

# Parents, young children and healthcare law

## Introduction

Being a parent brings with it manifold social, moral and legal responsibilities in relation to the physical, emotional and intellectual growth and development of the child as well as his or her safety, security, happiness and well-being. The purpose of this book is to examine the role of parents in caring for the health and well-being of young and dependent children. In the chapters which follow there is an examination of the range of care undertaken by parents from the everyday management of the health of children, to the demands placed upon parents whose child has a life-threatening illness or long-term disabilities, or whose future survival is uncertain due to disabilities arising from prematurity, complications during birth or accidental injury. In addition to undertaking an examination of the existing legal obligations imposed upon parents, this book makes the argument for a new conceptual framework to govern the role of parents in relation to the health of their children. Rather than argue for a legal framework firmly grounded in the rights of young and dependent children, as many commentators do, this book makes the argument for a legal framework situated within the responsibilities of parents and healthcare professionals for the management of children's health.

This book considers the responsibilities of parents and professionals in relation to the health of children who, by virtue of their age, or mental and physical impairments, are dependent upon others to ensure their health and well-being. Whilst newborn (up to twenty-eight days old) and infant (under the age of one) children are totally dependent upon others to interpret and meet their needs, at a young age – four or five, perhaps younger – children will, to varying extents, contribute to maintenance of their health and well-being. They will be able to take some responsibility for their daily care: for example, washing their hands and cleaning their teeth.

Cambridge University Press

978-0-521-86312-4 - Parental Responsibility, Young Children and Healthcare Law

Jo Bridgeman

Excerpt

[More information](#)

Furthermore, young children can be participants in their healthcare: for example, reporting symptoms, taking medicine, sitting still whilst a wound is tended or immunisation administered by injection. By this age, children will be able to understand explanations given in appropriate language and manner and thus can be involved in decisions about their healthcare before they start school. Each child is different. Indeed, that this should be recognised by the law is a central argument of this book. The extent to which each child wants, and is able, to be actively involved in their healthcare will vary. Whilst we would not expect a child of this age to take responsibility, we can demonstrate respect for each child as an individual person by involving them, consulting them and considering their views on the benefits and harms of what is proposed.<sup>1</sup> The extent to which each child can be involved is not only dependent upon the individual child but upon the appropriateness of the explanations given, the willingness of the caring adults to listen to the child and the circumstances in which such an exchange takes place. The responsibility of parents for the healthcare of their young and dependent child not only involves negotiations with healthcare workers but further involves negotiation with the child and, where the child is unable to express his or her views and feelings, careful consideration of their child's needs.

Whilst for most families care of their children remains a private matter, it was the scandal of the 'Bristol Heart Babies' and the revelations about the widespread retention of organs from deceased children which brought to public attention the neglect of children's healthcare services against the concern of parents to secure the best possible healthcare for their children. The evidence of parents to the Bristol Inquiry highlighted the responsibility taken by parents for securing professional help for their child's condition and for working together with professionals to ensure that their child received the best possible care. The revelations about the inadequate quality of care provided at Bristol left many parents with feelings of guilt arising from a sense that they had failed in their responsibility to their child. The abject horror, the raw distress, of parents who subsequently discovered

<sup>1</sup> Jane Fortin emphasises the distinction between children having the right to make decisions and the right to participation and consultation recognised in Article 12(1) of the United Nations Convention on the Rights of the Child, 1989. The latter recognises the importance of involving the child in decisions, even when the child is not considered to be an autonomous individual, without imposing responsibility for the decision upon the child: Jane Fortin, *Children's Rights and the Developing Law*, Reed Elsevier: London, 2003, at pp. 19–20.

