

‘Who Is Silent Gives Consent’:
Power And Medical Decision-Making For Children

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ABSTRACT

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‘Who is Silent Gives Consent’: Power and Medical Decision-Making for Children

This thesis seeks to examine how healthcare decisions are made for children, with a particular focus on situations where medical interventions that (1) are not intended to advance the medical welfare of the individual child (e.g. bone marrow donation and research without therapeutic intent involving young children), or (2) are contrary to the expressed will of the child (e.g. the imposition of life-saving treatment on adolescents who have refused it), are authorised by parents or the state. The authorisation of these procedures is contentious because they breach the child’s bodily integrity while either (a) lacking a clear therapeutic purpose with regard to that child, or (b) being imposed even though refused by a possibly competent adolescent. Their controversial nature has led to attempts to justify these procedures, generally by the application of ideal-type adult-child relationship theories. The four papers at the core of this thesis examine these legitimising propositions but demonstrate that they are insufficiently robust to justify the acts in question. Instead, this thesis raises questions about inequality; about why it is deemed acceptable to take the tissue of the vulnerable incompetent but not the capable adult; or why it is appropriate to impose different tests of mental capacity on the adolescent and the adult, or of competence on the ‘criminal’ child and ‘innocent’ teenager. It is proposed that the reason that inequitable treatment can occur is because adults sit in a position of power and authority relative to children. Thus, the themes common to all four papers are power, inequality and fairness. There is also a focus on the use of language. It is argued that terms are used in academic debate about the imposition of unchosen healthcare burdens on vulnerable populations that lack clarity and transparency. If we hold that children are morally relevant beings deserving of respect then discussions about matters that concern them should take place using language that avoids obfuscation and the cloaking of adult interests.

DECLARATION

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

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I joined the Bioethics & Medical Jurisprudence programme as part of a cohort, and in some ways this thesis represents a collective effort. My fellow travellers have listened and commented on many aspects of this thesis, which has served to improve it greatly. The friendship of Maria de Jesus Arellano, Paul Snelling and especially Fionnuala Gough, my constant flying companion, has made engagement with the programme much more fun than it otherwise might have been.

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This thesis is dedicated to the memory of my mother, Eilis, who taught me to always look on the bright side.

THE AUTHOR

My background training is in medicine, and prior to taking leave of absence to pursue a PhD, I was working in a children's hospital in the specialties of paediatric anaesthesia and critical care medicine. I also have a modular BA degree in philosophy and history. I have engaged in clinical/scientific research in the past and have authored a number of peer-reviewed papers.

Presentations

Some parts of this thesis were presented at academic meetings:

Society of Legal Scholars, Keele, September 2009:
Dying to be Responsible (Paper 4)

Postgraduate Law Conference, Manchester 2009:
The Obligations of Children (Paper 1)

Society of Legal Scholars, Southampton, September 2010:
The Good that is Interred in their Bones (Paper 3)

Postgraduate Law Conference, Manchester 2010:
Equality Before the Law? Egalitarianism and the Case of Research on Human Subjects (Paper 2)

5th Postgraduate Bioethics Conference, London 2011:
History, Children and Consent: Lessons from the Medieval Bedchamber.

Papers

The core of this thesis is made up of 4 articles. Two of these have been published:

1. B. Lyons. Dying to be Responsible: Adolescence, Autonomy and Responsibility. *Legal Studies* 2010; 30: 257-278.
2. B. Lyons. Obliging Children. *Med Law Rev* 2011; 19: 55-85.

The third has been accepted by the Medical Law Review:

3. B. Lyons. '*The Good that is Interred in their Bones*': *Are There Property Rights in the Child?*

The fourth, '*Equality and Research on Children*' has been submitted to *Bioethics*.

Three other papers: one peer reviewed article, one open peer commentary and one book review are also referenced in this thesis:

1. B. Lyons. Children, Best Interests and the Courts: A Response to Bridgeman. *Clinical Ethics* 2010; 5: 188-194.
2. B. Lyons. The Limits of Parental Authority? *Am J Bioethics* 2010; 10: 50-52.
3. B. Lyons. Book Review. Baby Markets: Money and the New Politics of Creating Families (ed. Michele Bratcher Goodwin) *EJHL* 2011; 18: 112-118.

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CHAPTER 1

THE PROBLEM

We claim to be a child-centered society, but in reality there is little evidence that we are. In many ways we are an adult-centred society where children are defined almost exclusively in terms of their impact on adult lives.¹

Children are treated differently to adults, or at least to rational adults. The latter constitute a relatively homogenous population in that they are presumed competent,² and enjoy the legal rights and responsibilities that flow from this status. As autonomous persons they can expect to manage their own affairs; to make their own decisions without undue interference and have those decisions respected. In terms of healthcare decision-making, the legal respect to be afforded to the autonomous adult was outlined by Lord Donaldson; a patient with the requisite mental capacity has the right to make a particular choice regardless of ‘whether the reasons for making that choice are rational, irrational, unknown or even non-existent.’³ Furthermore, ‘the law respects the right of adults of sound mind to physical autonomy’.⁴ In contrast, children are a heterogeneous group with varying capacities.⁵ Regardless of their cognitive diversity, no child enjoys the same autonomy rights as adults; younger children lack the competence to make healthcare decisions, while older children, even if competent by legal standards, are still denied many of the rights to self-determination that adults enjoy. For example, they cannot engage in a variety of health-endangering activities that are otherwise legal such as the purchase and consumption of tobacco or alcohol;⁶ and while older children may

¹ Mental Health Foundation. 1998. *The Big Picture: Promoting Children's and Young People's Mental Health*. London. pp4-5.

² Mental Capacity Act 2005, s1(2); *Re MB (Medical Treatment) (Court of Appeal)* [1997] 2 FLR 426 at 436 per Butler-Sloss LJ.

³ *Re T (Adult: Refusal of treatment)* [1993] Fam 95 at 116. However, some judicial decisions have not unequivocally embraced the patient's right to self-determination. J. Coggon. Varied and Principled Understandings of Autonomy in English Law: Justifiable Inconsistency or Blinkered Moralism? *Health Care Analysis* 2007; 15: 235–255.

⁴ *Re S (Hospital Patient: Court's Jurisdiction)* [1996] Fam 1 at 18.

⁵ How ‘children’ and ‘childhood’ are defined is discussed in chapter 2.

⁶ The Children and Young Persons (Sale of Tobacco etc.) Order 2007 No. 767; Licensing Act 2003, s146(1).

be able to consent to medical treatment,⁷ they may not be allowed to independently consent to participate in a clinical trial,⁸ nor can they refuse treatment if the consequences of such a refusal are serious and a responsible adult disagrees with their choice.⁹ However, the law's view of children is neither straightforward nor consistent; despite not being allowed to be responsible for the above choices, the law still attributes responsibility to children at a much younger age when they commit acts deemed to be criminal.¹⁰

Children are subject to a level of paternalistic interference that is not imposed on adults in liberal states. For the most part, this is not a problem except, perhaps, for the most devoted of child liberationists.¹¹ Paternalism is generally regarded as legitimate when exercised for the sake of promoting the interests of incompetent individuals who would otherwise be endangered by non-intervention.¹² If a child has an illness and is incapable of seeking treatment, or choosing between options, then it is important for the well-being of the child that a responsible person secures for them the necessary care and attention. In general, this role falls to the child's parents.¹³ However, in certain circumstances the state, exercising its role as *parens patriae*, may intervene. This may occur if the parental decision is likely to harm the child, or if a Gillick competent¹⁴ child disagrees with either parents or healthcare professionals and is likely to come to harm as a consequence.¹⁵

However, not all decisions by parents or state are unequivocally beneficent in nature. My aim in this thesis is to examine how healthcare decisions are made for children, with a particular focus on situations where medical interventions that

(a) are not intended to advance the medical welfare of the individual child, or

⁷ Family Law Reform Act 1969, s8(1). *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] AC 112. (Hereafter *Gillick*).

⁸ The Medicines for Human Use (Clinical Trials) Regulations 2004, Schedule 1, Part 4. For an overview of consent requirements for research on children see M. Brazier & E. Cave. 2007. *Medicine, Patients and the Law*. 4th edn. London: Penguin. pp422-5.

⁹ I explore this issue in paper 4.

¹⁰ Also see paper 4.

¹¹ See for example, J. Holt. 1975. *Escape from Childhood*. Harmondsworth: Penguin.

¹² F. Schoeman. Parental Discretion and Children's Rights: Background and Implications for Medical Decision-Making. *J Med Philos* 1985; 10: 45-62.

¹³ The Children Act 1989, s3(1) specifies that parental responsibility encompasses 'all the rights, duties, powers, responsibilities and authority which by law a parent of a child has in relation to the child and his property.'

¹⁴ 'Gillick competence' denotes that a child has 'sufficient understanding and intelligence to be capable of making up his own mind' and allows children who are felt to be competent to consent for themselves. *Gillick* at 186 as per Lord Scarman.

¹⁵ The reasons for state intervention will be discussed more fully in chapter 2.

(b) are contrary to the expressed will of the child, are authorised by parents or the state. Because of the nature of these procedures, I believe their authorisation to be controversial and contestable. With regard to procedures not intended to advance the medical welfare of the child, I will concentrate on two classes of intervention in young children¹⁶; (a) bone marrow donation and (b) research without therapeutic intent (RWTI). Apropos of interventions that are contrary to the expressed will of the child, I will examine the imposition of life-saving treatment on adolescents who have refused it. While these three aspects of medical practice might seem diverse, I believe that they have shared characteristics that make their collective study worthwhile.

With regard to their common features, firstly, all three are not brought about simply through parental choice; they are, in part at least, the object of official scrutiny. Bone marrow donation by young children must be sanctioned by the Human Tissue Authority (HTA),¹⁷ while children can only be enrolled in a research study when the project has been shown to fulfil criteria with regard to quality and safety to the satisfaction of the relevant Research Ethics Committee.¹⁸ The refusal of life-saving treatment by a minor is usually dealt with by the courts, unless there is agreement on the part of both parents and healthcare professionals that this is a reasonable course of action. Secondly, all involve what might be considered a breach of bodily integrity. RWTI entails what Ramsey referred to as an infringement on ‘children in ways which are not related to them as patients.’¹⁹ He regarded research on unconsenting children as being unfaithful to the child, and creating exceptions to this canon of faithfulness as having ‘forgotten the child’.²⁰ As bone marrow donation confers no medical benefit on the child, it is subject to similar accusations. Imposing treatment, even if life-saving, upon a competent adolescent who does not perceive such treatment to form part of his or her life-plan, might also be construed as a breach of bodily integrity - it certainly would if inflicted upon a competent adult.²¹

¹⁶ Children of an age where they are unable to meaningfully assent or consent to a healthcare procedure. A fuller definition is given in paper 1.

¹⁷ HTA. 2009. *Code of Practice 6: Donation of Allogeneic Bone Marrow and Peripheral Blood Stem Cells for Transplantation*. London. ss77-81.

¹⁸ Medicines for Human Use (Clinical Trials) Regulations 2004; Medical Research Council. 2004. *Medical Research Involving Children*. London.

¹⁹ P. Ramsey. 2002. *The Patient as Person*. 2nd edn. New Haven: Yale University Press. p12.

²⁰ Ibid. p13.

²¹ *Ms B v An NHS Hospital Trust* [2002] EWHC 429 at para 24.

Thirdly, all have been seen as contentious interventions subject to debate. The published literature pertaining to both adolescent autonomy and research on children is extensive. In contrast, while relatively little has been said about bone marrow donation, the use of young children as donors does not command universal acceptance.²² Fourthly, because these interventions are contentious and they breach the child's bodily integrity, it is usually felt necessary to justify them. Historically, because of the hierarchical nature of families and the proprietorial relationship between parents (especially fathers) and children, using a child as bone marrow donor, enrolling them as research subjects or countermanding their healthcare choices probably would have excited little comment. Today, such autarchic decision-making is apparently less acceptable, and these interventions are usually defended by invoking one, or more, of a number of justifying principles.²³

The main thrust behind these justifications is to legitimise the fact that children are being treated differently to adults. A competent adult may refuse to participate in medical research or to donate bone marrow to a sibling (or even to her own child) regardless of the consequences; a young child will have little choice regarding these events. A competent adult may make all manner of healthcare choices (although he may not demand treatment that physicians deem futile or unnecessary),²⁴ but an adolescent, even if apparently competent, may not. If children are not to be seen as being treated in an inequitable manner then the imposition upon them of non-beneficial or rejected interventions must be justified. This thesis seeks to analyse the justifications employed, and demonstrate that they are insufficiently robust to legitimise these acts. Instead, I will argue, children *are* treated in an unequal fashion, and the reason that this can occur is because adults sit in a position of power and authority relative to them. However, the fact that we employ justifications to gloss over the inequitable imposition of unchosen burdens indicates that we may have some moral discomfort about treating children in this manner.

At the heart of these issues is the notion of consent; for doctors to lawfully breach a child's bodily integrity in any of these situations they must have a consent

²² S. Holm. The Child as Organ and Tissue Donor: Discussions in the Danish Council of Ethics. *Camb Q Healthc Ethic* 2004; 13: 156-160. L. Delany. Protecting Children from Forced Altruism: The Legal Approach. *BMJ* 1996; 312: 240.

²³ For an overview see L. Hagger. 2009. *The Child as Vulnerable Patient: Protection and Empowerment*. Aldershot: Ashgate. S. Elliston. 2007. *The Best Interests of the Child in Healthcare*. London: Routledge-Cavendish.

²⁴ *R (Burke) v General Medical Council* [2005] 3 WLR 1132.

form signed by a person with legal responsibility for that child. One view of consent states that ‘a practice P, is morally permissible if all those who are parties to P are competent to consent, give their valid consent, and the interests of no other parties are significantly harmed.’²⁵ In the case of the young child, ‘the parties to P’ are the parents and the doctor. The child is effectively silent in the consent process. This brings to mind the ancient legal maxim *qui tacet consentire videtur*; he who is silent is considered to have given consent.²⁶ The young are subject to the wishes of their family, and they have limited means of dissent. Sometimes a child might not dissent because of a number of subtle factors that may affect his or her voluntary expressiveness: the power differential between adults and children, children’s desire to please and avoid conflict, and the influence of incentives.²⁷ Their silence, or at least the disregard of any dissent (which is presumed to be the result of unreflective preference), allows the procedure to take place. The corollary of this view of consent is that ‘a practice P, is morally impermissible if at least one of those who are parties to P, and who are competent to consent, does not give their valid consent’.²⁸ The older child who refuses to give consent to a life-saving intervention to which he objects, and has that refusal overridden, is not so much silent as silenced. He may be heard, but his opinion carries as much weight as if he did not speak. This turns the ‘morally impermissible’ into the permissible.

There is something not quite right about these positions. With regard to rape, the medieval canonist, Vincent of Beauvais,²⁹ held that ‘to remain silent when one could protest is to consent’ regardless of the circumstances.³⁰ This is clearly false. I do not wish to draw any parallel between rape and the imposition of healthcare burdens on children, but the concern that silence may be interpreted as non-dissent or tacit assent, or that resistance may be silenced and overridden, is common to both children’s welfare and sexual politics. I will discuss these issues further in chapter 2, and in particular, will question the legitimacy of the notion of parental ‘consent’.

²⁵ D. Archard. 1998. *Sexual Consent*. Boulder, Co: Westview Press. p3.

²⁶ For a discussion on this rule, and its later application in Canon law see P.D. Clarke. 2007. *The Interdict in the Thirteenth Century: A Question of Collective Guilt* Oxford: Oxford University Press. pp35-39.

²⁷ D. Wendler & S. Shah. Should Children Decide Whether They are Enrolled in Nonbeneficial Research? *Am J Bioeth* 2003; 3: 1-7.

²⁸ Archard (n25).

²⁹ c.1190-1245.

³⁰ Cited in I.M. Resnick. Marriage in Medieval Culture: Consent Theory and the Case of Joseph and Mary. *Church History* 2000; 69: 350-371. p362.

The introductory section of this thesis progresses in the following way: the *Ethical and Legal Background* examines the origins, extent and limits of parental authority with regard to healthcare decision-making for children, and considers the circumstances under which state intervention might occur. It also analyses why parental decisions about children's healthcare should require justification. The *Legal Approach* section evaluates the best interests standard, arguably the dominant principle guiding healthcare decision-making for children in both law and society, but finds that this principle, despite its laudable aim, is insufficiently action-guiding, suffers from inevitable subjectivity and is open to adult manipulation. Instead, I will argue, the decisions that are of concern to this thesis are made on the basis of the imbalance of power that exists between children and their parents, or the state. Thus, the *Philosophical Approach* section looks at the notion of power, and how this concept allow us to understand the dynamics of family decision-making processes and their consequences.

On a methodological note, many of the issues examined in this thesis are discussed from an historical perspective. There are two main reasons for this.³¹ Firstly, both bioethics and the law are fundamentally concerned with human behaviour. History is, in large part, the study of how people and societies have behaved, and how these past actions have lead to present situations. The laws of today have been developed as a reaction to events of the past, and history provides data that allows us to understand these developments. Secondly, historical events provoke moral contemplation. Frequently, for example, the treatment of children in the past evokes negative sentiments. Modern western society most likely would display moral outrage if the conditions of children in workhouses in Dickensian England, or the practice of child exposure from Ancient Rome, were replicated today (although they may persist in many other parts of the world). It seems reasonable to hold that our moral understanding of the biolegal complexities that face children in contemporary society can be enhanced by an investigation of their history. It thus seems illuminating to view the treatment of today's children through the lens of the past.

³¹ These are drawn from P. Stearns. *Why Study History?* *American Historical Association* 1998; Accessed on 1 June 2008 at <http://www.historians.org/pubs/free/WhyStudyHistory.htm>.

CHAPTER 2

ETHICAL AND LEGAL BACKGROUND: CHILDREN, PARENTS AND STATE

*What was the purpose, children, for which I reared you?*¹

2.1. CHILDREN

Before developing my research theme it would first seem sensible to define what I mean by the term ‘child’. In 1550 Thomas Becon, chaplain to Archbishop Cranmer, rhetorically asked ‘What is a child, or to be a child?’ His unsympathetic reply included ignorance, wickedness and an absence of godliness.² Social perceptions of, and attitudes towards, children and childhood have varied across generations.³ In the ‘first human economy’ (pre-agricultural hunter/gatherer societies) children were economic liabilities.⁴ They could not work effectively until they were about 14, were a drain on scarce resources and were difficult to care for in a nomadic existence. Therefore, abortifacient plants and infanticide were used to keep the number of children at a low level.⁵ The later agricultural economy saw children become ‘an essential part of the family labour force.’⁶ Families grew because children were economically valuable, although more than seven children usually unfavourably altered the productivity/consumption ratio. It was also desirable to have a late child, whose destiny was to care for the soon-to-be-elderly parents.⁷ The 20th century has seen a shift back to smaller families, and a change in perspective to the ‘economically worthless but emotionally priceless child’.⁸ What it is to be a child depends on the social construction of the time. As the girl selling watermelons on the streets of Victorian London informed Henry Mayhew, ‘I ain’t a

¹ Euripides. 1994. *Medea*. New York: Dove Publications. p33.

² Cited in H. Cunningham. 2006. *The Invention of Childhood*. London: BBC Books. pp12-13.

³ Ibid. p13.

⁴ P.N. Stearns. 2005. *Growing Up: The History of Childhood in a Global Context*. Waco: Baylor University Press. p10.

⁵ Ibid.

⁶ Ibid. p11.

⁷ Called the *Wunschkind* in Germany. Ibid.

⁸ V.A. Zelizer. 1994. *Pricing the Priceless Child: The Changing Social Value of Children*. Princeton, NJ: Princeton University Press. p3.

child ... I'm past eight I am'.⁹ In London today, there would be no doubt that she was a child.

In medico-legal terms there is little difficulty in defining childhood. The United Nations Convention on the Rights of the Child (CRC) uses the referent to denote 'every human being below the age of eighteen years'.¹⁰ The Children Act 1989 also classifies a child as 'a person under the age of eighteen',¹¹ while the European Union directive on medicinal products for paediatric use defines the 'paediatric population' as 'that part of the population aged between birth and 18 years'.¹² In this light, the answer to the question 'what is a child' essentially is an empirical account that allows for the drawing of boundaries around a stage of human life, whereby all those in the subset limited by these confines are labelled 'children'. However, childhood is a social construction rather than a period of life defined by predetermined chronological parameters, and therefore the age boundaries that are imposed are artificial rather than reflective of natural cut-off points.¹³ Childhood is thus an expedient legal designation of status premised upon dividing the population into children and adults on the basis of pragmatism rather than metaphysics, even though such delineation may be morally and biologically arbitrary. Nonetheless, for the purposes of this thesis birth is held to be a legally and existentially defining moment, while the upper age limit of childhood is taken to be 18 years, as it is only after this point that, in the healthcare setting, full autonomy is invested in the individual.¹⁴ Throughout this thesis I will hold that all children are persons, and that all persons possess a fundamental right to bodily integrity.

One of the problems inherent in the use of the idiom 'childhood' to describe the first 18 years of life is that there is a temptation to view all individuals falling under the umbrella of the term as a homogenous grouping. From an anatomical, physiological and psychological perspective this is not so. There are very obvious

⁹ H. Mayhew. 1864. *London Labour and the London Poor, Vol. 1*. London: Griffin, Bohn and Company. pp157-158.

¹⁰ Article 1.

¹¹ s105(1).

¹² Regulation (EC) No 1901/2006 of the European Parliament and of the Council of 12 December 2006 on Medicinal Products for Paediatric use and Amending Regulation (EEC) No 1768/92, Directive 2001/20/EC, Directive 2001/83/EC and Regulation (EC) No 726/2004. *Official Journal of the European Union*, 27.12.2006, L 378/1-L 378/19.

¹³ P. Daniels & J. Ivatts. 1998. *Children and Social Policy*. London: Macmillan Press. p2.

¹⁴ J. Fortin. Accommodating Children's Rights in a Post Human Rights Act Era. *MLR* 2006; 69: 299-326.

differences between the 17 year-old adolescent and the three month-old baby. The latter is utterly dependent upon caregivers for all aspects of its existence and patently lacks the capacity to participate in healthcare decision making, although he may put up clear physical and vocal resistance to all sorts of medical procedures. By contrast, the average adolescent has the capacity to engage meaningfully in decisions and, it is arguable, by convention and statute should be fully involved.¹⁵ In view of these developmental differences, children might be divided into

- (a) those that are capable of consenting to healthcare procedures (over 16 years of age or Gillick competent),
- (b) those incapable of consent but able to meaningfully engage in discussion about healthcare issues that concern them, and
- (c) those who are too young, or learning disabled, to participate in the decision-making process.

It is difficult to put an age limit on each of these divisions which arise from a taxonomy that, admittedly, is based on pragmatism for the purposes of analysis. The Roman tradition used the rule of sevens to divide childhood into three stages, although this had more to do with numeric superstition and magical connotations than theories of psychological development.¹⁶ Nonetheless, these age divisions had legal significance. Infancy defined that period between birth and seven years, the latter age being perceived as a significant milestone in the intellectual development of the child and prior to which they were perceived as ‘being incapable of acts’.¹⁷ Adolescence referred to the period between childhood and adulthood or from puberty till the attainment of full growth, which was viewed as the mature stage of human development and was considered as extending from 14 to 25 years in males, and from 12 to 21 in females.¹⁸ The stage in between referred to *infantia maiores* who were capable of acts of acquisition but not ‘so far as to do with obligation or alienation’.¹⁹ The age of 10 was also significant as at that age male citizens were

¹⁵ CRC 1989, Art. 12; Family Law Reform Act 1969, s8(1). *Gillick* [1986] AC 112.

¹⁶ B. Rawson. 2003. *Children and Childhood in Roman Italy*. Oxford: Oxford University Press. p136.

¹⁷ R. Pound. 1906. *Readings in Roman Law*. Lincoln, Nebraska: J. North. p63.

¹⁸ *Ibid.*

¹⁹ *Ibid.*

eligible for the grain dole at Rome, ‘a recognition of a kind of adulthood’.²⁰ Until late antiquity, however, these demarcations were not rigidly observed and individual development determined responsibilities.²¹ Interestingly, the ages 7, 10 and 14 retain significance today as developmental or legal milestones. In the United States (US) the National Commission supported by the American Academy of Pediatrics (AAP), has stated that children under seven years are not capable of providing assent and thus need not be asked.²² Under English law the age of criminal responsibility was seven years until the Children and Young Persons Act 1933, and 10 years of age following the 1963 Act.²³ The Criminal Justice and Public Order Act 1994 reduced the minimum age for detention from 14 to 10 years in the case of grave crimes, while the Crime and Disorder Act 1998 abolished the presumption of *doli incapax*, the common law doctrine that children under the age of 14 were presumed ‘incapable of evil’ until proven otherwise.²⁴

The term ‘child’ is generally limited by chronological end-points, and does not include mentally incapacitated adults (MIA) although it is uncertain to what extent they are treated differently to children, particularly when the concept of ‘mental age’ is applied. Certainly, history indicates that the learning disabled and children have constituted those social groups most grievously sinned against by doctors in the alleged pursuit of science.²⁵ Disability rights activists maintain that MIA continue to be treated poorly today, and to be perceived as morally impoverished beings even by bioethicists.²⁶ However, MIA are viewed differently to children under the law, and the parents of MIA have less discretion over welfare decisions than they do over younger children. In particular, the Mental Capacity Act 2005 contains extra safeguards with regard to the enrolment of MIA in medical

²⁰ Rawson (n16) p141.

²¹ Ibid. p135.

²² National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. 1977. *Report and Recommendations: Research Involving Children*. Washington: Government Printing Office, AAP Committee on Drugs. Guidelines for the Ethical Conduct of Studies to Evaluate Drugs in Pediatric Population. *Pediatrics* 1995; 95: 286-294.

²³ Children and Young Persons Act 1963, s16.

²⁴ s34.

²⁵ S.E. Lederer & M.A. Grodin. 1994. Historical Overview: Pediatric Experimentation. In *Children as Research Subjects: Science, Ethics & Law*. M.A. Grodin & L.H. Glantz, eds. New York: Oxford University Press: 3-28.

²⁶ R. Amundson & S. Tresky. Bioethics and Disability Rights: Conflicting Values and Perspectives. *J Bioethical Inquiry* 2008; 5: 111–123.

research or transplantation programmes as donors.²⁷ Within the confines of this work it is not possible to elaborate on the similarities and differences that exist between children and MIA with regard to non-therapeutic medical interventions. Despite the interesting issues that such an examination might reveal, this thesis is limited to a consideration of healthcare decision-making as it pertains to children, as defined above.

2.2. PARENTS

It is commonly accepted that the persons best positioned to make decisions for younger children are their parents.²⁸ Because of the intimacy of family relationships, even if there are significant parental failings, it is generally held that ‘The best person to bring up a child is the natural parent ... Public authorities cannot improve on nature.’²⁹ However, this is not to say that all parental decisions should be beyond scrutiny. Because such decisions can be wide-ranging and encompass all aspects of the child’s life, questions about the nature, scope and extent of parental discretion may be raised with regard to particular choices. There are also issues concerning the balance between the rights and responsibilities of parents, between the interests of children and the interests of parents, and between the interests of children and the public good or the needs of society, which may need to be evaluated in certain circumstances. These questions are not specific to matters of healthcare ethics and law, but are common to many considerations raised by child welfare policies.

Historically, the laws of England have endorsed a policy of minimal state interference in family matters, allowing parents broad discretion in how they bring up their children.³⁰ According to Eekelaar, the ideological thrust of the Children Act 1989 upholds this philosophy, with ‘many measures designed to reduce or inhibit ... supervision over parental conduct by state agencies.’³¹ Contemporary politics has

²⁷ ss31-33.

²⁸ The term parent is taken to denote those person(s) with parental responsibility as defined by the Children Act 1989, s2.

²⁹ *In re K. D. (A Minor) (Ward: Termination of Access)* [1988] A.C. 806 at 812 per Templeman LJ.

³⁰ R. Smith. 2004. *Values and Practice in Children's Services*. Basingstoke: Palgrave Macmillan. p25.

³¹ J. Eekelaar. Parental Responsibility: State of Nature or Nature of the State? *J Soc Welfare Fam Law* 1991; 13: 37-50. p46.

tended to celebrate and venerate the family as ‘the most important and valuable institution of culture and society’,³² its defence being ‘an essential commitment of liberalism.’³³ However, it is an institution with a chequered record; the location of much love and fulfilment on the one hand, but also of oppression, violence and injustice on the other.³⁴ It is also the site where parents exert enormous power and influence over children.³⁵ Parents come in many shapes and sizes and may perform their duties towards their children well or poorly. However, as long as they provide the basic necessities of life, and as long as parental decisions made are not seen to be particularly harmful or abusive,³⁶ in general they will be tolerated.³⁷ As outlined by Hedley J, there are philosophical and practical reasons for not interfering in parents decisions regarding their children:

Society must be willing to tolerate very diverse standards of parenting, including the eccentric, the barely adequate and the inconsistent. It follows too that children will inevitably have both very different experiences of parenting and very unequal consequences flowing from it. It will mean that some children will experience disadvantage and harm, while others flourish... These are the consequences of our fallible humanity and it is not the provenance of the state to spare children all the consequences of defective parenting. In any event it simply could not be done.³⁸

In what might seem out of keeping with this recognition of parental power, the Children Act appears to emphasise parental responsibilities in contrast to previously acknowledged parental rights.³⁹ Section 3(1) provides that

In this Act “parental responsibility” means all the rights, duties, powers, responsibilities and authority which by law a parent of a child has in relation to the child and his property.

³² C.M. Macleod. Conceptions of Parental Autonomy. *Politics & Society* 1997; 25: 117-140. p117.

³³ D. Archard & D. Benatar eds. 2010. *Procreation and Parenthood*. Oxford: Oxford University Press. p18.

³⁴ Macleod (n32) p118.

³⁵ Ibid.

³⁶ Children Act 1989, s31.2(a): ‘A court may only make a care order or supervision order if it is satisfied— (a) that the child concerned is suffering, or is likely to suffer, significant harm’.

³⁷ R. Probert, et al. eds. 2009. *Responsible Parents and Parental Responsibility*. Oxford: Hart Publishing. p13.

³⁸ *Re L (Care: Threshold Criteria)* [2007] FLR 20 at 50.

³⁹ M. Freeman. In the Child's Best Interests? Reading the Children Act Critically. *Current Legal Problems* 1992; 45: 173-212. p185.

However, one of the interesting aspects of this section is that the words reflecting parental prerogative - rights, powers and authority - outnumber and sit on either side of those words indicating parental obligation (duties and responsibilities). This arrangement may have been unintentional, and while the Act perhaps may have professed to prioritise parental duties over parental powers, it does not necessarily come across this way. Certainly, some commentators have expressed scepticism about the relative priorities the Act has afforded to parental powers compared to their obligations.⁴⁰ In *Gillick*, Lord Scarman noted that parental powers are derived from parental duties.⁴¹ However, in so doing he cited a passage from Blackstone's *Commentaries* which declared that the power which parents have over their children exists 'to enable the parent more effectually to perform his duty, and partly as a recompense for his care and trouble in the faithful discharge of it'.⁴² This would seem to acknowledge the fact that parenthood may be onerous, and perhaps endorse the view that parents may legitimately use their power to make self-regarding choices as compensation for their efforts. Ross points out that theories which solely focus on the nurturing aspect of parenthood fail to grasp 'the importance that adults ascribe to the creation of a home in which their values flourish',⁴³ and is dismissive of models that suggest that parents must act in a child's best interests.

One theoretical framework articulating this latter viewpoint is Blustein's priority thesis. Blustein proposed that parents only have power over children in order to advance the welfare of those children:

The family exists to serve the child, not vice versa, and parents have authority over their children only because they need it to carry out their duties to their children.⁴⁴

⁴⁰ See for example A. Bainham. *The Children Act 1989 - Welfare and Non-Intervention*. *Fam Law* 1990: 143.

⁴¹ *Gillick* at 184. I have used the term power here instead of rights. The Law Commission has argued that 'to talk of parental rights is not only inaccurate as a matter of juristic analysis but also a misleading use of ordinary language ... It might be more appropriate to speak of parental powers, parental authority'. Law Commission. 1982. *Family Law: Illegitimacy (Law Commission No. 118)*. London: TSO. para 4.18.

⁴² W. Blackstone. 1832. *Commentaries on the Laws of England: Volume 2*. 18 edn. London: Collins and Hannay. p452.

⁴³ L.F. Ross. 1998. *Children, Families and Healthcare Decision-Making*. Oxford: Clarendon Press. p9.

⁴⁴ J. Blustein. 1982. *Parents and Children: The Ethics of the Family*. New York: Oxford University Press. p111.

Even if one aspired to such a child-centered world, Blustein's thesis appears impractical in that it would seem to suggest that parents must be selfless in all their dealings with children, and even that there are universal, identifiable and implementable child-rearing goals. It also seems to suggest that there is some yardstick by which the quality of parenting can be judged. But what attributes make a good parent? Fox observes that many people are likely to disagree about the endpoints of 'good' parenting; that any moral judgment on particular parental goals and values is liable to be controversial.⁴⁵

Contrary to Blustein, Ross argues that while parents should secure their child's basic needs, there is no obligation to procure goods that are in excess of these, and certainly no requirement to maximise them.⁴⁶ Ross' conceptual paradigm is in keeping with the influential vision of parenting articulated by Goldstein and colleagues.⁴⁷ They submitted that parents have the right to make all kinds of decisions about their children and, even if harmful to the child, these should be respected unless they constitute frank abuse.⁴⁸ Within this theory, children have an 'entitlement to autonomous parents' and family privacy, as they benefit from having authoritative and omniscient parents.⁴⁹ This can only happen if parents feel free to make decisions without interference. In common with Goldstein et al, Schoeman has contended that the best interests principle should only come into play after the child becomes the object of official scrutiny, but not while still under parental rule. This allows parents to 'exercise authority over children that would be impermissible in other contexts between citizens or even between incompetents and state appointed guardians.'⁵⁰

The state sanctions parental authority; thus it would appear that the state allows parents to act in ways that are impermissible for itself; i.e. it allows parents to act against the interests of the child.⁵¹ Thus, even if the state ostensibly should act with the best interests of the child, at least as a primary goal,⁵² it does not hold that

⁴⁵ D. Fox. Parental Attention Deficit Disorder. *J Applied Phil* 2008; 25: 246-261. p246.

⁴⁶ Ross (n43) p44.

⁴⁷ J. Goldstein, et al. 1996. *The Best Interests of the Child*. New York: Free Press.

⁴⁸ Ibid. pp111-127.

⁴⁹ Ibid. p90.

⁵⁰ F. Schoeman. Parental Discretion and Children's Rights: Background and Implications for Medical Decision-Making. *J Med Philos* 1985; 10: 45-62. p49.

⁵¹ Ibid.

⁵² Children Act 1989, s1; CRC, Article 3(1).

parents must do so. This seems true with regard to many mundane family-oriented actions undertaken by parents.⁵³ It is implausible to hold that parents should, or even could, always act out of the best interests of a particular child. Within domestic situations, the interests of different children within the same family may be in conflict, and in certain circumstances the interests of children and those of the parent may be incommensurable. Failure to decide between competing interests will lead to familial paralysis, and it is the parent's job to make decisions as to which interests are afforded most respect in a given situation. It is likely that parents do not always make child-focused decisions, but instead take account of their own personal interests and needs. Such self-regarding decisions do not have to be counter to the interests of the child, but they are not made with the interests of the child as the primary determining factor. They are reflective, not just of the adult's deeply held 'purposes and aims' of parenthood,⁵⁴ but also of their personal ambitions and needs, and of their vision for the family unit.

Thus far, therefore, it would seem reasonable to hold that parents have power over their children, that this power is legitimate, and that it may be used to perpetuate their own personal values and convictions, employing the family as a vehicle to achieve this. Nevertheless, there are limits to the extent of parental powers. For example, parents may not kill or sell their children, they may not abuse or neglect them,⁵⁵ and they may not force young children to work⁵⁶ nor deprive them of essential education,⁵⁷ even if these acts are advantageous to the parents. However, outside of these prohibitions, there is little clarity concerning the specific content of parental rights, powers and authority.⁵⁸ What is apparent is that parental opinions are generally privileged above others, and while their discretion may be limited in certain circumstances, McCall Smith contends that they can pursue choices 'which society as a whole might find undesirable, but which it will tolerate'.⁵⁹ One question

⁵³ Schoeman (n50) p47.

⁵⁴ D. Archard. 2003. *Children, Family and the State*. Aldershot: Ashgate. p96.

⁵⁵ Children and Young Persons Act 1933, s1.

⁵⁶ Children and Young Persons Act 1933, s18.

⁵⁷ Education Act 1996, s7.

⁵⁸ Probert et al (n37) p14.

⁵⁹ A. McCall Smith. 1990. Is Anything Left of Parental Rights? In *Family Rights: Family Law and Medical Advance*. E. Sutherland & A. McCall Smith, eds. Edinburgh: Edinburgh University Press. p9.

that arises from this assertion is, to what extent may parents inflict harm upon their children in making choices?

An example of harm in the context of children's health (although it is uncertain how intolerable 'society as a whole' might find it) arises from parents choosing to expose their children to the dangers of environmental tobacco smoke when in a private vehicle or domicile. Passive smoking is widely acknowledged to be injurious to health. Recent legislation has afforded hospitality workers protection from public smoking.⁶⁰ Why then are children not similarly safeguarded from this threat to their health within their home? In its 12-point Children's Charter, the British Lung Foundation has proposed that 'Children should be able to enjoy a smoke free environment both inside and outside the home.'⁶¹ However, data from the US indicates that 54% of children between the ages of 3 and 11 years are exposed to second-hand smoke. Almost all (98%) children who live with a smoker are exposed and have measurable levels of toxic chemicals from cigarette smoke.⁶²

There are a number of possible reasons why children might not be protected from this domestic harm. First, it might be that the negative impact from parental smoking on children's health is perceived to be minimal. But there is abundant empirical evidence to demonstrate that this is not so.⁶³ Second, it could be that protecting children's health is unimportant, or at least low down the list of policy priorities. This does not seem to hold either, given the extensive efforts made at encouraging vaccination against various communicable diseases. In addition, a cessation of child exposure to tobacco smoke might well be cost-saving given the probable health benefits, thus incentivising policy decisions. Third, as opposed to monitoring adult smoking in public bars and restaurants, it might be viewed as impossible to police adult tobacco consumption in private spaces; that regulation or legislation in this domain is valueless because of the practical issue of unenforcability.⁶⁴ However, the privacy of the home is no longer inviolable, nor is

⁶⁰ Health Act 2006, s2.

⁶¹ British Lung Foundation. 2010. *Children's Charter*. Accessed 4 December 2010 at <<http://www.lunguk.org/media-and-campaigning/childrens-charter/read-the-charter>>

⁶² Centre for Disease Control. 2010. *Decline in US Adult Smoking Rate Stalled: Half of Children Still Exposed to Secondhand Smoke*. Press Release, 7 September 2010. Accessed on 4 December 2010 at www.cdc.gov/media/pressrel/2010/r100907.htm.

⁶³ For an overview see M. Öberg, et al. Worldwide Burden of Disease from Exposure to Second-Hand Smoke: A Retrospective Analysis of Data from 192 Countries. *Lancet* 2010; 377: 139-146.

⁶⁴ A. Ogus. Regulation Revisited. *Public Law* 2009: 332-346. p344.

the behaviour that occurs behind closed doors immune to surveillance when it comes to the perpetration of serious offences, such as the sexual abuse of children. There is no reason, in principle, to hold that effective policy implementation is impossible without at least trying first. Some empirical evidence indicates that the majority of children whose parents smoke dislike passive smoking, would prefer that their parents stopped smoking and worry about their parents' health.⁶⁵ If, for the present purposes, we assume that these findings hold for a broad group of children, then it is possible to see how a policy based on education,⁶⁶ report and perhaps non-invasive testing,⁶⁷ could be designed to minimise child exposure to second-hand smoke. It has already been shown that legislation prohibiting smoking in public places has improved children's health;⁶⁸ a ban on smoking in private space most likely would have an even greater effect.

The purpose of this argument is not to polemicize against smoking parents nor to outline possible policy measures, but rather to raise questions about parental discretion to harm children's health.⁶⁹ As part of this, it is interesting to think about why some policy designed to reduce child exposure to tobacco smoke has not been implemented, or even trialled. While people now go outside of bars in order to smoke, when they return home they may not provide their children with the same level of unpolluted air enjoyed by bar workers. Is the lack of policy initiative because bar workers are more worthy of consideration, or are more socially valuable than children? Perhaps some might hold this to be true, but it seems more plausible to suggest that official scrutiny of parental smoking habits would be viewed as being

⁶⁵ S. Muramatsu, et al. A Survey on Attitudes Towards Passive Smoking Among Schoolchildren and Students in Switzerland. *Sozial- und Präventivmedizin* 1983; 28: 82-84.

⁶⁶ See for example Children, Youth and Women's Health Service of South Australia. 2010. *Passive Smoking (Living With a Smoker)*. Accessed on 12 December 2010 at <<http://www.cyh.com/HealthTopics/HealthTopicDetailsKids.aspx?p=335&np=285&id=1606>>.

⁶⁷ It is possible to test for tobacco exposure non-invasively through analysis of hair, saliva or urine, so as to confirm exposure without distressing the child. M. Pellegrini, et al. Assessment of Exposure to Environmental Tobacco Smoke in Young Adolescents Following Implementation of Smoke-Free Policy in Italy. *Forensic Sci Int* 2010; 196: 97-100.

⁶⁸ D. Mackay, et al. Smoke-Free Legislation and Hospitalizations for Childhood Asthma. *N Engl J Med* 2010; 363: 1139-1145.

