals are subject to determination by the court, within the existing legal framework, justice prevails at the expense of care. A legal framework of abstract prioritisation of the competing rights of the unconnected other will not reflect the reality of those with responsibilities and determined to take responsibility for the care of a seriously ill child. In contrast the ethic of care, the principles of which inform the relational responsibilities approach, as Leslie Bender has observed,

'focuses attention on the unique context of the dispute and the parties' on-going relationships and interdependencies. The care-oriented problem-solver examines the connections between and among people, looking at their interpersonal responsibilities and needs. Preventing hurt, preserving relationships, and developing cooperative solutions rooted in the concrete particulars of the conflict are objectives of a care-oriented ethical analysis. A care-based problem-solver ... gather[s] more relevant information in order to better understand the full scope of the problem and the practical, material consequences of any decision. By considering the specific needs of all the parties, as articulated from those parties' own perspectives, and by attending to particularized contexts rather than abstract rights and universalizable rules, care-oriented problem-solvers frequently design creative, alternative solutions that may never occur to their justice-oriented counterparts' ((Bender (1990-1991) 37).

The legal framework should not just be content to protect the interests of individuals but should also encourage those involved to take more care of each other with consideration of the consequences for others, as well as themselves, of their actions and decisions. As Margaret Urban Walker stated,

'If the others I need to understand really are actual others in a particular case at hand, and not repeatable instances or replaceable occupants of a general status, they will require of me an understanding of their/our story and its concrete detail. Without this I really cannot know how it is with others towards whom I will act, or what the meaning and consequence of any acts will be' (Urban Walker (1989) 18).

I argue that a conceptual framework of relational responsibilities would better achieve child-centred care through recognition of the lived realities of caring responsibilities and inherent relationality of the child, parents and professions; it would situate decisions about a child's future medical treatment in the context of social responsibilities of public services and institutions to support caring responsibilities. Reframing welfare around relational responsibilities would ensure recognition of both justice and care.

December 2019

### **List of Cases**

*Alder Hey Children's NHS Foundation Trust v Evans* [2018] EWHC 308 (February 2018)  
*A National Health Service Trust v D* [2000] 2 FLR 677  
*An NHS Trust v A* [2007] EWHC 1696  
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*Re J (A Minor) (Wardship: Medical Treatment)* [1991] 2 WLR 140  
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*Re Wyatt (a child) (medical treatment: continuation of order)* [2005] EWCA Civ 1181  
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