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Excerpt

[More information](#)

that parts of their children's bodies were retained has been widely reported in terms which demonstrate sympathetic appreciation of their plight. That much of the attention has been directed at the retention of organs from children's bodies and less at the widespread common practice of retaining the organs of adults can be better understood in light of the particular value attributed to the child and the intimate relationship between children and those caring for them in our society:<sup>2</sup>

Indisputably, over the past two, or at most three, decades childhood has moved to the forefront of personal, political and academic agendas and not solely in the West. The moving spirit of this process is extremely complex and can be seen to involve an entanglement of factors such as: a structural re-adjustment to time and mortality in the face of quickening social change; a re-evaluation and a re-positioning of personhood given the disassembly of traditional categories of identity and difference; a search for a moral centre or at least an anchor for trust in response to popular routine cynicism; and an age-old desire to invest in futures now rendered urgent.<sup>3</sup>

The majority of parents will be spared the responsibility of deciding whether a very sick child should undergo life-threatening and potentially life-saving surgery. Most will not be faced with the decision whether their newborn babies should undergo separation surgery offering the chance of survival to one but causing the inevitable death of the other, as did the parents of Jodie and Mary, now known to be Gracie Rosie and Rosie Gracie Attard.<sup>4</sup> Courts have been asked to resolve disputes between parents and professionals concerning the healthcare of children, thereby establishing the legal framework for the respective duties of parents and professionals with regard to the healthcare needs of children. It is the premise of this book that judgments about the health of children need to be informed by a full consideration of the difficult issues confronting parents and professionals as they attempt to fulfil their responsibilities to children such as Jaymee Bowen,<sup>5</sup>

<sup>2</sup> Jo Bridgeman, 'When Systems Fail: Parents, Children and the Quality of Healthcare' (2005) 58 *Current Legal Problems*, Jane Holder and Colm O'Cinneide (eds.), Oxford University Press: Oxford, 183–213.

<sup>3</sup> Chris Jenks, 'Sociological Perspectives and Media Representations of Childhood' in Julia Fionda (ed.), *Legal Concepts of Childhood*, Hart: Oxford, 2001, 19–42, at p. 22.

<sup>4</sup> *Re A (Children) (Conjoined Twins: Surgical Separation)* [2001] 2 WLR 480: considered in chapters 4 and 5.

<sup>5</sup> *R v Cambridge District Health Authority, ex parte B* [1995] 1 FLR 1055: considered in chapter 2.

Cambridge University Press

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Excerpt

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Charlotte Wyatt,<sup>6</sup> David Glass,<sup>7</sup> Luke Winston-Jones<sup>8</sup> and all those children who remain anonymous in order to protect them and those caring for them from, amongst other things, intrusive media attention. This chapter explains the theoretical perspective from which the critique of the law governing the provision of healthcare to babies, infants, young and dependent children is undertaken. It ends with an outline of the chapters which follow to guide the reader through the book and point them to chapters which may be of particular relevance or interest.

## The legal construction of the young child

### *Perspectives on childhood*

Although as Eva Kittay reminds us in *Love's Labor* we are all 'a mother's child',<sup>9</sup> when we refer to 'child' we are more commonly referring to a particular type of person – one who is currently at a stage of biological, intellectual and emotional immaturity. But what we mean by 'child' is not simply a known given, rather, it is a cultural, social and legal construction. Contemporary concepts of 'child' within England and Wales are culturally and historically specific understandings of the characteristics, abilities, values and priorities of the child and not those of an individual child at a given time in relation to a specific issue. Current constructions of child within law and policy have been influenced by a history of ideas from a range of disciplines, including philosophy, sociology and psychology.<sup>10</sup>

As philosopher David Archard has pointed out, both the concept of childhood<sup>11</sup> (the understanding that children are different from adults)

<sup>6</sup> *Portsmouth NHS Trust v Wyatt and Wyatt, Southampton NHS Trust Intervening* [2004] EWHC 2247 (7 October 2004); *Portsmouth Hospitals NHS Trust v Wyatt and others* [2005] EWHC 117 (Fam) (28 January 2005); Unreported [2005] EWCA Civ 185 (9 February 2005); *Wyatt v Portsmouth NHS Trust and Wyatt (By her Guardian)* (No. 3) [2005] EWHC 693 (Fam) (21 April 2005); *Wyatt and another v Portsmouth Hospital NHS and another* [2005] EWCA Civ 1181 (12 October 2005); *Re Wyatt* [2005] EWHC 2293 (Fam) (21 October 2005); *Re Wyatt* [2006] EWHC 319 (23 February 2006): considered in chapter 5.