⁶⁹ Parental smoking in the presence of children has been described by an ex-Surgeon-General in the US as potentially being 'the next issue in child abuse.' C.E. Koop. Adverse Anesthesia Events in Children Exposed to Environmental Tobacco Smoke. *Anesthesiology* 1998; 88: 1141-1142. It is estimated that 40% of children worldwide are exposed to passive smoking, which is directly related to the deaths of 170,000 children annually. See Öberg et al (n63).

excessively intrusive; that the harm done to children is insufficient to warrant an infringement of parents liberty rights; that smoking behind closed doors is a private matter even if it has public consequences. If the absence of policy development and implementation has this basis, then this indicates unwillingness on the part of the state to police family life in circumstances where children are being harmed. This is unsurprising, as action usually will only be taken by state agencies to remedy a situation and protect a child if the harm (or potential harm) results from a serious level of physical violence (which the child suffers or witnesses), or sexual, psychological or emotional abuse, or significant neglect.⁷⁰ Absent such a grievous offence,

the law does not require parents to act in particular ways which positively advance a child's welfare or best interests, nor is the scope of parental discretion drawn in such a way as to avoid all harm to the child.⁷¹

Therefore, in the real world of family life, neither the priority thesis nor the best interests standard necessarily apply. Parents may act in their child's interest, but often it is not incumbent upon them to do so. Being part of a family usually is a very positive aspect of a child's life; the source of security, love and attention. But, being part of a family is not a free-ride, and as Schoeman observes, liabilities may be attached to membership.⁷²

2.2.1. *Healthcare Decision-Making by Parents*

This preamble becomes relevant when we come to consider parental medical decision-making. There are a number of occasions when parents will be asked to consider healthcare options that will affect their child. These are set out below, and may be broadly divided into *therapeutic*, *possibly therapeutic* and *non-therapeutic* decisions, although there is some overlap between the categories. These delineations are also contestable as some, for example, may disagree with the categorisation of social or religious benefits as *non-therapeutic*. However, I use the term *therapeutic* in a narrow sense; to denote an intervention that carries a quantifiable physical or mental health improvement.

⁷⁰ Probert et al (n37) p13.

⁷¹ S. Gilmore. 2009. The Limits of Parental Responsibility. In Probert et al (n37) p80.

⁷² Schoeman (n50) p57.

Categories of Intervention

1. *Therapeutic*
 - a. Critical life-saving treatment
 - b. Treatment affecting survival, but not immediately required
 - c. Treatment aimed at the management of physical or mental illness
2. *Possibly Therapeutic*
 - a. Critical intervention which is life-prolonging but not life-saving
 - b. Innovative treatment
 - c. Interventions aimed at preventing disease
 - d. Research with a possibility of therapeutic benefit
 - e. Physical intervention for psychological benefit
 - f. Interventions for behavioural control
3. *Non-therapeutic*
 - a. Physical intervention for cultural/religious reasons without direct healthcare benefit
 - b. Physical intervention for third party benefit
 - c. Research without therapeutic intent

The options open to parents in each instance are:

- (1) they can 'consent' to a procedure offered to them by medical staff. In doing so they sometimes may have to choose one option from a menu of proposed possibilities;
- (2) they can refuse to 'consent', and
- (3) they may request that a particular procedure be carried out.

Allowing parents (rather than physicians or the state) to make these healthcare choices, implicitly acknowledges the primary role that parents have in the lives of their children, and also that the consequences of illness and treatment fall most heavily upon parents.⁷³ As long as parents agree with each other on the choice to be made, the choice concerns a lawful intervention, and there is some licensed medical practitioner willing to perform the procedure, then many parental medical decisions proceed with little or no public oversight. However, some parental choices which are remarkable for the serious, irreversible effects that they will inflict on the child (e.g. sterilization or the refusal of life-saving treatment) will be the object of

⁷³ A.E. Buchanan & D.W. Brock. 1989. *Deciding for Others: The Ethics of Surrogate Decision Making* Cambridge: Cambridge University Press. p233.

public scrutiny or court intervention.⁷⁴ But many other controversial (at least from an academic perspective) parental choices, such as those concerning vaccination, circumcision or cosmetic procedures⁷⁵ are more discretionary in nature. Most parental decisions about children's healthcare are of little interest to the state, although under certain circumstances, as discussed later, they may be subject to interrogation and limitation by the courts. Goldstein has argued against such legal intervention in most situations:

In implementing this basic commitment to parental autonomy ... the law ... acknowledges not only how complicated man is, but also how limited is its own capacity for making more than gross distinctions about man's needs, natures, and routes of development. The law recognizes and respects the diverse range of man's religious, cultural, scientific, and ethical beliefs ... Thus a prime function of law is to prevent one person's truth (here about health, normalcy, the good life) from becoming another person's tyranny.⁷⁶

However, it would also seem important that there should not be unquestioning accession to parental decisions, not just because parents will not always do what is best for their child, but also because sometimes what they choose to do is objectively wrong for the child.⁷⁷ In this respect, it would seem reasonable to wonder about parental decisions where those choices impose a non-beneficial burden upon a child, such as those in the *possibly therapeutic* and *non-therapeutic* categories above. Given that the parental authority to make many of these decisions is legitimate, is there an objective limit to the risks or harms that a child might have to endure as a consequence of parental medical decision-making?

To some extent professional norms limit the interventions that parents can demand from healthcare providers. In particular cases a doctor may refuse to perform a procedure that he believes to be harmful.⁷⁸ It would seem reasonable that a doctor

⁷⁴ A.R. Ouellette. Growth Attenuation. Parental Choice, and the Rights of Disabled Children: Lessons from the Ashley X Case. *Hous J Health L & Policy* 2007-2008; 8: 207-244.

⁷⁵ By cosmetic procedures I do not mean operations such as 'facelifts' or breast augmentation, but rather those designed to 'normalise' the appearance of children such as otoplasty (for 'bat-ears') or tongue reduction and facial reconstruction in children with Down's Syndrome.

⁷⁶ J. Goldstein. Medical Care for the Child at Risk: On State Supervention of Parental Autonomy. *Yale L J* 1977; 86: 645-670. p664

⁷⁷ It would seem objectively wrong for parents to pray over a 2 year-old child with meningitis rather than take her to hospital for treatment. At the very least, the choice is neglectful in that it places parental wishes and values above minimal child welfare standards.

⁷⁸ General Medical Council. 2008. *Consent: Patients and Doctors Making Decisions Together*. London. p8.

should not subject a minor to unnecessary medical care just because of a parental request. The actions of a surgeon, who acceded to a parental wish and performed an appendectomy on a healthy child simply because the child's parents were anxious that the child might develop appendicitis in the future, appear non-beneficent, at best. This would seem to hold true even if the parents had some rational basis for their concern. The utility of a medical treatment is determined by a calculus of the burdens imposed upon the patient on one side of the equation, and the benefits that are likely to accrue on the other. In the notorious case of Ashley X, a severely disabled girl underwent aggressive hormone therapy, hysterectomy and excision of her breast buds at the request of her parents.⁷⁹ The purpose of these procedures was to eradicate the possibility of breast and menstrual discomfort, and render her smaller and lighter so that she could continue to be cared for in a loving family environment. The doctors acquiesced and, in the eyes of many commentators, inflicted unnecessary and significant harm on Ashley.⁸⁰ The debate over the 'Ashley Treatment' encapsulates the conflict of opinion that exists with regard to parental power to decide. In the US, a recent MSNBC poll of almost 80,000 people identified that 55% of respondents endorsed the view that 'families should be allowed to make their own decisions in every aspect of medical care' in response to the question 'should parents be allowed to refuse cancer treatments for their sick children?'⁸¹ The poll was explicitly based on a widely-reported real case where parents made a decision to refuse chemotherapy for their 13 year-old child with Hodgkins Lymphoma, a particularly treatable form of cancer. Without wishing to imbue an unscientific poll with validity, nonetheless it would seem to indicate that, for some people at least, the parental power to choose is more important than a child's survival.

In opposition to this prioritising of parental power, I would suggest that in a clinical relationship involving children it must be remembered that the child is the patient, and the doctor's primary covenant is with the child and not the parents. In an

⁷⁹ D.F. Gunther & D.S. Diekema. Attenuating Growth in Children With Profound Developmental Disability: A New Approach to an Old Dilemma. *Arch Pediatr Adolesc Med* 2006; 160: 1013-1017.

⁸⁰ This paragraph is taken (although not verbatim) from B. Lyons. The Limits of Parental Authority? *Am J Bioethics* 2010; 10: 50-52. For a sample of views endorsing, although mostly opposing, the 'Ashley treatment' see the other opinion pieces in the same edition of this journal.

⁸¹ See http://health.newsvine.com/_question/2009/05/15/2822182-should-parents-be-allowed-to-refuse-cancer-treatments-for-their-sick-children. Accessed 29 November 2010.

ideal world all decisions would result from the happy concordance of parental opinion, medical recommendation and a child's interests. However, in the real world such an accord may not occur. In situations where a proposed procedure does not carry direct and quantifiable physical or mental health benefits to the subject child, the fundamental purpose of the intervention, the possible benefits and the potential burdens must be clearly defined. This is the reason I have defined *therapeutic* in its narrow sense; if we cannot identify clear benefits for doing something, then that intervention is not therapeutic. There may be other grounds for carrying out a procedure, and I do not wish to imply that social, cultural or religious reasons are unimportant. Rather, I would argue that since the primary covenant is with the child, then in cases involving *possibly therapeutic* or *non-therapeutic* procedures, the privileging of putative metaphysical advantages over physical harms would seem to mandate further evaluation and justification. Metaphysical benefits may relate to the familial or social inclusion of a child, or to the perpetuation of a family's religious or spiritual beliefs.⁸² Religious observants often see nothing untoward about their child enduring some discomfort in order to please an omniscient deity,⁸³ and this value system will generally be tolerated in a secular state to allow for harmonious co-existence. However, the law gives content to a harm principle which dictates the parameters within which moral pluralism is allowed to operate.⁸⁴ Thus, while the parental request for certain *non-therapeutic* procedures or the refusal of some *therapeutic* ones may be tolerated within the legal framework, others will not. For example, some religious tenets oppose particular medical procedures,⁸⁵ or even reject medical practice entirely, preferring to rely on prayer and divine intervention.⁸⁶ Where serious harm results these practices contravene legal dictates concerning the

⁸² Although I have framed this argument in a particular way, I do not mean to suggest that (a) all religiously observant parents inflict theologically-motivated harm on their children; (b) secular parents do not harm their children; or (c) religious parents inflict harm more frequently or severely than secular parents. The purpose of the distinction is to draw out arguments about the motivation behind particular practices endorsed by some parents.

⁸³ For a perspective on this position see R.W. Garnett. Taking Pierce Seriously: The Family, Religious Education, and Harm to Children *Notre Dame L Rev* 2000; 76: 109-146.

⁸⁴ J. Coggon. 2011 (forthcoming). *What Makes Health Public?* Cambridge: Cambridge University Press.

⁸⁵ For example, the rejection of blood transfusions by Jehovah's Witnesses.

⁸⁶ One study in the US identified 23 Christian churches that eschew standard medical care; most prominently the Christian Science church. S.M. Asser & R. Swan. Child Fatalities from Religion-Motivated Medical Neglect. *Pediatrics* 1998; 101: 625-629.

welfare of children.⁸⁷ Sadly, despite the potential for legal repercussions, such faith-based practices have led to the deaths of some children who might otherwise have lived.⁸⁸

For any healthcare decision which imposes a non-beneficial burden on a child, whether it is the commissioning of a *non-therapeutic* procedure or the rejection of a *therapeutic* one, I believe that a justification is required. It is debatable whether the standard of justification required should be absolute, or dependent of the level of harm the child will or might suffer as a consequence of the decision. What is more important is that all justifications should be coherently expressed in order to allow for transparent debate on the burdens imposed on the child, and on the explicit reasons why inflicting harm on a vulnerable person is legitimate.⁸⁹ I believe that such justifications are required in order to protect children against parental and societal iatrogenesis, the imposition of an unacceptable healthcare burden on a child in order to benefit another person or group.⁹⁰

Before proceeding any further, two issues would seem in need of clarification. The first is the question of why a justification should be required for burdensome healthcare decisions when it is not needed for other harmful parental choices. The second relates to the legitimacy of the notion of parental consent.

2.2.2. *The Special Nature of Healthcare Burdens*

A mother puts her two children in the car on an icy evening so that she can visit her elderly aunt. She may want to do this because her aunt is sick, or because she visits regularly, or simply because she is fed up in the house and wants to get out.

⁸⁷ It would seem from Asser and Swan's data that not all parents who failed to procure medical care resulting in a child fatality were subjected to criminal prosecution. See also A. Dose. Government Endorsement of Living on a Prayer. *J Leg Med* 2009; 30: 515-528. However, in England this would be likely to be regarded as neglect under The Children's and Young Person's Act 1933, s1(2). Whether wilful neglect entailing a religiously motivated failure to procure medical care can be construed as manslaughter in the event that the child dies is uncertain. For a discussion on this matter see J. Bridgeman. 2007. *Parental Responsibility, Young Children and Healthcare Law* Cambridge: Cambridge University Press. pp85-98.

⁸⁸ Asser & Swan (n86).

⁸⁹ A framework of harms and reasonableness has been utilized in this context elsewhere. See S. Elliston. 2007. *The Best Interests of the Child in Healthcare*. London: Routledge-Cavendish. Also D. Diekema. Parental Refusals of Medical Treatment: The Harm Principle as Threshold for State Intervention. *Theor Med Bioeth* 2004; 25: 243-264.

⁹⁰ In the context of public health policy Christakis questioned the justifiability of what he termed 'social iatrogenesis', where one group is harmed by the instigation of policy that benefits a second group. N.A. Christakis. Indirectly Doing Harm. *BMJ* 2009; 339: 782.

The children do not want to go, and driving in the weather conditions will expose them to risk. The mother's decision will not be challenged unless she contravenes some legal statute, such as driving recklessly or while under the influence of alcohol or drugs, or perhaps not restraining her children appropriately in the car.

Alternatively, the mother may encourage her children to play football (risking injury) or even more dangerously, horse riding or black slope skiing. In all these instances the parental prerogative to encourage (or sometimes even coerce) their children to engage in risk-taking activities is largely unquestioned. In addition, in England parents legally may slap their children,⁹¹ causing pain and discomfort and risking physical or psychological harm.⁹² Thus, if parents can inflict physical punishment on children and expose them to all manner of risks, what is peculiar to healthcare harms that make them subject to special justification?

There are a number of conditions that appear to set healthcare decision-making apart from other life choices affecting children. In contrast to other social endeavours, such as visiting elderly aunts or engaging in sport, religious observance or education, healthcare is the only area of a child's life where a parent can authorise another person to deliberately inflict harm on the child. Parents may not licence others, for example, to hit their children. The Education (No 2) Act 1986 banned corporal punishment in schools in England and Wales, and this was upheld by the House of Lords in *Williamson v Secretary of State for Education and Employment and Others*.⁹³ However, a parent may authorise a surgeon to perform a procedure on a child which will cause harm to the child by damaging the skin or bodily structures. Of course, the aim of the medical intervention is to benefit the child in some sense, and the harm is 'collateral damage'. Doctors are licensed by the state to inflict beneficent harm on persons, and with regard to young children this arrangement is subject to an agreement between parents and healthcare professionals that is formal and legalistic in nature. Except in an emergency, doctors may not treat an

⁹¹ Children Act 2004, s58. The right to administer 'reasonable punishment' to children is limited by proportionality and severity.

⁹² E.T. Gershoff. Corporal Punishment by Parents and Associated Child Behaviors and Experiences: A Meta-analytic and Theoretical Review. *Psychol Bull* 2002; 128: 539-579.

⁹³ [2005] UKHL 15. Here, a parent with particular Christian beliefs requested that his children should be subject to physical chastisement in school. The argument in favour of this was rejected. Perhaps what was most striking about the case was, as Baroness Hale observed (at 71), its adult-centred nature. The case was brought by adults for adult rights; no one represented the child's point of view.

incompetent minor without parental authorisation for that specific act.⁹⁴ Parental authorisation is uncontentious for medical procedures that are clearly therapeutic, but healthcare decisions (authorisation or refusal) where the burden might be seen to outweigh the benefit are controversial and, in particular circumstances, may be justiciable. One example is male ritual circumcision, an apparently lawful operation,⁹⁵ but one which it is acknowledged offers little medical benefit to the child.⁹⁶ In the event of a parental dispute regarding the procedure, the court may intervene,⁹⁷ as it has with regard to immunisation,⁹⁸ the refusal of life-saving treatment⁹⁹ or the demand for ostensibly futile care.¹⁰⁰ In addition, interventions of questionable benefit to the participant child, such as tissue donation or research enrolment, can be subject to some form of official oversight.

Thus far, I have set out the case for healthcare harms as being apparently different to other forms of parentally inflicted burdens on children on the basis of (a) the harm being deliberately inflicted by a legally sanctioned third party, albeit with beneficent intent; (b) the formal and legalistic nature of the parental agreement with the third party regarding the particular act; and (c) the level of oversight that may occur whenever there is a contentious aspect to the proposed intervention.¹⁰¹ On another level, it is arguable that healthcare possesses a particular value to society that

⁹⁴ *Glass v United Kingdom* [2004] 1 FLR 1019.

⁹⁵ *Re J (Child's Religious Upbringing and Circumcision)* [2000] 1 FLR 571 at para 6.

⁹⁶ *Ibid* at para 11. This might be seen by some as a controversial claim, particularly in the case of protection against sexually transmitted HIV. See for example A.D. Wodak, et al. The Case for Boosting Infant Male Circumcision in the Face of Rising Heterosexual Transmission of HIV. *Med J Aust* 2010; 193: 318-319. The applicability of the data used to advance this position has been questioned; see M. Fox & M. Thomson. HIV/AIDS and Circumcision: Lost in Translation. *J Med Ethics* 2010; 36: 798-801. My own crude analysis of male birth rates (382,647 in England in 2009) and male heterosexual infection rates (1259 in 2009) indicates that 304 infant males would need to be circumcised in order for one, as a sexually irresponsible adult, to have a 40% reduction in his chance of acquiring HIV. In my view, a ratio of 1:1 might indicate that circumcision is reasonable; a ratio of 1:304 indicates that we would unnecessarily harm 303 children for adult benefit. If adult males wish to protect themselves against HIV and yet have no inclination towards abstinence or practicing safe sexual techniques, then it would seem reasonable that they should have themselves circumcised (even though the level of protection provided is modest) rather than inflicting unnecessary risk and pain upon unconsenting infants.

⁹⁷ *Re J* [2000] 1 FLR 571 at paras 31-32.

⁹⁸ *B (A Child)* [2003] EWCA Civ 1148 at para 11.

⁹⁹ See for example *Re A (Children) (Conjoined Twins: Surgical Separation)* [2001] Fam 147; *Re T (A Minor) (Wardship: Medical Treatment)* [1997] 1 WLR 242.

¹⁰⁰ See for example *Re C (Wardship: Medical Treatment)* [1989] 2 All ER 782; *Re J (A Minor) (Wardship: Medical Treatment)* [1990] 3 All ER 930.

¹⁰¹ There are other aspects of a child's life where some of these issues are relevant; e.g. the changing of a child's name. See *Re J* [2000] 1 FLR 571 at para. 31.

other social activities lack. It has been suggested that healthcare is morally important first, because of its potential to prevent or alleviate disease and suffering, and second, because it may positively redress the imbalance that has occurred from congenital or acquired disadvantage.¹⁰² Whether health should be prioritised above other welfare considerations is debatable.¹⁰³ Nevertheless, it is undoubted that healthcare will impact upon almost every person's life throughout their lifespan in a meaningful (if not necessarily positive) way. For these reasons, healthcare might be seen as being imbued with a special social significance that other social endeavours are not.

Given the central nature of health and healthcare in the lives of people, it seems reasonable that we should expect that in cases where the beneficial nature of a proxy decision is questionable, that some justification for the choice made is put forth. In the context of paediatric healthcare, the various academic justifications presented come in a variety of hues and may take the form of the best interests standard,¹⁰⁴ parental rights,¹⁰⁵ or an appeal to family intimacy¹⁰⁶ or relationships within a community;¹⁰⁷ to duties owed to children past whose sacrifice has made current medical knowledge possible,¹⁰⁸ to obligations owed to present or future children with particular diseases,¹⁰⁹ or to equal entitlements to some aspect of healthcare.¹¹⁰ The number of putative justifications may be put down to their context-sensitive use in different cases, but where different commentators employ different justifications to legitimise the same medical act, then perhaps we should raise a sceptical eyebrow and wonder about the value of this intervention to the individual child.

¹⁰² N. Daniels. 2008. *Just Health: Meeting Health Needs Fairly*. Cambridge: Cambridge University Press. Chapter 2.

¹⁰³ J. Wilson. Not So Special After All? Daniels and the Social Determinants of Health. *J Med Ethics* 2009; 35: 3-6.

¹⁰⁴ Elliston (n89).

¹⁰⁵ Goldstein et al (n47).

¹⁰⁶ R.A. Crouch & C. Elliott. Moral Agency and the Family: The Case of Living Related Organ Transplantation. *Camb Q Healthc Ethic* 2000; 8: 275-287.

¹⁰⁷ T.F. Ackerman. Nontherapeutic Research Procedures Involving Children With Cancer. *J Ped Oncol Nurs* 1994; 11: 134-136.

¹⁰⁸ P. Litton. Non-Beneficial Pediatric Research and the Best Interests Standard: A Legal and Ethical Reconciliation. *Yale J Health Pol Law Ethic* 2008; 8: 359.

¹⁰⁹ D.W. Brock. 1994. Ethical Issues in Exposing Children to Risks in Research. In *Children as Research Subjects: Science, Ethics & Law*. M.A. Grodin & L.H. Glantz, eds. New York: Oxford University Press: 81-102.

¹¹⁰ P.H.Y. Caldwell, et al. Clinical Trials in Children. *Lancet* 2004; 364: 803-811.

2.2.3. *The Legitimacy of Parental Consent*

Of course, it could be argued that a parent knows the child best and thus is in the optimal position to judge what is in his or her interests. Therefore, if a parent ‘consents’ or refuses to ‘consent’ to a procedure on behalf of the child then this is based upon their evaluation of the child’s interests and their wishes should be carried out. However, it is important to reflect upon what consent actually means before uncritically accepting this proposal. Consent is a legal term which denotes an agreement between two parties; it allows a second party to do something to the first party, or their property, without infringing the law.¹¹¹ To touch another person intentionally without their consent is to commit the tort of battery; to walk on their land without permission is trespass.¹¹² Consent is ‘morally transformative’; a process that affects the moral relationship between two persons in a manner such that the first person’s consent legitimates an action by the second that would otherwise be illegitimate.¹¹³ Consent is thus fundamental to our understanding of autonomous choices, insofar as the decision made affects the moral relationship between two individuals, such as between a patient and a surgeon. This seems a fairly uncontroversial definition, but this is not how the term is always used. Let us look at two examples, the first offered by Wertheimer in the context of sexual relations:¹¹⁴

- (1) (a) If B consents to A's doing X to B, then it is legitimate for A to do X to B.
- (b) B has consented to A's doing X to B.
- (c) Therefore, it is legitimate for A to do X to B.

This is the situation as it pertains to competent adults, and as long as X is a lawful activity,¹¹⁵ then the conclusion in (c) should hold.

- (2) (a) C consents to A's doing X to B
- (b) B has not consented to A's doing X to B.
- (c) It is still legitimate for A to do X to B.

¹¹¹ M. Brazier & E. Cave. 2007. *Medicine, Patients and the Law*. 4th edn. London: Penguin. p99.

¹¹² Historically, trespass was the crime of ‘direct and immediate interference with person or property, such as striking a person, entering his land, or taking away his goods without his consent’. J. Law & E.A. Martin eds. 2009. *A Dictionary of Law*. Oxford: Oxford University Press.

¹¹³ A. Wertheimer. Consent and Sexual Relations. *Legal Theory* 1996; 2: 89-112. p90.

¹¹⁴ Ibid.

¹¹⁵ An example where the parties consented but the activity was deemed illegal is *R v Brown* [1993] 2 All ER 75.

Whether the conclusion (c) is sound depends on a number of factors: (i) context, (ii) the status of A, B and C, and (iii) what X is. Currently, we believe that if X is sexual intercourse and B does not consent then (c) cannot hold regardless of the relationships of A, B and C. But if A is a surgeon, B is a child, C the child's parent and X an appendectomy then, as long as B has appendicitis, (c) holds true. This gives us some indication of the complexity of proxy 'consent'. As example 2 above indicates, parental 'consent' entails one party licensing a second party to do something to a third party. However, while parental 'consent' seems acceptable in the context of appendectomy, it might appear somewhat less legitimate when X represents a different practice (e.g. kidney donation). Concern about the validity of third party consent has been expressed before. Article 1 of the Nuremberg Code advocated for the indispensability of the 'voluntary consent of the human subject' who '*should have legal capacity to give consent*',¹¹⁶ while Brownsword questioned why parental consent was sufficient to burden a child with having to donate bone marrow to a sibling.¹¹⁷ With regard to medical research, the AAP describe consent as the:

prospective agreement of the individual to his or her own participation in research. The consentor is legally and functionally competent ... his or her consent does not require the approval of any other individual.¹¹⁸

They use the term 'parental permission' to signify the 'agreement of parent(s) to the participation of their child in research or medical care.'¹¹⁹ Parental permission is also used in this context by the Council for International Organizations of Medical Sciences (CIOMS),¹²⁰ the National Institute for Health (NIH)¹²¹ and the Institute of

¹¹⁶ My emphasis.

¹¹⁷ R. Brownsword. Happy Families, Consenting Couples, and Children with Dignity: Sex Selection and Saviour Siblings. *CFLQ* 2005; 17: 1-35. p4.

¹¹⁸ AAP Committee on Drugs (n22) p286.

¹¹⁹ Ibid.

¹²⁰ CIOMS. 2002. *International Ethical Guidelines for Biomedical Research Involving Human Subjects*. Geneva.

¹²¹ NIH. 1998. *NIH Policy and Guidelines on the Inclusion of Children as Participants in Research Involving Human Subjects*. Washington, DC.

Medicine (IOM)¹²² in the US. However, comparable bodies in England continue to use ‘parental consent’ in this circumstance.¹²³

‘Parental consent’ seems an uncertain notion. I believe that the term is representative of the injudicious use of a concept without a real analysis of its content; that it is one of those expressions which, as Justice Frankfurter put it,

is an excellent illustration of the extent to which uncritical use of words bedevils the law ... its felicity leads to its lazy repetition, and repetition soon establishes it as a legal formula, indiscriminatingly used to express different and sometimes contradictory ideas.¹²⁴

Any uncritical use is not limited to the field of medical law; the notion of parental consent has wide application. In particular, parental consent historically has been of the utmost importance in matrimony,¹²⁵ and it is to this practice that I will turn briefly in order to outline why I believe the term to be problematic.

In medieval times, at least among the members of the nobility, marriages were arranged for economic or political advantage.¹²⁶ There were three elements required to legitimise these marriages: first, a pact between two families; second, the exchange of property; and third, the consummation of the relationship through sexual intercourse. In practice, the patriarchal heads of the two families agreed on the matrimonial partners and what exchange of finance or property was required in order for the ceremony to take place. Then the couple were brought together and promises exchanged:

¹²² M.J. Field & R.E. Berman eds. 2004. *The Ethical Conduct of Clinical Research Involving Children*. Washington, DC: National Academies Press.

¹²³ See British Medical Association. 2001. *Consent, Rights and Choices in Health Care for Children and Young People* London BMJ Books. RCPCH. Guidelines for the Ethical Conduct of Medical Research Involving Children. *Arch Dis Child* 2000; 82: 177–182. I am unaware of any academic discussion concerning the distinctive terminologies used in different states.

¹²⁴ *Tiller v. Atlantic Coast Line Railroad Co.*, 318 U.S. 54 (1943) at 68.

¹²⁵ The relationship between consent in matrimony and healthcare was discussed by Prof. Margot Brazier in a paper entitled ‘What is Consent For?’ presented at *The Future of Consent*, Manchester, March 2010. The material here concerning parental consent is derived from a broader paper entitled ‘History, Children and Consent: Lessons from the Medieval Bedchamber’ presented at the 5th UK Postgraduate Bioethics Conference, London, January 2011.

¹²⁶ I.M. Resnick. Marriage in Medieval Culture: Consent Theory and the Case of Joseph and Mary. *Church History* 2000; 69: 350-371. p352.

The desires of the betrothed couple were almost irrelevant. A bride's mere presence at the *desponsatio* or betrothal was construed as a form of implied consent. Her explicit consent was useful but, in its absence, authorities simply assumed her obedience to paternal command.¹²⁷

However, in the mid-eleventh century Christian theologians and canonists wrestled with this issue, leading to the development of consent theory; the idea that the consent of the parties themselves constituted a necessary cause of marriage (consent denoting an internal disposition of the will).¹²⁸ A series of decretal letters from Pope Alexander III¹²⁹ formalised the canon law of marriage, and because of the ecclesiastical courts' exclusive jurisdiction over cases concerning marriage, these provisions remained in force in England until the middle of the eighteenth century.¹³⁰ The pope proposed to restrict the power traditionally held by parents and feudal overlords over marriage, and instead aimed to entrust the choice of marriage partners solely to the parties themselves.¹³¹ The new canon law model effectively limited paternal power, as it was the consent of the two marital parties that was essential. Parental approval remained preferable but was no longer necessary.¹³² However, as parents continued to 'play an active, even heavy-handed, role in matchmaking,' there remained the possibility that they might exert undue influence or even coercive force in procuring a marital arrangement that suited them. The English church was cognisant of this, and because of its focus on the consent of the parties, permitted annulments on these grounds.¹³³ Canon law also prohibited child marriage as the parties could not consent; the canonical age of consent being 12 for girls and 14 for boys. The Clandestine Marriage Act 1753 formalised the processes required for a

¹²⁷ Ibid, *ibid*.

¹²⁸ J.N. Perry. The Canonical Concept of Marital Consent: Roman Law Influences. *Cath Lawyer* 1980; 25: 228-236. p233.

¹²⁹ Alexander III was pope between 1159 and 1181.

¹³⁰ C. Donahue JR. The Canon Law On the Formation of Marriage and Social Practice in the Later Middle Ages. *J Fam Hist* 1983; 8: 144-158. p144.

¹³¹ J.A. Brundage. 1990. *Law, Sex, and Christian Society in Medieval Europe*. Chicago: University of Chicago Press. p333.

¹³² Resnick (n126). However, 'canon law did require that parental consent be given to the marriages of minor children'. But the absence of parental consent did not render the marriage void, but rather 'irregular'. R. Probert. Control over Marriage in England and Wales, 1753–1823: The Clandestine Marriages Act of 1753 in Context. *Law Hist Rev* 2009; 27: 413-450. p417.

¹³³ In approximately 15% of cases coming before the ecclesiastical court in the 14th and 15th centuries, one, or both, of the litigants alleged that they had been compelled into marriage against their will. S.M. Butler. "I Will Never Consent to be Wedded with You!" Coerced Marriage in the Courts of Medieval England. *Can J Hist* 2004; 39: 247-270.

marriage to be valid, but left the consent element intact, although it included a need for additional parental consent for those under 21.¹³⁴ The Age of Marriage Act 1929 raised the age limit for consent to 16 for both sexes, retaining the provision for parental consent, although largely as a formality.¹³⁵ This requirement is now only applicable to adolescents between the ages of 16 and 18.¹³⁶

Looked at in this historical marital context, the notion of parental consent would seem to speak to two norms. The first of these relates to the later historical period, and concerns parents giving formal permission to their child to exchange matrimonial vows with his or her chosen partner, when the child was of marriageable age but below the age of majority. In this context, parental consent reflects parental agreement with the child's choice. Parental consent alone was an insufficient cause of a marriage; parents could agree or disagree with a marriage, but they could not cause it.

The second case is different. Prior to the development of consent theory, a father could 'consent' to his child marrying, regardless of the wishes of the child. As children were effectively property of their parents, the father's consent simply allowed his property to be used in a particular way, without unlawful trespass occurring. Thus, the father's consent permitted, or authorised, a third party to act in a certain manner. In the case of a father consenting to his daughter's marriage, as consummation was essential to the realisation of the marital vows, the father was effectively authorising the groom to have sexual intercourse with his daughter regardless of her wishes. The term parental consent thus represents two very different things, agreement and authorisation. The first of these is child-centred and reflects agreement with his or her wishes; the second relates to parental power and may take no account of the child's desires, in fact, sometimes running contrary to them.

When we come to parental consent in healthcare we can see that it also entails these two norms. In the first instance, there are circumstances where an

¹³⁴ One of the main aims of the Act was to prohibit clandestine marriages. Marriage ceremonies had to be conducted by a minister in a parish church or chapel of the Church of England to be legally binding. Marriages of infants (those under the age of 21) were valid in the absence of parental (or guardian) consent. See R. Probert. 2008. *Marriage Law and Practice in the Long Eighteenth Century: A Reassessment*. Cambridge: Cambridge University Press.

¹³⁵ s1.

¹³⁶ Family Law Reform Act 1969, s2.

adolescent may be competent, but parental ‘consent’ also may be required. This occurs, for example, in relation to research participation,¹³⁷ or tissue donation.¹³⁸ However, as the child has competently chosen to undergo a particular intervention, parental ‘consent’ reflects ‘parental agreement’. Akin to the marriage of a child (below the age of majority) to the partner of their choice, it represents a concordance with what the child has already decided, either alone (with the doctor) or in association with his or her parents.

In the second case, the child is not legally competent to consent. However, the medical practitioner needs a consent form to be signed so that he is protected against charges of battery with relation to performing intervention X on the child. The child’s parents sign the consent form and authorise the doctors to carry out X. If the parents actually ‘consented’ then, by logically applying the definitional characteristics of the term ‘consent’, we would seem to be designating the child to be either an extension of the parent, or parental property. As we no longer wish to consider the child to be property,¹³⁹ then the term ‘parental consent’ would seem invalid and perhaps parental ‘authorisation’ is more reflective of the process that takes place.¹⁴⁰ This authorisation can take two forms. If the child has a particular illness and the doctor wishes to institute a standard and effective treatment for this disease process, then parental authorisation of this treatment would seem uncontentious. However, if the parent authorises interventions that are not beneficial and may even be harmful, or the parent refuses to authorise beneficial care, then

¹³⁷ Medicines for Human Use (Clinical Trials) Regulations 2004/2006.

¹³⁸ HTA. 2009. *Code of Practice 6: Donation of Allogeneic Bone Marrow and Peripheral Blood Stem Cells for Transplantation*. London. s75: ‘Even if the child is competent to consent, it is good practice to consult the person who has parental responsibility’.

¹³⁹ See for example R. Noggle. 2002. Special Agents: Children’s Autonomy and Parental Authority. In *The Moral and Political Status of Children*. D. Archard & C.M. Macleod, eds. Oxford: Oxford University Press. ‘Virtually all reasonable people hold that children are persons, and not, for example, pets or property.’ At p6. However, I am sceptical of the notion that parents no longer ever treat their children as property. For an example, see paper 3 and the conclusions section.

¹⁴⁰ This use of authorisation instead of consent is not original, nor is my concern with the terminology employed. Similar points were made by Brazier: ‘I am not alone in being troubled by the language of consent in this context. The Scottish Independent Review Group on the *Retention of Organs at Post Mortem* (chaired by Professor Sheila McLean) has proposed that, rather than speaking of consent in the context of organ retention, we should speak of authorisation.’ M. Brazier. *Organ Retention and Return: Problems of Consent*. *J Med Ethics* 2003; 29: 30-33. p30. Independent Review Group. 2001. *Retention of Organs at Post Mortem. Final Report*. Edinburgh: TSO.

perhaps the exercise of such parental power is redolent of that possessed by the medieval patriarch.

Does it matter if we speak of parental consent or parental authorisation; is it merely an exercise in linguistic semantics? I believe it is important for two reasons. First, if we hold that children are not the property of their parents then we should avoid the use of terminology that runs counter to this position. If, definitionally, consent pertains to the person and property of the individual concerned then, if we allow for parental consent, the child must be part of this person or his property. If we wish to escape this conclusion then we should alter our nomenclature. Second, the incorrect use of concepts leads to opacity. Consent has a particular legal connotation, and the mere use of the term in association with an act would seem to give validity to that deed. By contrast, labelling an event as resulting from the third party authorisation of an intervention might lead us to wonder more about how that act might impact on the first party, and its legitimacy. The meaning of consent is a voluntary agreement entered into by two parties with the capacity to do so. Outside of the context of competent adults the term becomes misleading. I would suggest that parents can authorise the treatment of their child or agree with their choice, but neither of these is the same as consent.¹⁴¹

2.3. STATE

Parents, as outlined earlier, are invested by the state with the power to make decisions on behalf of their children. However, although the state, in its role as defender of the family, values parental authority,¹⁴² it also has another, contradictory position, that of the interventionist ‘state as parent’.¹⁴³ Balancing these conflicting functions has proven difficult on occasion, and the agencies that the state devolves interventionist powers to have been widely criticised for sometimes being too slow to act,¹⁴⁴ or too precipitous at other times.¹⁴⁵ The difficulties in achieving a consistent approach while remaining cognisant of the potentially clashing ambitions of the state were observed in the *Cleveland Inquiry* report:

¹⁴¹ Thus, I have tended to use the term ‘parental authorisation’ throughout this thesis.

¹⁴² J. Masson. The State as Parent: The Reluctant Parent? *J Law Soc* 2008; 35: 52-74.

¹⁴³ L. Fox Harding. 1997. *Perspectives in Child Care Policy*. 2nd edn. New York: Longman.

¹⁴⁴ Lord Laming. 2003. *The Victoria Climbié Inquiry Report (Cm. 5730)*. London: TSO.

¹⁴⁵ E. Butler-Sloss. 1988. *Report of Inquiry into Child Abuse in Cleveland*. London: HMSO.

It is a delicate and difficult line to tread between taking action too soon and not taking it soon enough. Social services whilst putting the needs of the child first must respect the rights of the parents ... Inevitably a degree of conflict develops between those objectives.¹⁴⁶

Despite this, in the contexts of health and healthcare the state (or its agencies) has sometimes intervened in particular circumstances; (1) where there has been serious harm caused through physical, mental or emotional abuse (or the risk of harm is great); (2) where parents insist on treatment that is felt (usually by healthcare professionals) not to be in the child's best interests, generally in the context of end-of-life care; (3) where parents refuse treatment, and such a refusal will cause the child serious harm; and (4) where parents disagree over a particular intervention. In these instances, the Children Act has emphasised that 'the child's welfare shall be the court's paramount consideration'.¹⁴⁷ The legal utility of the best interests doctrine is discussed in the next chapter, so I will not dwell further on these cases here.

However, the state may also intervene in family life when a child makes a healthcare decision that a legally responsible adult, be it a parent or healthcare professional, deems to be contrary to the child's interests and the consequences of which are likely to be harmful.¹⁴⁸ Again we have a situation of divergent ambitions; that 'the ascertainable wishes and feelings of the child concerned (considered in the light of his age and understanding)' should be given due regard¹⁴⁹ on the one hand, and also that the state exercise its protective welfare function towards the child on the other. However, if a child is competent to make a particular decision then the rationale for state intervention must be open to question, assuming that the decision pertains to a lawful act.

¹⁴⁶ Ibid. p244.

¹⁴⁷ s1(1).

¹⁴⁸ There are a number of cases where the courts have contested a minor's right to take such decisions. These are discussed in paper 4. See, for example, *Re R (A Minor) (Wardship: Consent to Treatment)* [1992] Fam 11 CA; *Re W (A Minor) (Medical Treatment)* [1992] 4 All ER 627 (hereafter *Re W*); *Re E (A Minor: Wardship: Medical Treatment)* [1993] 1 FLR 386 (hereafter *Re E*); *Re L (Medical Treatment: Gillick Competency)* [1998] 2 FLR 810 (hereafter *Re L*); *Re M (Child: Refusal of Medical Treatment)* [1999] 2 FLR 1097 (hereafter *Re M*).

¹⁴⁹ Children Act 1989, s1(3).

2.3.1. State Intervention, Welfare and Competent Minors

In cases where the risk of harm is significant, the courts have generally overridden the express wishes of the adolescents involved to decline treatment.¹⁵⁰ While the judiciary sometimes have declared themselves to be conscious of the views of the minor involved,¹⁵¹ James suggests that there is a political, legislative and judicial inability to view the child as a social actor in his own right. He further points out that in the context of family proceedings the child is defined as ‘a person under disability’.¹⁵² Sawyer argues that this ‘fundamental disability elides easily into abdication of their recognition as members of the polity’.¹⁵³ Both of these authors appear to agree that, in the context of family law, there exists a deeply entrenched reluctance to recognise the child as a legal actor; a purported lack of educated reason leading to a denial of agency. Thus, despite the ratification of a Convention asserting ‘children's legal personhood’¹⁵⁴ it is uncertain that the English courts truly embrace this status, particularly when it comes to hard cases.

Despite its imperfections¹⁵⁵ the CRC, as the only internationally ratified convention specific to children, is probably the most important child advocacy tool currently in existence.¹⁵⁶ Rights listed in the CRC are sometimes divided into groups that may be referred to as the ‘three Ps’, signifying provision, protection, and participation.¹⁵⁷ Section 1 of Article 12 provides that:

¹⁵⁰ See paper 4.

¹⁵¹ See for example, *Re E* at 393: ‘In considering what his welfare dictates, I have to have regard to his wishes. What he wishes is an important factor for me to take into account’.

¹⁵² A.L. James. Children, the UNCRC, and Family Law in England and Wales. *Fam Court Rev* 2008; 46: 53-64. p55. See also Family Proceedings Rules, S.I. 1991, No. 1247 (L.20), Rule 9.1. Accessed on September 30, 2008 at http://www.opsi.gov.uk/si/si1991/ukSI_19911247_en_1.

¹⁵³ C. Sawyer. The Child is Not a Person: Family Law and Other Legal Cultures *J Soc Welfare Fam Law* 2006; 28: 1-14. p13.

¹⁵⁴ Ibid. p3.

¹⁵⁵ The CRC took ten years of negotiation amongst delegates before the text was finalised. There were five major areas where consensus was difficult to achieve: freedom of thought, conscience and religion (Islamic concerns were prominent here); inter-country adoptions (reservations were expressed by Latin American countries); the rights of the unborn child (religious and cultural divisions in attitude); traditional practices (most notably female circumcision); and on the duties of children. The United Kingdom questioned the need for a convention at all. See M. Freeman. 1997. *The Moral Status of Children: Essays on the Rights of the Child* The Hague: Kluwer Law International. pp53-4.

¹⁵⁶ C.M. Lyon. Interrogating the Concentration on the UNCRC Instead of the ECHR in the Development of Children's Rights in England? *Children & Society* 2007; 21: 147-153. p148.

¹⁵⁷ B. Franklin. 2002. Children's Rights and Media Wrongs. In *The New Handbook of Children's Rights: Comparative Policy and Practice*. B. Franklin, ed. London: Routledge: 15-44. p20.

States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.

Despite this declaration, it has been suggested that ‘few governments have any philosophical problems with the first two. It’s the third part (participation) that worries them.’¹⁵⁸ As a consequence this Article, while appearing congenial to adolescent sensitivities, may lack substance in certain circumstances. For example, with regard to family law proceedings Masson has argued that there is little belief that children should be active participants in legal processes that affect them.¹⁵⁹ Apropos of healthcare decisions, adolescents appear quite welcome to participate as long as they acquiesce; once competent they can consent to medical care. If, however, they refuse to consent to treatment where such a decision may potentially be physically harmful to them then, as Balcombe LJ stated in *Re W*: ‘...there must come a point when the court, while not disregarding the child’s wishes, can override them in the child’s best interests, objectively considered.’¹⁶⁰ In reviewing one such case, Grubb has argued that the courts contrive to alter the legal concept of capacity so that it is

very difficult if not impossible for a teenager ever to be legally competent...The court’s approach is not directly related to the question of the child’s maturity...Rather, it is a device patently intended to justify a finding of incompetence.’¹⁶¹

Here, Grubb is uncovering a presumption which effectively denies the rationality of children. This perspective, which is possibly widely held, was articulated more colourfully by DH Lawrence:

We’ve got to educate our children, which means we’ve got to think for them; day after day, year after year, we’ve got to go on deciding for our children.

¹⁵⁸ Richard Reid of UNICEF cited in S. Rafferty. Giving Children a Voice - What Next? A Study from One Primary School *Spotlights No 65* 1997: SCRE. Accessed on 1 September 2008 at <http://www.scre.ac.uk/spotlight/spotlight2065.html>.

¹⁵⁹ J. Masson. 2003. Paternalism, Participation and Placation: Young people’s Experiences of Representation in Child Protection Proceedings in England and Wales. In *Family Law: Processes, Practices, Pressures*. J. Dewar & S. Parker, eds. Oxford: Hart Publishing: 79–98. p80.

¹⁶⁰ *Re W* at 643.

¹⁶¹ A. Grubb. Commentary on *Re L* (Medical Treatment: Gillick Competency). *Med Law Rev* 1999; 7: 58-61. p60.

It's not the slightest use asking little Jimmy 'What would you like dear?' because little Jimmy doesn't know. And if he thinks he knows, it's only because as a rule he's got some fatal little flaw into his head.¹⁶²

Franklin suggests that being labelled a child has more about power than chronology.¹⁶³ The courts have wielded this power to set out a social norm; adolescents are insufficiently rational to be capable of making decisions about themselves which might be perceived to damage their long term interests. This all seems well and good, the courts prioritising the welfare of children over their liberty rights. However, it is not as straightforward as it might seem. In *Re E*, *Re L* and *Re M* judicial decisions to deny their competency to refuse treatment hinged, to some extent, upon their alleged lack of capacity to understand the exact nature of death.¹⁶⁴ Jackson suggested that the level of competence required of these adolescents 'was extremely high, and perhaps even unattainable.'¹⁶⁵ Similarly Grubb observed that should similar tests of capacity be 'applied to adults, it would call into question their competence.'¹⁶⁶ There are two issues here. The first is whether these children were competent or not. If they were not competent, then there is little discussion to be had; it would seem uncontentious to protect the life of an incompetent child instead of giving way to a non-rational choice. If they were competent, then we have to provide a convincing justification for overriding their wishes. The second issue is similar. If they were competent, then were they treated the same as all others who also have the capacity to make that particular decision? Again, any difference in treatment merits justification.

2.3.2. Competence and Adolescence

In medieval times, the assessment of competence was largely a practical matter; the age of majority of a person being dependent on their gender and their ability to do their particular job:

¹⁶² Quoted in Franklin (n157) p22.

¹⁶³ Ibid. p19.

¹⁶⁴ *Re E* and *Re L* concerned adolescent Jehovah Witnesses refusal of blood transfusions; in *Re M* a 15 year-old girl declined a heart transplant.

¹⁶⁵ E. Jackson. 2006. *Medical Law*. Oxford: Oxford University Press. p238.

¹⁶⁶ Grubb (n160) p60.

thus a young burgess was of full age when he could count money or measure cloth, a sokeman when he was fifteen. The mistress of a household achieved cove and keye at about the same age. At the top of the social scale, for a male who held land by knight's service, majority was later, at 21; for an unmarried female it was 16 and for a married female 14.¹⁶⁷

If they looked old enough and were physically and mentally capable of fulfilling their role, then their majority was established. In the case of a legal dispute (e.g. relating to inheritance, litigation or pertaining to a coroner's inquest), then the courts sometimes sought to establish age through a more formal process.¹⁶⁸

In more modern and less pragmatic times (particularly since the 1970s), the competence of minors, especially with regard to healthcare decision-making, has been the subject of much academic and polarised debate. Some commentators hold that adolescents are not competent,¹⁶⁹ while others argue that some children are capable of making serious decisions (particularly those who have chronic illness),¹⁷⁰ and still other academics contend that it does not matter if the child is competent or not as it is the parental opinion which should be determinative.¹⁷¹ Rather than attempt to arbitrate between these positions, which is impossible in any case because of the paucity of data upon which to base an empirical claim, it is probably more instructive to look at the commentary of one legal academic. In support of the court's repeated refusal to recognise the right of adolescents to decline medical care, Fortin contends that because 'teenagers often make reckless choices, believing themselves to be immune from any dangerous outcomes' they need to be protected from taking harmful healthcare decisions.¹⁷² In doing so she appeals to pertinent 'research material on the cognitive development of the average child and adolescent' (although conveniently ignoring contrary data). Her baseline position is one where:

It is perfectly appropriate for society to protect children from being required to make significant choices if it considers that they may suffer unnecessarily

¹⁶⁷ W.S. Deller. Thirteenth-Century Proofs of Age: The Development of a Hybrid Legal Form. *J Leg Hist* 2010; 31: 245-272. p245.

¹⁶⁸ Ibid.

¹⁶⁹ Most recently B.C. Partridge. Adolescent Psychological Development, Parenting Styles, and Pediatric Decision Making. *J Med Philos* 2010; 35: 518-525.

¹⁷⁰ See for example, P. Alderson & J. Montgomery. 1996. *Health Care Choices: Making Decisions with Children*. London: Institute for Public Policy Research.

¹⁷¹ Ross (n43).

¹⁷² Fortin (n14) p314.

from being involved in decision-making before they are sufficiently mature.¹⁷³

Fortin suggests that children could take an appeal against being forced to undergo treatment against their will under the Human Rights Act claiming the protection of several Articles, but

as long as the treatment is medically perfectly orthodox and life-saving, a domestic court might authorise treatment against the teenager's wishes, without necessarily falling foul of articles 3 or 8.¹⁷⁴

The basis for this presumption is that forcing treatment upon adolescents is not degrading if it is 'is intended to preserve their physical and mental health' and justifiable if necessary to safeguard life.¹⁷⁵ Stated plainly, Fortin allows that paternalism can be justified as a means of protecting the child's welfare, and that the autonomy or participation rights of allegedly competent minors are subordinate to the protective duties of responsible adults. Her position appears to reflect current reality. In *Re W*, Nolan LJ argued that the courts would not countenance the refusal of lifesaving treatment by an adolescent; that it is 'the duty of the court to ensure so far as it can that children survive to attain that age (18)'.¹⁷⁶ The bar for independent treatment refusal thus seems to be set at 18 years of age. This raises the question as to whether this is fair.

On one level it seems a strange and somewhat arbitrary notion that the state can have a legitimate interest (expressed through the courts) in the welfare of adolescents and yet not in the welfare of adults, even though the only difference between the two may be a momentary change in existential status. However, as Archard points out, policy decisions often require cut off points that may lead to apparent unfairness.¹⁷⁷ I might be displeased to be subject to legal sanction for driving at 61mph in a 60mph zone, whereas if I had been driving at 59mph I would have incurred no liability. The difference between the two seems insignificant, but because policy requires a set standard, minor deviations can have significantly

¹⁷³ J. Fortin. 2005. *Children's Rights and the Developing Law*. 2nd edn. Cambridge: Cambridge University Press. pp75-6.

¹⁷⁴ Fortin (n14) p316.

¹⁷⁵ *Herczegfalvy v Austria* [1992] 15 EHRR 437 at 82-86. The European Court of Human Rights also found that the state was entitled to protect its citizens from a real risk of serious physical harm or injury. *Laskey, Jaggard and Brown v UK* [1997] 24 EHRR 39 at 41-46.

¹⁷⁶ At 647.

¹⁷⁷ D. Archard. 2004. *Children: Rights and Childhood*. New York: Routledge. p85.

different consequences.¹⁷⁸ With regard to competence, Archard identifies three possible objections to a set age limit; (1) ‘the arbitrariness of any particular age’; (2) ‘the unreliability of correlation by age’; and (3) ‘the preferability of a competence test’.¹⁷⁹ The first argues that some younger children are more competent to perform a task or make a decision than their older peers, so setting a particular cut-off age limit is wrong. The second, similar to the first, states that there is no strict correlation with regard to the attainment of competence and age. The third objection posits that since it is competence or incompetence that matters with regard to decision-making, then it makes more sense to test for the relevant competence rather than use some arbitrary age.¹⁸⁰ These objections all have merit but, when it comes to setting a cut-off point when implementing a policy decision, it is practically impossible to test the competence of the entire population, and any set age limit will fall foul of the first two objections. While there is no way around this, it is possible to protest against the wrongfulness of a particular age limit. For example, while it is not plausible to hold that two year-old children would be competent to vote, I am unconvinced that 14 year-olds could not exercise the franchise to vote in a responsible manner.

However, none of this would seem relevant when it comes to adolescent rejection of medical care, as there is no specific legislatively endorsed policy that has set a defined cut-off age in this context. Instead, there is a general declaration with regard to attentiveness to the ‘ascertainable wishes and feelings of the child’.¹⁸¹ As will be discussed in paper 4, there is a judicial preference for declining to view the adolescent as a fully autonomous healthcare decision-maker until they pass their 18th birthday. Adolescents may share this particular court-designated status with pregnant women¹⁸² and sometimes prisoners.¹⁸³ However, if we value autonomy; if we hold it to be a principle that is of ‘considerable importance in good medical practice ... and

¹⁷⁸ Ibid. p86.

¹⁷⁹ Ibid.

¹⁸⁰ Ibid. pp85-87.

¹⁸¹ Children Act 1989, s1.3(a).

¹⁸² See R. Scott. The Pregnant Woman and the Good Samaritan—Can a Woman Have a Duty to Undergo a Caesarean Section? *OJLS* 2000; 20: 407-436.

¹⁸³ Contrast *Re C* (where a chronic schizophrenic in Broadmoor was deemed competent to refuse the amputation of a gangrenous leg) with *Brady*, where the prisoner was found not competent to refuse food). *Re C (Adult: Refusal of Medical Treatment)* [1994] 2 FCR 151; *R v Collins and another, ex parte Brady* [2000] 58 BMLR 173. The judiciary also declined to recognise patient/prisoner healthcare autonomy in *Re W* [2002] WL 32068016.

... law',¹⁸⁴ then we should be very careful in refusing to recognise the healthcare autonomy rights of competent individuals. As Coggon observes

We see that generally to exercise autonomy is good. Further, we see that a limit to that exercise inflicted by society needs justification. Thirdly, we see that where we can respect it, we do so by allowing people to make lawful decisions.¹⁸⁵

It is not always possible to respect autonomy. It is not feasible to assess the competence of every child aged between 14 and 18 years who might wish to buy cigarettes; the potential number of candidates would make any process impractical. Thus, it seems reasonable to implement a policy that is broadly protective, even though some competent adolescents will be prevented from acting as they wish. But, healthcare decision-making is not like tobacco buying. Only seven children have refused life-saving treatment and had their case heard by the courts over a 20 year period.¹⁸⁶ The number of similar cases involving adults is in excess of this, but is still a relatively small figure. There thus seem no good policy grounds why those who refuse life-saving treatment against medical advice cannot be subjected to an assessment of competence. Given the seriousness of the decision, or at least of the potential consequences, there appear no plausible reasons why this should not happen, nor why adolescents and adults should not be subject to the same test. The content of such an assessment is not germane here, rather that any test be applied equally regardless of chronological age.¹⁸⁷ Partridge argues that there is 'a qualitative difference between adolescent versus adult decision making'; and that

even if adolescents can with proper coaching from their social environment make choices similar to those of competent adults, they do so with their decisional capacities overlaid by an impulsivity and inability to envisage the long-range consequences of their decisions that separate the decisional capacities of most adolescents from those of most adults.¹⁸⁸

However, even if this is true of the majority of adolescents, it is unlikely to be true of all. In addition, the reason behind denying adolescents full autonomy seems

¹⁸⁴ J. Coggon. Varied and Principled Understandings of Autonomy in English Law: Justifiable Inconsistency or Blinkered Moralism? *Health Care Analysis* 2007; 15: 235–255. p235.

¹⁸⁵ Ibid. p243.

¹⁸⁶ See paper 4 for details.

¹⁸⁷ A fuller discussion of the concept of equality is held in paper 3.

¹⁸⁸ Partridge (n169) p518.

not to be that they lack the cognitive capacity to make decisions, but rather that they may make judgements that are whimsical, impetuous, imprudent or merely foolish. If imprudence is a functional standard that competence is judged against, and this does not seem an unreasonable standard, then should it not be a criterion applicable to adults also? If prudence is important then some empirical evidence has suggested that adolescents from the age of fourteen on are no more imprudent than adults, or even that the contrary might actually be true.¹⁸⁹ If one takes illegal substance use, alcohol abuse or suicide to be socially imprudent activities, then national mortality statistics would suggest that (particularly male) adults up to the age of 44 years are inherently imprudent.¹⁹⁰ In reality, medical autonomy is arbitrarily denied to children regardless of their capacity for *rational* decision-making. If we contrast the adolescent in *Re E* with the adults in *Re C* and *Ms B*, it seems unlikely that they were more competent to refuse treatment than he.¹⁹¹ In effect, adolescents exist in a decisional limbo, a state that we might term dysautonomy.¹⁹² They may consent to, but not dissent from, medical investigations or treatment, rendering the individual concerned neither autonomous nor non-autonomous, but rather places them in a disordered position. Logically, competent children should be treated like other competent persons and have their autonomous decisions respected. In response, the

¹⁸⁹ J.J. Conger. 1973. *Adolescence and Youth: Psychological Development in a Changing World*. New York: Harper and Row. Alderson & Montgomery (n170).

¹⁹⁰ Office for National Statistics. 2006. *Mortality Statistics: Review of the Registrar General on Deaths by Cause, Sex and Age, in England and Wales, 2005*. London: HMSO.

¹⁹¹ While Ward LJ described himself as being ‘impressed [by E’s] obvious intelligence’, he was particularly concerned that E was unable to foresee the exact nature of his death (at 391). When E was 18, he again refused a transfusion and died, apparently distressed by having committed an ungodly act at 16. *Re C* concerned a man with chronic schizophrenia. *Ms B* had tetraplegia and was dependent on artificial ventilation. At one point she had been determined to lack capacity. She wished to have the ventilator removed which would almost certainly have resulted in her death. While the medical staff accepted that *Ms B* was competent at that point, they were greatly concerned ‘that she was unable to give informed consent, not because of a lack of capacity in general but her specific lack of knowledge and experience of exposure to a spinal rehabilitation unit and thereafter to readjustment to life in the community.’ *Ms B v An NHS Hospital Trust* [2002] EWHC 429, para. 63. If she were an adolescent this deficiency would most likely have made her incapable of consenting to the withdrawal of care. See *Re L*, further discussed in paper 4.

¹⁹² The Oxford English Dictionary does not list the term dysautonomy. The inseparable prefix, dys- implies notions of hard, bad or unlucky; of destroying the good sense of a word, or increasing its bad sense. It is often used in medicine to describe a bodily function whose operational status is impaired because of abnormality or difficulty, for example dysarthria is the disordered articulation of speech. B. Lennox & M.E. Lennox eds. 1986. *Heinemann Medical Dictionary*. London: William Heinemann Medical Books.

courts might argue that they have taken particular decisions regarding adolescents in their best interests.

It is to the varied judicial interpretations of this principle that I will now turn, particularly with regard to incompetent children.

CHAPTER 3

LEGAL APPROACH: BEST INTERESTS¹

*Deeds, not Words Shall Speake to me*²

3.1. INTRODUCTION

The ‘best interests of the child’ is often invoked to justify medical interventions in children,³ and the phrase is enshrined in English law, requiring that it be a paramount consideration of the courts in cases concerning children which come before them.⁴ This section, however, argues that the *best* interests of a child are difficult to determine in many pertinent circumstances, and that the principle lacks the objective criteria required to make it a useful decisional or justificatory tool. Without sinking into philosophical scepticism, it is arguable that we cannot know the thoughts, feelings, emotions, values or future plans of another unless they directly report them to us; such is the subjective nature of being.⁵ Without internalising these we cannot fully appreciate the interests of others, nor fully discern where their welfare best lies.⁶ When there is a close relationship between two individuals, such as between parent and child, it would seem reasonable to suppose that if one party was incompetent (e.g. the child), then the competent party (parent) would be in the best place to decide the interests of the other. However, as outlined in the previous section, parents do not always act in the best interests of their children, and when medical cases have come before the courts, the judiciary have usually sided with the doctors’, rather than the parents’, perception of best interests.⁷ The courts rule on

¹ Much of this section is drawn from B. Lyons. Children, Best Interests and the Courts: A Response to Bridgeman. *Clinical Ethics* 2010; 5: 188-194.

² J. Fletcher. 1750. The Lovers Progress. In *The Works of Mr Francis Beaumont and Mr John Fletcher, Volume the Fifth*. London: J. and R. Tonson and S. Draper. p404.

³ See S. Elliston. 2007. *The Best Interests of the Child in Healthcare*. London: Routledge-Cavendish. Especially chapter 1.

⁴ Children Act 1989, s1(1).

⁵ T. Nagel. What is it Like to be a Bat? *Phil Rev* 1974; LXXXIII: 435-450.

⁶ K. Atkins. Autonomy and the Subjective Character of Experience. *J Appl Phil* 2000; 17: 71-79. Atkins states: ‘Appreciation of the subjective character of experience brings with it the necessity for an epistemological humility with respect to the lives of others’. p71.

⁷ See for example *Re J (A Minor) (Wardship: Medical Treatment)* [1990] 3 All ER 930; *Re C (A Minor: Medical Treatment)* [1998] 1 FCR 1; *Re A (Children) (Conjoined Twins: Surgical*

these cases because there is a conflict of opinion about where the child's best interests lie. The number of paediatric medical best interests cases is not large, yet many of the judgments (as discussed below) have been the subject of severe academic criticism, usually on the basis that the judicial reasoning employed in reaching a decision is flawed.⁸ The following analysis looks at the judicial use of the best interests principle in a number of cases, but concludes that the best interests of the child are not necessarily singular but are likely to depend on perspective. What turn out to be taken to be the child's best interests are what the person who is invested with the power of ultimate decision-maker deems them to be.

3.2. THE BEST INTERESTS PRINCIPLE

The legislative concept of the 'best interests of the child' first appeared in the Infant Guardianship Act 1925 which advocated that 'the welfare of the infant shall be the first and paramount consideration'.⁹ In reviewing the history of the Bill, Cretney identified that the wording changed from 'sole consideration' in the original text to 'first and paramount'. Lord Haldane, the Lord Chancellor, stated that:

we ought not to look solely at the welfare of the infant, because there may be other considerations which affect the welfare of the infant which should be taken into account. After all, the infant is a member of a social unit, the family.¹⁰

The 'paramountcy principle' came to be echoed in case law where, for example in *Re J*, it was stated that 'it is settled law that the court's prime and paramount consideration must be the best interests of the child'.¹¹ The principle also appears in the CRC, although here the best interests of the child are 'a primary consideration'.¹² During the drafting of the CRC, an attempt by Poland to make welfare paramount

Seperation) [2001] Fam 147; *Re Wyatt (A Child) (Medical Treatment: Parent's Consent)* [2004] EWHC 2247 (Fam).

⁸ See for example B. Hewson. Killing off Mary: Was the Court of Appeal Right? *Med Law Rev* 2001; 9: 281-298. S. Michalowski. Is It In The Best Interests Of A Child To Have A Life-Saving Liver Transplantation? *CFLQ* 1997; 9: 179-190.

⁹ s1(1).

¹⁰ Cited in S.M. Cretney. "What Will the Women Want Next?": The Struggle for Power Within the Family 1925-1975. *LQR* 1996; 112: 110-137. p131.

¹¹ *Re J* [1990] 3 All ER 930 at 943.

¹² Article 3(1).

was rejected, the US objecting most to this proposal.¹³ It is possible to construe the arguments put forward by the various delegates in denying the pre-eminence of the child's best interests in two ways; (a) as an honest perspective that the child is not an isolated entity but lives in a family and a community whose interests on occasion may differ, and thus competing interests must be balanced against each other, or (b) that the Articles were formulated and constructed by adults who took the view that the interests of the child should never take primacy over the rights of adults. Where sole interests are considered they would appear to be determinative in ascribing the course to be followed, while 'primary considerations' would appear to legitimise the trumping of the child's best interests by other concerns.

With regard to healthcare the courts may become involved in determining what a patient's best interests might be in certain situations, the relevant circumstances being outlined by Bingham MR in *Re S*:

The law respects the right of adults of sound mind to physical autonomy ... This simple rule cannot be applied in cases of minors and those subject to serious mental illness, because they may be unable to form or express any, or any reliable, judgment of where their best interests lie. In such situations the law provides for parents or next friends or guardians to speak for the minor or the mental patient ... in cases of controversy and cases involving momentous and irrevocable decisions, the courts have treated as justiciable any genuine question as to what the best interests of a patient require or justify.¹⁴

According to Butler-Sloss P, when applied the 'best interests test ought, logically...give only one answer.'¹⁵ When the court has been required to make serious healthcare decisions in the best interests of minors, Ward LJ had no doubts about the law's ability to reach this singularly correct conclusion:

In the past decade an increasing number of cases have come before the courts where the decision whether or not to permit or to refuse medical treatment can be a matter of life and death for the patient. I have been involved in a number of them. They are always anxious decisions to make but they are invariably eventually made with the conviction that there is only one right answer and that the court has given it.¹⁶

¹³ S. Detrick, et al. eds. 1992. *The United Nations Convention on the Rights of the Child: A Guide to the "Travaux préparatoires"* Dordrecht: Martinus Nijhoff Publishers. pp131-140.

¹⁴ *Re S (Hospital Patient: Court's Jurisdiction)* [1996] Fam 1 at 18.

¹⁵ *Re SL (Adult Patient) (Medical Treatment)* [2000] 2 FCR 452 at 464.

¹⁶ *Re A* [2001] Fam 147 at 155.

Despite his certitude a number of commentators have expressed concerns about both the concept and the practical implementation of this principle.¹⁷ In order to determine the best interests of an individual, Buchanan and Brock suggest a balance sheet:

The best interest principle states that a surrogate is to choose what will ... maximally promote the patient's good. Thus, according to the best interest principle, the surrogate must try to determine the net benefits to the patient of each option, after assigning weights reflecting the relative importance of various interests affected when subtracting the "costs" from the "benefits" for each option.¹⁸

The Children Act 1989 contains a checklist of items that the court should weigh up in order to develop an holistic perspective of a child's welfare,¹⁹ including

- a) the ascertainable wishes and feelings of the child concerned (considered in the light of his age and understanding);
- b) his physical, emotional and educational needs;
- c) the likely effect on him of any change in his circumstances;
- d) his age, sex, background and any characteristics of his which the court considers relevant;
- e) any harm which he has suffered or is at risk of suffering;
- f) how capable each of his parents, and any other person in relation to whom the court considers the question to be relevant, is of meeting his needs; and
- g) the range of powers available to the court under this Act in the proceedings in question.

Although this appears quite comprehensive Breen contends that

there remains a wide variety of circumstances that cannot be accounted for both in the present and in the future, which may distort the validity of the decision as being in the child's best interests. Consequently, according such ability to a decision-maker is to bestow upon him or her shaman-like qualities for the prediction of future events.²⁰

If the principle were to work, then the 'best interests' of the *child* should always prevail over those of parents or society. This is not to say that the interests of others are irrelevant to any consequential analysis, but rather if the 'best interests' of the *child* is to mean what it says, then the interests of others should be subordinate to

¹⁷ For a review of objections to the principle see Elliston (n3) pp1-45.

¹⁸ A.E. Buchanan & D.W. Brock. 1989. *Deciding for Others: The Ethics of Surrogate Decision Making* Cambridge: Cambridge University Press. p94.

¹⁹ s1(3).

²⁰ C. Breen. 2002. *The Standard of the Best Interests of the Child: A Western Tradition in International and Comparative Law*. Dordrecht: Martinus Nijhoff. p17.

those of the child. It should also provide children with judicial protection against decisions that are likely to be harmful; where the burden exceeds the benefit. Yet this appears not always to be the case, and judgments sometimes do seem to run counter to what objectively might seem the child's best interests, particularly if viewed in isolation.

3.3. BEST INTERESTS: SIMILAR CASES, DIFFERENT OUTCOMES

When asked to adjudicate the court sometimes seem to have taken the child's welfare to be the primary concern, including cases where the vaccination²¹ or circumcision²² of a child, or the sterilisation of an incompetent minor has been concerned. With regard to this latter procedure, decisions have not always been uniform, and to illustrate this point I propose to contrast *Re D*²³ and *Re P*²⁴. In *Re D* an application was made to the court that an 11 year-old girl diagnosed with Sotos syndrome might be sterilised. Although attributed with 'dull-normal intelligence' D's mother was convinced her child was 'seriously mentally retarded' and lacked the ability to care for herself.²⁵ D's paediatrician concurred deeming 'that she would always remain substantially handicapped and that she would therefore be unable either to care for or maintain herself or to look after any children she might have'.²⁶ Her mother, worried that D might be seduced and possibly give birth to an abnormal child, wished her to be sterilised. The paediatrician agreed, and made arrangements for the operation to be carried out. Other professionals concerned with D's welfare challenged the reasons for performing the operation and applied for D to be made a ward of court.²⁷ Heilbron J ruled that 'the operation was neither medically indicated nor necessary, and it would not be in D's best interests for it to be performed'.²⁸ D's

²¹ *Re C* [2003] 2 FLR 1095 CA.

²² *Re J* [2000] 1 FLR 571. The issue of the child's interests and circumcision was only reviewed because the parents disagreed on the matter. If both had wanted a circumcision then, almost certainly, it would never have come before the court. But in *Re J*, the mother refused and since the child was not being brought up in the Muslim faith, then circumcision was adjudged not to be in his interests. The vaccination case above became the object of legal scrutiny because of a similar parental disagreement.

²³ *Re D (a minor) (Wardship: Sterilisation)* [1976] 1 All ER 326.

²⁴ *Re P (A Minor) (Wardship: Sterilisation)* [1989] 1 WLR 182.

²⁵ *Re D* at 326.

²⁶ *Ibid.*

²⁷ The application was made by Mrs Hamidi, who was an educational psychologist attached to the educational department of D's local authority.

²⁸ *Re D* at 335.

mental and physical future prospects were unpredictable, and although she was as yet unable to understand or appreciate the implications of the operation, it was likely that in later years she would be able to make her own choice.

This judgment contrasts markedly with that of Eastham J in *Re P*. An application was made to the court that a 17 year-old girl, with an apparent mental age of six, might be sterilised. The court approved the application on the basis that

given the evidence that the ward was attractive with normal sexual urges, that she was particularly vulnerable and had some maternal instincts and that it would be a disaster if any baby when born were removed from the ward, the risk of her becoming pregnant should be avoided at all costs. In those circumstances, the ward's welfare dictated that she should have the operation and leave would be given for the sterilization to be carried out.²⁹

This judgment seems wrongheaded for a number of reasons. First, if a girl with a learning disability is likely to become sexually active, then she needs to be given the tools to stay safe from sexual predation and the risks of sexually transmitted disease, rather than simply rendered unable to become pregnant. There are also other, less drastic, methods of preventing conception, and most of these were available in 1989. Second, if being 'vulnerable to seduction' is the criterion by which sterilisation is approved, almost all women with learning disabilities might be subjected to such procedures. Unfortunately, there is a long history of legally sanctioned sterilisation of the 'mentally defective' in many countries.³⁰ Third, it was clear that the girl's designated mental age of six was not true across all domains of capacity. It was apparent that she had a comprehension of what was involved in sexual intercourse; she could deal with her own bodily functions herself and demonstrated some maternal feelings. A psychiatric report indicated that she had evolving capacities in terms of 'general emotional awareness, self-care skills and social skills.'³¹ There was evidence that 'were she to encounter a socially competent, reasonably intelligent man upon whom she could depend...marriage and the raising of a child might be feasible'.³² One psychiatrist acknowledged that she might even have the capacity to consent to sterilisation, that 'with patient and skilled explanation...[she] could come to understand that a sterilization operation meant that she could not have children in

²⁹ *Re P* at 182.

³⁰ E.A. Brantlinger. 1995. *Sterilization of People With Mental Disabilities: Issues, Perspectives, and Cases*. Westport CT: Greenwood Publishing Group. pp17-36.

³¹ *Re P* at 190-1.

³² *Re P* at 192.

the future.’³³ There is no evidence in *Re P* that any such dialogue took place. Finally, that becoming pregnant might be a disaster is something that could be said in the case of many, if not all, young girls. This does not provide a rationale for sterilisation. Despite the undoubted best intentions of the judge, in this instance the decision to sterilise served the interests of P’s family and community by removing their need to be concerned about one aspect of her life.

What are we to make of these two contradictory judgments? Eastham J suggested that the child in the case of *Re D* had less of a disability than the child in *Re P*, yet he provided no empirical evidence to substantiate this justificatory claim. There was also conflicting psychiatric evidence and Eastham J chose to accept the evidence of one psychiatrist over another, again providing no substantive reasons for doing so. The best interests of the individuals at the centre of these two similar cases ultimately turned out to be determined as being considerably different; one was sterilised and one was not. Yet this difference appears to hinge upon an unsubstantiated empirical claim and an unjustified judicial preference for the testimony of one psychiatrist over another. If the concept of best interests is so critical in determining outcomes to decisions of momentous import in the lives of young people, it must rest upon something more philosophically secure than a judicial whim.

3.4. IN THE BEST INTERESTS OF THE CHILD?

Notwithstanding, or perhaps because of, the ambiguous nature of the best interests concept, there would appear to have been some particularly contentious applications of the doctrine. Perhaps the most controversial attribution of best interests to a child came in *Re A*, a case of conjoined twins. Jodie was the larger twin, sharing a bladder and aorta with Mary to whom she was attached at the spine. Mary was incapable of independent survival, as she was dependent on blood flow from Jodie, who had a reasonable chance of survival with surgical separation. Such a procedure would inevitably kill Mary. In his judgment, Walker LJ opined that it was in Mary’s best interest to suffer such surgical destruction, because death would grant her ‘bodily integrity’ and thus dignity.³⁴ Brooke LJ concurred:

³³ *Re P* at 190.

³⁴ *Re A* [2001] Fam 147 at 184.

the doctrine of the sanctity of life respects the integrity of the human body. The proposed operation would give these children's bodies the integrity which nature denied them.³⁵

It is undoubted that Mary was dependent upon her sister for life, and that it was unlikely to be in Jodie's best interests for this dependence to continue. There was thus an apparent conflict of interests between the twins, the resolution of which would involve the sacrifice of one or the death of both of them. According to Jackson, the court decided to take a utilitarian approach and try to save the life of Jodie against the wishes of her parents.³⁶ This position dictated that the interests of one twin, who could potentially survive independently, trumped those of the second twin, who could not. The particular merits of this judgment have been discussed extensively elsewhere and need not concern us here.³⁷ However, the mechanism for arriving at this decision is relevant. In *Re F* Lord Brandon stated that treatment of incapacitated individuals could only lawfully proceed if

the operation or other treatment concerned is in the best interests of such patients. The operation or other treatment will be in their best interests if, but only if, it is carried out in order either to save their lives, or to ensure improvement or prevent deterioration in their physical or mental health.³⁸

The proposed operation was not going to provide Mary with either an extension of her life or a material improvement in her health and, despite judicial protestation, there would not appear to be much integrity in a body with no aorta, bladder or blood flow. Yet according to Brooke and Walker LJ it was in the interests of both twins to surgically separate them. It seems to require a particularly lateral interpretation of a child's best interests to suggest that for Mary surgical destruction was somehow preferable to continued dependence.

However, whenever such an end-of-life case comes before the courts, a decision must be made about whether to continue or institute life-saving treatment.

³⁵ Ibid at 240.

³⁶ E. Jackson. 2006. *Medical Law*. Oxford: Oxford University Press. p980. However, the judges claimed to be making a principled decision, rather than a consequentialist one. The principles advanced related to the doctrines of best interests, human dignity and double-effect (Walker LJ), self-defence (Ward LJ) and necessity (Brooke LJ), and were largely derived from the 'right to life'. Hewson (n8) argues that the individual judgments are difficult to reconcile with each other, and at times are internally contradictory. p291.

³⁷ See for example, J. Harris. Human Beings, Persons and Conjoined Twins: An Ethical Analysis of the Judgment in *Re A*. *Med Law Rev* 2001; 9: 221-236. Hewson (n8).

³⁸ *Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1 at 55.

These cases generally reach the court because there are opposing positions; usually that of the parents who generally wish for treatment to continue, and that of the healthcare professionals, who argue that continuing care is futile or maleficent.³⁹ Many of these cases require that value judgments are made about the quality of life of disabled individuals,⁴⁰ and some standard of a life worth living must be invoked in order to make a judgment possible. In *Re B Templeman* LJ argued that the child's life must be demonstrably awful before non-treatment is contemplated.⁴¹ In *Re C* Sir Stephen Browne stated that withholding care was in C's 'best interests to prevent her from suffering'.⁴² In *Re J Taylor* LJ tried to apply the doctrine of substituted judgment: 'The test must be whether the child in question, if capable of exercising sound judgment, would consider the life tolerable.'⁴³ The standard set therefore appears to be that for a life to be worth living it must be tolerable, not awful and without suffering from the perspective of the healthy adult. For the purposes of this discussion we may put aside the potential objection that this may not be the same perspective as that of the seriously ill or disabled child who is the subject of legal scrutiny. If this is the standard to be applied and the child's best interests are the most important concern then this should be clearly reflected in judicial conclusions.

However, this position seems incompatible with the judgement in *Re T*, where the court appears to have decided that the interests of others outweighed those of the child.⁴⁴ In this case, the Court of Appeal acceded to a maternal wish to refuse lifesaving treatment for her child because 'the mother was loving and caring and was acting in good faith in what she believed to be the best interests of T'.⁴⁵ The court agreed with the position taken by T's mother despite overwhelming medical evidence that T would die without the proposed and potentially very successful liver transplant. In determining T's best interests Roch LJ argued thus:

If the proper stance for parents is that, whenever there is a treatment which may prolong the life of their child, then that treatment should be accepted, a

³⁹ Sometimes the positions are reversed such as in *Re B (A Minor) (Wardship: Medical Treatment)* [1982] 3 FLR 117 where the parents refused consent for surgeons to operate on their son because he had Down's syndrome. See also *Re A*.

⁴⁰ See for example *Re Wyatt* [2004] EWHC 2247 (Fam).

⁴¹ *Re B* [1982] 3 FLR 117 at 122.

⁴² *Re C* [1998] 1 FCR 1 at 10.

⁴³ *Re J* [1990] 3 All ER 930 at 945.

⁴⁴ *Re T (A Minor) (Wardship: Medical Treatment)* [1997] 1 WLR 242. Although the child in question was referred to as C throughout the case, I will refer to him as T to avoid confusion.

⁴⁵ *Re T* at 244.

decision not to accept that treatment would be unreasonable. But in my opinion that cannot be and will not be the answer in every case ... The presumption in favour of the sustaining of life is not irrebuttable.⁴⁶

If the proposed treatment in *Re T* was arguably futile then one could understand the judicial position, but, in fact, T 'was... a good candidate with good prospects for a favourable outcome.'⁴⁷ Nevertheless, Roch LJ continued:

At present the evidence indicates that this child has a happy and secure life with his parents in country AB. It is true that that life will be a very short life which will end when the child is still a baby, but at a time before the child can become aware of the significance of his condition and its consequences. I do not consider that it is in the child's best interests to disrupt his present life by the court giving its consent to his undergoing a liver transplant operation and ordering the mother to return with him to this country with all the distress and uncertainties that that will inevitably entail for the child in the special circumstances that exist in this case.⁴⁸

The court preferred that the child should have a short happy life rather than (most likely) a significantly longer life involving medical intervention where the level of happiness T might attain would be speculative.

In the original hearing Connell J did attempt to evaluate T's best interests in light of the quality of life he would most likely enjoy after the liver transplant, and as a consequence decided that the maternal refusal to consent to a life-saving operation was unreasonable.⁴⁹ But the Court of Appeal overturned this decision, but in so doing had to consider the judgment in *Re B*.⁵⁰ This case concerned a baby girl born with Down's syndrome and an associated intestinal obstruction. Without surgery, which the parents refused, she would die within a very short time. With a successful operation her life expectancy was 20 to 30 years. Templeman LJ, in considering the baby's best interests, stated that the court had

to decide whether the life of this child is demonstrably going to be so awful that in effect the child must be condemned to die, or whether the life of this child is still so imponderable that it would be wrong for her to be condemned to die.⁵¹

⁴⁶ *Re T* at 256.

⁴⁷ *Re T* at 255.

⁴⁸ *Re T* at 257.

⁴⁹ Michalowski (n8) pp179-180.

⁵⁰ *Re B* [1982] 3 FLR 117.

⁵¹ At 122.

In her judgement Butler-Sloss LJ distinguished between *Re B* and *Re T* on the basis that the surgery involved in the latter would be more severe and require greater maternal aftercare. However, the long-term prognosis in both cases would be dependent on the level of carer devotion, the outcome for a learning disabled child with Down's syndrome being especially reliant upon the level of care. As a consequence, Michalowski argued that the 'appropriateness of the distinction made by Butler-Sloss LJ can thus be questioned.'⁵²

Re T is a case where the law seems to have decided that the child's interests must be balanced against other competing interests, that they 'must take their place in a world full of interests.'⁵³ However, Jackson states 'this was not in fact a case where there could reasonably be any disagreement about where the child's best interests lay.'⁵⁴ The Court of Appeal, in overturning the judgement of Connell J, decided that ultimately the child's interests were subordinate to those of the parents. Despite insistence that this case is an anomaly (the court giving undue and 'erroneous' weight to the apparent reasonableness of the mother's refusal)⁵⁵, it is, nonetheless, illustrative of the fact that the best interest concept is subject to adult manipulation. In *Re P* and *Re T* it is clear that adult concerns have weighed more heavily with the court than the child's interests. Such decisions may sometimes be in the best overall interests of a family or community, but not necessarily in the best interests of a child. As Eekelaar observes the doctrine 'might fail to provide sufficient protection to children's interests because its use conceals the fact that the interests of others...actually drive the decision.'⁵⁶

3.5. THE PROBLEM WITH BEST INTERESTS

This brief review obviously contains a selective perspective of the best interests concept, and it might be argued that it is not legitimate to cherry-pick a number of cases to make a general point. But, if this notion going to be used in a determinative fashion, if its application should yield a single answer, and if the judiciary are always correct in its interpretation, then it should not be possible to identify any cases where the outcome is contrary to the child's best interests. But this

⁵² Michalowski (n8) p185.

⁵³ J. Eekelaar. Beyond the Welfare Principle. *CFLQ* 2002; 14: 237-249. p239.

⁵⁴ Jackson (n36) p230.

⁵⁵ Ibid. p230.