<sup>7</sup> *R v Portsmouth Hospitals NHS Trust, ex parte Glass*, 50 BMLR 269 (web.lexis-nexis.com/professional/) and *R v Portsmouth Hospitals NHS Trust, ex parte Glass* [1999] 2 FLR 905; *Glass v United Kingdom* [2004] 1 FLR 1019: considered in chapter 5.

<sup>8</sup> *Re L (Medical Treatment: Benefit)* [2004] EWHC 2713 (Fam): considered in chapter 5.

<sup>9</sup> Eva Feder Kittay, *Love's Labor: Essays on Women, Equality and Dependency*, Routledge: New York, 1999, at p. 23.

<sup>10</sup> Alison Diduck, *Law's Families*, LexisNexis UK: London, 2003, at p. 74.

<sup>11</sup> As David Archard explains, this is not a singular concept, rather multiple, contradictory and inconsistent concepts co-exist: *Children: Rights and Childhood*, Routledge: London, 2004, at pp. 27–9.

Cambridge University Press

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Excerpt

[More information](#)

and the specific conception of the particular ways in which children differ from adults take the adult as the point of comparison. Children are not-adults, ‘not-men’:<sup>12</sup> dependent in contrast to adult independence; innocent or ignorant in contrast to the experience of adulthood; irrational and capricious rather than rational and reasoned. By their difference, their lack, the child gives definition to the particular characteristics which identify an individual as an adult.<sup>13</sup>

The ideal adult is equipped with certain cognitive capacities, is rational, physically independent and autonomous, has a sense of identity, and is conscious of her beliefs and desires, and thus able to make informed free choices for which she can be held personally responsible . . .

Childhood is defined as that which lacks the capacities, skills and powers of adulthood. To be a child is to be not yet an adult. Adulthood is something which is gained, and although there may be losses in leaving childhood behind, what is lost tends to be construed as that which could never possibly serve the adult in an adult world.<sup>14</sup>

This lack is not permanent. Unlike ‘women, animals, madmen, foreigners, slaves, patients and imbeciles’<sup>15</sup> children have the potential to develop their capacities: that is, the potential to develop the rationality and reason required of citizens to consent to authority and exercise their rights.<sup>16</sup> Indeed, the development by children of these capacities is considered a normal, ordinary, expected and natural process. As Alan Prout and Allison James explain, in the twentieth century psychological approaches to child development dominated, with material impact upon child-rearing practices, educational theory and the law.<sup>17</sup> This natural developmentalism resulted in a focus within sociology upon the socialisation of the child,<sup>18</sup> and rendered natural the confinement of children to the private sphere whilst they develop the capacities and

<sup>12</sup> Judith Hughes, ‘The Philosopher’s Child’ in Morwenna Griffiths and Margaret Whitford (eds.), *Feminist Perspectives in Philosophy*, Macmillan: Hampshire 1988, 72–89, at p. 72, ‘in contrast with which male philosophers have defined and valued themselves’.

<sup>13</sup> *Supra*, n. 11, at p. 29. <sup>14</sup> *Ibid.*, at p. 39. <sup>15</sup> *Supra*, n. 12, at p. 72.

<sup>16</sup> Barbara Arneil, ‘Becoming versus Being: A Critical Analysis of the Child in Liberal Theory’ in David Archard and Colin Macleod (eds.), *The Moral and Political Status of Children*, Oxford University Press: Oxford, 2002, 70–94, at p. 70.

<sup>17</sup> Alan Prout and Allison James, ‘A New Paradigm for the Sociology of Childhood? Provenance, Promise and Problems’ in Allison James and Alan Prout (eds.), *Constructing and Reconstructing Childhood: Contemporary Issues in the Sociological Study of Childhood*, Falmer Press: London, 1997, at p. 9. <sup>18</sup> *Ibid.*, at p. 12.