⁵⁶ Eekelaar (n53) p237.

is not so, and Elliston has identified a number of pertinent reasons why the test does not work.⁵⁷ Most importantly, it relies upon the subjective values of the decision-maker, and his or her speculative view of indeterminate outcomes.⁵⁸ Values and perceptions differ, and thus Wilkinson suggests that while the ‘best interests of the child is a laudable standard to appeal to...it may provide little practical guidance to decision making.’⁵⁹ Perhaps of greater concern, as Mnookin and Szewad observe, is that

The phrase is so idealistic and high sounding that it defies criticism and can delude us into believing that its application is an achievement in itself. Its mere utterance can trap us into believing that we are doing something effective and worthwhile.⁶⁰

The doctrine of ‘best interests’ is used in a wide variety of legal cases, not just in those concerning healthcare issues.⁶¹ Despite the divergent nature of the cases, however, there remains a common theme: the subjective adult lens through which the concept is viewed. Whenever there is a conflict of opinion about how to manage a child’s affairs, whether it concerns which parent the child should live with or whether physicians should withhold life-sustaining treatment against parental wishes, adult protagonists on either side of the dispute are likely to appeal to the child’s best interests as a means of legitimising their arguments. If wholly different outcomes are being petitioned for by opposing camps and Butler-Sloss P’s assertion that the ‘best interests test ought ...give only one answer’⁶² is true then, logically, in every dispute either one side is misapplying the concept or both sides are in error and a third way reflects what is best for the child. However, the child’s welfare is not just appealed to as a matter of course in these cases, but often passionately and with great conviction by opposing sides.⁶³ This should raise the (possibly unwelcome) idea in the mind of

⁵⁷ Elliston (n3).

⁵⁸ S. Parker. The Best Interests of the Child - Principles and Problems. *Int J Law Policy Family* 1994; 8: 26-41.

⁵⁹ D. Wilkinson. Is it in the Best Interests of an Intellectually Disabled Infant to Die? *J Med Ethics* 2006; 32: 454-459. p459.

⁶⁰ R.H. Mnookin & E. Szwed. 1983. The Best Interests Syndrome and the Allocation of Power in Child Care. In *Providing Civil Justice for Children*. H. Geach & E. Szwed, eds. London: Hodder Arnold. p8.

⁶¹ B. Resetar & R.E. Emery. Children's Rights in European Legal Proceedings: Why are Family Practices so Different from Legal Theories? *Family Court Review* 2008; 46: 65-77.

⁶² *Re SL* at 464.

⁶³ See for example *Re A* [2001] Fam 147; *Re Wyatt* [2004] EWHC 2247 (Fam); *Re J* [2000] 1 FLR 571.

the court that the answer may not necessarily be singular, but rather depend upon perspective. To accept this, however, would be to acknowledge that the concept lacks objective value.

Ultimately, however, the law is a matter of binary decisions, and it is the judicial reading of a child's best interests that determines whether that child will be sterilised or not, or whether she will live or die. In her response to an article critical of the use of the best interest principle in deciding treatment for critically-ill children,⁶⁴ Bridgeman endorsed the notion that the judiciary could arrive at a decision that is in the *best* interests of the *child*, and cited the ruling of Holman J in *An NHS Trust v MB*⁶⁵ as a paradigm case.⁶⁶ Yet this decision did not reflect the child's best interests from either the parents' or the healthcare professionals' perspective, but rather was Holman J's perception based on the facts of the case examined in light of *his* values. During the debate on the wording of the CRC it was noted by a delegate that the phrase best interests was 'inherently subjective and that its interpretation would inevitably be left to the judgment of the person, institution or organization applying it'.⁶⁷ Similar scepticism regarding the utility of the principle was articulated in an Australian High Court case concerning the sterilisation of a learning disabled girl:

it must be remembered that, in the absence of legal rules or a hierarchy of values, the best interests approach depends upon the value system of the decision-maker. Absent any rule or guideline, that approach simply creates an unexaminable discretion in the repository of the power.⁶⁸

I suggest that the best interests doctrine has little to offer in resolving disputes, as it appears to be a device which allows opposing parties to adopt ever more trenchant positions. Where resolution proves impossible then contested paediatric medical cases may end up in court, the judge thus becoming the 'repository of the power'. The court must come to a decision, but it seems illogical to hold that the judge can divine the best interests of the child better than either the parents or the medical and nursing staff caring for the child. A judge's ruling is nothing other than a

⁶⁴ P. Baines. Death and Best Interests. *Clinical Ethics* 2008; 3: 171–175.

⁶⁵ [2006] EWHC 507 (Fam).

⁶⁶ J. Bridgeman. A Response to 'Death and Best Interests'. *Clinical Ethics* 2009; 4: 15-18.

⁶⁷ P. Alston. The Best Interests Principle: Towards a Reconciliation of Culture and Human Rights. *Int J Law Policy Family* 1994; 8: 1-25. p11.

⁶⁸ *Secretary, Dept of Health and Community Services v JWB and SMB* (1992) 175 CLR 218 at 271 per Brennan J (in dissent).

dispassionate legal decision, and to invest it with some sort of prophetic vision seems absurd.

3.6. CONCLUSIONS

Despite my scepticism, I am not denying that the best interests concept has some utility. It reminds us that children have interests as individuals that must be considered in any decision-making process. The issue is not whether it is a good thing to advance a child's interests, but rather that where incompetent children are concerned, we cannot sufficiently identify what those interests are. Thus, I remain uneasy over claims concerning the identification of a child's best interests in such cases, and also wary of justificatory claims made by academics about the use of the principle. Rather, I would suggest, as per Brennan J, that decisions are made by those with the power and authority to do so. While sometimes such decisions might accord with the child's *actual* best interests (should it be possible to divine what they are), the decision generally reflects the perspective and/or interests of those with decisional power.

CHAPTER 4

PHILOSOPHICAL APPROACH: POWER

*The laws of social dynamics are laws which can only be stated in terms of power*¹

4.1. BIOETHICS, CONFLICT AND POWER

Bioethics, it has been argued, most often examines issues of power and conflict, disputes about ‘value, interest, opinion, or worldview’.² Annas has proposed that the discipline has ‘always been concerned with power ... bioethics has been a reaction against the arbitrary use of power’.³ Similarly, Benatar has contended that

A major focus within the modern bioethics debate has been on reshaping power relationships ... Empowerment of the vulnerable has been achieved through an emphasis on human rights and respect for individual dignity. However, power imbalances remain pervasive within healthcare.⁴

While these statements mostly deal with the power balance between doctors and patients, taken together they reflect much of the substance of practical bioethics; of the forces that are at play when we seek to answer the question ‘what is the right or good thing to do?’ in the context of a moral problem. Conflicts of opinion lead to disputed outcomes in contested cases. Frequently, the problem is not so much that there is no answer to ‘what is the right or good thing to do’, but rather that there is not a singular solution.⁵ Instead, there may be a number of mutually exclusive reasoned moral responses that have greater or lesser degrees of legitimacy, depending on perspective.⁶ Sometimes these differing viewpoints are of academic interest, as in the case of transhumanism for instance; but more often they are of enormous importance in the lives of individuals and groups. In these situations the conflict between the ideals, values and interests of disputing parties holds real life

¹ B. Russell. 1975. *Power*. London: Unwin Books. p9.

² M.B. Brown. Three Ways to Politicize Bioethics. *Am J Bioethics* 2009; 9: 43–54. p44.

³ G.J. Annas. 2005. *American Bioethics: Crossing Human Rights and Health Law Boundaries*. New York: Oxford University Press. p xv.

⁴ S.R. Benatar. Bioethics: Power and Injustice. *Bioethics* 2003; 17: 387-398. p387.

⁵ J.D. Arras. Common Law Morality. *Hastings Cent Rep* 1990; 20: 35-37. p37.

⁶ M. Powers. Bioethics as Politics: The Limits of Moral Expertise. *Kennedy Instit Ethic J* 2005; 15: 305-322. p317.

(and sometimes death) significance.⁷ The recent case of Tony Nicklinson, a 56 year-old man with locked-in syndrome who wishes to end his life, is a paradigm case.⁸ He is unable to commit suicide, and to die quickly would need assistance. His wish to have an assisted death is opposed by the legislative state, medical representative bodies and religious institutions. While this might seem to be a 'hard case' in the face of a general policy, it also represents a conflict between a profoundly disabled individual and the collective might of the state over the control of his body.⁹ The outcome of the conflict is not just of significance in determining how Mr Nicklinson (or others in a similar situation) lives and dies, but holds wider consequences for society in that it reflects the balance of power between the state and the autonomous individual with regard to what a person might do with their body.

Does the moral and legal dispute between Mr. Nicklinson and the state constitute conflict? While the term might seem to pertain only to war or violent arguments, many social theorists hold that conflict is a general social form that is not restricted to just overtly vicious confrontations.¹⁰ Conflict is a physical or symbolic confrontation in which one party's words or actions are opposed by another in the belief that they have irreconcilable objectives.¹¹ At its simplest, conflict is thus a category of social behaviour where two parties attempt to attain something which they both cannot have.¹² In the context of bioethics, conflict occurs when some individuals or groups with a stake in some aspect of biomedicine perceive that their goals related to policy, research, care or outcomes are being frustrated by the incompatible aims of others.¹³ Some bioethical disputes, such as those relating to 'end of life' and 'right to life' issues, or those pertaining to the allocation of scarce healthcare resources may, on occasion, entail overt (and sometimes violent)

⁷ A.R. Jonsen. The Birth of Bioethics. *Hastings Cent Rep* 1993; 23: S1-4. pS2.

⁸ R. Booth. 'Locked-In' Syndrome Man Demands Right To Die. *The Guardian* Monday, 19 July 2010.

⁹ M. Foucault. 1998. *The History of Sexuality, Vol.1: The Will to Knowledge*. Harmondsworth: Penguin. p143.

¹⁰ K. Allan. 2006. *The Social Lens: An Invitation to Social and Sociological Theory*. Thousand Oaks, CA: Pine Forge Press. p211.

¹¹ L. Kriesberg. 2006. *Constructive Conflicts: From Escalation to Resolution* 3rd edn. Lanham MD: Rowman & Littlefield. p2.

¹² R.J. Rummel. 1976. *Understanding Conflict and War, Vol. 2: The Conflict Helix*. Beverly Hills: Sage. 26.1.

¹³ L.M. Edelstein, et al. Communication and Conflict Management Training for Clinical Bioethics Committees. *HEC Forum* 2009; 21: 341-349. p342.

confrontation.¹⁴ Others, such as arguments between parents over vaccination, usually remain at the level of social, moral and legal discourse. Conflict theories aim to explain and map conflict in society; how conflict starts and varies, and what effects it brings. A substantial number of theories have been proposed by social scientists, philosophers, historians and psychologists relating to issues of wealth, class, nationality, ethnicity and gender amongst others. All of these matters are germane to bioethics, and they provide a backdrop against which moral issues are viewed.

Both power and conflict are intrinsically neutral concepts. Power may be used for good or evil; a conflict might be just or unjust, but there is no moral bias inherent in either notion. As an example of this neutrality we might consider an end-of-life conflict relating to the withholding or withdrawing of care from a critically-ill child. Here conflict may occur when parents want ‘everything possible’ done, and doctors hold that particular interventions are futile, or even maleficent. Parents seek to exercise their power as primary carers, doctors theirs which is based on status and knowledge. As discussed previously both sides may well appeal to the best interests of the child in order to achieve primacy, but in neither case are the antagonists attempting to use their power for malevolent ends. When the dispute appears intractable, the outcome is likely to be adjudicated upon by the courts, which have usually favoured the medical position.¹⁵

The social theorist, Lewis Coser, has proposed that most conflict arises from the unequal distribution of one or more of three elements: scarce resources, status, or power.¹⁶ Thus, one of the fundamental concerns of conflict theories is the distribution of power, where it is located, who uses it (or does not), how they use it and to what effect. There are many definitions of power, but common to most conceptions are (1) power as control over resources; (2) power as control over actors; and (3) power as control over outcome.¹⁷ These divisions may be simplified into two: (a) *power over* something or somebody, and (b) *power to* effect some change, or achieve an intended goal. All forms may be employed in getting from the initial

¹⁴ R. McVeigh & D. Sikkink. God, Politics, and Protest: Religious Beliefs and the Legitimation of Contentious Tactics. *Social Forces* 2001; 79: 1425-1458.

¹⁵ M. Brazier. An Intractable Dispute: When Parents and Professionals Disagree. *Med Law Rev* 2005; 13: 412-418.

¹⁶ L. Coser. 2002. Conflict. In *The Blackwell Dictionary of Modern Social Thought*. W. Outhwaite, ed. Oxford: Blackwell: 106-108.

¹⁷ Z. Maoz. Power, Capabilities, and Paradoxical Conflict Outcomes. *World Politics* 1989; 41: 239-266. p240.

moral problem to the disputed outcome in contested cases. Power plays a pivotal role in conflicts, the exercise of power being essential to the resolution of the particular issue. In essence, power determines who gets to decide; it is the primary factor that determines social relations.¹⁸ It has been stated that it is rarely the situation that one party is powerless; even in the above example Mr Nicklinson is not suffering an absolute deprivation of power – he has the facility to initiate legal proceedings, to fight his corner, so to speak.¹⁹ However, most young children are powerless, and in the absence of having a voice they remain vulnerable to potential abuse at the hands of those with power.

4.2. CONFLICT OF INTERESTS

However, social conflict is not necessarily bounded by antagonism or overt opposition. Coser has argued that

A distinction between conflict and hostile sentiments is essential. Conflict, as distinct from hostile attitudes or sentiments, always takes place in interaction between two or more persons. Hostile attitudes are predispositions to engage in conflict behavior; conflict, on the contrary, is always a transaction.²⁰

As an example of this Rummel outlines conflicts which may take place between what he terms ‘altruistic powers’, through the processes of accommodation, obligation, or beneficence:

We do not think of altruism (or love) and conflict as joined together, but clashing inductive vectors are a common experience among lovers. For example, consider the possible exchange of lovers over the last piece of cake. “You take it.” “No, that's all right, it's yours.” “No, I really don't want it.” Each really desires it, knows that the other does also, and selflessly tries to give it to the other. Such altruistic conflicts are a common measure of social solidarity.²¹

The point of this is that conflict may occur between people who love each other and who wish to act for the betterment of the other. If we take the example of ritual male circumcision we can briefly examine this idea, although in this instance it is one party acting in accordance with what they perceive to be the benefit of the second

¹⁸ M. Foucault. 1983. The Subject and Power. In *Michel Foucault: Beyond Structuralism and Hermeneutics*. H. Dreyfus & P. Rabinow, eds. 2nd edn. Chicago: U of Chicago Press. p200.

¹⁹ W. Korpi. Conflict, Power and Relative Deprivation. *Am Pol Sci Rev* 1974; 68: 1569-1578

²⁰ L. Coser. 1956. *The Functions of Social Conflict*. New York: Free Press. p37.

²¹ Rummel (n12) 27.1.

party. Even if one accepts that the majority of parents who have their sons circumcised love that child, nonetheless, it is quite easy to construct an argument stating that infant circumcision, for non-medically indicated reasons, is a breach of the child's bodily integrity brought about through state-endorsed parent power.²² It is not a procedure performed to improve the health of the child, and although some commentators might contend that circumcision might offer health benefits (most recently with regard to sexually transmitted HIV infection), this is not the underlying reason for circumcising the child in the first place. Ritual, rather than the sort of domestic cleansing rationale advocated for many years by American family physicians,²³ constitutes the marking of a boy's inclusion in a particular cultural or spiritual community. In religious terms, circumcision is a symbol that distinguishes the believer from the non-believer.²⁴ Parents who love their children and are part of a particular group where circumcision is an essential feature of kinship are going to want their child also to be enmeshed in the society that is a vital part of their being. Thus, there is a tension between the child's right to bodily integrity and his parents' wish for his inclusion in their community. This particular conflict is resolved through parental control of the child's foreskin, an empowerment that is judicially and medically reinforced. In this specific instance the British Medical Association has held that 'parents should be entitled to make choices about how best to promote their children's interests, and it is for society to decide what limits should be imposed on parental choices'.²⁵

'Society', thus far, has not prohibited ritual circumcision and while not specifically legislated for, the Law Commission²⁶ has endorsed the *obiter dicta* comments of Lord Templeman which suggested that the procedure is one of a number of 'lawful activities' that 'involve actual bodily harm'.²⁷ Thus, in situations of conflict of interests, although parents may love a child (and vice versa), there are

²² See for example M. Fox & M. Thomson. A Covenant with the Status Quo? Male Circumcision and the New BMA Guidance to Doctors. *J Med Ethics* 2005; 31: 463-469.

²³ G.P. Miller. Circumcision: Cultural-Legal Analysis. *Virginia J Soc Pol Law* 2002; 9: 497-585.

²⁴ S.K. Hellsten. Rationalising Circumcision: From Tradition to Fashion, from Public Health to Individual Freedom - Critical Notes on Cultural Persistence of the Practice of Genital Mutilation. *J Med Ethics* 2004; 30: 248-253. p252.

²⁵ British Medical Association. 2003. *The Law and Ethics of Male Circumcision: Guidance for Doctors*. London: BMA. p3.

²⁶ Law Commission. 1995. *Consent in the Criminal Law (Consultation Paper 139)*. Norwich: TSO. para 9.3.

²⁷ *R v Brown* [1993] 2 All ER 75 at 78-9.

certain ways in which parents may use their power to harm a child, even if it is for their putative overall good. The idea that acts can be performed on children because 'it is for their own good' seems widespread, and is particularly prominent in justifying the use of corporal punishment.²⁸ Physical chastisement is the quintessential embodiment of adult power, and while purportedly exercised for the good of the child, the possibility that any benefit will accrue to a child from being disciplined in this way is hotly contested.²⁹

4.3. FAMILIES AND POWER

It seems obvious that families are constructed around a set of power relations. In families with young children, parents make the decisions. Even as children get older, more articulate and knowledgeable, parents still have a dominant voice when it comes to choices. In everyday life parents have considerable influence over their children's bodies; through direct physical power, by offering rewards or threatening punishments, or by influencing opinions,³⁰ and the exercise of parental power shapes children's lives in many ways. The source of this power is historical in origin. The theologian, Karl Barth, held that 'the essential basis of parental authority is not biological in origin or seniority or assumed or established virtue'.³¹ Rather, parents hold their position through divine grace, and 'from the standpoint of children ... are ... God's natural and primary representatives'.³² This position was arrived at through biblical exegesis; and the bible provides a rich account of parental power, including the right to have put to death the 'stubborn and rebellious son'.³³ The point of this is not to argue that parental power is divine in origin, but rather that parents today have power over their children because parents have always had power over their children, and in many societies this position is reinforced through laws enshrined in religious texts.³⁴ Although parents have always had power, its content has varied according to cultural norms across societies and eras. Thus, condemning children to death for

²⁸ C.G. Ellison & D.E. Sherkat. Conservative Protestantism and Support for Corporal Punishment. *Am Sociol Rev* 1993; 58: 131-144.

²⁹ Council of Europe. 2008. *Eliminating Corporal Punishment: A Human Rights Imperative for Europe's Children*. Strasbourg: COE.

³⁰ Russell (n1) p25.

³¹ W. Werpehowski. 2001. Reading Karl Barth on Children. In *The Child in Christian Thought*. M.J. Bunge, ed. Cambridge: Eerdmans: 386-405. p394.

³² Ibid. p395.

³³ Deuteronomy 21:18-21.

³⁴ Ellison & Sherkat (n28).

disobedience is no longer acceptable in liberal societies, but the imbalance of power between parent and child persists. It is not straightforward to legitimate this power without some reference to a person's power over what they have created (or acquired in the case of adoption). One could appeal to the retrospective consent of the ex-child, but this is problematic. An adult may have suffered a particularly unhappy childhood wrought by the attitudes and behaviour of his parents, but if he survives it and retains some sense of filial affection or obligation, he may well provide retrospective consent.³⁵ However, this cannot invest all parental actions with moral legitimacy.

On the other hand, some commentators have tried to circumvent this problem by suggesting that it is not so much the parents making decisions as 'the family'. Ross, for example, argues that parents act as 'agents of the family', an institution where intimacy creates a sense of shared well-being. Other-regarding and self-regarding activities blur into each other, and 'the difference between egoism and altruism collapses'.³⁶ Thus, family decisions are not parental decisions but family-as-a-whole decisions. However, this seems a little odd. A family is not a democracy where each individual has equal voting rights. Nor is it a collective unit where decisions are only put into action when there is universal agreement.³⁷ Instead, parents sit in the position of decisional power, although in certain cultures the grandparents, or patriarchal head of the extended family, may have considerable influence over decisions taken. As Houlgate has observed, it makes little

sense to say that a family has decided to go on holiday, rather one can infer that certain individuals within the Smith family (such as the parents) have reached this decision ... and imposed upon the rest.³⁸

Because of their dominant position, parents make decisions which have an enormous influence on the life of the developing child. They decide what a child will be named, what she will eat, drink, wear and play with; whether and where she will go to religious worship, what kind of punishments she will be subject to for breaches of

³⁵ D. Archard. 2010. *The Family: A Liberal Defence*. London: Palgrave MacMillan. p37.

³⁶ L.F. Ross. 1998. *Children, Families and Healthcare Decision-Making*. Oxford: Clarendon Press. p31.

³⁷ A.E. Buchanan & D.W. Brock. 1989. *Deciding for Others: The Ethics of Surrogate Decision Making* Cambridge: Cambridge University Press. p237.

³⁸ L. Houlgate. 1988. *Family and State: The Philosophy of Family Law*. Totowa, NJ: Rowman and Littlefield. p36.

discipline and who she can associate with outside of school. In essence, outside of legally mandated minimal educational requirements and child labour and welfare statutes, parents may make wide-ranging decisions that affect almost every aspect of a child's life.³⁹ While contemporary parental powers fall short of those possessed by the Roman patriarch, nonetheless they are extensive.

4.4. STATE, FAMILIES AND POWER

It would also seem true that the state sits in a position of power with respect to the family unit. State agencies may intrude upon family privacy in certain circumstances, and overall will be the arbiter of whether parents retain power over their children, or whether the state will invest that power in others, such as in one of its own organisations. The extent of state interference in family matters is organic, a continuously evolving process as governments perceive different social roles for children and families. For example, in 1807, as part of the Poor Law provisions, a Bill advocating that children should receive two years of formal education between the ages of seven and 14 was proposed, but rejected on the grounds of expense, the possible creation of social dissatisfaction amongst the underclass, and the removal of a vital part of the manual labour force from their workplace.⁴⁰ Subsequently, the Factory Acts of 1833, 1844, and 1867 imposed limits on children's working hours and conditions, partly in response to increased mechanisation and a diminished need for child labour.⁴¹ By this time other countries, Germany in particular, had become economically superior to Britain, a position that was put down (in part at least) to the development of progressive and technical education systems.⁴² Although impoverished parents protested at the impositions of the various Acts⁴³ - they could no longer send their children out to work as they wished and thus were deprived of essential income in many cases⁴⁴ - the government passed the Education Act in 1870. Amongst the various provisions contained in the Act was mandatory school

³⁹ R. Probert, et al. eds. 2009. *Responsible Parents and Parental Responsibility*. Oxford: Hart Publishing. Chapter 1.

⁴⁰ K. Woodroffe. The Making of the Welfare State in England: A Summary of Its Origin and Development. *J Soc Hist* 1968; 1: 303-324.

⁴¹ C. Nardinelli. Child Labor and the Factory Acts. *J Econ Hist* 1980; 40: 739-755.

⁴² J. Joll. 1990. *Europe Since 1870*. 4th edn. London: Penguin. p2.

⁴³ J. Merriman. 1996. *A History of Modern Europe Vol. II: From the French Revolution to the Present*. London: W.W. Norton. pp698-9.

⁴⁴ A. Ure. 1835. *The Philosophy of Manufactures*. London: Charles Knight. pp404-408

attendance for children aged between five and 13. The purpose of compulsory education was 'less to spread literacy and improve life chances than to inculcate morality and social order and to further national integration.'⁴⁵ Today, education remains obligatory although contemporary parental perception tends to be one where scholarly attainment equates with success and status. Nonetheless, the state retains the power to enforce minimal educational provisions regardless of whether the wishes of parent or child are in opposition to this position.⁴⁶

4.5. MEDICAL POWER

Associated with state power, and central to much bioethical conflict, is the concept of medical power which is traditionally (but disputably) assumed to be based on status and knowledge.⁴⁷ The 1960s and '70s view of medicine (in the UK in particular) was one of a profession which occupied a hegemonic position, a state-backed monopoly supplying a valued resource on its own terms, creating its own expanding market and retaining imperialistic control over its sphere of interest.⁴⁸ If professional authority is a consequence of political and historical conditions, then a change in those circumstances is likely to affect that dominant position. Given the recent imposition of external regulation, an increasingly knowledgeable population and the rise of patient autonomy as the primary bioethical principle, one might plausibly suggest that there has been a decline in medical power with regard to certain ethical matters. Certainly, considerable attention recently has been paid to restructuring power relationships between doctors and patients.⁴⁹ As the principles of autonomy and human rights have become more prominent in bioethics, patients have become more empowered.⁵⁰ If power is considered as a zero-sum game then inevitably doctors must now possess less power with regard to their patients. Even if the amount of power present in a given relationship is not finite, the relative power balance in the doctor-patient relationship must have altered unless medical power has

⁴⁵ R. Gildea. 2003. *Barricades and Borders: Europe 1800-1914*. 3rd edn. Oxford: Oxford University Press.

⁴⁶ Education Act 1996, ss7-8.

⁴⁷ M.A. Elston. 1991. The Politics of Professional Power: Medicine in a Changing Health Service In *The Sociology of the Health Service*. J. Gabe, et al., eds. New York: Routledge. pp58-88.

⁴⁸ Ibid.

⁴⁹ Benatar (n4) p387.

⁵⁰ Ibid.

also increased. Despite patient empowerment, however, it would seem that power imbalances remain pervasive within healthcare.⁵¹ This seems particularly true of paediatrics where the state, with its capacity to exercise coercive power, continues to be aligned with medical opinion in most biolegal conflicts that come to a public hearing.⁵²

4.6. CONCLUSION

Although state forces appear to be aligned against them in biolegal disputes, parents are not entirely powerless; in end-of-life cases, for example, they may initiate a legal challenge that extends beyond the state,⁵³ or engage with the media in order to advance their perspective.⁵⁴ However, despite a number of high profile cases receiving ‘massive media attention’,⁵⁵ the courts have still tended to endorse the position advanced by the medical profession rather than parents. The nub of this is that parents are invested with the power to affect their children’s lives in many ways, but the state has the capacity to limit, or even remove this power in particular situations.

⁵¹ Benatar (n4) p388.

⁵² Apart from clinical negligence claims. This proposal has recently been evaluated with regard to end-of-life disputes in the US. See J.M. Luce. A History of Resolving Conflicts Over End-of-Life Care in Intensive Care Units in the United States *Critical Care Medicine* 2010; 38: 1623-1629.

⁵³ *Glass v United Kingdom* [2004] 1 FLR 1019.

⁵⁴ For most recent example see A. France & E. Morton. I Won’t Let Docs Kill My Baby. *The Sun* 4 February 2011: 1.

⁵⁵ M. Brazier. Letting Charlotte Die. *J Med Ethics* 2004; 30: 519–520.

CHAPTER 5

OUTLINE OF SUBMITTED PAPERS

Of the four papers submitted for publication, the first three concern young children.⁵⁶ The first article, *Obliging Children*, examines the justification that using children as bone marrow donors or enrolling them as research subjects is acceptable because children have obligations to others as a consequence of their relationships within families and society. The obligation thesis arose because of an acknowledgment of the inadequacies of the welfare principle as an explanatory model in this context; an admission that being a research subject or tissue donor is not necessarily in the best interest of the individual child. I argue that the obligation proposal also does not hold because it confuses the notions of ‘being under an obligation’ to do something and ‘being obliged’ to perform the same act. This is the difference between voluntarily undertaking to do something and being compelled to do the same thing. Adults may be under a moral obligation to participate in research or donate bone marrow to a sibling, but may reject these obligations regardless of consequences; a young child is powerless to reject them and is obliged, or compelled, to participate or donate as required. If children are obliged to undergo such procedures, and yet adults possess no such enforceable obligations, then this opens up the possibility that children are treated differently to adults in morally relevant ways. The second paper, *Equality and Research on Children*, examines the inequality that arises from imposed ‘obligations’; that young children can be enrolled in research projects to serve social need while adults can refuse to consent to participation, or not, according to their personal values and preferences, and regardless of the needs of society. A similar argument regarding inequality could be used for bone marrow donation or for claims to autonomy by adolescents. If we insist on treating children differently to adults, and not necessarily in a good way, why is this inequality permissible? I will suggest that such treatment persists because of the imbalance of power that exists between adults and children. In the third article, *‘The Good that is Interred in Their Bones’*, I argue that parental power can lead to situations that are best explained by the common law property-type rights that

⁵⁶ A full definition of the term ‘young child’ is given in paper 1. In general it refers to children who are below the age of consent or assent.

adults (allegedly historically) have enjoyed over children. Although there is much academic protestation that such rights no longer exist, that the child is not property, the adult power to authorise the transfer of bone marrow from an unconsenting child to a third, albeit related, party strongly evokes notions of property rights over tangibles. The fourth paper, *'Dying to be Responsible'*, changes tack and deals with adolescent autonomy. However, it is also about power and inequality and argues that the courts manipulate the concept of capacity in order to hold children responsible for criminal acts, while prohibiting them from being responsible for serious healthcare decisions. A full examination of the concept of responsibility indicates that although the state clearly has the power to impose these positions on young people, its basis for doing so is jurisprudentially insecure.

A common theme throughout these papers is a focus on the use of language. When dissected, it becomes clear that terms such as obligation, equality and responsibility are used in academic debate about children's healthcare issues without a full and comprehensive discussion of their meaning. This leads to obfuscation; to a lack of clarity and transparency in discussions about the imposition of unchosen healthcare burdens on vulnerable populations. The purpose of this thesis is not to argue that the interventions discussed are bad of themselves, nor that parents who authorise doctors to perform such procedures on their children are in some way uncaring. Rather it is an appeal for recognition of the realities of the politics of childhood. The outcomes of the aforementioned interventions might well be seen as desirable; declining to acknowledge adolescent autonomy means that a child will live, authorising the transfer of bone marrow from one sibling to another means that a child might possibly live, and enrolling a child into a research programme means that some children of the future might also survive when otherwise they might not. However, good outcomes do not confer moral validity on the decisions made, and there are costs involved, not least for the child.

CHAPTER 6

PAPER 1¹

OBLIGING CHILDREN²

*I cannot thinke my Sister in the least Would faile her Obligation.*³

6.1 INTRODUCTION

Most contacts children have with healthcare professionals are uncontroversial. Child C with disease X needs investigation Y and treatment Z in order to improve her health status, and parental consent to allow this care to proceed falls readily under standard notions of medical beneficence and parental duty.⁴ If, for

¹ B. Lyons. Obliging Children. *Med Law Rev* 2011; 19: 55-85.

² The term ‘children’ generally denotes those individuals who are less than 18 years of age. This paper specifically deals with a subgroup of the child population: those who are too young to, or by virtue of a learning disability, are unable to meaningfully engage in the process of consent or assent, and the opinions of whose parents are taken to be determinative. While there is no specific age limit to this group, with regard to medical research the Royal College of Paediatrics states that ‘researchers should obtain the assent or agreement of school age children to their involvement in the research, and should always ensure that the child does not object’: Child Health Ethics Advisory Committee. Guidelines for the Ethical Conduct of Medical Research Involving Children. *Arch Dis Child* 2000; 82: 177–182, p180. In the US, the National Commission, supported by the American Academy of Pediatrics (AAP), state that young children (under an intellectual age of 7 years) are not capable of providing assent and thus need not be asked: National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. 1977. *Report and Recommendations: Research Involving Children*. Washington: Government Printing Office; AAP Committee on Drugs. Guidelines for the Ethical Conduct of Studies to Evaluate Drugs in Pediatric Population. *Pediatrics* 1995; 95: 286-294. Alderson advises that age-stage theories under- or overestimate many children’s abilities, and indicates that some children below the age of five with chronic healthcare problems are capable of making informed decisions; P. Alderson, et al. Children as Partners with Adults in Their Medical Care. *Arch Dis Child* 2006; 91: 300-303. I agree with Alderson. Accordingly, this article explicitly relates to children under school going age (or those who have profound learning disability and are under 16 years) who lack the competence to assent to specific healthcare procedures or research. Incompetent adults may be treated similarly to children in many respects but, although occasionally alluded to in the text, a full discussion of any differences is beyond the remit of this paper. In addition, although other jurisdictions are mentioned, this paper refers specifically to the laws of England and Wales.

³ W. Shakespeare. 2007. King Lear. In *Complete Works of William Shakespeare*. Oxford: Wordsworth Editions: II, iv, 140. II, iv, 140.

⁴ In general, the responsibility to make healthcare decisions on behalf of incompetent children falls onto parents. See Children Act 1989, s3(1): ‘In this Act “parental

example, C is a two-year old child who develops leukaemia, and needs bone marrow (BM) analysis in order to plan appropriate treatment, then parental consent will be sought, and almost invariably given, so that the medical staff can lawfully proceed with the necessary investigation.⁵ This position seems reasonably straightforward, but some decisions are less clear cut. Supposing C is a healthy two-year old child whose BM is being harvested in order to donate it to a sick sibling; the proposed operation is obviously not going to improve C's health. Or perhaps C does have leukaemia and the doctors wish to perform an extra BM aspiration at the end of a chemotherapy cycle, not as part of C's treatment plan, but as part of a research protocol designed to enhance scientific knowledge about the disease. In either case C has been exposed to potential risks through medical procedures that convey no healthcare benefit to her.⁶ These procedures might be considered as non-beneficent interventions (NBI), a term that encompasses any medical (physical, mental, social or emotional) infringement of an individual's integrity without intent to advance the health of that person. Physical investigations or interventions without therapeutic intent may include:

(1) Procedures that promote the health status of others through the direct transfer of tissue (e.g. peripheral blood stem cell, BM or solid organ donation);

(2) Procedures that promote the health status of others by advancing scientific knowledge and understanding. Children may participate in non-therapeutic research by contributing biological material or by undergoing some novel procedure.⁷

responsibility" means all the rights, duties, powers, responsibilities and authority which by law a parent of a child has in relation to the child and his property'.

⁵ Where the intended treatment is clearly medically beneficial to the child, parental consent to such care is largely unproblematic in practice. See M. Brazier & E. Cave. 2007. *Medicine, Patients and the Law*. 4th edn. London: Penguin. p395.

⁶ The potential risks are not just physical in nature, but may also include exposure to psychological and emotional harms.

⁷ Although the distinction between therapeutic and non-therapeutic research was dropped by the Declaration of Helsinki revision of 2000 following criticism that it failed to distinguish levels of risk, nonetheless the notion of research without therapeutic intent (RWTI) remains a useful concept, and is one that I shall utilise throughout this paper. It is arguable that children involved in research which comes under the Medicines for Human Use (Clinical Trials) Regulations 2004 could be included under this concept. Although Part 4 s10 states that there must be some direct benefit for the group of patients involved in the clinical trial, there is no guarantee that a particular child will profit. If it was known that an individual child would derive benefit and suffer no harm from an intervention then there would be no need for research on this proposed therapy. By its very nature the outcome of research is uncertain. However, the difference between research conducted under the Clinical Trials

(3) Procedures that promote the social acceptance of the child, including interventions such as ritual circumcision and ‘cosmetic’ procedures that affect the child’s appearance.⁸

This paper concerns itself specifically with the use of young children as BM donors or their enrolment in non-therapeutic research.⁹ In these instances the child accrues no healthcare advantage from the intervention, and thus parental or proxy consent to such infringements of the child’s bodily integrity might be seen to be legally or ethically questionable. Historically, children were considered the property of their parents and such decisions would have required little justification beyond parental agreement.¹⁰ Today the exercise of parental authority based on a claim of property rights in the child would seem to be unacceptable.¹¹ Thus, an alternative basis on which to justify the legitimacy of parental consent in these circumstances must be found. In the first instance the welfare principle, as enshrined in the Children Act 1989, is frequently invoked as it articulates the view that in all matters pertaining to a child’s upbringing, his or her best interests should have a determining influence on any decisions made.¹² However, the applicability of the welfare principle in the context of paediatric healthcare decision-making has been the subject of criticism on a variety of grounds.¹³ A second justification argues that, as they are part of a family or of a larger community, children possess obligations to other members of these social groups.¹⁴ Thus, parental consent to NBI simply allows a child to fulfil her

Regulations and RWTI is that the former holds out some possibility of direct benefit which is absent from the latter.

⁸ An example of ‘cosmetic’ surgery was described by Oullette when she discussed eye surgery on Asian infants in order to westernise their appearance. A. Ouellette. *Eyes Wide Open: Surgery to Westernize the Eyes of an Asian child. Hastings Cent Rep* 2009; 39: 15-18.

⁹ While some of the arguments contained in this paper may be extended to ‘procedures that promote the social acceptance of the child’, a full discussion of this group of interventions would require engagement with models of parental authority and religious or cultural freedoms. This is beyond the scope of this paper.

¹⁰ In many cultures, including England up until late Victorian times, parents (particularly fathers) had dominion over almost all aspects of a child’s life. See W. Blackstone. 1850. *Commentaries on the Laws of England Vol. 1*. New York: Harper and Brothers. pp452-453; D. Archard & C.M. Macleod eds. 2002. *The Moral and Political Status of Children* Oxford: Oxford University Press. p1; A.P. Derdeyn. Child Custody Contests in Historical Perspective. *Am J Psychiatry* 1976; 113: 1369-1376.

¹¹ Archard & Macleod, *ibid*, pp1-4.

¹² s1(1).

¹³ For an overview of the relevant arguments see S. Elliston. 2007. *The Best Interests of the Child in Healthcare*. London: Routledge-Cavendish.

¹⁴ See for example J. Dwyer & E. Vig. Rethinking Transplantation between Siblings. *Hastings Cent Rep* 1995; 25: 7-12. L.A. Jansen. Child Organ Donation, Family Autonomy,

obligations. This claim has been subjected to far less scrutiny than the standard best interest approach, and so this paper seeks to evaluate the assertion that children possess obligations to improve the health of others.¹⁵

My aim in this paper is to rebut the claims of those who propose the ‘obligation model’, the notion that children possess positive obligations to advance the health status of others. This is not an objection to particular NBI; rather my problem is with the justifications employed to legitimise them. With regard to the ‘obligation model’ this paper finds that it fails as a justificatory paradigm because it is based upon a confusion between the notion of ‘being under an obligation to do something’ and that of ‘being obliged to do something’.¹⁶ Instead the ‘obligation model’ is similar to the ‘best interests’ concept in that it is a device employed to put a justificatory gloss upon a consequentialist decision-making process. Removing the ‘legitimising’ gloss might allow for a more transparent debate about parental rights and the relationship between such rights and an individual child’s right to bodily integrity.

6.2 JUSTIFYING NON-BENEFICIENT HEALTHCARE INTERVENTIONS

Children are different to adults. The Anglo-American doctrinal position emphasises the sovereignty of adult autonomy: any trespass on the integrity of a competent person can only be carried out with their explicit and uncoerced consent.¹⁷ Rational adults can decide whether a proposed investigation, treatment or research

and Intimate Attachments. *Camb Q Healthc Ethic* 2004; 13: 133-142. T.F. Ackerman. Nontherapeutic Research Procedures Involving Children With Cancer. *J Ped Oncol Nurs* 1994; 11: 134-136. D.W. Brock. 1994. Ethical Issues in Exposing Children to Risks in Research. In *Children as Research Subjects: Science, Ethics & Law*. M.A. Grodin & L.H. Glantz, eds. New York: Oxford University Press: 81-102.

¹⁵ There are other models besides ‘best interests’ and the ‘obligation’ thesis which might be used to justify NBI. These include the ‘parental discretion’ and the ‘not against the best interests of the child’ arguments. An examination of these is beyond the scope of this article. An example of the former is Ross’ ‘constrained parental autonomy’ model: see L.F. Ross. 1998. *Children, Families and Healthcare Decision-Making*. Oxford: Clarendon Press., and a critique by M. Freeman. *Whose Life is it Anyway?* *Med Law Rev* 2001; 9: 259-280. For a review of the ‘not against the best interests of the child’ standard see Elliston (n13).

¹⁶ H.L.A. Hart. 1961. *The Concept of Law*. Oxford: Clarendon Press. p80.

¹⁷ This principle was classically outlined by Cardozo J. in *Schloendorff v Society of New York Hospital* (1914) 21 1 NY 125: ‘Every human being of adult years and sound mind has a right to determine what shall be done with his own body: and a surgeon who performs an operation without his consent commits an assault’. See also *Sidaway v Board of Governors of the Bethlem Royal Hospital* [1985] AC 871, 882: ‘A doctor who operates without the consent of his patient is, save in cases of emergency or mental disability, guilty of the civil wrong of trespass to the person: he is also guilty of the criminal offence of assault’.

protocol is likely to be desirable or undesirable for themselves, as they subjectively and holistically perceive their lives.¹⁸ However, this possibility is not open to incompetent children. And, as Buchanan and Brock observed, legal and moral philosophers have not over-extended themselves in elucidating mechanisms that guide decision-making on behalf of incompetent individuals in general, on what (and when) paternalistic interventions are allowable in the medical lives of such persons.¹⁹ One suggestion, proffered by Mill, was that we could only allow for interference with the liberty of those persons who are not competent to decide for themselves in order to advance their welfare or prevent self-harm.²⁰ If this view is applied to young children, then C could not be a bone-marrow donor, or participant in non-therapeutic research, unless it could be argued that these NBI somehow promoted her wellbeing.²¹

It is by invoking a welfare principle that the law and bioethics have frequently sought to justify living tissue or organ donation by incapacitated individuals.²² In England, although the harvesting of BM from healthy children has been described as ‘relatively routine’,²³ and solid organ donation from minors has occurred,²⁴ the courts have never specifically considered these procedures. In the only case to touch on this subject, *Re Y*, Connell J approved the donation of BM from a mentally incapacitated adult who lived in residential care to her sister who had a pre-leukaemic condition.²⁵ Drawing on the American case of *Curran v Bosze*²⁶ the court ruled that for Y to donate would be in her best interest, although the process of

¹⁸ *Re T (Adult: Refusal of Treatment)* [1993] Fam 95, 113 (Lord Donaldson): ‘...the patient’s right of choice exists whether the reasons for making that choice are rational, irrational, unknown or even non-existent’.

¹⁹ A.E. Buchanan & D.W. Brock. 1989. *Deciding for Others: The Ethics of Surrogate Decision Making* Cambridge: Cambridge University Press. p3.

²⁰ J.S. Mill. 1859. *On Liberty*. Raleigh, N.C: Alex Catalogue.

²¹ Some research trials may compare standard treatments with innovative or new therapies. In such instances there is the possibility of direct benefit. This paper is not concerned with these cases.

²² J. Herring. 2002. Giving, Selling and Sharing Bodies. In *Body Lore and Laws*. A. Bainham, et al., eds. Oxford: Hart Publishing: 43-62.; Elliston (n13) pp243-271.

²³ Human Fertilisation and Embryology Authority. 2004. *Preimplantation Tissue Typing*. London: HFEA. para 26.

²⁴ N. Webb & P.-M. Fortune. Should Children Ever be Living Kidney Donors? *Pediatr Transplant* 2006; 10: 851–855.

²⁵ *Re Y (Mental Patient: Bone Marrow Donation)* [1996] 2 FLR 787.

²⁶ (1990) 566 NE 2d 1319.

reasoning used to arrive at this end has been described as ‘convoluted’;²⁷ the benefit to Y seeming ‘somewhat remote on the facts of the case’.²⁸ Subsequent Department of Health guidance suggested that BM donation is a ‘more than “minimal burden”’ which ‘to be lawful ... must be in the child’s best interests’.²⁹ The Human Tissue Authority (HTA) code of practice for England and Wales indicates that parents can consent on behalf of their incompetent children

if the donation is assessed as being in the child’s overall best interests, taking into account not only the medical but also emotional, psychological and social aspects of the donation, as well as the risks. The consent of only one person with parental responsibility is necessary.³⁰

Parental authorisation for the transfer of BM from one sibling to another has thus far proceeded without judicial oversight, although since 2006 the HTA must approve all donations made by children who are not competent to give consent.³¹ However, as the HTA has never turned down a proposed child donor³² it would seem that, once the donation has medical legitimacy,³³ the decision for one sibling to donate to another is one that generally falls within the purview of parental rights. These rights are more limited when it comes to non-regenerative tissues. In *Re Y*, Connell J did not believe his judgment could ‘act as a useful precedent in cases where the surgery involved is more intrusive’,³⁴ such as live solid, or non-regenerative, organ donation.

²⁷ S.E. Mumford. Donation Without Consent? Legal Developments in Bone Marrow Transplantation. *Br J Haem* 1998; 101: 599-602. The putative benefits accruing to Y were largely psychological in nature. According to Connell J, if Y’s sister died then Y’s mother would be less available to visit her because (a) she would be emotionally distraught, and (b) she would be occupied in minding Y’s niece. On the other hand, should Y donate and her sister survive, then this would enhance the relationship between Y and her mother.

²⁸ Brazier & Cave (n5) p455.

²⁹ Department of Health. 2001. *Seeking Consent: Working with Young People*. London. p25.

³⁰ HTA. 2009. *Code of Practice* 6. ss77-81.

³¹ Unlike children, in cases where the potential donor is an adult lacking capacity to consent, the case must be referred to a court for a declaration that the proposed intervention is lawful. Only then can it be referred to the HTA for a decision on the donation. *Ibid*, s93.

³² Since the HTA began regulating in September 2006, there have been no cases of proposed adult donors lacking the capacity to consent. Between September 2006 and the end of March 2010, 258 incompetent children have been proposed as donors of either BM or peripheral blood stem cells. Thus far, all paediatric donors have been approved. In a number of cases, however, the HTA has requested that further support be given to the child (e.g. further play therapy) before approving the donation. Information provided by HTA on 12 August 2010.

³³ That the BM donation is a medically viable treatment for the disease process in question, has some possibility of success, and the BM of the proposed donor has the inherent qualities required for a successful donation.

³⁴ *Re Y* at 794. However, see *obiter* remarks by Lord Donaldson in *Re W* [1992] 4 All ER 627 at 635 which suggest that a parent could consent to organ donation by a minor.

The British Transplant Society suggests that minors should rarely be considered as live kidney donors,³⁵ a view supported by the British Medical Association,³⁶ and internationally by the Amsterdam Forum.³⁷ Guidance on the Human Tissue Act 2004 indicates that children can be considered as living organ donors in rare circumstances, subject to parental consent, court approval and the agreement of an HTA panel.³⁸

Recently in the US, the AAP reaffirmed that children could act as live donors of non-regenerative organs, albeit within specific and limited circumstances.³⁹ Courts in the US have dealt with a number of living-related kidney donation cases involving minors as donors, and have approved them on the basis that it was in the donor's best interest to donate.⁴⁰ As any tissue or organ donation, *prima facie*, cannot serve the donor's healthcare interest, then the courts must believe there to be other non-medical benefits accruing to the child,⁴¹ and that these are sufficient in magnitude to offset any risks.⁴² The factors that purportedly tip the risk / benefit scales in a positive direction tend to be psychological or emotional in nature, and are largely related to enhanced self-esteem or status in the family,⁴³ or the security or companionship afforded by the continuing existence of the surviving recipient.⁴⁴ According to Price, the courts use of putative psychological benefits to justify organ donation by minors has sometimes been seen as being reliant upon 'incredible feats of mental gymnastics'.⁴⁵

³⁵ British Transplantation Society. 2004. *United Kingdom Guidelines for Living Donor Kidney Transplants*. Accessed on 26 January 2010 at <<http://www.bts.org.uk>>.s3.5.

³⁶ British Medical Association. 2001. *Consent, Rights and Choices in Health Care for Children and Young People* London BMJ Books. p165.

³⁷ The Ethics Committee of the Transplantation Society. The Consensus Statement of the Amsterdam Forum on the Care of the Live Kidney Donor. *Transplantation* 2004; 78: 491-492.

³⁸ HTA. 2009. *Code of Practice 2: Donation of Solid Organs for Transplantation*. London: TSO. ss47-48.

³⁹ L.F. Ross, et al. Minors as Living Solid-Organ Donors. *Pediatrics* 2008; 122: 454-461.

⁴⁰ *Strunk v Strunk* (1969) 445 SW 2d 145, Ky; *Hart v Brown* (1972) 29 Conn. Supp. 368, 289 A.2d 386, Super. Ct.; *Little v Little* (1979) 576 SW (2d) 493, Tex.

⁴¹ In the context of incompetent adults see *Re MB* [1997] BMLR 175 at 188 (Butler Sloss LJ): 'Best interests are not limited to medical best interests'.

⁴² A. Spital. Donor Benefit Is the Key to Justified Living Organ Donation. *Camb Q Healthcare Ethic* 2004; 13: 105-109.

⁴³ *Little v Little* at 499 per Cadena CJ.

⁴⁴ *Strunk v Strunk* at 149; *Re Y* at 793.

⁴⁵ D.P. Price. 2000. *Legal and Ethical Aspects of Organ Transplantation* Cambridge: Cambridge University Press. p351.

The best interests standard has also been applied to enrolling children in research projects.⁴⁶ However, as set out in the Report of the International Bioethics Committee of UNESCO, this is not necessarily a valid yardstick in the context of children entered into RWTI:

Research activities involving children are carried out to learn more about the nature of paediatric development, disease and potential treatments. Though one might hope that it will in some cases be beneficial to the research participant, the activity cannot be said to be specifically designed for this purpose because of the nature of the research question. Here it differs from clinical treatment per se. As a result, parents cannot consent their children into research simply on the basis of the assumption that they are the ones who have the best interests of their child at heart, for the research procedures are not aimed specifically to ensure the best interests of their child. We do not know at this stage whether they are likely to be beneficial or not – indeed that is the research question being asked. Those who stand to benefit are future children for whom the results of the research will be valuable in informing their treatment.⁴⁷

It is not the purpose of this paper to critique the best interests standard. This has been done effectively by Elliston in her book *The Best Interests of the Child in Healthcare*.⁴⁸ Elliston challenges the value of the standard in the context of medical interventions and, finding it wanting in a number of regards, proposes that it is replaced with an assessment of the reasonableness of parental decisions and the potential harms that may accrue from such decisions. I am in broad agreement with her thesis. With regard to the specific concerns of this paper, the lack of utility of the best interests principle in the context of paediatric research has been articulated by the International Bioethics Committee,⁴⁹ and its inherent vagueness, speculative nature, and inapplicability to young children expressed by a number of advocates of live paediatric organ donation.⁵⁰

⁴⁶ P. Allmark, et al. Is it in a Neonate's Best Interest to Enter a Randomised Controlled Trial? *J Med Ethics* 2001; 27: 110-113. For an overview see Elliston (n13) pp191-242.

⁴⁷ IBC. 2007. *Report of the International Bioethics Committee of UNESCO (IBC) on Consent*. Paris: UNESCO. III.2.2.87.

⁴⁸ (n13).

⁴⁹ (n47).

⁵⁰ Dwyer & Vig (n14); Jansen (n14); R.A. Crouch & C. Elliott. Moral Agency and the Family: The Case of Living Related Organ Transplantation. *Camb Q Healthc Ethic* 2000; 8: 275-287. L.F. Ross. Moral Grounding for the Participation of Children as Organ Donors. *J Law Med & Ethics* 1993; 21: 251-257. D. Steinberg. Kidney Transplants From Young Children and the Mentally Retarded *Theor Med Bioeth* 2004; 25: 229-241.

Instead this paper is concerned with an alternative justification for the practice of some NBI. This rationalisation contends that, as members of a family children have ‘obligations that are implicit in relationships’,⁵¹ and that in the correct circumstances these inherent familial obligations may justify the risk of tissue or organ donation by a child. In addition, it has been suggested that the obligations of children extend beyond immediate family, and into wider society. Some commentators have contended that these broader obligations serve as a basis for the enrolment of children into research trials.⁵²

6.3 THE NATURE OF OBLIGATIONS

Before evaluating these claims it would first seem reasonable to examine what the term ‘obligation’ might mean. The Oxford English Dictionary defines an obligation as the ‘action of constraining oneself by oath, promise, or contract to a particular course of action; a mutually binding agreement.’ With regard to the law it is ‘a binding agreement committing a person to a payment or other action’.⁵³ Brandt suggests that the word ‘obligation’ paradigmatically points to talk about promises or agreements, observing that to ‘say “I have an obligation” will, unless the context points explicitly in another direction, imply or suggest that I have either promised or accepted a favour’.⁵⁴ This is unsurprising given the historical derivation of the family members of ‘oblige’ from *ob* and *ligare*, meaning ‘to bind’.⁵⁵

Hart argued that any statements about obligations presuppose the existence of social rules. The purpose of these rules is to set the standards of behaviour expected in order to meet a particular obligation, and also to articulate the potential consequences of failing to meet it.⁵⁶ Obligation imposing rules have several features that distinguish them from other social rules. They are ‘necessary to the maintenance of social life’; are supported by serious social pressure (such as the application of physical or psychological sanctions) in the event of deviations from the rule; and, as they impose behaviour contrary to what we may actually wish to do,

⁵¹ Dwyer & Vig (n14).

⁵² Brock (n14).

⁵³ J. Simpson & E. Weiner. 1989. *Oxford English Dictionary*. 2nd edn. Oxford: Clarendon Press.

⁵⁴ R.B. Brandt. The Concepts of Obligation and Duty *Mind* 1964; 73: 374-393. p386.

⁵⁵ Ibid.

⁵⁶ Hart (n16) p82.

characteristically involve ‘sacrifice or renunciation’.⁵⁷ Moral and legal rules of obligation and duty have significant similarities, and their main differences lie in the specific nature of legal rules, and the form of sanction applied in the case of non-conformity. In the case of moral rules disapproval is expressed in an attempt to elicit guilt, shame or remorse, and possibly a change in behaviour, while in the legal case specific penalties may be imposed.⁵⁸ However, with regard to moral obligations, sanctions will generally only be applied in the event of a volitional violation of a rule; this may not always be true of breaches of legal rules.⁵⁹ Hart contended that the facility to fulfil one’s moral and legal obligations is ‘within the capacity of any normal adult’,⁶⁰ but made no comment on the ability of children to discharge obligations. This raises the question of whether children are the kind of entities that can bear obligations.

6.4. THE LEGAL OBLIGATIONS OF CHILDREN

Despite Hart’s allusion to the notion of capacity, children do appear to be subject to a number of legal obligations. Once over the age of 10 years, they are under an obligation to obey the criminal law at the risk of the imposition of sanctions should they infringe it.⁶¹ Children under 10, although apparently *incapax*, may still be subject to safety or curfew orders should they engage in anti-social behaviour.⁶² Even younger children are under an obligation to obey school rules or face the possibility of an exclusion order.⁶³ Children also have obligations under the law of contract. Although the Family Law Reform Act 1969 set the age of capacity for entering into contracts at 18 years, the Minors’ Contracts Act 1987 retains the provision that contracts for ‘necessaries’⁶⁴ and contracts of apprenticeship, education

⁵⁷ Ibid. pp83-85.

⁵⁸ Ibid. pp165-176.

⁵⁹ Ibid. p173.

⁶⁰ Ibid. p167.

⁶¹ Children and Young Persons Act 1963, s16.

⁶² The Crime and Disorder Act 1998, ss11-15.

⁶³ Office for Standards in Education. 2009. *The Exclusion from School of Children Aged Four to Seven*. Accessed on 30 December 2009 at <<http://www.ofsted.gov.uk/Ofsted-home/Publications-and-research/Browse-all-by/Documents-by-type/Thematic-reports/The-exclusion-from-school-of-children-aged-four-to-seven>>.

⁶⁴ According to *Chitty on Contracts* necessities are: ‘Such things as relate immediately to the person of the minor, as his necessary food, drink, clothing, lodging and medicine, are clearly necessities for which he is liable. But the term is not confined to such matters only as are positively essential to the minor’s personal subsistence or support; it is also employed to

and service are enforceable regardless of age. Other contracts may be made by minors, but are voidable should they choose to repudiate them. However, it has been questioned whether 'a very young child has the mental capacity to enter a contract, even where the contract is of a type which would normally be held valid'.⁶⁵ In *R v Oldham MBC Ex p. G*, Scott LJ noted

If a minor is to enter into a contract with the limited efficacy that the law allows, the minor must at least be old enough to understand the nature of the transaction and, if the transaction involves obligations on the minor of a continuing nature, the nature of those obligations.⁶⁶

To some extent this reflects the observations of Lord Kenyon CJ in *Jennings v Rundall*:

The law of England has very wisely protected infants against their liability in cases of contract ... where an infant has made an improvident contract with a person who has been wicked enough to contract with him, such person cannot resort to a Court of Law to enforce such contract.⁶⁷

In theory, children 'of all ages are subject to the same tort obligations as adults',⁶⁸ there being no set minimum age below which tortious liability does not exist. The liability of an individual is simply dependent upon whether the requirements of the tort in question have been fulfilled, but the capacity of the defendant may be pertinent in establishing whether those conditions are, in fact, satisfied.⁶⁹ As indicated in *Jennings*, a child cannot be sued in tort as a means of enforcing a contract which would be otherwise voidable because of the age of the minor.⁷⁰ In addition, the standard of behaviour expected of a minor is not that of an adult, but rather that of a prudent and reasonable child of similar age in the particular

denote articles purchased for real use, so long as they are not merely ornamental, or are used as matters of comfort or convenience only, and it is a relative term to be construed with reference to the minor's age and station in life. The burden of showing that the goods supplied are necessities is always on the supplier'. H. Beale ed. 2008. *Chitty on Contracts*. 30th edn. London: Sweet and Maxwell. Vol 1, Pt 3, Chap 8, s2, 8-008.

⁶⁵ Ibid. 8-003.

⁶⁶ *R v Oldham MBC Ex p. G* [1992] 24 HLR 726 at 742.

⁶⁷ [1799] 101 ER 1419 at 1421-2.

⁶⁸ R. Bagshaw. 2001. Children Through Tort. In *Legal Concepts of Childhood*. J. Fionda, ed. Oxford: Hart Publishing: 127-150. p127.

⁶⁹ K. Oliphant. 2006. Children as Tortfeasors under the Law of England and Wales. In *Children in Tort Law Part I: Children as Tortfeasors*. M. Martin-Casals, ed. Vienna: Springer: 147-168. p153.

⁷⁰ At 1420.

situation. *Mullin v Richards*⁷¹ concerned two 15 year-old schoolgirls who were fencing with plastic rulers, an activity which resulted in one sustaining a permanent eye injury. The Court of Appeal, drawing on the Australian case of *McHale v Watson*,⁷² declined to attribute negligence. In *McHale*, Owen J held that ‘the standard by which ... conduct is to be measured is... that reasonably to be expected of a child of the same age, intelligence and experience’.⁷³

Thus, although children do bear obligations under law, the age and capacity of the child appears relevant to her liability. In particular, the legal obligations of young children would seem to be especially limited. Despite this, those that propose the obligation model argue that such individuals do possess significant and potentially burdensome moral obligations with regard to healthcare.⁷⁴

6.5. MORAL OBLIGATIONS, CHILDREN AND HEALTHCARE

6.5.1. Moral Obligations to Family

Rather than a conglomeration of atomistic individuals who merely occupy similar earthly orbits, Crouch and Elliot suggest that it might be more fruitful to regard the family as a moral unit.⁷⁵ This is best construed as a collective entity without internal moral boundaries. In this morally diffused union, the interests of one member become a shared interest of all through the promotion of an ‘other-’ rather than a ‘self-regarding’ ethic. In such an environment it becomes permissible, and even obligatory on occasion, for individuals to sacrifice their personal interest for the good of another member.⁷⁶ Dwyer and Vig contend that this is reasonable when the sacrificial risk taken by one member is commensurate with both the strength of relationship, and the benefit to be accrued by the recipient.⁷⁷ When extended to the decision-making process about whether a child should be a donor or not, they also suggest that the determination should take account of moral interests. This would not

⁷¹ [1998] 1 WLR 1304.

⁷² [1966] 115 CLR 199.

⁷³ *Ibid* at 234.

⁷⁴ It is arguable that incompetent adults are subject to the same obligations. In England the Human Tissue Act 2004 (see *Code of Practice* 6, s93) and the Mental Capacity Act 2005 (ss30-33) may provide additional safeguards in the contexts of tissue donation and medical research.

⁷⁵ Crouch & Elliott (n50).

⁷⁶ Dwyer and Vig (n14).

⁷⁷ *Ibid*.

be the simple addition of ‘moral feelings’ into the best interests’ calculus, but rather ‘the injunction to do the right thing, all things considered.’⁷⁸ They continue:

Donating tissue to a sibling is not what we normally think of as altruism... There are obligations to those to whom we are related in complex ways: our parents, children, siblings, friends, and neighbors. We can simply think of obligations as important aspects of various relationships.⁷⁹

Assuming that potentially substantial benefits will accrue to the recipient, and allowing (for the moment) that such obligations exist, there is a moral expectation that family members undertake some risk in donating. For Dwyer and Vig, this allows for ‘parents to undergo significant risks, siblings to undergo some risks, and strangers (at least occasionally) to undergo slight risks.’⁸⁰ While they admit that it may appear strange to speak of young children having obligations or duties, this is only so if we believe that ‘all duties must be grounded in voluntary action or consent’, rather than there being a natural duty to assist others.⁸¹ Pentz et al concur that obligations to family serve as ‘the moral justification for allowing young children to be donors’⁸² but do not analyse the basis of this obligation.

There are a number of possible objections to ‘intra-familial obligation’ arguments. Firstly, the question arises as to whether individual family members actually do have obligations towards each other. English has claimed that adult children do not owe their parents anything; there are no vertical intergenerational obligations that flow from child to parent, rather the obligations flow the other way.⁸³ Parents choose to have children and thus take on the duties associated with parenthood.⁸⁴ Children do not choose to be born, do not contract with their parents and so incur no debt towards them. While this might seem an impoverished view of parent-child relations, it does not argue that there are not many things that children

⁷⁸ Ibid. p9.

⁷⁹ Ibid.

⁸⁰ Ibid. p11.

⁸¹ Ibid. p10.

⁸² R.D. Pentz, et al. Designing an Ethical Policy for Bone Marrow Donation by Minors and Others Lacking Capacity. *Camb Q Healthcare Ethic* 2004; 13: 149-155. p150.

⁸³ J. English. 1979. What Do Grown Children Owe Their Parents? In *Having Children*. O. O'Neill & W. Ruddick, eds. New York: Oxford University Press: 351-356.

⁸⁴ In theory this would mean that a parent would be under an obligation to donate an organ to an offspring who needed it. But this is not an enforceable duty. As a court in Washington State noted: ‘I would not have the right to require the woman to donate an organ to one of her other children, if that child were dying’. Quoted in V.E.B. Kolder, et al. Court-Ordered Obstetrical Interventions. *N Eng J Med* 1987; 316: 1192-1196. p1194.

should want to do for their parents, but rather that these acts are based upon desire borne out of mutual respect rather than the presence of filial obligation. As Callahan has pointed out, the real world picture of family life may differ significantly from the ideal version:

Just as not all children are lovable, neither do all parents give the welfare of their children their serious attention and highest priority. Many children do not find their parents lovable and feel no special sense of duty toward them. Many parents are not happy with the way their children turn out, or with the kind of lives they live, and do not seek to remain intertwined with them.⁸⁵

If children do not have obligations towards their parents then there seems no reason to hold that they have obligations to siblings, other family members or to the family unit as a whole. There may be things that children are compelled to do on behalf of their family, and others that they do because they wish to, but these actions confer no legitimacy on the obligation model.

Secondly, this model fails to take account of the imbalance of power that naturally exists in the family unit, particularly when children are young. Parents are the assessors of interests, and when there are competing interests between siblings, or between parents and children, the authority to choose which interest should predominate resides with them. Thus, while the 'intra-familial obligation' paradigm might seem to suggest that each individual's interests are taken account of, in reality the entirely reasonable preoccupation parents have with a terribly ill leukaemic child might well result in them attributing less weight to the potentially conflicting interests of a donor child. It is understandable if parental loyalties are divided between the sick child and the potential donor, and equally comprehensible if that division is not equal. If we take the case of the previously mentioned C (aged 2) and her sick sibling (S), it is likely that C's parents will consent to the medical removal of some of her BM and its transfer to her sister. To them, the burden placed on one child may well seem acceptable in light of the possible benefits accruing to the other and, assuming the procedure is medically indicated, they can authorise the procedure because they are invested with the power to do so, albeit subject to HTA approval.

It is also possible to argue that S's parents may perceive themselves as having a responsibility to provide her with appropriate medical treatment, and might

⁸⁵ D. Callahan. What Do Children Owe Elderly Parents? *Hastings Cent Rep* 1985; 15: 32-37. p32.

construe as neglectful any failure to do so when a matching donor (C) is available. The point is that most parents love and cherish their children and will do whatever it takes to enable their offspring to fight illness and survive. However, unrestricted parental power in this regard could pose a substantial threat to the rights of some family members (particularly young ones), rights which might be significantly infringed in the name of the parental vision of ‘doing the right thing’.⁸⁶ The issue then becomes one of the permissible extent to which the bodily integrity of a child might be impinged upon for the benefit of another family member, and in the case of non-regenerative organs this becomes a matter for the courts to consider.⁸⁷

While the obligation thesis seems to present intra-familial obligations as something a child acquires passively on being born, Harris and Holm take an alternative view. They also hold that we have a fundamental moral obligation to help other people in need, but rather than assuming a ‘non-voluntary’ grounding for the attribution of obligations to children, they base their theory firmly in agency:

If children are moral agents, and most of them, except very young infants are, then they have both obligations and rights; and it will be difficult to find any obligations that are more basic than the obligation to help others in need.⁸⁸

They continue by asserting that parents must take the moral agency of their children seriously, and thus must make decisions on their offspring’s behalf that are commensurate with that child discharging her moral obligations. Although Harris and Holm were concerned specifically with the obligation of children to participate in scientific research, it seems reasonable that their argument might be extended to sibling tissue donation. Thus (on this broadened view of Harris and Holm’s argument), if C’s sister S has leukaemia and needs a BM donation, and C is the best HLA match for S, then C’s parents would seem to have no great decision to make. S is in need and C has the capability to help her. Hence, C has a moral obligation to

⁸⁶ Jansen (n14) p135.

⁸⁷ HTA (n32).

⁸⁸ J. Harris & S. Holm. Should We Presume Moral Turpitude in our Children? – Small Children and Consent to Medical Research. *J Theor Med Bioeth* 2003; 24: 121-129. p125. Infants who are not yet moral agents are described as moral agents *in spe* (in-waiting). The authors do not say what obligations such infants might have to bear.

help S and C's parents ought to consent to the donation, regardless of the actual or possible preferences of C.⁸⁹

This, however, is not as straightforward as it might seem. On the one hand, children exhibit moral behaviour towards other beings from an early age,⁹⁰ and Alderson has demonstrated that even young children are capable of making appropriate healthcare decisions, and of considering the moral dimensions of these choices.⁹¹ On the other hand, societal and legal recognition of the scope of children's agency is severely limited. Whatever the possibility of a Gillick-competent minor's agency being acknowledged,⁹² it is unlikely that a two, three or four year-old child will be ascribed agency if, in this instance, agency means having the decision-making capacity to choose whether or not one will fulfil one's obligations. May has argued that, as a child is not a moral agent, he could not be a bearer of moral obligations, even presumptive ones.⁹³ In general terms, agency entails making life choices and carrying out an action plan based upon the choices made. It seems a rather peculiar conception of agency where all decisions are taken by another rather than the actor herself, as in the instance in C and her parents above. In the case of BM donation, C's parents are making a decision which she has to abide by. Thus, while C is undoubtedly a moral being - and possibly an agent in other aspects of her life - she is not a moral agent in this scenario. It might be stated that C's parents are teaching her to behave in a prescribed moral manner, but while such educative processes may result in a child developing a particular moral outlook, this does not equate with actual agency in relation to this particular act.

⁸⁹ If C has an obligation to donate to S then her parents' views would appear to be irrelevant. If, for example, C's parents actually love her more than S and refuse to consent to the inter-sibling donation in order to avoid C becoming upset, should the parents' views carry any weight? If C truly has an obligation then should this not be enforced regardless of parental wishes?

⁹⁰ C.A. Brownell & C.B. Kopp eds. 2007. *Socioemotional Development in the Toddler Years: Transitions and Transformations* New York: Guilford Press.

⁹¹ P. Alderson & J. Montgomery. 1996. *Health Care Choices: Making Decisions with Children*. London: Institute for Public Policy Research.

⁹² In *Gillick*, Lord Scarman refers to a 'child's right to make his own decisions when he reaches a sufficient understanding and intelligence to be capable of making up his own mind'; at 420.

⁹³ W.E. May. *Experimenting on Human Subjects*. *Linacre Q* 1974; 41: 238-252.

6.5.2. Moral Obligations to Society

In the celebrated Ramsey – McCormick debate on whether children should ever be enrolled in RWTI, Ramsey argued in accordance with the Nuremberg Code: that non-therapeutic experimentation on children or the incompetent was illegitimate because of the absence and impossibility of their voluntary consent.⁹⁴ McCormick's contrary position was that parental consent to RWTI was 'morally valid precisely insofar as it is a reasonable presumption of the child's wishes.'⁹⁵ This presumption was premised on the belief that the child's wishes were inextricably linked to what the child *ought* to do. Thus, with regard to medical treatment the child, if competent, would choose the treatment 'because he ought to choose the good of his life.' McCormick posits that there are other goods 'definitive of his growth and flourishing', besides physical well-being, that a child ought to want:

To pursue the good that is human life means not only to choose and support this value in one's own case, but also in the case of others when the opportunity arises. ... It can be good for one to pursue and support this good in others.... If this is true of all of us up to a point and within limits, it is no less true of the infant.⁹⁶

Thus, parents could legitimately consent to their child's participation in RWTI, because this is what the child ought to want to do. McCormick denied Ramsey's claim that his language of ought was 'implying or imputing moral obligation and moral agency' to an infant,⁹⁷ but this refutation appears undermined by his contention that his concerns lie with minimal social duties: 'our willingness to experiment on children (and fetuses) when risk, discomfort, and pain are minimal or nonexistent points to a duty that we all have to be willing to bear our fair share that all may prosper.'⁹⁸ Bartholome, although disagreeing with Ramsey, had little doubt that McCormick's idea of duties implied obligation.⁹⁹

⁹⁴ P. Ramsey. The Enforcement of Morals: Nontherapeutic Research on Children. *Hastings Cent Rep* 1976; 6: 21-30.

⁹⁵ R. McCormick. Proxy Consent in the Experimental Situation. *Perspect Biol Med* 1974; 18: 2-20. p12.

⁹⁶ Ibid.

⁹⁷ R.A. McCormick. Experimentation in Children: Sharing in Sociality. *Hastings Cent Rep* 1976; 6: 41-46. p42.

⁹⁸ R.A. McCormick. Experimental Subjects: Who Should They Be? *JAMA* 1976; 235: 2197.

⁹⁹ W.G. Bartholome. Parents, Children, and the Moral Benefits of Research *Hastings Cent Rep* 1976; 6: 44-45.

In the context of medical research, it has been argued that not only does a child apparently have obligations to existing children, but they also have duties to past and future generations.¹⁰⁰ The basis for these obligations is that children benefit from medical progress which has only been possible through the sacrifices of previous generations of children; the moral obligation is thus grounded in a duty to fairness.¹⁰¹ Although Brock acknowledges that children do not ‘freely participate’ in choosing which medical care they undergo, he suggests we can presume upon their hypothetical consent to participate in research studies. If children were rational self-interested beings, then they would realise that ‘the expected benefits of such research over time exceed ... its burdens’ and therefore would agree to participate in and accept the benefits of research.¹⁰² Ignoring for the moment Litton’s argument that it is impossible to wrong either children of the past or the future in this context,¹⁰³ Brock’s contention remains that, as each child hypothetically consents to the benefits accruing from research, then they have an obligation to other generations of children to participate in research in order to distribute fairly any burdens and benefits.¹⁰⁴

In sum, the position outlined by Ramsay states that as medical science has treated vulnerable individuals badly in the past, such persons require protection. Therefore, non-therapeutic research should not be carried out upon anybody who is not capable of giving explicit consent. The contrary thesis argues that (a) children ought to contribute to scientific research because it is a social good; or (b) because they do, or will, derive healthcare benefit from prior research, they have a duty born out of justice to contribute to future research. As a consequence, it can be presumed that children, if they were capable, would consent to being a research subject, because that is what they ought to do. These latter claims, however, appear subject to a number of problems.

Firstly, there appears an underlying assumption that medical research necessarily will result in good things and thus children would choose to participate.

¹⁰⁰ Brock (n14). It is uncertain whether Brock, or any other commentator, holds that children with a specific illness have a particular duty towards other children who suffer from the same disease process, or whether the obligation is to society in general.

¹⁰¹ For opposing views on whether or not this duty exists for adults see: J. Harris. Scientific Research is a Moral Duty. *J Med Ethics* 2005; 31: 242-248. I. Brassington. John Harris' Argument for a Duty to Research. *Bioethics* 2007; 21: 160-168.

¹⁰² Brock (n14) p92.

¹⁰³ P. Litton. Non-Beneficial Pediatric Research and the Best Interests Standard: A Legal and Ethical Reconciliation. *Yale J Health Pol Law Ethic* 2008; 8: 359. p406.

¹⁰⁴ Brock (n14) p92.

While some undoubtedly has brought about life-extending or enhancing therapies, some has significantly harmed research participants.¹⁰⁵ Sometimes the risks are not apparent until after the event,¹⁰⁶ and occasionally researchers act without beneficent intent.¹⁰⁷ It has also been claimed that many clinical trials are not completed or published,¹⁰⁸ and that the results of many research publications are, in fact, false.¹⁰⁹ While these latter issues result in a less tangible form of harm to research participants,¹¹⁰ it seems unlikely that competent individuals would willingly consent to be part of a research project that would never yield meaningful results, or might be published in a misleading fashion. All of this might lead the rational actor to question whether he should participate in a clinical trial, and sometimes a substantial number of competent adults do refuse to become research subjects.¹¹¹ Given this, there seems no good reason to hold that it can be presumed that children would automatically consent if they were competent.

Secondly, even if one lived in a society where there existed a legal obligation to assist others in need, there are no grounds to presume that such an obligation would require a person to undertake risks, both concrete and intangible, by participating in medical research. To date, no duty-to-rescue laws have been enacted in England, while only three US states (Minnesota, Rhode Island, and Vermont) impose any liability for ‘bad Samaritanism’.¹¹² Thus, any such obligation remains largely a moral rather than a legal matter.¹¹³ Barth observed that the biblical Good Samaritan cared for the beaten and robbed traveler ‘but he did not put himself in any

¹⁰⁵ R.S. Saver. Medical Research and Intangible Harm *U Cincinnati L Rev* 2006; 74: 941-1012.

¹⁰⁶ News Roundup. Healthy Woman Dies in Research Experiment. *BMJ* 2001; 322: 1565.

¹⁰⁷ In 2007, the Office of Research Integrity assessed 222 complaints of professional misconduct with regard to research. See *Annual Report 2007*, Washington D.C., DHSS.

¹⁰⁸ One study identified that over half of all FDA approved trials were not published within 5 years: K. Lee, et al. Publication of Clinical Trials Supporting Successful New Drug Applications: A Literature Analysis. *PLoS Med* 2008; 5: e191. See also M.K. Krzyzanowska, et al. Factors Associated with Failure to Publish Large Randomized Trials Presented at an Oncology Meeting. *JAMA* 2003; 290: 495-501.

¹⁰⁹ J.P.A. Ioannidis. Why Most Published Research Findings Are False. *PLoS Med* 2005; 2: e124.

¹¹⁰ Saver (n105).

¹¹¹ See for example: N.S. Abraham, et al. A Systematic Review of Reasons for Nonentry of Eligible Patients into Surgical Randomized Controlled Trials. *Surgery* 2006; 139: 469-483.

¹¹² K. Levy. Killing, Letting Die, and the Case for Mildly Punishing Bad Samaritanism. *Georgia L Rev* 2010; 44: 607-695.

¹¹³ S. Harnay & A. Marciano. Should I Help My Neighbor? Self-Interest, Altruism and Economic Analyses of Rescue Laws. *Eur J Law Econ* 2009; 28: 103-131. p105.

peril by doing so. Perhaps this is about as much as can be reasonably asked of the ordinary mortal man.’¹¹⁴ Being a research subject naturally exposes a person to risk, although the level of ‘peril’ may often be small. While competent adults have a choice about whether or not to place themselves in jeopardy by participating in medical research, young children do not. Conventional legal and ethical wisdom suggest that the difference between adults and children lies in the inherent vulnerability of the latter, and that, in general, the response to this defencelessness should be protective. However, if children are expected to be research Samaritans, a risk which competent adults can choose to avoid, then this suggests that the primary response to children’s vulnerability is not always protective.

Thirdly, young children do not voluntarily derive the benefits of prior medical research. They do not consent to the medical care they receive, nor do they choose what kind of therapy it is. It has been argued those who benefit from medical research without contributing to future research are acting as ‘free-riders’, and that such behaviour is contrary to the principle of fairness.¹¹⁵ Harris and Holm contend that children should ‘share the obligation to participate in medical research.’¹¹⁶ Can children who do not participate in research be free-riders? Whatever the merits of the free-rider argument,¹¹⁷ it would seem that in order to be a free-rider one would have to choose to avail of medical care and opt to contribute nothing (or an insufficient amount) in return. If, for example, one wished, but was unable for some reason, to contribute to research then it would seem unfair to be labelled a free-rider. Similarly, if one eschewed all standard western medical care for an illness, while at the same time refusing to participate in research, then one could hardly be a free-rider. Young children have little choice in either their medical care or research participation. If they were competent they might reject either, or both. It thus makes little sense to speak of their presumed or hypothetical consent in this regard. Rather Brock has fabricated a fiction of children’s presumed consent in order to shoehorn them into a position where they are under a putative obligation to participate in research, to not be a free-rider. But since young children are without choice, then Brock’s argument would appear to be without foundation.

¹¹⁴ A. Barth. 1966. The Vanishing Samaritan. In *The Good Samaritan and the Law*. J.M. Ratcliffe, ed. Garden City, NY: Anchor Books: 159-169. p159.

¹¹⁵ Harris (n101).

¹¹⁶ Harris & Holm (n88) p125.

¹¹⁷ For an analysis see Brassington (n101).

Alternatively, Ackerman has proposed that ‘the rights of individuals must be balanced against societal needs’ and that a denial of ‘the moral authority of parents and health professionals to involve children in activities that do not promote their own welfare’ might be seen to be ‘excessively individualistic’.¹¹⁸ In order to fulfil these societal needs, and in particular the needs of the gravely ill, everyone is under an obligation to concede their own interests in order to advance the interests of others. The obligations of children might include ‘participation in research involving non-therapeutic procedures [which] might promote the welfare of other children who suffer from catastrophic diseases.’¹¹⁹ While Ackerman might rail against ‘excessive’ individualism, the hallmark of autonomy in liberal societies is the recognition of an individual’s ‘right to a life structured by his own values’.¹²⁰ These values may, or may not, entail a commitment to medical research. Those with the capacity to exercise their autonomy may make healthcare choices that are individualistic regardless of societal need, and to perform research on an unconsenting autonomous subject would constitute a breach of ethical principles and infringe the criminal law.¹²¹ It does not seem unreasonable that decisions concerning children’s healthcare issues would be made according to the same criterion. However Ackerman, by imposing obligations on children, is appealing for choices concerning them to be made according to a different, communal norm. It is arguable that the standard to which Ackerman is appealing is a double one.

6.6. OBLIGING CHILDREN

Hart has argued that sometimes there is a confusion between ‘the assertion that someone was obliged to do something and the assertion that he had an obligation to do it.’¹²² The statement ‘he had an obligation’ does not tell us anything about the fulfilment of the obligation; the presence of the obligation is independent of whether the relevant individual acted in accordance with the obligation or not.¹²³ In contrast,

¹¹⁸ Ackerman (n14) p134.

¹¹⁹ Ibid. p135.

¹²⁰ R. Dworkin. 1993. *Life's Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom*. New York: Alfred A Knopf. Cited by Lord Steyn in *Chester v Afshar* [2005] 1 AC 134 HL at 144.

¹²¹ *Schloendorff v Society of New York Hospital* (1914) 21 1 NY 125; *Sidaway v Board of Governors of the Bethlem Royal Hospital* [1985] AC 871 at 882.

¹²² Hart (n16) p80.

¹²³ Ibid. p81.

according to Hart, ‘the statement that someone was obliged to do something, normally carries the implication that he did’ it.¹²⁴ The essential difference between the two statements lies in the notion of coercion. Being obliged to do something occurs when the coerced individual is subjected to a real threat of serious harm if he does not comply with the demand issued to him. Hart’s interest lay in the behaviour of the rational adult, and his notion of the coercive mechanism underlying ‘being obliged’ might not seem to be particularly germane to the present discussion. It might thus be useful to think in terms of compulsion rather than coercion. On Hart’s reading, the difference between the notions of ‘being under an obligation’ and ‘being obliged’ hinges on the concept of voluntariness. Whether an adult fulfils any moral or legal obligations he is under, or not, is down to choice. If he chooses not to perform an act when under an obligation to do so, he faces reactive attitudes and possible sanction. If, on the other hand, an individual is obliged to perform an act, then he will be coerced or compelled to do so.

In order to illustrate this point we might return to two year-old C, who is about to be a BM donor for her sister S. The reality is that C has no choice in this matter, and even if she objects to any part of the procedure at the time (and many two year-old children might), she will be obliged to donate (unless her parents change their mind).¹²⁵ This is in contrast with the case of Robert McFall, a 39 year-old asbestos worker who suffered from aplastic anemia. His adult cousin, David Shimp, was a matching donor, but refused to donate his BM. He stated that his immediate family responsibilities outweighed his obligation to assist his cousin. In summing up Flaherty Jr, J stated:

¹²⁴ Ibid.