Cambridge University Press

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Excerpt

[More information](#)

learn the appropriate behaviour of adulthood. Acceptable adulthood is the natural end of a process, whether the child originates from a position of innocence or evil:

Locke's idea of the child as a blank slate, his empirical developmentalism, can be contrasted with the moral developmentalism of Thomas Hobbes, who theorised children as innately evil and therefore in need of taming and saving on their way to adulthood, or that of Rousseau who thought children were born with a natural goodness, clarity of vision and innocence. These conflicting ideas of 'immanent childhood' remain in modern policy.<sup>19</sup>

Possessed of this potential, the focus of concern has been the protection of the autonomous adult the child will become, with a failure to see children as living, active, contributing persons.

The new sociology of childhood, most notably the work of Chris Jenks, Allison James and Alan Prout,<sup>20</sup> exposes the discursive construction of the concept of 'childhood'. Various constructions of childhood have been identified across academic disciplines and historical periods of study: James, Jenks and Prout identify the evil child, the innocent child, the immanent child, the naturally developing child and the unconscious child.<sup>21</sup> The construction of the child as evil presents the child as 'demonic, harbourers of potentially dark forces which risk being mobilized if, by dereliction or inattention, the adult world allows them to veer away from the "straight and narrow" path that civilization has bequeathed to them'.<sup>22</sup> The innocent child is portrayed as pure and uncorrupted, living according to values which adults would do well to attempt to emulate.<sup>23</sup> The immanent child is understood to embody potential, a future person, 'becoming', but is a blank canvas requiring the right environment for appropriate development.<sup>24</sup> And the naturally developing child hurdles over milestones to the inevitable achievement of adulthood and must along their route be subjected to 'measuring, grading, ranking and assessing', compared against other children and against the 'norm'.<sup>25</sup>

<sup>19</sup> *Supra*, n. 10, at p. 75.

<sup>20</sup> Chris Jenks, *Childhood*, Routledge: London, 1996; Allison James and Alan Prout (eds.), *Constructing and Reconstructing Childhood: Contemporary Issues in the Sociological Study of Childhood*, Falmer Press: London, 1997; Allison James, Chris Jenks and Alan Prout, *Theorizing Childhood*, Polity Press: Cambridge, 1998; Allison James and Adrian James, *Constructing Childhood: Theory, Policy and Social Practice*, Palgrave Macmillan, Basingstoke, 2004. <sup>21</sup> James, Jenks and Prout, *Ibid.*, at pp. 10–21. <sup>22</sup> *Ibid.*, at pp. 10–13, p. 10.

<sup>23</sup> *Ibid.*, at pp. 13–15. <sup>24</sup> *Ibid.*, at pp. 15–17. <sup>25</sup> *Ibid.*, at pp. 17–19, p. 19.

Cambridge University Press

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Jo Bridgeman

Excerpt

[More information](#)

There may be competing and conflicting constructions of the child within any particular discourse – for example, the child as both innocent and inherently evil – or one understanding of the idea of child may come to dominate. Either way, constructions of the child operate to silence alternative understandings of what children are, provided, for example, through the experiences of children themselves or of those involved in caring for them. The discursive construction of child thus influences the way in which children are understood and consequently treated in, for example, law. Constructions of the child as innocent, lacking capacity, as *becoming*, can inhibit awareness of children as agents, as *beings* who are not merely the object of concern but subjects actively participating in life. To understand that ideas of child are constructed by discourses and that these ideas have a material impact upon the treatment of children opens up the opportunity for recognition of children's different experiences and identities. Appreciation of the agency of children has had an impact upon some academic writing about children and the law,<sup>26</sup> and some influence upon the extent to which older children have been recognised as being able to participate in decisions affecting their lives. There has been less readiness within academic writing, case law and policy developments to embrace the agency of younger children.