¹²⁵ In general the HTA’s accredited assessor (AA) interviews the potential donor (at a level appropriate to their age and understanding) to assess whether the HTA requirements have been met. However, ‘where the potential donor is a very young child and not able to comprehend information about the planned procedure, the AA’s discussion should be held with the person/s consenting on the donor’s behalf – in most cases, this is likely to be the person/s with parental responsibility.’ (n15) ss55-6. No mention is made of the younger child who protests at hospitalisation or anaesthesia, most likely because oppositional behaviour is often reactive rather than the product of reflective choice. Even where children are older and capable of articulating reasoned choices, empirical data identifies that many paediatric donors experience emotional distress. In part this is because they ‘believe that they did not have a choice about whether to serve as a marrow donor’. AAP Committee on Bioethics. Children as Hematopoietic Stem Cell Donors. *Pediatrics* 2010; 125: 392-404. p395.

one human being is under no legal compulsion to give aid or to take action to save [another] human being. . . . [Yet,] in the view of the courts, the refusal of the defendant is morally indefensible.¹²⁶

Regardless of sanctions, obligations involve choice and require agency to exercise that preference. One can refuse to fulfil one's obligations, moral or legal, and face the opprobrium of the court or society, or punishment. Being obliged to do something is premised on the notion that that thing *will* be done. In England, there is no obligation to rescue imposed on capable adults.¹²⁷ Assuming that an individual has not brought about the event and owes no duty of care, then that individual cannot be prosecuted for standing by and not undertaking a risk in order to save a drowning person. Similar considerations pertain to illness. Although it may be a moral ideal to donate an organ to a critically ill relative, a capable adult cannot be obliged to do so.¹²⁸ Again in *McFall*, the judgment maintained

For our law to compel the defendant to submit to an intrusion of his body would change every concept and principle upon which our society is founded. To do so would defeat the sanctity of the individual, and would impose a rule which would know no limits . . . For a society, which respects the rights of one individual, to sink its teeth into the jugular vein or neck of one of its members and suck from it the sustenance for another member, is revolting to our hard wrought concepts of jurisprudence.¹²⁹

In reviewing the case Meisel and Roth concurred with these latter sentiments:

No matter how idiosyncratic Shimp's reasons for refusal, his mere wish not to donate marrow should not be overridden . . . It is he who would have had to bear the risks of donation, even if they were relatively slight, and it is he who now bears the costs of refusing – public notoriety, guilt, family discord. These are inherently personal choices. Who is to say that the death of a cousin is inherently more serious than the breakup of one's marriage or the chance of one's own death or incapacitation from general anesthesia? Shimp decided that, placed in this obviously difficult situation, the costs of donation were greater than the costs of refusing to be a donor. His choice must be honored.¹³⁰

¹²⁶ *McFall v Shrimp* (1978) 10 Pa. D.&C 3d 90 Allegheny County Court at 90.

¹²⁷ There is no legal duty to act as a Good Samaritan, regardless of how grave the need of another, nor how simple it might be to assist them. See *Dorset Yacht Co Ltd v Home Office* [1970] AC 1004 at 1061 per Lord Diplock: 'the priest and the Levite would have incurred no civil liability in English law'.

¹²⁸ Steinberg (n50) p229.

¹²⁹ *McFall v Shrimp* at 90.

¹³⁰ A. Meisel & L.H. Roth. Must a Man Be His Cousin's Keeper? *Hastings Cent Rep* 1978; 8: 5-6. p6.

It does seem peculiar that vulnerable young children can be obliged to undertake the very risks that Shimp rejected, resoundingly supported by some commentators at least. In a nutshell, it would seem that young children are not the bearers of moral obligations that commit them to voluntary participation in tissue donation or research programmes. Rather, they are in a position where they may be obliged or compelled to do so.

Against this, it might be argued that while children may not be fully fledged moral agents, parents have a duty to educate their child to recognise, and discharge their obligations to others. Battaglia asked the question:

If parents say yes to those medical procedures which are 'therapeutic'- that is, the procedures are directed at improving the growth and development of the child, a form of 'biologic good' – can the parents then say yes to those actions which they believe enable the child to participate in his or her 'moral good'?¹³¹

Many parents who do enrol their children in medical research studies claim to do so for altruistic reasons; in order to benefit other children in society.¹³² Advancing the moral good of the child might seem an irresistible prospect. However, if children are *obliged* to participate in RWTI or tissue donation, then the process would seem to be more about the exercise of power than education. The oft repeated case described by Gaylin is illustrative of this point. A researcher sought permission to take some blood from a child in the context of a non-therapeutic research study. The child, afraid of needles, dissented but was overruled by his father who stated:

This is my child. I was less concerned about the research involved than with the kind of boy I was raising. I'll be damned if I was going to allow my child, because of some idiotic concept of children's rights, to assume he was entitled to be a selfish, narcissistic little bastard.¹³³

Leaving aside concerns about the ability of small children, or severely learning-disabled individuals, to comprehend and assimilate the appropriate moral messages allegedly inherent in such procedures, the course of action itself seems peculiar.

¹³¹ Cited in Ramsey (94) p23.

¹³² S. Harth & Y. Thong. Sociodemographic and Motivational Characteristics of Parents Who Volunteer Their Children for Clinical Research. *BMJ* 1990; 300: 1372-1375.

¹³³ W. Gaylin. 1982. Competence: No Longer All or None. In *Who Speaks for the Child: The Problems of Proxy Consent*. W. Gaylin & R. Macklin, eds. New York: Plenum Press: 27-56. p94.

Altruism concerns actions that are ‘motivated solely or primarily by regard for others.’¹³⁴ Nagel defined it as the ‘willingness to act in consideration of the interests of persons, without the need of ulterior motives.’¹³⁵ The altruistic extent of an act is generally judged by the amount of risk or self-sacrifice an individual endures in its performance.¹³⁶ Given that it is the child who suffers whatever harms there are, then clearly the parent is not engaged in an altruistic act, unless we regard the child as a possession or extension of the parent. Neither is the child engaged in an altruistic act because, as has been pointed out, ‘forced altruism is not altruism’.¹³⁷

The case described by Gaylin does raise questions about research participation and the dissenting younger child. If research involvement is a moral obligation then, unless it is a weak duty, it would seem that parents should ‘encourage’ objecting children to participate regardless of remonstrations. However, a number of guidelines suggest that ‘children and young people should not usually be involved in research if they object or appear to object in either words or actions, even if their parents consent’.¹³⁸ The Royal College of Paediatrics asserts that researchers ‘should always ensure that the child does not object’ but seem to limit their discussion to the child of school-going age.¹³⁹ Such assertions seem to tacitly equate non-dissent with assent. However, this seems suspect as children often go along with their parents wishes regardless of their personal preferences. For example, in the context of BM transplantation many paediatric donors believe they have little choice about whether they will donate or not, and feel compelled to do so.¹⁴⁰ The Medical Research Council guidelines state that a ‘child's refusal to participate or continue in research should always be respected’,¹⁴¹ but later indicates that any objection should be *deliberate*.¹⁴² Whether the actions of particularly young children are indicative of reflective rejection or general unhappiness may be difficult to decipher on occasion.

¹³⁴ W. Glannon & L. Ross. Do Genetic Relationships Create Moral Obligations in Organ Transplantation? *Camb Q Healthc Ethic* 2002; 11: 153-159.

¹³⁵ T. Nagel. 1970. *The Possibility of Altruism*. Princeton, N.J: Princeton University Press. p78.

¹³⁶ Glannon & Ross (n134) p154.

¹³⁷ S. Zink & S.L. Wertlieb. Forced Altruism is not Altruism. *Am J Bioeth* 2004; 4: 29-31.

¹³⁸ General Medical Council. 2007. *0–18 years: Guidance for all Doctors*. London. para 38. See also Council of Europe. 2005. *The Additional Protocol to the Convention on Human Rights and Biomedicine* Strasbourg. ss15.1(v) and 15.2.

¹³⁹ RCPCH (n2) p182.

¹⁴⁰ AAP Committee on Bioethics (n125).

¹⁴¹ Medical Research Council. 2004. *Medical Research Involving Children*. London, s1.3.

¹⁴² *Ibid.* s5.1.6.

In addition, as Cave observes, whilst the Clinical Trials Regulations 2004 ‘require that a minor’s explicit wishes are ‘considered’, they do not give his views or wishes any legal force’.¹⁴³ It is difficult to know how these guidelines are implemented in practice, when a researcher is faced with consenting parents but a dissenting young child. Regardless, a distinction must be made between children being obliged to participate in a medical endeavour that they have not chosen, and children being forced, screaming, to donate a blood sample for the purposes of research. Just because a parent has the power to enrol a child in a non-therapeutic research study does not mean that his or her power is, or should be, unlimited in this respect.

6.7. THE CALCULUS OF CHILDHOOD MUNIFICENCE

The ‘obligation model’ is no more successful than the ‘best interests’ concept in justifying NBI. In reality, such interventions happen as the product of a fundamentally consequentialist decision-making process. Children who become tissue donors or research subjects are members of captive populations.¹⁴⁴ A parent does not volunteer a child to become a tissue donor simply because that child is seen to be morally impoverished and in need of ethical enhancement, or has low self-esteem and tissue donation is being used as a means of boosting self-regard.¹⁴⁵ Rather, the child has a relative who needs a tissue donation in order to treat some disease process, and the child is the best, or only, match.¹⁴⁶ Any justification is secondary to the primary fact of underlying need.

On a naïve utilitarian calculus, BM transplantation might appear a net good. A child may be a tissue donor for her sibling because on a harm-benefit analysis the greatest good is likely to be achieved by sacrificing the integrity of one child in order to sustain the life of another. BM harvesting allegedly provides a small risk to a child and some temporary discomfort.¹⁴⁷ As the procedure is relatively common it would

¹⁴³ E. Cave. Seen but not Heard? Children in Clinical Trials. *Med Law Rev* 2010; 18: 1-27.

¹⁴⁴ This term is used by Ross in the context of some forms of research. See L.F. Ross. 2006. *Children in Medical Research: Access versus Protection*. Oxford: Oxford University Press. p6.

¹⁴⁵ D. Steinberg. Response to (CQ Vol 13, No 2): A Critique. *Camb Q Healthcare Ethic* 2005; 14: 301-305.

¹⁴⁶ The Supreme Court of Illinois ruled that the donor should have ‘an existing, close relationship with the recipient’, although it declined to define what might constitute such a relationship. *Curran v Bosze* at 1345.

¹⁴⁷ Although the risk of death is approximately 1/10,000. AAP Committee on Bioethics (n125) p394.

appear that most parents (and doctors) deem this a reasonable price to pay for the potential to save the life of another of their offspring. Savulescu suggests that sibling BM donation is ‘about distributing benefits and burdens within a family’.¹⁴⁸

Most children who become participants in a non-therapeutic research project are also members of a captive population; they suffer from some illness, or are part of a particular community which is the object of scientific scrutiny. Their enrolment into a study straightforwardly is to address a deficit in scientific knowledge which researchers feel is to the detriment of children generally. Pence referred to this as the ‘Good-of-Others View’ of medical research:

It is important to understand that most research involving children is intended to benefit other children, albeit children who may not yet have been born or children who have no relation to the subjects ... On this (utilitarian) view, a small risk to any particular child is justified through its expected contribution to the good of most children.¹⁴⁹

The brief of the Amici Curiae of the Association of American Medical Colleges and others, submitted to the Maryland Court of Appeal in the case of *Grimes*, echoed this point, although it was bolstered with an unproven empirical claim:

The overall cost of such a rule in terms of lost advances in medical and health knowledge (and ultimately lost opportunities to cure diseases and prevent suffering and the loss of life) will far outweigh the asserted advantage of protecting individual rights.¹⁵⁰

On this view, the frequently articulated mantra of ‘a child’s interests should always prevail over society and science’¹⁵¹ is simply untrue in trials that involve children who are incompetent because of age or illness, and who will derive no healthcare benefit from the research project. Instead the child is enrolled with the principal aim of affecting the future care of other children. This is a laudable aspiration entailing a morally uncertain process. As Kopelman points out, paediatric research is in a moral

¹⁴⁸ J. Savulescu. Substantial Harm but Substantial Benefit. *BMJ* 1996; 312: 241-242.

¹⁴⁹ G.E. Pence. Children's Dissent to Research: A Minor Matter? *IRB: Ethics and Human Research* 1980; 2: 1-4. p2.

¹⁵⁰ Brief of Amici Curiae. Association of American Medical Colleges, Association of American Universities, Johns Hopkins University and University of Maryland Medical System Corporation in support of appellees motion for reconsideration. *Grimes v Kennedy Krieger Inst Inc* (2001) CA Md 128.

¹⁵¹ H. Sammons. Ethical Issues of Clinical Trials in Children: A European perspective. *Arch Dis Child* 2009; 94: 474-477. p475.

bind.¹⁵² Policies that aim to protect children by not allowing any subject to participate in a study without their explicit informed and competent consent obviously exclude most children. However, unless some research is carried out on children, there will be little progress made in paediatric healthcare.¹⁵³ Notwithstanding this, from the perspective of the ill or the impoverished, participation in research which entails some cost on their behalf may seem like a case of double jeopardy.

There are clear advantages to admitting the consequentialist motivation behind NBI, not least that it would provide for a more honest and transparent debate. Primarily, it would focus attention on the legitimacy of proxy authorisation when a child or incompetent individual is obliged to undergo procedures that are not of medical benefit to her. In general terms, consent holds only between the consenting party and the recipient of the consent. Thus, consent to inflict harm on a third party is not necessarily a sufficient justification.¹⁵⁴ Brownsword expresses the issue thus:

Suppose, for example, that when the ... child is about a year old a BM transplant for the sake of the ailing sibling is proposed. Currently, if the couple endorse this course of action, no awkward questions are likely to be asked. Yet, can it be right that a couple, simply by consenting to this procedure to be carried out on their donor child, cover it with legitimacy? If the child had authorised its parents to act as its proxy, the consent would be traceable to the will of the child and the integrity of the child's rights (assuming that the child is conceded, at this time, to be a rights-holder in relation to its own BM) would be maintained. However, without any suggestion of a proxy authorisation, it is wholly unclear why the consent of the couple should be thought to cast a justified burden on the rights-holding child.¹⁵⁵

One answer to this apparent dilemma is that the state entrusts parents with a broad discretion to raise their children as they see fit, including decisions which may expose the child to risks.¹⁵⁶ Such parental authority seems to entail the right to

¹⁵² L.M. Kopelman. Children as Research Subjects: Moral Disputes, Regulatory Guidance, and Recent Court Decisions *Mt Sinai J Med* 2006; 73: 596-604. p603.

¹⁵³ This, of course, assumes that a lack of 'progress' in the field of medical science is a bad thing, a view that has been contested. See for example I. Illich. 1975. *Medical Nemesis: The Expropriation of Health* London: Calder & Boyars.

¹⁵⁴ R. Brownsword. Happy Families, Consenting Couples, and Children with Dignity: Sex Selection and Saviour Siblings. *CFLQ* 2005; 17: 1-35. p4.

¹⁵⁵ Ibid.

¹⁵⁶ N. Fost. Ethical Issues in Research and Innovative Therapy in Children with Mood Disorders. *Biological Psychiatry* 2001; 49: 1015-1022. p1019; L.F. Ross. Informed Consent

require one child to donate tissue to benefit another, or to participate in a research project to the advantage of present or future members of a community.¹⁵⁷ However, it is arguable that this seems to license parents to treat their unconsenting child as a means to an end in some healthcare contexts, a position that is very different to the jealously guarded right to bodily integrity enjoyed by themselves, as autonomous adults.¹⁵⁸

6.8. CONCLUSIONS

This paper is not a polemic against either BM donation by young children or their participation in RWTI; both are important interventions that may save the lives of some children and improve the lot of others. It is an argument against the ‘obligation model’ as a justification for these procedures. It also seeks to question why there is a necessity to defend these interventions by stating that they are in a child’s best interest, or that they allow children to fulfil their obligations to their family or society. A need for justification would seem to indicate some discomfort around the legitimacy of the procedures. I suggest that there are two reasons for this uneasiness. Firstly, there have been a number of instances in the past when vulnerable persons have been treated badly by medicine and science, and so there is a need to defend interventions lacking direct benefit in these populations.¹⁵⁹ Secondly, ‘obliging’ unconsenting children but not rational adults might indicate some inequality between the way children and adults are treated.

It does not seem unreasonable to suggest that all persons¹⁶⁰ should be treated in a similar fashion unless there is a compelling reason to behave differently towards one group when compared to others. As things stand, children can be obliged to act as donors of tissue or scientific information, whereas competent adults cannot. One argument that could be made in favour of preserving this position is that it serves a

in Pediatric Research. *Camb Q Healthc Ethic* 2004; 13: 346-358. p348; Buchanan & Brock (n19) p239.

¹⁵⁷ F. Schoeman. Parental Discretion and Children's Rights: Background and Implications for Medical Decision-Making. *J Med Philos* 1985; 10: 45-62. Buchanan & Brock (n19) p233; Ross, *ibid*; Fost, *ibid*.

¹⁵⁸ Although the courts have not always dealt with adult autonomy in a consistent manner. See J. Coggon. Varied and Principled Understandings of Autonomy in English Law: Justifiable Inconsistency or Blinkered Moralism? *Health Care Analysis* 2007; 15: 235–255.

¹⁵⁹ See for example M.A. Grodin & L.H. Glantz eds. 1994. *Children as Research Subjects: Science, Ethics & Law* New York: Oxford University Press.

¹⁶⁰ This assumes, as the dictum of Dame Butler-Sloss stated, that the ‘child is a person’. E. Butler-Sloss. 1988. *Report of Inquiry into Child Abuse in Cleveland*. London: HMSO. p245.

social function that outweighs a child's right to the equal protection of the law;¹⁶¹ that the purpose is sufficient to override the right to bodily integrity of children but insufficient to breach that of adults. In order for this to be so, it would seem that it should hold that there is a far greater social need for children to be medical Samaritans than adults. It is uncertain that this is the case, as there is also a significant deficit of adult research volunteers¹⁶² and tissue donors.¹⁶³ It is possible to suggest that there are special claims on children because, for example, the paucity of prior research has meant that many drugs used in paediatrics have never been tested on children.¹⁶⁴ Thus, if pharmaceutical trials do not involve children who are too young to consent, then improper drug administration may occur leading to harm to other children. However, adults are not free from similar claims. A lack of adult volunteers may inhibit or retard the development of new treatments, which also causes harm to others. In both instances a failure of 'volunteerism' will lead to suboptimal therapy delivery and consequential harm.

If, with regard to NBI, children were to be treated in a similar fashion to adults then this would leave us with two basic possibilities. The first position would preclude NBI from being performed on any individual without their express consent. This 'integrity model' would mean that no young child could act as a research participant in a non-therapeutic trial or be a tissue donor. The second position (the 'obligation model') would suggest that all persons would have, as a minimum duty, a requirement to be a research subject or tissue donor in certain circumstances (for example, situations where the need is great and the cost to the individual small). Neither of these paradigms might seem attractive to some;¹⁶⁵ the 'integrity model' would lead to a slow down in some scientific advancement, while the 'obligation model' clearly impinges on adult autonomy. Thus, the extant position is the one that

¹⁶¹ McGillivray examined and dismissed this argument in the context of domestic corporal punishment. See A. McGillivray. Child Physical Assault: Law, Equality and Intervention *Manitoba Law J* 2004; 30: 133-170.

¹⁶² See for example A. Mathur. Should Patients Have to Agree to Medical Research? *BBC News* 09 December 2009: Accessed on 1 March, 2010 at <http://news.bbc.co.uk/2/hi/business/7935768.stm>

¹⁶³ Anthony Nolan Trust. 2008. *Why Join the Donor Register?* Accessed on 30 December 2009 at < <http://www.anthonynolan.org.uk/donating/> >. See also Statistics and Audit Directorate. 2009. *Transplant Activity in the UK 2008-2009*. London: NHS Blood and Transplant. p4.

¹⁶⁴ P.H.Y. Caldwell, et al. Clinical Trials in Children. *Lancet* 2004; 364: 803-811.

¹⁶⁵ A full discussion of the merits of either of these positions is beyond the scope of this paper.

is likely to continue. Adults have the power to oblige children but not other rational adults to undergo NBIs, regardless of need. Despite devising principles that indicate the contrary, the practice of both law and bioethics appear to offer greater protection to competent adults than incompetent children.

CHAPTER 7

PAPER 2¹

EQUALITY AND RESEARCH ON CHILDREN

First man: "How are your children?"

*Second man: "Compared to what?"*²

7.1. INTRODUCTION

The Nuremberg Code set out the requirements for the inclusion of participants in human subject research:

The voluntary consent of the human subject is absolutely essential ... *the person involved* should have legal capacity to give consent ... be able to exercise free power of choice, without ... constraint or coercion; and should have sufficient knowledge and comprehension ... to enable him to make an understanding and enlightened decision.³

While there is no specific reference to children, the inclusion of unconsenting persons as research subjects would seem to have been explicitly rejected. If the Code was intended to preclude children from research participation, then as a norm it stands alone. Guidelines issued by the Royal College of Paediatrics and Child Health (RCPCH),⁴ the British Medical Association (BMA),⁵ the Medical Research Council (MRC),⁶ the American Academy of Pediatrics (AAP),⁷ the Council for International Organizations of Medical Sciences (CIOMS),⁸ international declarations by the World Medical Association (*Declaration of Helsinki*) and the Oviedo Convention;⁹

¹ Submitted to *Bioethics*.

² H. Frankfurt. Equality as a Moral Ideal. *Ethics* 1987; 98: 21-43.

³ Article 1. My emphasis.

⁴ RCPCH. Guidelines for the Ethical Conduct of Medical Research Involving Children. *Arch Dis Child* 2000; 82: 177-182.

⁵ BMA. 2001. *Consent, Rights and Choices in Health Care for Children and Young People*. London: BMJ. pp188-98.

⁶ MRC. 2004. *Medical Research Involving Children*. London

⁷ AAP Committee on Drugs. Guidelines for the Ethical Conduct of Studies to Evaluate Drugs in Pediatric Populations. *Pediatrics* 1995; 95: 286-294.

⁸ CIOMS. 2002. *International Ethical Guidelines for Biomedical Research Involving Human Subjects*. Geneva.

⁹ UNESCO. 2005. *Universal Declaration on Bioethics and Human Rights*. Paris. Art 7.

and European, English and American legislation such as EU Directive 2001/20/EC, the Medicines for Human Use (Clinical Trials) Regulations 2004/2006 and the Code of Federal Regulations 21CFR50, all support the enrolment of incompetent children as research subjects. In fact, English legal instruments and international declarations dealing with human subject research seem to have set a number of different age- and capacity-related standards for consent:

(1) research on a competent adult may only be undertaken with his or her express consent;¹⁰

(2) incompetent adults may become research participants subject to a number of legal constraints;¹¹

(3) children with varying degrees of competence may assent or consent to research participation, usually in association with the permission of a responsible adult;¹² and

(4) an incompetent child (one who is too young or learning disabled to be able to provide consent or assent) may become a research participant subject to the authorisation of a person with parental responsibility for that minor.¹³

For the purposes of this paper, I am interested in the first and last categories, competent adults and incompetent children. I am also predominantly concerned with research conducted without therapeutic intent, rather than experimentation which has the aim of improving the subject's health. Such research, according to the RCPCH, 'is not necessarily either unethical or illegal'.¹⁴ The difference between competent adults and incompetent children is that unconsenting competent adults may not be

¹⁰ See for example *Convention on Human Rights and Biomedicine* 1997, (ETS no. 164) ss15-17; *Universal Declaration on Bioethics and Human Rights* 2005 Articles 6-7; EU Directive 2001/20/EC; the Medicines for Human Use (Clinical Trials) Regulations 2004/2006 (hereafter CTR).

¹¹ In England and Wales these are legislated for under the Mental Capacity Act 2005, ss32-33. Similar limits and checks are contained in the CTR sch. 1, pt 5.

¹² The MRC (n6) para 5.3.1.a, and the General Medical Council (GMC) suggest that parental consent, even for competent adolescents, is advisable. GMC. 2007. *0-18 Years: Guidance to All Doctors*. London. para 38.

¹³ CTR Schedule 1, pt 4. Under the CTR the clinical trial should relate directly to the clinical condition from which the minor suffers, or be of such a nature that it can only be carried out on minors. There should also be some direct benefit for the group of patients involved in the clinical trial, but not necessarily for the individual. With regard to research that falls outside the ambit of the CTR, English common law has had little to say. Ethical guidelines from the MRC (para 5.1.4.a) state that: 'If the research is thought not to offer potential benefit to the child, parents/guardians can still consent provided the risks are sufficiently small to mean that research can be reasonably said not to go against the child's interests'.

¹⁴ RCPCH (n4).

entered into clinical trials, while unconsenting incompetent children may. As the Nuremburg Code holds for adults but not for children, does this represent unequal, unjust or unfair treatment?

Professional norms specify that doctors should ‘Never discriminate unfairly against patients’,¹⁵ effectively articulating Aristotle’s principle of justice which proposed that individuals should be treated equally unless they are unequal in some relevant respect.¹⁶ If unconsenting adults and unconsenting children are treated differently with regard to research enrolment, then for this not to be unjust, there must be some difference between the two groups that renders the situation explicable and fair. I propose that there are two possible candidates for this difference; (a) age, and (b) social need. However, I will argue that both are morally insufficient to legitimise the imposition of a research burden on the incompetent child while not imposing a similar responsibility on the competent adult. If, as a matter of fairness, we are to eradicate this inequality, then there are two alternatives: (a) prohibit all research on individuals incapable of providing consent; or (b) make participation in medical research an enforceable obligation for all, regardless of age or wish.

7.2. RESEARCH ON CHILDREN

The ethics of research on incompetent children has been dissected in numerous articles and books, and most reveal the tension that exists between society’s responsibility to protect individual children on the one hand, and its obligation to ensure children as a class receive the best treatment on the other.¹⁷ The various guidelines, declarations and laws relating to paediatric research make different stipulations about levels of risk and benefit that participants should be exposed or party to,¹⁸ but this is not germane to the present discussion. In any case, as the International Bioethics Committee (IBC) points out, we do not know the risks and benefits to individuals at a study’s inception, this ‘is the research question being

¹⁵ GMC. 2006. *Good Medical Practice*. London.

¹⁶ Aristotle. 1999. *Nicomachean Ethics*. 2nd edn. Indianapolis: Hackett. 1131a10-b15.

¹⁷ For an overview, see: R. Nicholson. 1986. *Medical Research with Children: Ethics, Law and Practice*. Oxford: Oxford University Press. M.A. Grodin & L.H. Glantz eds. 1994. *Children as Research Subjects: Science, Ethics & Law*. New York: Oxford University Press; L.F. Ross. 2006. *Children in Medical Research: Access versus Protection*. Oxford: Oxford University Press.

¹⁸ S.D. Edwards & M.J. McNamee. Ethical Concerns Regarding Guidelines for the Conduct of Clinical Research on Children. *J Med Ethics* 2005; 31: 351-354.

asked'.¹⁹ Much research on children will not benefit the participants; instead its purpose is often 'to learn more about the nature of paediatric development, disease and potential treatments.'²⁰ The problem is that research conducted on adult volunteers is not directly translatable into paediatric practice, because children are not small adults and they suffer disease processes unique to them.²¹ Without specific paediatric research studies, advances in children's healthcare are likely to slow down, although Truog probably overstates the issue by claiming that 'efforts to protect individual children may mean that we jeopardize the health and safety of children overall'.²² Nonetheless, the point is well made that incompetent children may need to undergo medical research procedures in order to advance the healthcare of others. This reasoning holds children to a collective standard; they may be enrolled in research studies to address the needs of society. Competent adults, on the other hand, are not held to this collective norm, but may agree or refuse to participate in research according to personal values regardless of society's medical insufficiencies. Any refusal cannot be ignored without violating the ethical and legal principle of respect for autonomy.

It might be contended that treating incompetent children in this way is not treating them without consent; their parents have agreed to the relevant interventions on their behalf, and this is sufficient to make the situation lawful. However, in the context of medical research where the child will undergo risk for the benefit of others, it is unclear how parental permission morally justifies this imposition, particularly when adults are free to reject any such burden. Here, consent is about the free and uncoerced choice of the subject to 'become a joint adventurer in the common cause of medical research.'²³ Incompetent children do not choose to become adventurers, and thus are unconsenting. Ramsay described experimentation 'on children in ways not related to them as patients' as a 'sanitized form of barbarism', to which no parent should or could morally consent.²⁴ One does not have

¹⁹ IBC. 2007. *Report of the International Bioethics Committee of UNESCO (IBC) on Consent*. Paris: UNESCO.

²⁰ Ibid. para 87.

²¹ R.E. Kauffman. 1994. Scientific Issues in Biomedical Research with Children. In Grodin & Glantz eds. (n17) pp29-46.

²² R.D. Truog. Increasing the Participation of Children in Clinical Research. *Intens Care Med* 2005; 31: 760-761.

²³ P. Ramsey. 2002. *The Patient as Person: Explorations in Medical Ethics*. 2nd edn. New Haven: Yale University Press. p14.

²⁴ Ibid.

to share Ramsay's absolutist view to agree with the thrust of his claim. This is a situation in which it is proposed to justify research on incompetent children by applying a standard which appeals to the common good. However, adults are only held to a personal value system. This difference would appear to represent the application of a double standard; one which is inequitable and unfair.

7.3. EQUALITY

Some commentators have framed the argument for including children in research in terms of equality; children having an equal right to advances in biomedical science, to beneficial therapies and to the avoidance of harmful therapies.²⁵ It is also sometimes expressed that children have the right to have research undertaken on the diseases that affect them and the drugs used to treat them,²⁶ and an equal right to participate in trials,²⁷ although real equality of participation would seem to demand the explicit consent of the participant. Failure to conduct such research has been labelled as discrimination.²⁸ However, the CIOMS guidelines recognise that the inclusion of vulnerable individuals may lead to 'an inequitable distribution of the burdens and benefits of research participation.'²⁹

In general, people support the notion of equality.³⁰ Or, perhaps more specifically, few people will argue that inequality is a good state of affairs when it is expressed in broad terms. Most of us have encountered a situation, even if trivial, where we feel we have not been treated equally because of some characteristic we possess that was not germane to the distribution of goods at that time. Such characteristics might include our gender, or some aspect of our physical appearance including skin colour, weight or height.³¹ Unequal treatment in this regard strikes us

²⁵ P.H.Y. Caldwell, et al. Clinical Trials in Children. *Lancet* 2004; 364: 803-811. M.J. Field & R.E. Berman eds. 2004. *The Ethical Conduct of Clinical Research Involving Children*. Washington DC: National Academic Press. p1.

²⁶ T. Stephenson. New Medicines for Children: Who is Protecting the Rights of the Child? *Curr Paediatr* 2002; 12: 331-335.

²⁷ Caldwell et al (n25).

²⁸ E. Webb. Discrimination against Children. *Arch Dis Child* 2004; 89: 804-808.

²⁹ CIOMS (n8).Commentary on Guideline 13.

³⁰ D. Parfit. Equality and Priority. *Ratio* 1997; 10: 202-221. p204.

³¹ Shorter males (though still within the normal height range) are less likely to get a job or be promoted when competing against taller, but equally qualified, counterparts. They also earn less money. J. Rachels. 1995. Prejudice and Equal Treatment. In *Ethical Issues in Contemporary Society*. J. Howie & G. Schedler, eds. Carbondale, IL: Southern Illinois University Press: 54-77.

as being unfair or unjust. Equality appears to be associated with justice and fairness, although how these principles exactly relate to each other is a matter of debate.³² As there is no space here to investigate this complex issue, I propose, following Dworkin, to hold that we use “equality” in its normative sense ... to indicate the respect or respects in which ... people should be ... treated the same way, as a matter of justice.’³³

Over the course of human history, persons with power derived from birthright or office have regarded some other individuals or communities as less than equal. Frequently, those affected have been deemed to lack the full rational capacity for agency, and as a consequence they have been relegated to having a lower status and thus as possessing fewer, or no, legal rights. Contemporary moral and political theories tend to decry such inequalities. Some have argued that ‘every plausible political theory has the same ultimate value, which is equality.’³⁴ In practical terms, most political action aimed at equality tends to focus on the eradication of particular inequalities rather than the advancement of equality itself.³⁵ This is apparent in some international declarations and legislation. For example, *The International Covenant on Civil and Political Rights* (1976) asserts that:

the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.³⁶

Jefferson’s opening to the *Declaration of Independence* specified that ‘all men are created equal’.³⁷ In many ways this statement has never been true, with humans being subject to the vagaries of their genetic heritage and their acquired environment, resulting in economic, intellectual and physical inequalities. Thus, one of the problems with egalitarian theories has been the question ‘equality of what’, or

³² For a perspective of the complex relationship between justice and equality see D. Miller. *Equality and Justice*. *Ratio* 1997; X: 222-237.

³³ R. Dworkin. What is Equality Part 3: The Place of Liberty. *Iowa L Rev* 1988; 73: 1-54. p7.

³⁴ See W. Kymlicka. 2002. *Contemporary Political Philosophy*. 2nd edn. Oxford: Oxford University Press. p4.

³⁵ S. Benn. 1967. Egalitarianism and the Equal Consideration of Interests. In *Equality: Nomos IX* J.R. Pennock & J.W. Chapman, eds. New York: Atherton Press: 61-78.

³⁶ Art. 26.

³⁷ Accessed on 10 Sept 2010 at http://www.archives.gov/exhibits/charters/declaration_transcript.html.

‘what kinds of inequalities are morally impermissible’?³⁸ Benn expressed the view that everyone should be treated equally, unless the differences are germane to the particular situation and justify unequal treatment. Where there are no relevant differences between two cases, there is no rational reason to treat them differently.³⁹ If persons are to be treated differently, then, as Bedau has argued, it seems reasonable that the discriminator should have to provide a justification for the imposition of differential treatment.⁴⁰

Within a healthcare system, the application of these principles would seem to lead to the situation where, if there are no relevant differences between them, two competent adults have an equal claim to the same treatment. Relevant differences might include, for example, specific medical details about individuals. Consider, for instance, two adult males *A* and *B*. *A* has an infection; *B* has a broken leg. It makes little sense to treat them both the same, as antibiotic therapy would be useful to *A*, but not to *B*. Equal treatment, in this instance, is not identical treatment but is dependent on the notion of utility. Therefore, giving *A*, but not *B*, antibiotics is not unequal treatment because it is based upon a relevant difference. However, *B* is entitled to equality of care, to be treated in an equally effective manner insofar as that is possible. Suppose, however, that *A* and *B* have the same infection. *A* is treated with an antibiotic, but *B* is not because he is Irish or homosexual or Catholic. Such a decision is not equitable because it is based upon a non-relevant difference. *B* is denied treatment because of his race, religion or sexual orientation; he is being unequally treated because he is wrongly perceived to be unworthy of equal treatment. The history of medicine is replete with examples of this kind, whereby those humans perceived as having a lower status (e.g. slaves, women, those with physical or intellectual disability) have been treated unequally.⁴¹ What if *B* were replaced by a child *C*, who also did not get antibiotics for the same infection? If the only difference between *A* and *C* is age, is this a relevant or non-relevant difference?

³⁸ L.P. Pojman & R. Westmoreland. 1997. *Equality*. New York: Oxford University Press. p1.

³⁹ Benn (n35). Lucas described such pertinent differences that permit different treatment as *criteria of relevance*. J.R. Lucas. Against Equality. *Philosophy* 1965; 40: 296-307. p301.

⁴⁰ H.A. Bedau. 1971. Radical Egalitarianism. In *Justice and Equality*. H.A. Bedau, ed. Englewood Cliffs, NJ: Prentice-Hall: 168–180.

⁴¹ Examples might include the Tuskegee Experiment, or the routine sterilisation of mentally incompetent women. A.M. Brandt. Racism and Research: The Case of the Tuskegee Syphilis Study. *Hastings Cent Rep* 1978; 8: 21-29. D.S. Diekema. Involuntary Sterilization of Persons with Mental Retardation: An Ethical Analysis. *Ment Retard Dev Disabil Res Rev* 2003; 9: 21-26.

If age is relevant then we cannot say that the treatment *C* received was necessarily unequal. Since children do not have the same political, economic or legal status as adults, perhaps some might argue that age is a relevant difference. I will return to this possibility later.

7.4. EQUALITY AND RESEARCH

Imagine now that *A* and the parents of *C* are approached so that *A* and *C* might participate in a research trial which would impose similar burdens and risks upon both. *A* reads the consent form and refuses to participate. *C*'s parents sign the consent form. *C* has thus been committed to suffer the burdens and risk that *A* has declined. It might be argued that the parents of *C* are morally good people, and *A* relatively morally impoverished. But in what way are the parents of *C* morally good? It has been suggested that parents who permit scientists to conduct research on their children do so for altruistic reasons.⁴² But if altruism entails self-sacrifice,⁴³ *C*'s parents are not being altruistic. *C* will potentially suffer whatever harms are involved in the trial, and thus his parents will not be subject to peril. Alternatively, it could be contended that the parents of *C* have some empathy with the disease sufferers targeted by the research. *A* would appear to lack, or have less of, this quality. A virtue theorist might hold that, if empathy is a virtue, the parents of *C* are more virtuous than *A*. But it is easy to be 'virtuous' when it requires little personal sacrifice. This is not to denigrate the actions of *C*'s parents, but rather to point out that just because they signed a consent form and *A* did not, this does not necessarily endow them with any moral characteristics that are superior to those possessed by *A*.

This situation appears one of inequality; the unconsenting *A* will not be a research subject for as long as he declines to consent, the unconsenting *C* will. *C* will be exposed to burdens and risks, *A* will not. Thus, two unconsenting individuals are being treated differently. In order for this unequal treatment to be just, there must be a relevant difference between *A* and *C* that allows them to be treated differently. There are two possible candidates that might act as appropriate criteria of relevance: age and social need.

⁴² S.C. Harth & Y.H. Thong. Sociodemographic and motivational characteristics of parents who volunteer their children for clinical research: a controlled study. *BMJ* 1990; 300: 1372-1375.

⁴³ T. Nagel. 1970. *The Possibility of Altruism*. Princeton, N.J: Princeton University Press.

7.4.1. Age

Age is a relevant discriminating factor in many aspects of human life. Young children who lack the requisite rationality are incapable of participating in many areas of social endeavour. Because of their developing bodies and minds they are also vulnerable, and as such need to be protected by responsible adults. Many of the age-related differences in treatment that occur are not unjust inequalities because, in these instances, age is a relevant factor. Thus, the different treatment often is either not discriminatory because it pertains to matters that are of little concern to developing children, or it is protective in nature. However, this is not always the case and one pertinent example might be the treatment of pain. It has been well demonstrated that infants often have been denied analgesia (or anaesthesia) for painful procedures,⁴⁴ while older children have received disproportionately less painkilling medication than adults following similar operations.⁴⁵ An analysis of why children might not receive sufficient pain relief identified some specious, unscientific and prejudicial reasoning.⁴⁶ It would seem manifestly unfair to deny some persons pain relief but not others, unless there is a very good reason to do so.

It could be argued that this holds true for *persons*, but as only rational adults qualify as fully-fledged persons, it is equality of the members of this subset of the human population which should concern us.⁴⁷ This would be problematic for children, as the young may not meet the intellectual criteria for ascription of personhood. Some commentators have condemned the use of cognitive states as a means of attributing moral personhood or moral standing.⁴⁸ It is unclear how a cognitive capacity which lies above or below some arbitrarily set threshold tells us anything about the moral status of the person possessing that capacity. However, if

⁴⁴ Editorial. Pain, Anaesthesia, and Babies. *Lancet* 1987; 2543-2544. F.L. Porter & K.J. Anand. Epidemiology of Pain in Neonates. *Res Clin Forum* 1998; 20: 9-16.

⁴⁵ N. Schechter, et al. Status of Pediatric Pain Control: A Comparison of Hospital Analgesic Usage in Children and Adults. *Pediatrics* 1986; 77: 11-15, J. Beyer, et al. Patterns of Postoperative Analgesic Use with Adults and Children Following Cardiac Surgery. *Pain* 1983; 17: 71-81. E. Cummings, et al. Prevalence and Source of Pain in Pediatric Inpatients. *Pain* 1996; 68: 25-31.

⁴⁶ AAP Task Force on Pain in Infants Children and Adolescents. The Assessment and Management of Acute Pain in Infants, Children, and Adolescents. *Pediatrics* 2001; 108: 793-797.

⁴⁷ B.B. Green & N.K. Klein. The Mentally Retarded and the Right to Vote. *Polity* 1980; 13: 184-206.

⁴⁸ T.L. Beauchamp. The Failure of Theories of Personhood *Kennedy Inst Ethics J* 1999; 9: 309-324. E.F. Kittay. At the Margins of Moral Personhood. *Ethics* 2005; 116: 100-131.

qualities such as rationality or intelligence really are important discriminators of moral standing then logically, humans should be separated according to those qualities rather than according to age. The interests of human beings would therefore be weighted according to their intelligence quotient (IQ) or some similar mechanism for determining rationality.⁴⁹ Under this scheme the interests of particularly clever children would override those of less intelligent adults, or even those of average or young children would be preferred to those of adults with cognitive impairments such as dementia. However, it seems morally problematic to justify the distribution of basic goods on the basis of cognitive elitism, with the incompetent and vulnerable suffering most.

Incompetence equates to powerlessness. Competent adults can ask for or demand a particular treatment, or procure it for themselves. Pre-verbal children cannot, and are reliant on adults to protect them while vulnerable. Much research on incompetent children places a burden upon the subject child without commensurate benefit. The incompetent child is powerless to reject this burden, while the competent adult is not. It is possible to suggest that the child research subject may derive benefit by looking back in later life and feeling a sense of satisfaction at having contributed to the well-being of others. However, it is also plausible that a child may be traumatised by research participation, regardless of the efforts and intentions of researchers. Divining whether the outcome will be smiles or tears, or whether any future satisfaction accruing to the child research participant is sufficient compensation for the burden imposed, is a matter of speculative psychology. The fact remains that the unconsenting child will bear a burden that is not of their choosing; the unconsenting competent adult will not. There seems no ethically sound reason to hold that age is a morally relevant criterion to distinguish between those who will be subjected to the risks and harms of research without benefit, and those who will escape these hazards.

⁴⁹ R.J. Arneson. 1999. What, If Anything, Renders All Humans Morally Equal? In *Singer and His Critics*. D. Jamieson, ed. Oxford: Blackwell: 103-128. J. McMahan. 2002. *The Ethics of Killing*. New York: Oxford. pp204-232.

7.4.2. Social Need

The second possible criterion of relevance is ‘social need’, the idea that research on unconsenting children is essential in order to advance the medical welfare of all children. Kopelman expressed the issue thus:

unless some research is done with pediatric subjects, there can be no genuine improvement in care for children. If clinicians are forced to use untested interventions, they will probably endanger their patients. On the other hand, if they use only tested interventions and research is not permitted, then they are severely limited in their treatment options.⁵⁰

The justification from social need thus articulates the position that no research without consent means little or no paediatric research, which in turn would lead to a reduction in the pace of advances in paediatric healthcare, and result in children suffering. If unconsenting children are to be treated differently in a legitimate way, then this social need must exist for them, but not for competent adults. For this to hold, an adequate number of competent individuals must volunteer as research participants so that the research needs of competent adults are satisfied. If this is so, then the need for knowledge enhancement might be seen to be sufficient to override the right to bodily integrity of unconsenting children, but insufficient to breach that of unconsenting adults. While this might seem a reasonable rationale for experimenting on children, some of the claims implicit in this justification deserve further evaluation.

Firstly it must be asked, what are the aims of researchers and policy makers with regard to paediatric research? While the intention may be to improve the health of the child population, is the ultimate aim to deliver some basic minimum level of health provision, or to increase knowledge to some defined level X at which point research on children will stop, or is the goal to provide the best healthcare possible for children? The *Convention on the Rights of the Child* (1989) recognises ‘the right of the child to the enjoyment of the highest attainable standard of health’.⁵¹ The BMA expresses the view that excluding children from research is unjust as it is a ‘breach of their right to the best attainable standards of health and of appropriate health care.’⁵² The *International Covenant on Economic, Social and Cultural Rights*

⁵⁰ L.M. Kopelman. Children as Research Subjects: Moral Disputes, Regulatory Guidance, and Recent Court Decisions *Mt Sinai J Med* 2006; 73: 596-604. p597.

⁵¹ Article 24.

⁵² BMA (n5) p186.

(1966) also argues for the universal right ‘to the enjoyment of the highest attainable standard of physical and mental health.’⁵³ Thus, it seems reasonable to assume that the purpose of both adult and child research is to achieve the highest realizable level of health and healthcare.

The justification from social need implies that there is already a sufficient number of adult volunteers participating in clinical research ventures. This claim does not stand up to scrutiny. A variety of strategies (including payment) aimed at increasing adult participation in clinical trials have been identified.⁵⁴ If the number of adult volunteers is already adequate then these strategies are unnecessary. But this is not the case. As the Cochrane Review Group observe:

Many trials do not recruit sufficient participants and this can make it more difficult to use the results of the research in practice. Effective strategies for improving recruitment would be of great benefit to researchers designing and running trials.⁵⁵

Abraham and colleagues have argued that the inability to recruit an adequate number of participants is the greatest threat to the success of randomized controlled trials (RCTs).⁵⁶ It has been reported that in some instances less than 3% of all eligible patients enter RCTs,⁵⁷ and that almost one-fifth of medical RCTs ultimately recruit less than 50% of their target numbers.⁵⁸ These deficits have led some scientists to argue that if people want treatment for their illnesses, they should be obliged to take part in research.⁵⁹

If the aim of medical research is to achieve the highest attainable level of healthcare and health for individuals then, from the researcher’s perspective, the recruitment of incompetent children into research is the means to achieve the paediatric end of this goal; research on current children will prevent future children from suffering unnecessarily. Similarly, research on current adults will prevent future

⁵³ Article 12.1.

⁵⁴ S. Treweek, et al. Strategies to Improve Recruitment to Randomised Controlled Trials. *Cochrane Database of Systematic Reviews* 2010: MR000013.

⁵⁵ Ibid.

⁵⁶ N.S. Abraham, et al. A Systematic Review of Reasons for Nonentry of Eligible Patients into Surgical Randomized Controlled Trials. *Surgery* 2006; 139: 469-483.

⁵⁷ A. Benson, 3rd, et al. Oncologists’ Reluctance to Accrue Patients onto Clinical Trials: An Illinois Cancer Centre Study. *J Clin Oncol* 1991; 9: 2067-2075.

⁵⁸ AA. Haidich & J. Ioannidis. Patterns of Patient Enrollment in Randomized Controlled Trials. *J Clin Epidemiol* 2001; 54: 877-883.

⁵⁹ A. Mathur. Should Patients Have to Agree to Medical Research? *BBC News* 09 December 2009: Accessed on 1 March, 2010 at <http://news.bbc.co.uk/2/hi/business/7935768.stm>.

adults from needless suffering. If, as currently appears the case, there are insufficient numbers of adult volunteers, then it seems that future adults will be deprived of therapies that they could have had were it not for the choices of others. If social need is a sufficient justification for the recruitment of unconsenting children into research, then it would also seem to warrant the enrolment of unconsenting adults.

7.5. 'EQUALISING' CHILDREN

Assertions are frequently made about the need to include unconsenting children in medical research because of perceived knowledge deficits.⁶⁰ It has been argued that children constitute a special case because, for example, an historic lack of research has meant that many drugs used in paediatrics have never been tested on children.⁶¹ Thus, if trials do not involve children who are too young to consent, then improperly administered therapies will cause harm to future children. This justification for conducting research on children relies on an putative obligation to advance the health status of others.⁶² The existence of any such obligation is contestable.⁶³ However, adults are not free from similar claims. An insufficiency of adult volunteers will negatively impact upon the development of new treatments, which will also cause harm to others. A failure of 'volunteerism' will lead to suboptimal therapy delivery and consequential harm. Whether adults have obligations to other adults in this regard is a matter of debate,⁶⁴ but there seems no good reason to hold that children should bear these obligations while adults would be free from them. In the absence of clear proof that we are further away from the highest attainable standard of knowledge with regard to childhood illness and care than we are with respect to the understanding and treatment of adult disease, there seems no rational reason to treat the two groups differently. If the view that persons should be treated equally is to obtain, then with regard to medical research this would leave two possible options.

The first option, the 'integrity model', would preclude research from being performed on individuals who do not explicitly consent. This would mean that no

⁶⁰ Field & Berman eds. (n24) pp58-92.

⁶¹ Caldwell et al (n25) p803; AAP Committee on Drugs (n44) p286.

⁶² T.F. Ackerman. Nontherapeutic Research Procedures Involving Children With Cancer. *J Ped Oncol Nurs* 1994; 11: 134-136.

⁶³ See paper 1.

⁶⁴ J. Harris. Scientific Research is a Moral Duty. *J Med Ethics* 2005; 31: 242-248, I. Brassington. John Harris' Argument for a Duty to Research. *Bioethics* 2007; 21: 160-168

young child could act as a research participant in a non-therapeutic trial. The second option, the 'obligation model', would be one whereby all persons could be obliged to become research subjects regardless of age or inclination. Instead the determinant would be social need, although the amount of potential harm that unconsenting persons would be exposed to would be minimal, in order to prevent a recurrence of the kind of research abuses that history has recorded.⁶⁵ Both models have their drawbacks; the 'integrity model' would reduce the rate of biomedical advancement, while the 'obligation model' would be marked by a decline in respect for autonomy in order to further more collective ideals. Which of these options is better depends on one's worldview. Biomedical researchers might feel that a small loss in autonomous status is a price worth paying for the lives potentially saved by an acceleration in research activity. Autonomous persons may be reluctant to countenance any infringement of their right to self-determination, and particularly to give up this status to researchers who have shown themselves to be less than trustworthy in the past.⁶⁶ Whichever model should obtain, there is no reason for it not to hold for children and adults alike.

7.6. CONCLUSIONS

It might be argued that if the integrity model were to obtain then there would be no research performed on young children, while some adult research would continue through competent volunteers leading to a position of inequality of knowledge. However, this is not so because the purpose of this paper is to question the legitimacy of research that does not offer the possibility of therapeutic benefit, rather than trials where there is a possibility of healthcare gain. The problem of why children should be subjected to potentially harmful processes that adults are free to reject remains. In reality, it occurs because adults have the power to enrol incompetent children but not other rational adults as research subjects, regardless of need. Researchers identify knowledge gaps and contend that it would be better for children in general if research was carried out on this matter. Some parents concur, and the unconsenting child is enrolled. The child is powerless in this situation. The same knowledge gap might be identified with regard to adult disease, and similarly it would be better for adults in general for research to be undertaken. However,

⁶⁵ H.K. Beecher. Ethics and Clinical Research. *N Eng J Med* 1966; 74: 1354-1360.

⁶⁶ Ibid.

competent adults have the personal power to refuse to participate. Power and powerlessness, rather than equality, are the determinants of research enrolment. Paediatric research may well be to the ultimate benefit of all children, but we should not delude ourselves about the moral underpinnings of this endeavour.

CHAPTER 8

PAPER 3¹

‘THE GOOD THAT IS INTERRED IN THEIR BONES’: ARE THERE PROPERTY RIGHTS IN THE CHILD?

*And since what belongs to the son is his father's...*²

8.1. INTRODUCTION

We use the possessive pronouns ‘my’ and ‘mine’ in a number of different senses. The simple possessive ‘my’ refers to that which belongs to me, or that ‘which I have, hold, or possess’, and denotes objects which I believe I own, such as my car or my house. ‘My’ may also be used in a relational sense, and this pertains to things or people which I do not own but stand in some sort of relationship to; for example, my friends or my parents.³ However, when we say ‘my child’, do we use the pronoun in the possessive or relational sense? Nedelsky contends while our everyday use might imply the possessive, there is no confusion either in law or social exchange that we in any sense own our children. While acknowledging the ‘overlap between property and the law relating to children’, she argues that we do not hold that children are the property of their parents.⁴ Nonetheless, at a recent public lecture the Ombudsman for Children in Ireland felt the need to remark ‘Children are not property subject to ownership.’⁵ This should seem an odd statement. After all, it is never thought necessary to argue that other social groups such as civil servants or teachers, Muslims or Catholics are not property. However, one difference between children and these others is that, in some respects, children traditionally were

¹ Accepted for publication by the *Medical Law Review*.

² T. Aquinas. 1947. *Summa Theologica*. New York: Benzinger Brothers. Q57, Art 4, Reply to Objection 1.

³ J. Simpson & E. Weiner. 1989. *Oxford English Dictionary*. 2nd edn. Oxford: Clarendon Press.

⁴ J. Nedelsky. Property in Potential Life - A Relational Approach to Choosing Legal Categories. *Can J L & Jurisprudence* 1993; 6: 343-366. p358.

⁵ Cited in J. Murphy. Children's Rights - The Public Policy Challenge. *Irish Med J* 2010; 103: 4.

regarded as property.⁶ Although this status is now supposedly an historical footnote, ‘the child is a person not property’ remains a frequently articulated mantra.⁷ Implicit in this recurring iteration is a sense that in some ways children continue to be treated as property. If this notion did not persist then there would be no need to present a contrary thesis, to continually uphold the ‘non-proprietary’ status of children. These statements often seem reflexive in nature, and fail to examine scenarios in which parents exert their authority over their children in ways that at least mimic traditional parental property rights.⁸

This paper does not contend that parents should own children. Instead it argues that despite socio-legal protestations to the converse, there are circumstances where parents appear to retain some property rights in children, or at least in some of their bodily material. The property of interest to this paper lies within the child’s body, specifically in his or her bone marrow (BM). The harvesting of BM from healthy children for transplantation is a ‘relatively routine’ procedure.⁹ While this intervention has been defended on a number of grounds, I will argue that the parental right to authorise the removal of a child’s BM and its subsequent disposal is essentially proprietary in nature. This is not to imply that BM donation by young children is not a social good; nor is it my intention to suggest that children should be viewed as property. Rather, this paper argues that if the parentally authorised transfer of biological material from an unconsenting human to another is legally permissible, it must be on the basis of an implicitly acknowledged property right in the child.

⁶ This claim is discussed later.

⁷ See for example E. Butler-Sloss. 2003. Are We Failing the Family? Human Rights, Children and the Meaning of Family in the 21st century. In *The Paul Sieghart Memorial Lecture*. British Institute of Human Rights, King's College London: Accessed on 17 November 2008 at <http://www.dca.gov.uk/judicial/speeches/dbs030403.htm>. R.N. Nwabueze. 2007. *Biotechnology and the Challenge of Property: Property Rights in Dead Bodies, Body Parts, and Genetic Information*. Aldershot: Ashgate Publishing. C.L. Betz. Children are not property. *J Ped Nurs* 1995; 10: 1-2. H. Reece. 2009. The Degradation of Parental Responsibility. In *Responsible Parents and Parental Responsibility*. R. Probert, et al., eds. Oxford: Hart: 85-102. pp86-8; R. Noggle. 2002. Special Agents: Children's Autonomy and Parental Authority. In *The Moral and Political Status of Children*. D. Archard & C.M. Macleod, eds. Oxford: Oxford University Press. p72. Nedelsky (n4).

⁸ Notable exceptions include Archard & Macleod (n7) pp1-3, 147-8. J. Montgomery. Children as Property? *MLR* 1988; 51: 323-342. J. Bridgeman. 2009. Parental Responsibility, Relational Responsibility: Caring for and Protecting Children after their Death. In R. Probert et al, eds. (n7) p255.

⁹ Human Fertilisation and Embryology Authority. 2004. *Preimplantation Tissue Typing*. London: HFEA. para 26.

8.2. BONE MARROW DONATION BY MINORS

English courts have never specifically considered the harvesting of BM from children. Department of Health guidance comments that BM donation is a ‘more than “minimal burden”’ which ‘to be lawful ... must be in the child’s best interests’.¹⁰ The Human Tissue Authority (HTA) also uses the welfare principle as the standard to be met if parents are to consent legitimately on behalf of their incompetent children. While the HTA must sanction all such donations,¹¹ no proposed child donors have ever been turned down.¹² It would thus seem reasonable to hold that once the donation is deemed medically appropriate, a parental decision for one sibling to donate to another is likely to be upheld. However, Brownsword has expressed uncertainty about parental rights in this regard:

can it be right that a couple, simply by consenting to this procedure to be carried out on their donor child, cover it with legitimacy? If the child had authorised its parents to act as its proxy, the consent would be traceable to the will of the child ... However, without any suggestion of a proxy authorisation, it is wholly unclear why the consent of the couple should be thought to cast a justified burden on the rights-holding child.¹³

If the donation was clearly in the best interests of the incompetent donor then Brownsword’s objection might carry little weight. But BM donation is not obviously in the donor’s best interests.¹⁴ Within families there are often conflicts of interest and

¹⁰ Department of Health. 2001. *Seeking Consent: Working with Young People*. London. p25. However, some commentators do not accept this position. For example, Ross’ ‘constrained parental autonomy’ model argues that parents should be allowed to authorise a BM donation from one child to another because ‘it serves family goals.’ Authorisation should not be dependent on some concept such as the child’s future consent or his coming to view the procedure as having been in his best interests. Instead, Ross contends, parents should be permitted to ‘make decisions that go beyond the best interests of family members’ as long as their basic needs are not sacrificed. L.F. Ross. 1998. *Children, Families and Healthcare Decision-Making*. Oxford: Clarendon Press. p30.

¹¹ HTA. 2009. *Code of Practice 6: Donation of Allogeneic Bone Marrow and Peripheral Blood Stem Cells for Transplantation*. London. ss77-81. Unlike children, where the potential donor is an adult lacking capacity to consent, the case must be referred to a court for a declaration that the proposed intervention is lawful.

¹² Between September 2006 and March 2010, 258 children were approved as BM or peripheral blood stem cell donors. Data supplied by the HTA on 12 August 2010.

¹³ R. Brownsword. Happy Families, Consenting Couples, and Children with Dignity: Sex Selection and Saviour Siblings. *CFLQ* 2005; 17: 1-35. p4.

¹⁴ The screening process implemented by the HTA seemingly should guard against obviously egregious (not in the child’s best interests) cases. The *Code of Practice 6* specifically requires that assessors look for evidence of coercion or reward (ss82-6), and that if there is any doubt about the procedure being in the donor’s best interests then the matter must be referred to the courts (ss A8-A13). No cases have been referred thus far. This is

in such circumstances it is implausible to hold that parents will, or even can, always act in the best interests of an individual child.¹⁵ In the context of inter-sibling BM transplantation there is a tension between the potential donor's (D's) right to bodily integrity and the recipient's need. As donating can hardly be said to be to D's physical advantage, the welfare principle in this circumstance must refer to emotional bonds and psychological benefits. The best interests standard in this context has attracted opposing viewpoints and, as the various perspectives on this issue have been extensively reviewed elsewhere,¹⁶ I shall not repeat the many arguments here.

However, in brief, children who become BM donors have a sibling (S) in need of this tissue in order to treat some disease process. Whether donating will turn out to be in D's best interests, or not, is unknowable. It is impossible to predict which of the possible outcomes will turn out best for D: (a) to donate and for S to survive; (b) to donate and for S to die; or (c) to not donate and for S to die.¹⁷ We like to hold that (a) is in D's best interests, but we cannot know that this is so. It is a matter of speculation whether S's continued existence will enhance or blight D's life, whether they will remain close as siblings or not, whether S's survival will affect the amount of time his parents will have free to spend with D or impact upon the bond between D and his parents. It is arguable that (b) might be best for D, as he will reap the plaudits for heroic behaviour and not have to share parental love with S. Alternatively, it might be best for D if unconsenting children were prohibited from donating; then D would not have to suffer the burden of the procedure, be subject to

interesting, given that international data indicates that some paediatric donors feel emotional distress related to their role as donor, and also feel coerced to donate. AAP Committee on Bioethics. Children as Hematopoietic Stem Cell Donors. *Pediatrics* 2010; 125: 392-404. p395. In addition, whether something turns out to be in an individual's best interests or not can only be known after the event. Yet, there is no requirement in either the Human Tissue Act 2004 or the *Code of Practice* that mandates the follow up of child donors.

¹⁵ Eekelaar divided arguments against the welfare principle into 'lack of transparency' and 'lack of fairness' objections; J. Eekelaar. Beyond the Welfare Principle. *CFLQ* 2002; 14: 237-249. With regard to the latter, Reece argued for a framework which recognises that 'the child is merely one participant in a process in which the interests of all the participants count'. H. Reece. The Paramountcy Principle: Consensus or Construct? *Curr Leg Prob* 1996; 49: 267-304.

¹⁶ S. Elliston. 2007. *The Best Interests of the Child in Healthcare*. London: Routledge-Cavendish.

¹⁷ This assumes that D not donating and S surviving is not a possibility. It also does not account for the possibility of D dying during the donating procedure, regardless of whether S survives or not. The risk of D dying is approximately 1:10,000; AAP Committee on Bioethics (n14). It is taken as self-evident that D dying would not be in his best interests.

no blame, and enjoy less diluted parental attention. Our belief in (a) is a social fabrication brought about by our emotive desire to do something to help S, and our wish to believe that D will be better off if S survives. The decision may turn out to be in D's best interests, but it is not made for that purpose. Instead, the parental choice for D to donate rests on a socially supported harm-benefit analysis; sacrificing D's bodily integrity to secure S's survival is a reasonable price to pay as parents see it.

If we accept that D being a donor satisfies some micro-utilitarian concept of the family good, from where does the parental authority to approve the expropriation of his bodily tissue derive? The Children Act 1989 indicates that parents have rights with regard to their child and his property, although the extent of these is not defined.¹⁸ According to Lord Olivier in *re K. D.*:

Parenthood, in most civilised societies, is generally conceived of as conferring upon parents the exclusive privilege of ordering, within the family, the upbringing of children of tender age, with all that that entails. That is a privilege which, if interfered with without authority, would be protected by the courts, but it is a privilege circumscribed by many limitations imposed both by the general law and, where the circumstances demand, by the courts.¹⁹

Despite these caveats, historically the law has tended to support a 'laissez-faire' attitude to parent child-relations. Smith suggests that this approach was particularly influential during the Victorian era, and under the New Right Conservative government of 1979–97.²⁰ This model places few restrictions on parents and allows them to raise their children as they see fit with minimal interference.²¹ It has been argued that the Children Act continues this non-interventionist stance, its tenor promoting the idea of 'an exaggerated legislative "hands-off" approach' to family autonomy.²² Thus, while there is a change in language from parental right to responsibility, the non-intervention principle enshrined in section 1(5) would seem to promote parental wishes in the event that they agree with one another. Bainham has

¹⁸ s3(1): 'all the rights, duties, powers, responsibilities and authority which by law a parent of a child has in relation to the child and his property'.

¹⁹ *In re K. D. (A Minor) (Ward: Termination of Access)* [1988] AC 806 at 825.

²⁰ R. Smith. 2004. *Values and Practice in Children's Services*. Basingstoke: Palgrave Macmillan. p25.

²¹ J. Goldstein, et al. 1996. *The Best Interests of the Child*. New York: Free Press. p87.

²² J. Fortin. 2005. *Children's Rights and the Developing Law*. 2nd edn. Cambridge: Cambridge University Press. p9. See also S. Cretney. *Privatising the Family: The Reform of Child Law*. *Denning LJ* 1989: 15. A. Bainham. *The Privatization of the Public Interest in Children*. *MLR* 1990; 53: 206.

argued that the welfare standard effectively has been weakened by the non-intervention principle as primacy is accorded to the interests of adults.²³ Fortin suggests that the Act ‘does not attempt to change the habits of the minority but keeps faith with the majority of parents who ... can be trusted not to treat their children as chattels’.²⁴ The European Convention on Human Rights enshrines this adult ‘right to respect for his private and family life’ which shall not be interfered with except in specific and limited circumstances,²⁵ while the Convention on the Rights of the Child also refers to, but does not elaborate on, parental rights.²⁶ Freeman evaluated the nature and extent of parental rights with regard to healthcare and argued that while it is generally accepted that parents have rights, it is less certain why they so do.²⁷ On further investigation, and after examining and dismissing postulates relating to biology, genetics and intention, he concluded that there is no compelling reason that explains why parents do have rights. He continued: ‘Let us grant, then, that parents have rights whilst remembering not only their limits but the shaky foundation upon which the ascription rests.’²⁸ The Independent Review Group on Retention of Organs at Post-Mortem in Scotland also ‘explored ... possible avenues which might explain the legitimacy of the role of parents clearly and unequivocally.’²⁹ Having dismissed ‘a property-based model’ on the basis that ‘it would be inappropriate to use the language of property about what has once been a person’,³⁰ the Report then seemed to endorse Page’s view that parenthood possesses a special value of itself, and that

²³ A. Bainham. The Children Act 1989 - Welfare and Non-Intervention. *Fam Law* 1990: 143.

²⁴ Fortin (n21) p9.

²⁵ Article 8.2: ‘... except such as is in accordance with the law ... in the interests of national security, public safety or the economic well being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.’

²⁶ Article 5.

²⁷ M. Freeman. Whose Life is it Anyway? *Med Law Rev* 2001; 9: 259-280.

²⁸ Ibid. p272. An examination of paediatric end-of-life cases reveals one of the limits of parental rights. Where parents demand treatment for their critically-ill children which doctors consider futile, the courts generally have sided with medical opinion. However, in the more recent case of *An NHS Trust v MB* [2006] EWHC 507, Holman J steered a middle course between parental and medical wishes, allowing for the withholding but not the withdrawal of treatment.

²⁹ Final Report of the Independent Review Group on Retention of Organs at Post-Mortem in Scotland. 2000. Accessed on 8 February 2011 at <http://www.sehd.scot.nhs.uk/scotorgrev/Final%20Report/ropm.pdf>. para 13.

³⁰ Ibid.

this 'special value ... constitutes the ultimate foundation of parental rights.'³¹ For Page the reason why

parents should have special rights is not to protect their individual interests, although of course their interests are involved, but to protect parenthood - and this means to protect parenthood as a condition of human existence, to protect the possibility of parenthood.³²

The argument would thus seem to be that, as parenthood is a critical social institution, its continuance must be promoted. An essential element in the furtherance of parenthood is the provision of parents with rights. It is notable that Page maintained

that we must remember that parental rights are those rights which people have simply as parents, not as good parents. Parents cannot properly be called on to justify the possession of the special rights they have, as parents, by showing that they act in the interests of their children when they exercise those rights.³³

Returning to Brownsword's objection, this articulates the view that although the consent of D's parent(s) makes his donation lawful, there remains the problem of why this is sufficient to permit the redistribution of his biological wealth.³⁴ In general, it would seem to hold that one person cannot legitimately take something from another and then give it to a third as a gift unless either (a) the second party explicitly consents to the process, or (b) the first person believes the item to be theirs to give.³⁵ As D cannot consent, this leaves us with the latter explanation: that D's parents somehow believe that his BM is theirs to redistribute.

³¹ E. Page. Parental Rights. *J Appl Phil* 1984; 1: 187-203. p196. Page argues that parenthood evidently has a special value because (a) most people choose to do it, (b) it is an activity that is desired for its own sake; it is an end in itself, and (c) it 'is generally thought to enhance human life' (p197). He derives this special value of parenthood through an analogy with 'producers' rights' although he states that it would 'be absurd to argue that parental rights are simply a particular instance of producers' rights' (p196).

³² Ibid.

³³ Ibid. p189.

³⁴ Brownsword (n13).

³⁵ The Theft Act 1968, s2 states that: 'A person's appropriation of property belonging to another is not to be regarded as dishonest- (a) if he appropriates the property in the belief that he has in law the right to deprive the other of it, on behalf of himself or of a third person; or (b) if he appropriates the property in the belief that he would have the other's consent if the other knew of the appropriation and the circumstances of it'. The case of parents as trustees will be dealt with later

8.3. THE CASE OF SAM

In a paper dealing with the therapeutic uses of human tissue, Brazier outlined the fictional case of a three year-old child, Sam, who after contracting meningitis makes a miraculous recovery.³⁶ Tests reveal that Sam has extraordinary biological properties and an analysis of Sam's tissues is likely to lead to the development of effective treatments for many human illnesses. Brazier suggests that if Sam's parents consent to doctors taking tissue samples, then moral objections 'might be subdued', while legally the procedures may be viewed as not being against his interests.³⁷ Furthermore, what if Sam's parents withhold consent unless they are financially rewarded? If parents are permitted to make money out of their 'beautiful' children appearing in advertisements, is it different if Sam's parents take similar advantage of their son's immunological prowess?³⁸

It seems reasonable to classify Sam's enhanced capacity to fight disease as a biological asset,³⁹ but the fictitious scenario outlined above gives rise to questions about the nature of his BM. Might it be regarded as property, as something that can be owned and traded?⁴⁰ And if there are property rights in Sam's bodily matter, to whom do they belong? Applying his theory of property,⁴¹ Munzer has argued that umbilical cord blood is the property of the newborn baby, but parents have discretionary disposal rights over it.⁴² If the secrets of Sam's immunocompetence are locked in his BM then, by extending Munzer's argument, this tissue would seem to be Sam's property. However, as Sam is too young to be competent, can his parents exercise property rights over this asset for his, or their own, benefit?

To some, perhaps the hypothetical Sam might appear an implausible creation. Nonetheless, some individuals have donated tissue which holds important biological

³⁶ M. Brazier. 2006. Human(s) (as) Medicine(s). In *First Do No Harm: Law, Ethics and Healthcare*. S.A.M. McLean, ed. Aldershot: Ashgate: 187-202. p187.

³⁷ *S v S* [1970] 3 WLR 366.

³⁸ Brazier (n36) p200.

³⁹ In *Green v. Commissioner*, 74 T.C. 1229 (1980), the court determined that Margaret Cramer Green, who had a rare blood type (AB negative), earned her living from selling this product (95 sales in 1977). That this was taxable income was not in dispute. What the court determined was that her high protein diet (which was needed to rapidly replenish her stock of red blood cells) was a deductible expense, as were her travel costs, because uniquely the 'petitioner was the container in which her product was transported to market' (at 1238).

⁴⁰ For a full discussion on the nature of property see Nwabueze (n7) chapter 1.

⁴¹ S.R. Munzer. 1990. *A Theory of Property*. New York: Cambridge University Press.

⁴² S.R. Munzer. The Special Case of Property Rights in Umbilical Cord Blood for Transplantation. *Rutgers L Rev* 1999; 51: 493-568.

information, and occasionally is of significant commercial worth.⁴³ Even if Sam is a normal child his BM has both pecuniary and non-pecuniary value.⁴⁴ With regard to the latter, consider the scenario where Sam has a ten year-old brother with leukaemia who needs a BM transplant. Sam may be required to act as a donor to his sibling, Rob,⁴⁵ but as he lacks capacity the decision as to whether this will happen or not is likely to be made through ‘the legal tool [of] ... parental power.’⁴⁶ Sam’s parents have the power to authorise the appropriation of his BM and its conveyance to Rob,⁴⁷ an operation that entails the property-like transfer of a biological asset from one child to another.

There are two immediate objections that might be raised to the suggestion that Sam’s parents have property rights in his biological material. The first is that, even if BM donation is not in Sam’s best interests, an alternative parental model such as the trust model might explain his parents’ capacity to utilise his tissue in this manner. The second objection is the argument that bodies cannot be property. I will deal with these objections in order.

8.4. THE CHILD IN TRUST

A number of authors have submitted that the relationship between parent and child needs revision away from the traditional parental authority paradigm. One

⁴³ G. Kolata. Who Owns Your Genes? *New York Times* May 15, 2000.A1: In the 1980s two men who had repeated unprotected sex with HIV positive partners did not contract the virus. Both donated tissue to a research centre which discovered that they had a genetic capability to block the virus from entering cells. The researchers patented the discovery, excluding the donors. The most celebrated example of third party financial gain from the donations of a non-beneficiary is the case of John Moore. In 1990, the Mo cell line extracted from Moore’s tissue was estimated to be worth approximately \$3bn. See Spleen Rights. *Economist* 1990: 38.

⁴⁴ Family members may derive non-financial (psychological/emotional) benefits from donating BM to a sick relative. However, a recent case in the United States gives some indication of the commercial value of BM. David Deier, who needed a BM transplant, allegedly gave \$37,500 to his brother Michael, a perfect match, as a ‘loan’ prior to donating. However, after receiving the money, Michael reportedly did not keep his end of the bargain. A third brother ultimately provided the required tissue. In September 2009, David filed a lawsuit in Hillsborough County Circuit Court, Florida, seeking the return of his money. *St Petersburg Times*, 5 September 2009, ‘Brother Took Money for Bone-Marrow Donation then Reneged, Lawsuit Claims’.

⁴⁵ Recipient Of BM.

⁴⁶ Montgomery (n8) p340.

⁴⁷ HTA (n11) para78.

suggestion devised to meet this is the fiduciary or trustee model.⁴⁸ The fiduciary concept provides that, in the presence of an imbalance of power in a relationship, the stronger party undertakes a strict duty of loyalty and selflessness in looking after the weaker party's legal and practical interests.⁴⁹ Portraying parents as fiduciaries implies that the parent-child relationship bears significant similarities to other, more conventionally defined, fiduciary relationships such as trustees and trust beneficiaries.⁵⁰ In this paradigm parent-child legal relationships would be child-rather than adult-centred; parental power would be exercised, not to advance parents' rights, but to address children's needs.⁵¹ According to Woodhouse, the acceptance of parental power imposes the obligations of protection and provision on responsible adults. Fulfilling these obligations justifies parental decision-making authority and gives the parents legal standing in disputes concerning children's welfare.⁵²

The fiduciary or trust model is not a new concept. Locke's natural rights theory defended the view that individuals owned what they created through the exercise of their labour.⁵³ Since children would seem to be the fruits of their parent's labour then, logically they should be their parent's property. Locke found this conclusion unpalatable and argued that children are not produced in a manner that makes them subject to ownership. As it is God who controls the procreative process parents have no entitlement to the end product. Instead Locke argued that parents hold their children in trust for God.⁵⁴

There are a number of difficulties inherent in this trust model. Firstly, it is an expression of an ideal parent-child relationship, rather than a representation of the real world as experienced by many parents and children. Even the best of parents have a hierarchical relationship with their children which often, and sometimes

⁴⁸ R. Dingwall, et al. 1995. *The Protection of Children: State Intervention in Family Life*. 2nd edn. Aldershot: Avebury. M. Bryan. Parents as Fiduciaries: A Special Place in Equity. *Int J Child Rights* 1995; 3: 227-262. E.S. Scott & R.E. Scott. Parents As Fiduciaries. *Virginia L Rev* 1995; 81: 2401-2476. C.K. Beck, et al. Rights of Children: A Trust Model. *Fordham L Rev* 1977-1978; 46: 669-780. B.B. Woodhouse. Of Babies, Bonding, and Burning Buildings: Discerning Parenthood in Irrational Action. *Virginia L Rev* 1995; 81: 2493-2521.

⁴⁹ Bryan (n48).

⁵⁰ MA Fineman, *The Autonomy Myth: A Theory of Dependency* (New Press, New York 2004) 301-5.

⁵¹ Scott (n48) p2402.

⁵² Woodhouse (n48) p2500.

⁵³ J. Locke & Peter Laslett (ed). 1967. *Two Treatises On Government*. 2nd edn. New York: Cambridge University Press.

⁵⁴ Ibid. s56.

necessarily, entails expressions of authority and coercion. And, as Probert and colleagues point out, not all parents are ideal; many are simply adequate and some inadequate.⁵⁵ The state is reluctant to interfere in family matters, generally only intervening in the event of negligence or abuse causing actual harm.⁵⁶ It does not engage in the kind of oversight that would remove parental authority from parents who do not fulfil their obligations in accordance with the standards outlined by the trust model. It does not, for example, concern itself with parents who inflict healthcare harm on their children by not providing them with appropriate nutrition and exercise,⁵⁷ nor with parents who continue to expose their children to passive smoke,⁵⁸ despite the well-publicised long-term damage that such behaviours may cause to children.

Secondly, the trust model does not seem to explain how decisions are made in cases of conflict. Rob's parents are acting according to their obligations to protect him and provide for his basic needs by securing for him a BM donor. However, as Sam will be the donor, it is uncertain how they will fulfil their protective obligations towards both, unless the greater needs of one are seen to override the obligation to protect the other. The trust model does not seem to offer practical guidance on how to balance such conflicting obligations. In the end, the decision-making process would seem to come down to the parental power to choose, a position which does not seem all that different to that which would obtain under the traditional parental authority model.

Thirdly, with regard to Locke's position, Nozick found this unpersuasive as excluding procreation from the class of labours that entitle one to an item would seem to outrule the products of crop and animal husbandry from being considered as property.⁵⁹ While Locke's notion of children being held in trust for God might seem an archaic irrelevance to some, it does raise interesting questions about the implications of the trust model. Trusts are complex instruments, but in general terms relate to the legal relationships between a settlor, a trustee and a beneficiary. In the

⁵⁵ Probert et al. eds. (n7) p13.

⁵⁶ Children Act 1989, s31.

⁵⁷ One-fifth of English children are obese. NHS. 2009. *Statistics on Obesity, Physical Activity and Diet*. Accessed on 10 June 2010 at <<http://www.ic.nhs.uk/webfiles/publications/opan09/OPAD%20Feb%202009%20final.pdf>>.

⁵⁸ BBC News. 8 March 2008. *Smokers Make Their Children Ill*. Accessed 9 March 2008 at <http://news.bbc.co.uk/go/pr/fr/-/2/hi/uk_news/england/merseyside/7284793.stm>

⁵⁹ R. Nozick. 1980. *Anarchy, State and Utopia*. Oxford: Blackwell pp288-9.

trust model parents are the trustees with the child's rights held in trust for the beneficiary child. However, with regard to Sam's BM, it is uncertain how this would work without resorting to the concept of property. If Rob is the beneficiary and the parents are the trustees then Sam's BM must be the equity/property being invested. Notwithstanding this issue, if Sam is also a beneficiary and if he is unhappy with the investments made by the trustees, he can litigate to recover what he feels he has lost. However, no such action seems to be available to him; his parents would seem to have no liability regarding their disposal of his BM. Two issues would seem apparent here: firstly, if a person's tissues are what are held in trust, then they are property/equity. Second, trustee liability is a mandatory component of any trust; without such liability there is no trust. Thus, if we argue that Sam's BM is not property, then it is difficult to see how the trust model explains the BM transfer. Against this, it might be argued that the model is based on an analogy rather than a strictly legal approach to trusts. However, if one removes oversight and liability from the notion of trusts, then one is left with the position where those with power have the authority to determine interests as they wish, within the parameters of the law. This again does not advance us far from traditional notions of parental authority, or perhaps from best interests. The trust model remains an aspirational standard, a vision of what the ideal parent-child relationship might be like,⁶⁰ but offers no insight into how the real world parents of Sam and Rob can authorise the transfer of biological material from one to the other.

8.5. THE BODY IS NOT PROPERTY?

The second objection relates to the common law rule which states that there is no property in the body.⁶¹ According to this view Sam's BM cannot be property and so no property rights can be exercised over it. The origins of the 'no property' rule are obscure and initially pertained to dead bodies. The oldest cited common law source of the canon is *Haynes's Case*,⁶² although it has been argued this has been

⁶⁰ However, fiduciary analysis has been used by adult survivors of incest in civil litigation in Canadian and US courts. Bryan (n48).

⁶¹ *R v Kelly and Lindsay* [1999] QB 621.

⁶² (1613) 12 Coke Reports 113. The relevant part of the judgment stated that 'a dead body being but a lump of earth hath no capacity' to own property.

wrongfully used as authority.⁶³ The shift from the judicial observation in *Haynes* that *a corpse cannot own property* to the maxim that *there is no property in a dead body* might well reflect what Mason and Laurie term distortion through ‘easy use.’⁶⁴

Despite the principle’s uncertain lineage ‘it has now been common law for 150 years at least that neither a corpse nor parts of corpse are in themselves and without more capable of being property protected by rights’.⁶⁵ In making this assertion Rose LJ referred to the judgment of Erle J in *R v Sharpe* where it was held that ‘Our law recognises no property in a corpse’.⁶⁶ *Sharpe* is amongst a number of 18th and 19th century cases that provide support for the ‘no property’ dictum.⁶⁷

The twentieth century, however, saw a number of exceptions to the ‘no property’ rule.⁶⁸ In particular, two of these (the ‘next of kin’ and ‘work and skill’ exceptions) have been applied in a number of cases.⁶⁹ The first pertains to the possessory rights of estate administrators to the custody of the deceased for the purpose of burial. In *Dobson v North Tyneside Health Authority* the Court of Appeal held that there is

no property in a corpse ... although the executors, administrators or other persons charged with the legal duty of interring the body had a right to the custody and possession of it until it was properly buried.⁷⁰

A second way a dead body can become the subject of property rights is where it has undergone the application of skill. This exception, which has been enshrined in the Human Tissue Act 2004,⁷¹ was first applied in *Doodeward v Spence*⁷² and

⁶³ K. Mason & G. Laurie. Consent or Property? Dealing with the Body and Its Parts in the Shadow of Bristol and Alder Hey. *MLR* 2001; 64: 710-729.

⁶⁴ *Ibid.* p713.

⁶⁵ *R v Kelly* at 630 .

⁶⁶ (1857) Dears & B 160 at 163.

⁶⁷ See for example, *R v Lynn* (1788) 2 T R 394; *Foster v Dodd* (1866) LQ 1 QB 475, (1867) LR 3 QB 67; *R v Price* (1884) 12 QBD 247; *Williams v Williams* (1882) 20 Ch D 659.

⁶⁸ R. Taylor. Human Property: Threat or Saviour? *Murdoch U E J L* 2002; 9: Accessed on 5 September 2008 at <http://www.murdoch.edu.au/elaw/issues/v2009n2004/taylor2094.html>.

⁶⁹ M. Pawlowski. Property in Body Parts and Products of the Human Body. *Liverpool L Rev* 2009; 30: 35. p40.

⁷⁰ [1997] 1 WLR. 596.

⁷¹ s32.9(c). The Human Tissue Act 2004 prohibits any commercial dealing (s32.1) or advertisement of such activity (s32.2) with respect to material which ‘(a) consists of or includes human cells, (b) is, or is intended to be removed, from a human body, (c) is intended to be used for the purpose of transplantation’. (s32.8). Exempt from this proscription are ‘(a) gametes, (b) embryos, and (c) material which is the subject of property because of an application of human skill’ (s32.9).

⁷² [1908] 6 CLR 406.

subsequently affirmed in *Kelly* and *AB v Leeds*.⁷³ In *Kelly* the Court of Appeal held that

parts of a corpse could be “property” for the purposes of section 4 of the Theft Act 1968 if they had acquired different attributes by virtue of the application of skill, such as dissection or preservation techniques.⁷⁴

The ‘work and skill’ exception has also been appealed to by the courts when it comes to disputes over ownership of material separated from living bodies. In *Kelly* the preservation of specimens as anatomical exhibits was sufficient for them to amount to property.⁷⁵ Herring and Chau suggest that a similar line of thinking might underpin the conviction for theft of drivers who removed their blood⁷⁶ or urine⁷⁷ samples from police custody.⁷⁸

In general, the law has tended to deny the property rights of individuals in their bodily tissues, and particularly their right to commercially exploit those tissues.⁷⁹ However, a chronic shortage of transplantable organs and emerging biotechnological advances have pointed to a growing role for human tissue in medical treatment, and prompted a re-evaluation of the moral and legal value of the ‘no property’ rule. The consequent academic debate has tended to result in the expression of two polarised opinions.⁸⁰ On the one hand, some commentators can see no defensible reason for not investing full property rights in a person’s body.⁸¹ The counter-claim centres on fears about the commodification of human beings, the

⁷³ [2005] QB 506.

⁷⁴ At 621.

⁷⁵ J. Herring & P.L. Chau. My Body, Your Body, Our Bodies. *Med Law Rev* 2007; 15: 34-61. p36.

⁷⁶ *R v Rothery* [1976] RTR 550.

⁷⁷ *R v Welsh* [1974] RTR 478.

⁷⁸ Herring & Chau (n75).

⁷⁹ Human Tissue Act 2004, s32; Council of Europe’s Convention on Human Rights and Biomedicine, s21; Trillium Gift of Life Network Act 1990, s10; Uniform Anatomical Gift Act 2007, s16.