### *The young child in healthcare law*

Children have been treated within law not as legal subjects but as objects of their parents:

They have been reified, treated as objects of intervention rather than as legal subjects, labelled as a 'problem population', reduced to being seen as property. They complete a family rather as the standard consumer durables furnish a household.<sup>27</sup>

One of the reasons for this, Katherine O'Donovan has argued, is the perception that the child lacks the capacities of a legal subject:

<sup>26</sup> In relation to healthcare, in the work of Priscilla Alderson and Jonathan Montgomery, *Health Care Choices: Making Decisions with Children*, IPPR: London, 1996; Fortin, *supra*, n.1; Alison Diduck, 'Solicitors and Legal Subjects' and Hilary Lim and Jeremy Roche, 'Feminism and Children's Rights' in Jo Bridgeman and Daniel Monk (eds.), *Feminist Perspectives on Child Law*, Cavendish: London, 2000.

<sup>27</sup> Michael D. A. Freeman, 'Taking Children's Rights More Seriously' (1992) 6 *International Journal of Law and the Family* 52–71, at p. 54.

Cambridge University Press

978-0-521-86312-4 - Parental Responsibility, Young Children and Healthcare Law

Jo Bridgeman

Excerpt

[More information](#)

There is a space in legal discourse, an emptiness, where a child's individuality should be. General social conditions of children's vulnerability and dependence largely account for this, but also, perhaps, adult power. There are reasons of legal method also. Consider, for example, the standard legal subject that legal discourse constructs for itself. This subject is rational and reasonable, qualities that law does not attribute to children.<sup>28</sup>

This legal subject has been subjected to scrutiny and analysis by feminists:

The public subject of Western law was born out of this way of thinking about the self: as one who is sovereign to himself, a self-possessing being, essentially a creature of reason – of the mind – autonomous and self-determining . . . The legally regulated subject of the public realm was, and largely remains, also an impersonal, rationally instrumental being. In the public realm, life is appropriately conducted at a physical and emotional distance and 'individuals secure their agreement through contract', not through trust and affection . . . In the public sphere, legal subjects relate as minds, not as sexed bodies: physical and emotional autonomy and separation are intrinsic to the traditional legal ideal of public life.<sup>29</sup>

This public subject of law stands in opposition to the female subject, confined to the private, theoretically beyond the reach of the law, and existing as non-subject, 'other' to, whilst defining the boundaries of, the public subject of, law.<sup>30</sup> It is my argument, demonstrated in the analysis of the law which follows, that the child is similarly positioned within healthcare law as 'other' to the legal subject. An approach to the legal regulation of the provision of healthcare to children which is based upon this understanding fails to accord with the reality of the lives of young children and leads to an inadequate response within law.

Infants, babies and young children are vulnerable and potential beings, dependent upon others to meet their needs – emotionally, physically and financially – for protection and nurture. This way, children grow and develop physically, intellectually and emotionally. The dependency of young children highlights the relationship which they have with those upon whom they depend for food, water, shelter, support, stimulation and

<sup>28</sup> Katherine O'Donovan, *Family Law Matters*, Pluto Press: London, 1993, at p. 90.

<sup>29</sup> Ngaire Naffine, 'Sexing the Subject (of Law)' in M. Thornton (ed.), *Public and Private: Feminist Legal Debates*, Oxford University Press: Australia, 1995, 18–39, at pp. 23–4.

<sup>30</sup> *Ibid.*, at p. 26.



Cambridge University Press

978-0-521-86312-4 - Parental Responsibility, Young Children and Healthcare Law

Jo Bridgeman

Excerpt

[More information](#)

encouragement, and love. As Alison Diduck has argued, by virtue of their dependence, young children challenge traditional ways of understanding the self:

[A] child becomes the best example of the embodiment of a connected, interdependent subject. Unlike adult subjectivity, this intimate and dependent subjectivity is difficult for liberal notions of justice to accommodate, based as they are on abstracted autonomy, independence and disconnection from other subjects and social conditions.<sup>31</sup>

But it is my argument, developed in the chapters which follow, that young children are understood and treated within healthcare law as nothing more than dependent, vulnerable and in need of protection. In order to protect them, decisions are made according to the welfare or best interests of the child.<sup>32</sup> The welfare principle is the vehicle through which adults can protect the child, giving effect to *their* understanding of what is best for the child.<sup>33</sup> Yet, unless consideration is given to the individual child, to the person they are, their personality, character, feelings of pleasure and pain, and relational interests (relationships with those upon whom they depend), determinations about the best interests of the child are reached according to current ideas about the child and according to adult memories of childhood.

Studies of parents' experiences of caring for their children identify the ways in which parents appreciate their child as a person, as a distinct individual with their own character.<sup>34</sup> The study by Priscilla Alderson, Joanna Hawthorn and Margaret Killen of parents of premature newborn babies in neonatal intensive care identified ways in which the character of their baby differed from others. They note how the babies in their study 'appeared to express hurt, misery, calm, contentment, relief, pleasure and excitement'.<sup>35</sup> They noticed how the babies in neonatal intensive care put a lot of effort, physical and mental, into surviving,<sup>36</sup> and further that parents and

<sup>31</sup> Alison Diduck, 'Justice and Childhood: Reflections on Refashioned Boundaries' in Michael King (ed.), *Moral Agendas for Children's Welfare*, Routledge: London 1999, 120–37 at pp. 124–5.

<sup>32</sup> *Supra*, n.28. at p.90.

<sup>33</sup> Ann Oakley, 'Women and Children First and Last: Parallels and Differences between Children's and Women's Studies' in Berry Mayall (ed.), *Children's Childhoods: Observed and Experienced*, Falmer Press: London, 1994, 13–32, at pp. 16, 28.

<sup>34</sup> Berry Mayall and Marie-Claude Foster, *Child Health Care: Living with Children, Working for Children*, Oxford: Heinemann Nursing, 1989, at p. 18.

<sup>35</sup> Priscilla Alderson, Joanna Hawthorn and Margaret Killen, 'The Participation Rights of Premature Babies' (2005) 13 *International Journal of Children's Rights* 31–50, at p. 40.

<sup>36</sup> *Ibid.*, at p. 39.

Cambridge University Press

978-0-521-86312-4 - Parental Responsibility, Young Children and Healthcare Law

Jo Bridgeman

Excerpt

[More information](#)

professionals talked of babies both fighting for life and appearing to have had enough. Babies, they argue, “speak” in an expressive language of sounds, facial expressions and body movements that can be “read”.<sup>37</sup>

Appreciation that even premature newborn babies have characters and personalities, different levels of tolerance of pain and of medical interventions and different attitudes to life provides the starting point for the required recognition of the individuality of young children and their needs as determined by the child themselves. What becomes important is that adults who are responsible for caring for them pay attention to the child and learn to interpret their expressed needs. Whilst purporting to assess the best interests of the individual child, there is little reference in reported judgments to the child as an individual. Within judgments given in cases considering the medical treatment of young children the child is present as an ideal rather than as a real child with feelings, preferences, attitudes and needs. A desire to ensure that the child survives can preclude honest assessment of the harm and hurt involved, the pain and distress to which they will be exposed or the ability of the child to cope with their condition or treatment. As Priscilla Alderson has argued: ‘the view that all means possible should be pursued in order to preserve life, so that in the future the patient may attain or regain full autonomy, can reinforce medical dominance with legal coercion, preventing individual responses to patients’.<sup>38</sup> A focus upon the future adult the child could become can result in a failure to see the child as a person living their life. Or, conversely, due to limited understanding and prejudiced views, the child may be seen as lacking the potential for adulthood, with inadequate appreciation of the quality of life of a disabled child. And, in cases considering obligations to disabled children, there is no examination of the responsibility taken by parents to meet their child’s needs or acknowledgement of the impact upon their ability to care of the resources available to them, environmental obstacles and discriminatory attitudes.

### *Parents and liberal individualism*

Within the discourse of healthcare law, there is a further prevailing understanding: liberal individualism. Within liberal individualism, persons are perceived as primarily separate individuals who can, by free agreement,

<sup>37</sup> *Ibid.*, at p. 34.

<sup>38</sup> Priscilla Alderson, ‘Consent to Children’s Surgery and Intensive Medical Treatment’ (1990) 17 *Journal of Law and Society* 52–65, at p. 56.