⁸⁰ An analysis of this debate is beyond the scope of this paper. There are a number of excellent books outlining the various positions: Nwabueze (n7). E.R. Gold. 1996. *Body Parts: Property Rights and the Ownership of Human Biological Materials* Washington, DC: Georgetown University Press. C. Fabre. 2006. *Whose Body is it Anyway?: Justice and the Integrity of the Person*. Oxford: Oxford University Press, R. Hardcastle. 2009. *Law and the Human Body: Property Rights, Ownership and Control*. Oxford: Hart Publishing.

⁸¹ L. Andrews & D. Nelkin. Whose Body is it Anyway? Disputes Over Body Tissue in a Biotechnology Age. *Lancet* 1998; 351: 53-57. M. Quigley. Property and the Body: Applying Honore. *J Med Ethics* 2007; 33: 631-634. C.A. Erin & J. Harris. An Ethical Market in Human Organs. *J Med Ethics* 2003; 29: 137-138. J.S. Taylor. Autonomy and Organ Sales, Revisited. *J Med Philos* 2009; 34: 632-648.

possibility of the exploitation of the impoverished, and the potential for the degradation of human dignity and a reduction in altruistic donations.⁸²

While the limited jurisprudence available implies that the courts do not particularly wish to endorse the notion that individuals should have bodily property rights, it has been suggested that the recent case of *Yearworth* may preface a shift in this position.⁸³ This case concerned six claimants who had samples of semen frozen and stored prior to undergoing treatment for cancer. During storage the men's sperm was severely and irreversibly damaged when the refrigeration unit failed and the semen thawed. In the County Court, Griggs J held that the harm to the sperm did not constitute a personal injury and declined to find that claimants had a property interest in this material. The Court of Appeal upheld the original judgment with regard to personal injury, but reversed that concerning property and found the Trust to be liable in bailment. Nwabueze has argued that the influence of *Yearworth* on future cases is uncertain. The judgment, he observes

is open to two interpretations: a narrow view suggesting that sperm, and possibly other similar products of the human body, qualify as property; and a broad view that recognises every tissue removed from or generated by the human body as property ... The doctrine of *ratio decidendi*, however, is likely to compel a narrower interpretation.⁸⁴

8.5.1. *Property in the Bodies of Children?*

The number of cases concerning property and children's bodies is small. In *the Matter of X* the Jersey Royal Court identified that a minor had 'an interest in the nature of ownership' with regard to her aborted foetus.⁸⁵ A similar view was held by the court in *Janicki v Hospital of St Raphael*, where it was adjudged that a stillborn foetus was neither mere tissue nor property, but a form of quasi-property entitled to legal protection.⁸⁶ *Greenberg v Miami Children's Hospital Research Institute* concerned research which aimed to isolate the gene for Canavan disease, a rare and

⁸² N. Scheper-Hughes. Rotten Trade: Millennial Capitalism, Human Values and Global Justice in Organs Trafficking. *J Hum Rights* 2003; 2: 197-226. D. Joralemon & P. Cox. Body Values: The Case against Compensating for Transplant Organs. *Hastings Cent Rep* 2003; 33: 27-33. M.J. Radin. Market-Inalienability. *Harvard L Rev* 1987; 100: 1849-1937.

⁸³ *Jonathan Yearworth and Others v North Bristol NHS Trust* [2009] EWCA Civ 37; M. Quigley. Property: The Future of Human Tissue? *Med Law Rev* 2009; 17: 457-466.

⁸⁴ R.N. Nwabueze. Death of the "No-Property" Rule for Sperm Samples. *King's L J* 2010; 21: 561-568.

⁸⁵ [2003] JCA 050.

⁸⁶ 744 A. 2d 699 (1997).

fatal genetic disorder.⁸⁷ The plaintiffs consisted of a number of afflicted families (and non-profit organisations) who located other ‘Canavan families’ and persuaded them to donate tissue (including post-mortem specimens from children), as well as providing financial support to researchers. Upon isolating the gene, the defendants successfully submitted a patent application and sought to apply restrictive licensing and royalty fees. The plaintiffs, who had envisioned a free and widely available test, brought an action under six headings, including conversion. Moreno J dismissed all claims except unjust enrichment, declining to find that the plaintiffs had a ‘cognizable property interest in body tissue and genetic matter donated for research’.⁸⁸ *AB v Leeds Teaching Hospitals NHS Trust*⁸⁹ involved a group action initiated by the parents of children whose organs had been removed at post mortem, retained and disposed of by the hospitals without their knowledge or consent. They claimed damages for psychiatric injury on the basis that the hospitals had committed the tort of wrongful interference. Gage J believed that the claim for wrongful interference was in the nature of conversion, but adjudged that conversion with regard to the body was not a recognised cause of action in an English court. However, he opined that it might exist in particular situations:

If, on the other hand, a parent or parents when consenting to a post-mortem specifically asked for the return of an organ I can see that in certain circumstances it might be arguable that a cause of action based on conversion exists.⁹⁰

Gage J conceded that there was ‘uncertainty and lack of clarity’ in English law on the matter of bodily property rights.⁹¹ In *Kelly Rose* LJ observed that

the common law does not stand still. It may be that ... courts will hold that human body parts are capable of being property ... if they have a use or significance beyond their mere existence. This may be so if, for example, they are intended for use in an organ transplant operation.⁹²

Regardless of the court’s uncertainty, particularly with regard to transplantable tissue, a distinction must be drawn between a situation where the law has been

⁸⁷ 264 F. Supp. 2d 1064 - Dist. Court, SD Florida, Miami Div. 2003.

⁸⁸ At 65.

⁸⁹ [2004] 2 FLR 365.

⁹⁰ At 404.

⁹¹ At 397.

⁹² At 630.

engaged and circumstances where no proceedings have been instituted. Neither the courts nor the HTA have ever contested the parental right to authorise the harvesting of their child's BM for transplantation. If BM is 'donated' to a family member then, as Brownsword observes, no awkward questions are likely to be asked.⁹³ In the case of Jamie Bowen, evidence was presented regarding a prior BM donation from a younger sibling.⁹⁴ The court made no comment on this matter. In general, the right to sanction the removal of a child's BM and its subsequent disposal would seem to lie within the ambit of parental authority. And the modern version of this power has its antecedents in historic property-type rights over the child.

8.6. THE CHILD AS PROPERTY

The concept of the child as property has a long history. Aristotle, reflecting Ancient Greek tradition held that the child, owned by the head of the household, was comparable to a tooth or piece of hair.⁹⁵ As such, he suggested that it would not be possible to construe any act that the father might commit against the child as unjust, as 'there is no unqualified injustice in relation to what is one's own; one's own possession, or one's child'.⁹⁶ In Roman Law, the *Lex Duodecim Tabularum* stated that 'A father shall have the right of life and death over his son born in lawful marriage, and shall also have the power to render him independent, after he has been sold three times.'⁹⁷ Dionysius of Halicarnassus⁹⁸ interpreted this law as 'giving greater power to the father over his son than to the master over his slaves' since it allowed a father 'to make a profit by selling his son as often as three times'.⁹⁹ Despite the assertions of Dionysius, it is unlikely that *patria potestas*¹⁰⁰ was ever perceived as granting the same ownership powers as *dominica potestas* (power over a slave). Nonetheless, in addition to having the power of life and death over his

⁹³ Brownsword (n13).

⁹⁴ *R v Cambridge Health Authority ex parte B* [1995] 1 WLR 898.

⁹⁵ Aristotle (n505) 1161b 22-24.

⁹⁶ Ibid. 1134b 10-13.

⁹⁷ Table IV, Law I as cited in S.P. Scott ed. 1932. *The Civil Law. Volume I: The Laws of the Twelve Tables*. Cincinnati: Central Trust Company.

⁹⁸ Born 53 BCE.

⁹⁹ Dionysius of Halicarnassus. 1937. *Roman Antiquities, Volume I, Books 1-2*. Cambridge, MA: Loeb Classical Library

¹⁰⁰ The patriarchal authority asserted by a Roman father over his household including his children, grandchildren, and other descendants. G. Long. 1875. *Patria Potestas*. In *A Dictionary of Greek and Roman Antiquities*. W. Smith, ed. London: John Murray: 873-875.

children, a father could also could mancipate his child to another person¹⁰¹ or hand a child over to an injured party as recompense for the delicts of the child. In addition, a father could put his child up for adoption, exheredate him and substitute another as his heir. The more severe aspects of this code were gradually phased out from law. For example, in 313 AD, after Constantine authorised the sale of infants the need for child-exposure fell, and it was ultimately prohibited around 374 AD.¹⁰²

Over a millennium later, Hobbes' political perspective on childhood was reminiscent of the *Lex Tabularum*. Although basing his theory on presumed consent rather than property, the dominion Hobbes allowed parents over their children was very similar to ancient law:

Children therefore, whether they be brought up and preserved by the father, or by the mother, or by whomsoever, are in most absolute subjection to him or her, that so bringeth them up, or preserveth them. And they may alienate them, that is, assign his or her dominion, by selling or giving them in adoption or servitude to others; or may pawn them for hostages, kill them for rebellion, or sacrifice them for peace.¹⁰³

While the law may not have allowed all that Hobbes proposed, fathers (in particular) had almost unlimited control over their children. In colonial states the children of slaves (or even those born as a result of a liaison between master and slave) were chattels that could be bought and sold.¹⁰⁴ As befitting puritanical notions based on the Book of Deuteronomy, children were obliged to be obedient.¹⁰⁵ As a consequence, Mason notes that 'The existence of these common law rights have led

¹⁰¹ Mancipated individuals held an intermediate status between free persons and slaves. They were not *sui juris*, and anything they acquired was due to the person to whom they were mancipated.

¹⁰² W.V. Harris. Child-Exposure in the Roman Empire. *J Rom Stud* 1994; 84: 1-22.

¹⁰³ T. Hobbes & J. Gaskin. 1994. *The Elements of Law, Natural and Politic*. Oxford: Oxford University Press. p92.

¹⁰⁴ M.A. Mason. 1994. *From Father's Property To Children's Rights: A History of Child Custody*. New York: Columbia University Press. Chapter 1.

¹⁰⁵ For example, the Stubborn Child Law of Massachusetts 1646 provided that: 'If a man have a stubborn or rebellious son of sufficient years of understanding ... that when they have chastened him will not harken unto them... Such a son shall be put to death'. Cited in L.R. Sidman. The Massachusetts Stubborn Child Law: Law and Order in the Home. *Fam Law Q* 1972; 6: 33-58. pp42-43. As late as 1971 the Massachusetts Supreme Judicial Court adjudged that 'the State may properly require that unemancipated children obey the reasonable and lawful commands of their parents, and it may impose criminal penalties on the children if they persistently disobey such commands.' *Commonwealth v. Brasher*, 1971 Mass. Adv. Sh. 907 at 913, 270 N.E.2d 389 at 394.

some contemporary legal historians to conclude that the law regarded children as a property right, to be treated as chattel.¹⁰⁶

By Victorian times, although paternal power had become less extensive, a father still retained substantial control over a child's upbringing.¹⁰⁷ The paternal power extended to the right to the association (custody as against all parties)¹⁰⁸ and services (the labour, or earnings if they were hired out to a master) of legitimate children.¹⁰⁹ Loss of control through the seduction of a daughter, or the enticement of a son to leave home, was actionable because the father would be deprived of their services or wages.¹¹⁰ Blackstone's *Commentaries* noted that 'the inferior hath no kind of property in the company, care, or assistance of the superior, as the superior is held to have in those of the inferior.... the child hath no property in his father or guardian; as they have in him'.¹¹¹ There were reciprocal duties involved in these relationships but, as Michals observes, ownership flowed in one direction only. The difference between children and slaves was not that the former were not property, but that the latter were 'nothing but property'.¹¹²

Absolute paternal power declined over the nineteenth century, gradually eroded by women's claims for equal custody rights.¹¹³ Lowe suggests that during this period the courts increasingly considered the interests of the child in custody decisions,¹¹⁴ and the welfare principle became enshrined in the Guardianship of

¹⁰⁶ Mason (n104) p6.

¹⁰⁷ In *Re Agar-Ellis* (1883) 24 ChD 317, Cotton J commented: 'the Court should not, except in extreme cases interfere with the discretion of the father but leave to him the responsibility by exercising that power which nature has given by the birth of the child' (at 334).

¹⁰⁸ In England paternal legal authority could be exercised to the exclusion of the mother and regardless of the child's welfare. *R v De Manneville* (1804) 5 East 321, *R v Greenhill* (1836) 4Ad & E624, *Re Agar-Ellis* (1883) 24 ChD 317.

¹⁰⁹ Mason (n104) p6.

¹¹⁰ Enticement and seduction as a cause of action were removed from statute by the Law Reform (Miscellaneous Provisions) Act 1970, s5.

¹¹¹ W. Blackstone. 1832. *Commentaries on the Laws of England: Volume 2*. 18 edn. London: Collins and Hannay. p115. However, Blackstone also refers to the 'insuperable degree of affection' which parents hold for their children. Vol.1, p368.

¹¹² T. Michals. "That Sole and Despotie Dominion": Slaves, Wives, and Game in Blackstone's *Commentaries Eighteenth-Cent Stud* 1993-1994; 27: 195-216. p202.

¹¹³ Some concessions to the equal rights of women were made under the Infants Custody Act 1839, Custody of Infants Act 1873 and the Guardianship of Infants Act 1886. See A.H. Manchester. 1980. *A Modern Legal History of England and Wales, 1750-1950*. London: Butterworths. pp390-3.

¹¹⁴ N.V. Lowe. The Legal Position of Parents and Children in English Law. *Singapore J Legal Stud* 1994: 332-346. p337.

Infants Act 1925.¹¹⁵ However, the history of its inclusion is interesting. The Bill, which was originally proposed in an attempt to give equal custody rights to mothers, proved highly divisive. Lord Chancellor Cave thought that ‘to give the mother legal equality in this respect would be destructive of all domestic felicity’,¹¹⁶ while others postulated that divided authority was bad for children.¹¹⁷ The welfare principle was introduced as a compromise measure. By inserting a provision that specified the paramountcy of the welfare of the child, this ensured that ‘a mother would only have parental authority as and when a court conferred it on her.’¹¹⁸ Cretney claimed that this history ‘must indeed cast serious doubt on whether the 1925 Act was intended to give greater weight than in the past to the welfare of the child in deciding disputes about upbringing.’¹¹⁹

Since the advent of children’s rights advocacy the child is purportedly no longer perceived in a proprietorial manner. Noggle sums this modern position up as ‘Virtually all reasonable people hold that children are persons, and not, for example, pets or property.’¹²⁰ In an era where the welfare principle allegedly predominates judicial thinking,¹²¹ Noggle’s assertion would seem a truism. Yet this position is not undisputed. On reviewing Aristotle’s concept of the child, the philosopher of childhood Gareth Matthews commented that while the property model of childhood might appear anachronistic, arguably it remains prevalent today.¹²² In his analysis of *Gillick*, Montgomery has pointed out that the Court of Appeal appeared to consider children to be items of property, although this view was rejected by the House of Lords.¹²³ Some commentators on both sides of the Atlantic have also articulated the

¹¹⁵ s1.

¹¹⁶ S.M. Cretney. "What Will the Women Want Next?": The Struggle for Power Within the Family 1925-1975. *LQR* 1996; 112: 110-137.

¹¹⁷ Ibid. p116.

¹¹⁸ Ibid. p130.

¹¹⁹ Ibid. p131.

¹²⁰ Noggle (n7) p97.

¹²¹ Children Act 1989, s1 (1): ‘When a court determines any question with respect to - (a) the upbringing of a child; or (b) the administration of a child’s property or the application of any income arising from it, the child’s welfare shall be the court’s paramount consideration.’

¹²² G. Matthews. 2005. The Philosophy of Childhood. In *Stanford Encyclopedia of Philosophy*. E.N. Zalta, ed. Accessed on 10 June 2008 at <<http://plato.stanford.edu/archives/win2005/entries/childhood/>>.

¹²³ Montgomery (n8).

view that proprietorial concepts of children remain prevalent in custody disputes.¹²⁴

Hasday describes it as a:

story in the family law canon ... that common law property norms no longer shape the law of parenthood. This story contends that the law of parenthood is now structured around children's interests, having shed a common law tradition that used property norms to guide the law of parenthood ... [and] presented as a narrative of progress and equality.¹²⁵

Instead, she contends, the situation really is that the

canonical story of the demise of common law property norms importantly misdescribes family law and its governing principles. It overstates the changes that have occurred in family law over time ... there is substantial evidence within family law to support an excluded counter-narrative: the story of the persistence of common law property norms in the law of parenthood. Parents retain substantial elements of many of their common law rights, even where those rights potentially conflict with their children's interests.¹²⁶

The common law of property evolved between 1153 and 1215, providing for the protection of an individual's claim to the title to a parcel of land by a rule-based bureaucratic authority rather than through force or feudal relationships.¹²⁷ Property ownership thus became associated with the legal power to control and protect interests. More recently, Waldron defined ownership as the correlation of an object with the name of some person. This association is acknowledged by a rule-based system as placing that individual in a 'privileged position' with regard to the object, as it is he who possesses the final decision in the event of a dispute arising over the objects disposal.¹²⁸ Gold observed that 'property discourse is that combination of conceptions, assumptions, and language used ... to decide to whom and in what circumstances we ought to grant rights of control over a good.'¹²⁹ In many ways these observations on ownership fit in with our concept of parenthood. A child is

¹²⁴ D.I. Bonina & R.A. Bahe-Jachna. The Treatment of Children as Chattel in Recent Adoption Decisions. *Human Rights* 1999; 28: Accessed on 10 February 2008 at <http://www.abanet.org/irr/hr/sp2099bonina.html>. C.D. Gill. Essay on the Status of the American Child, 2000 A.D.: Chattel or Constitutionally Protected Child-Citizen. *Ohio N U L Rev* 1991; 17: 543-580. M.D.A. Freeman. Towards a Critical Theory of Family Law. *Current Legal Problems* 1985; 38: 153-185.

¹²⁵ J.E. Hasday. The Canon of Family Law. *Stanford L Rev* 2004; 57: 825-900. p847.

¹²⁶ Ibid. p849.

¹²⁷ R.C. Palmer. The Origins of Property in England. *Law Hist Rev* 1985; 3: 1-50.

¹²⁸ J. Waldron. What is Private Property. *OJLS* 1985; 5: 313-349. p333.

¹²⁹ Gold (n80) p43.

almost universally ‘correlated’ with his parents, and the authority vested in them by the state generally makes parents the ultimate decision-makers in matters concerning their child.¹³⁰ This authority is not unlimited. As Ross points out, parents are not allowed to sell or martyr their children.¹³¹ But many forms of property are subject to constraint with regard to their use. Modern legal systems often limit such rights, and thus while owners can dispose of particular incidents through sale, lease or consumption, governments may restrict this exercise in the public interest.¹³² The point here is not whether parents have wholesale property rights over children, but rather that it is questionable whether ideal theories of parent-child relations fully describe all the real life issues and decisions that face families. It seems doubtful that this relationship has truly evolved to the position where, given the persistence of the imbalance of power between parent and child, parents no longer retain any aspects of their historic common law rights.

8.7. BONE MARROW: PROPERTY IN THE CHILD?

Although property rights in body parts remains controversial, Munzer proposes that ‘sometimes some persons have some property rights in some body parts’.¹³³ One part that he suggests should be subject to property rights is umbilical cord blood.¹³⁴ His theory articulates three main principles for justifying property: a principle of utility and efficiency, a principle of justice and equality, and a principle

¹³⁰ Children Act 1989, s3(1).

¹³¹ L.F. Ross. Justice for Children: The Child as Organ Donor. *Bioethics* 1994; 8: 105-126.

¹³² J.M. Meyer. The Concept of Private Property and the Limits of the Environmental Imagination. *Political Theory* 2009; 37: 99-127.

¹³³ Munzer (n42) p510.

¹³⁴ Ibid. Munzer’s assumption that the umbilical cord blood belongs to the baby is supported by other commentators who suggest that this material is the baby’s (rather than the mother’s) because it is developmentally, biologically and genetically part of the child. See G.J. Annas. Waste and Longing — The Legal Status of Placental-Blood Banking. *N Engl J Med* 1999; 340: 1521-1524. J. Gunning. 2006. Umbilical Cord Cell Banking: A Surprisingly Controversial Issue In *Ethics, Law, and Society, Volume 2* J. Gunning & S. Holm, eds. Farnham: Ashgate: 17-26. However, Dickenson takes the opposite view. For her, umbilical ‘cord blood is simply the mother’s own property’, arguing that it is so ‘on labour-desert grounds’. D. Dickenson. 2007. *Property in the Body: Feminist Perspectives*. Cambridge: Cambridge University Press pp97-100. Dickenson has consistently argued from a feminist perspective ‘that the most genuine and legitimate form of property in the body is that which women possess in their extracted reproductive tissue, specifically in tissue products of their reproductive labour’. D. Dickenson. The Lady Vanishes: What’s Missing from the Stem Cell Debate. *J Bioethical Inquiry* 2006; 3: 43-54. p47.

of dessert based on labour.¹³⁵ The first states that property rights should be allocated in order to maximize utility and efficiency with regard to the use, possession and transfer of things. The second relates to the sharing of benefits and burdens, and allows for inequality in property holdings if each individual has a minimum amount of property, and any inequality does not fundamentally weaken the lives of those with less. The third is a dessert-based principle and relates to the fairness of acquisition through the application of work and skill. Applying these principles to the question of property rights in cord blood, Munzer argues that the following conclusions should obtain: (1) that a neonate has initial property rights in his or her own cord blood; (2) that parents have the power to donate this cord blood to another of their children, or even to an unrelated individual in need; and (3) disagreement between parents with regard to the disposal of the cord blood qualifies their right, and indicates the need for a court-appointed guardian.¹³⁶ Munzer is not keen on extending his analysis to BM, because the process of retrieving it contains more risk,¹³⁷ but given that BM harvesting is a common procedure then there seems no good reason why his analytical framework should not apply to it.

In *Yearworth*, Clarke LCJ adjudged that the plaintiffs had a property interest in their sperm because ‘by their bodies, they alone generated and ejaculated the sperm’,¹³⁸ a reference that appears ‘somewhat neo-Lockean’.¹³⁹ In general, it seems reasonable to argue that if a man takes his property and invests it, then it is likely that he has a property interest in the produce of that investment. Following this line of argument, it seems logical to suggest that parents have a property interest in their child and his tissue. And in reality, parents do have considerable dominion over the disposal of their child’s BM, although it is subject to certain limitations. Against this,

¹³⁵ Munzer (n41).

¹³⁶ Munzer (n42) p495. Munzer argues for a number of other propositions, but these are not germane to the present article.

¹³⁷ Ibid. pp502-3.

¹³⁸ At 45.

¹³⁹ Quigley (n83) p462. It should be noted that the Court of Appeal did not principally rely on the ‘application of human skill’ exception in deciding as they did; ‘we prefer to rest our conclusions on a broader basis’, *Yearworth* at para 45(e). This position was justified by an appeal to the ‘developments in medical science [which] now require a re-analysis of the common law’s treatment of and approach to the issue of ownership of parts or products of a living human body’. At para 45(a). In reaching its conclusions the Court of Appeal relied upon the judgment in *Hecht v Superior Court of Los Angeles County*, which held that ‘at the time of his death, decedent had an interest, in the nature of ownership, to the extent that he had decisionmaking authority as to the sperm’. *Hecht v. Superior Court (Kane)* (1993) 16 Cal.App.4th 836 , 20 Cal.Rptr.2d 275 at 847.

it might be said that neither a child nor his tissues are the kind of entity that can be subject to property rights.

However, if we analyse, using Munzer's principles, the rights of Sam's parents apropos his BM, then it would seem that they could have a property interest in this tissue. Firstly, neither Sam nor his BM would exist without their application and work, and hence they would appear to be able to claim an entitlement to Sam's BM on the principle of labour-based desert. Second, Sam probably has a surfeit of BM, while the sick Rob has none. Sam could give up some of his BM without suffering much harm.¹⁴⁰ An appeal to the principle of justice and equality would seem to mandate that Sam's parents redistribute this biological asset in order to rebalance the allocation of benefits and burdens between Sam and Rob. This is not to argue that Rob has a claim against Sam, but rather that there is an inequitable distribution of healthy BM between the siblings, a substance over which their parents have the power of control. The re-allotment of biological assets would also seem to fulfil the principle of utility and efficiency. Without the donation and transplant Rob will die and Sam survive. With the procedures Rob may well live, as, of course, will Sam.

This analysis does not give Sam's parents untrammelled rights over his tissues. The principles of justice and utility would not be fulfilled if they took Sam's BM and simply destroyed it. Sam's parent's property interests in his tissues are thus encumbered. But this does not mean that they are non-existent; many property rights are limited. As Cohen noted:

if any property owner could really do anything he pleased with his own property, the rights of all his neighbors would be undermined...In fact, private property as we know it is always subject to limitations based on the rights of other individuals in the universe.¹⁴¹

However, Radin has suggested that in a commodified world all things considered to be property seem expected to be alienable, fungible and commensurable.¹⁴²

Effectively this means that an item of property can be sold or traded for its value in

¹⁴⁰ Although the procedure is both painful and subject to risk. See AAP Committee on Bioethics (n14).

¹⁴¹ F.S. Cohen. The Pragmatic Meaning of Private Property. *Rutgers L Rev* 1954-1955; 9: 357-387. p362.

¹⁴² Radin (n82) p1859.

money, or for something of equal worth. Given that Sam's parents are limited in their disposal of his BM, how does this fit in with their property rights?

8.8. THE PROBLEM OF COMMENSURABILITY

While international law has increasingly come to recognise life-forms as commodities,¹⁴³ the Convention of Human Rights and Biomedicine (article 21) and the Human Tissue Act (section 32) prohibit the trading of human material.¹⁴⁴ If alienability is an essential component of property rights then it is possible to assert that Sam's BM is not property. There are three possible responses to this claim.

8.8.1. Property Does Not Have To Be Alienable

With regard to human tissue, Beyleveld and Brownsword have argued that the Convention of Human Rights and Biomedicine presupposes that there is property in bodies, although not necessarily a right to commercially exploit any items.¹⁴⁵ In his analysis of private property, Waldron proposed that:

In principle, it is possible to argue that there should be private property in material resources without committing oneself to the view that private owners should have a power to alienate the resources that they owned. For this reason, it is best to say that the power of alienation is a characteristic of some but not all conceptions of private ownership.¹⁴⁶

The notion of inalienable property has a long history. The traditional model of property was land which was transmitted through family inheritance, rather than being sold in the marketplace.¹⁴⁷ About half of the land in England was entailed during the eighteenth century, and thus while this property could be leased, its ownership remained within the family, ensuring the preservation of their socio-legal status.¹⁴⁸ Also from an historical perspective, Harris has argued that racial identity and property are intimately connected, and posited that 'whiteness' engendered non-alienable property right-type expectations in people, interests that remain protected

¹⁴³ *Diamond v Chakrabarty* 447 U.S. 303 (1980).

¹⁴⁴ However, tissue that is 'property' as a result of the application of human skill legitimately can be traded.

¹⁴⁵ D. Beyleveld & R. Brownsword. My Body, My Body Parts, My Property? *Health Care Analysis* 2000; 8: 87-99.

¹⁴⁶ Waldron (n128) p343.

¹⁴⁷ Michals (n112) p200.

¹⁴⁸ Manchester (n113) p6.

under contemporary American law.¹⁴⁹ The relationship between property and expectations can be traced back to Bentham:

Property is only a foundation of expectation - the expectation of deriving certain advantages from the thing said to be possessed, in consequence of the relations in which one already stands to it.¹⁵⁰

Harris contends that the relationship between expectations and property remains legally significant, and while not all expectations give rise to property, ‘those expectations in tangible or intangible things that are valued and protected by the law are property.’¹⁵¹ Sam’s parents have expectations with regard to his tangible BM, expectations that are legally reinforced under the auspices of the HTA.

If we accept that some forms of property can be market-inalienable, then the control that Sam’s parents exercise over his BM can be construed as a property interest. A number of authors have argued that human tissue and organs should be regarded as market-inalienable property.¹⁵² This paradigm would allow for the continued donation of bodily material for research and transplantation, provide a greater degree of protection for the interests of individuals against the misuse or misappropriation of their tissues than is currently allowed under privacy laws, and protect against the possibility of exploitation.¹⁵³

8.8.2. *There may be Non-Economic Commensurability*

In his economic analysis of the family, Becker views all interactions between family members as market transactions.¹⁵⁴ One example of this is Becker’s conclusion that parents invest more in selfish children as an indirect means of saving for old age. The premise is that selfish children are more likely to succeed, and Becker calculated that the rate of return from investing in children often exceeds that of pension or savings funds. To some extent this is a gamble, as under common law parents cannot legally compel their children to look after them. As a consequence

¹⁴⁹ C.I. Harris. *Whiteness As Property*. *Harvard L Rev* 1993; 106: 1707-1791.

¹⁵⁰ J. Bentham. 1838. *The Works of Jeremy Bentham, Part 2 Volume 1*. Edinburgh: William Tait. p308.

¹⁵¹ Harris (n149) p1729.

¹⁵² See for example Nwabueze (n7); Radin (n82).

¹⁵³ Nwabueze (n7) pp84-95

¹⁵⁴ G.S. Becker. 1991. *A Treatise on the Family* Cambridge, MA: Harvard University Press.

they may engage in emotional manipulation, arousing feelings of ‘guilt, obligation, duty and filial love that ... effectively... commits children to helping them out.’¹⁵⁵

While portraying intimate family relations as a series of economic strategies might seem unappealing, nonetheless it is possible to understand familial interactions as a series of transactions. If we believe that it is in Sam’s best interests for Rob to receive his BM, then it seems reasonable to hold that Sam has exchanged his tissue for emotional and psychological satisfaction.¹⁵⁶ However, it is Sam’s parents who have handed over his BM. Whether the three year-old Sam will benefit or not is a matter of speculation. What we can say is that Sam’s parents believe that it is in the collective interest that Rob receives Sam’s BM. Sam’s parents are exchanging his BM for the possibility of Rob’s survival, the preservation of the family unit and the emotional benefits that will accrue to them as a consequence of the transaction. Thus, the commensurable value of Sam’s BM is a life, or at least the hope of a continued existence.

8.8.3. *Could There be Economic Commensurability?*

Could Sam’s BM ever be sold, or at least be traded against something of a more defined monetary worth? Obviously it would only have a market value if someone was willing, and legally permitted, to pay for it. In the US, the National Organ Transplant Act 1984 (NOTA) prohibits payment for organs including BM. A lawsuit contesting the constitutionality of NOTA has been filed¹⁵⁷ contending that the law infringes upon both equal protection rights (because it arbitrarily regards BM as akin to non-regenerable organs rather than as a renewable tissue like blood) and substantive due process rights (because it violates the right to participate in a conventional, legal and lifesaving medical treatment).¹⁵⁸ The aim of the challenge is not to promote an open market, but to encourage donations by offering economically

¹⁵⁵ G.S. Becker. 1997. The Economic Way of Looking at Life. In *Nobel Lectures in Economic Sciences, 1991-1995*. T. Persson, ed. London: World Scientific: 38-58.

¹⁵⁶ See *Re Y (Mental Patient: BM Donation)* [1996] 2 FLR 787.

¹⁵⁷ *Flynn v Holder*, USDC CA (filed 28 Oct. 2009).

¹⁵⁸ S.L. Crockin. A Legal Defense for Compensating Research Egg Donors. *Cell Stem Cell* 2010; 6: 99-102. Update note 15 March 2011: The 9th US Circuit Court of Appeals heard arguments on 15 February 2011 after the trial court had dismissed the case in March 2010 in favour of the government. See ‘Lawsuit Seeks Compensation for Bone Marrow Donors’ at <<http://www.ama-assn.org/amednews/2011/03/14/prsd0315.htm>>.

commensurable compensation, such as scholarships, to donors. If the suit is successful, then it is possible that BM may become a saleable commodity in the US.

However, might Sam's tissue already be a tradable item? Consider the situation where Sam has previously 'donated' to Rob, but the treatment has been unsuccessful. Rob needs further therapy, but this is both costly and experimental, and the NHS refuses to fund it. Sam's parents are simply incapable of coming up with the £100,000 that the private hospital will charge to carry out the required procedures.¹⁵⁹ However, the child (C) of wealthy parents also suffers from leukaemia and needs a BM transplant, but a suitable donor cannot be found. Sam's tissue type is a match for C, and her parents suggest that they will pay Rob's hospital bills if Sam donates his BM to C. Sam's original donation was designed to save Rob's life. His donation to C would also potentially be life-saving for Rob (and for C). While this exchange might be proscribed under the Human Tissue Act 2004 (s32), any such prohibition might seem legally inconsistent. If Sam's first donation was putatively in his best interests, then it would seem incoherent to suggest that the second donation would not.¹⁶⁰ If this transaction was legitimate, then in this instance Sam's BM would seem to have a market value of £100,000. However, this scenario, while plausible, is likely to be uncommon. Under current legislation Sam's BM could not be sold, although that does not mean that it is without value.

8.9. CONCLUSIONS

The relationship between parent and child is one in which the power is vested in the adult.¹⁶¹ In her discussion of family law, Symes refers to the 'intimate relationship between property and power'.¹⁶² The political theorist Renner examined this association, observing that 'the right of ownership ... is the power of control, the power to issue commands and to enforce them'.¹⁶³ If, as Symes suggests, 'property has come to be viewed as a right of access, or a right to exercise choice' then it is clear that parents are invested with the political power to command this. The laws

¹⁵⁹ This is not an implausible scenario. See *R v Cambridge Health Authority ex parte B* [1995] 1 WLR 898.

¹⁶⁰ It would also seem to serve the principles of utility, efficiency and justice.

¹⁶¹ Freeman (n124).

¹⁶² P. Symes. Property, Power and Dependence: Critical Family Law. *J Law Soc* 1987; 14: 199-216. p200.

¹⁶³ K. Renner & A.J. Treviño. 2009. *The Institutions of Private Law and Their Social Functions*. Califon, NJ: Transaction Publishers. p107.

protecting family privacy give parents wide latitude to decide how to deal with their children, and by extension, their organs and tissues. Doctors have taken skin,¹⁶⁴ blood,¹⁶⁵ BM,¹⁶⁶ kidneys,¹⁶⁷ liver segments¹⁶⁸ and small bowel¹⁶⁹ from living children and given these tissues and organs to others, all at the behest of parents.

While the law might stipulate that BM donation by minors should only be carried out when it is in their best interests,¹⁷⁰ such legal ‘proclamations do not necessarily describe social reality. Rather, they present public images about what social reality should be.’¹⁷¹ Gold argued that, with regard to a body part, to have a property right is ‘to have the power to make decisions’ about its fate.¹⁷² Sam’s parents have the power to make decisions about his BM, and the exercise of this power appears of little interest to the courts. Under this rubric Sam’s parents have property rights, albeit encumbered, in his BM.

Some may find the suggestion of Sam’s parents having such property rights repugnant. As stated earlier, the aim of this paper is not to argue that parents should have property rights in children, but to seek to understand the transfer of biological material between siblings where the donor is incapable of providing consent. In this instance the ascription of a property right is simply a way of denoting parental power over tissue transfer. Nothing in it implies that Sam’s parents do not love and cherish him, or that the exercise of their property rights devalues him. Instead, the property model provides the clearest mechanism to explain the parental right to authorise the transfer of biological material from an unconsenting human to a third party.

¹⁶⁴ S.J. Tildent. Ethical and Legal Aspects of Using an Identical Twin as a Skin Transplant Donor for a Severely Burned Minor. *Am J Law Med* 2005; 31: 87-116.

¹⁶⁵ E. Gluckman, et al. Outcome of Cord-Blood Transplantation from Related and Unrelated Donors. *N Engl J Med* 1997; 337: 373-381.

¹⁶⁶ HFEA (n9).

¹⁶⁷ N. Webb & P.-M. Fortune. Should Children Ever be Living Kidney Donors? *Pediatr Transplant* 2006; 10: 851-855.

¹⁶⁸ M. Olbrisch, et al. Children as Living Organ Donors: Current Views and Practice in the United States. *Curr Opinion Organ Transplant* 2010; 15: 241-244.

¹⁶⁹ T. Berney, et al. Five-Year Follow-Up After Pediatric Living Related Small Bowel Transplantation Between Two Monozygotic Twins. *Transplant Proc* 2004; 36: 316-318.

¹⁷⁰ HTA (n11).

¹⁷¹ J. Eekelaar. The Emergence of Children's Rights. *Oxford J Legal Studies* 1986; 6: 161-182. p163.

¹⁷² Gold (n80) p2.

CHAPTER 9

PAPER 4¹

DYING TO BE RESPONSIBLE: ADOLESCENCE, AUTONOMY, AND RESPONSIBILITY.

*'But to judge some people impartially we must renounce certain
preconceived opinions and our habitual attitude...'*²

9.1. INTRODUCTION

In September 1990, a hospital authority sought leave to administer blood to a Jehovah's Witness, aged 15³/₄, who was refusing life-saving transfusions. Ward J found that while the adolescent was intelligent enough to take decisions about his own well-being, he failed to appreciate the full implications (especially regarding the exact nature of his death) of his choice, and the authority was granted leave to give the required treatment.³ Three years later, two 11 year-old boys, one of whom was psychologically and emotionally immature,⁴ were found guilty of murder at Preston Crown Court following an 'act of unparalleled evil and barbarity' committed when they were just 10.⁵ Taken together, these two cases seem to indicate that one can have a sufficient comprehension of the character and consequences of fatal actions to be deemed culpable of murder at the age of 10, yet lack this same understanding when significantly older should the act in question create a risk of harm-to-self, rather than to others. In essence, legislation and case law in England indicates that should E have committed a homicide, he could be held criminally responsible for that act from the age of 10.⁶ In contrast the age at which he could legally become

¹ B. Lyons. Dying to be Responsible: Adolescence, Autonomy and Responsibility. *Legal Studies* 2010; 30: 257-278.

² F.M. Dostoyevsky. 1958. *Crime and Punishment*. New York: Bantam Books. p458.

³ *Re E* [1993] 1 FLR 386 (hereafter *Re E*). Although the adolescent in question was referred to as 'A' throughout the case, in this paper I shall refer to him as E to avoid confusion.

⁴ *V v UK* [2000] 30 EHRR 121 at 134.

⁵ Cited in *R v Secretary of State for the Home Department, ex p Venables and Thompson* [1998] AC 407, HL at 439.

⁶ Children and Young Persons Act 1963, s16.

fully responsible for making choices about his personal medical welfare,⁷ and in particular refusing life-saving treatment, is 18.⁸ Thus, as a 10 or 15 year-old he is held to be simultaneously *capax* and *incapax*, to have the capacity to be criminally culpable on the one hand, but to be ultimately incapable of making serious healthcare decisions on the other. This discrepancy, that the courts treat children differently depending on whether they are accused of a criminal offence or are appealing to be allowed to make decisions concerning their own healthcare, has been noted before⁹ but is a dichotomy that appears not to have been subjected to detailed analysis.

Hollingsworth suggests that the age difference between criminal culpability and medical autonomy might be explained in terms of the attribution of responsibility; that there is a difference in the timing and nature of the responsibility being ascribed:

conferring responsibility on a child to consent or refuse medical treatment is a pre-condition to the actual decision-making act itself. Responsibility must be conferred before the child can (in a legal sense) make the decision, and the child's capacity affects whether or not they are given that responsibility in the first place. But where a child is being held legally *liable*, the action or decision has already been taken by the child (the offence ... has already been committed), and he is then being held responsible in an *ex post* manner.¹⁰

This might seem a reasonable account but is, I believe, deficient in unpacking the issues surrounding both the ascription and meaning of responsibility in the context of

⁷ The relationship between responsibility and autonomy is a complex one and has been the subject of recent philosophical debate; see J.M. Fischer. Recent Work on Moral Responsibility. *Ethics* 1999; 110: 93-139. p98. In this paper I will assume equivalence between the notions of 'responsibility for self-determination' and 'autonomy' as applied to healthcare decision-making. This is a position I will discuss later.

⁸ Nolan LJ has argued that the courts would not countenance the refusal of lifesaving treatment by an adolescent. See *Re W* [1992] 4 All ER 627 at 647 (hereafter *Re W*). It is clear from Johnson J in *Re P* that the judgement in *Re W* defines the law on this subject. *Re P* [2004] 2 FLR 1117 (hereafter *Re P*). However, the Mental Capacity Act 2005 indicates that there should be a presumption that all adults (aged 16 or over) have full legal capacity to make decisions for themselves. How the courts might interpret this in future cases that concern adolescent refusal of treatment is uncertain.

⁹ See for example M. Brazier & C. Bridge. Coercion or Caring: Analysing Adolescent Autonomy. *Legal Studies* 1996; 16: 84-109. K. Hollingsworth. Responsibility and Rights: Children and Their Parents in the Youth Justice System. *Int J Law Policy Family* 2007; 21: 190-219. Royal College of Psychiatrists. 2006. *Child Defendants (Occasional Paper OP56)*. London RCPsych.

¹⁰ Hollingsworth, *ibid.* p195. (Italics in original).

both criminal law and autonomy.¹¹ The main aim of this paper is to explore the referents of ‘responsibility’ and how they are applied in the two different legal situations in question.

Keating has recently contrasted the different approaches taken by criminal law and family law with regard to the age at which children are held to be responsible, and suggested that in these contexts ‘the concept of responsibility itself is being manipulated’.¹² While it might be argued that the law should not set a uniform age of responsibility across all legal domains in order to comply with some ‘unadorned principle of consistency’,¹³ nonetheless, it seems reasonable that any lack of consistency be justifiable.¹⁴ I believe that there is considerable overlap in the types of responsibility alluded to when we refer to ‘criminal responsibility’ and ‘responsibility for healthcare decision-making’, most particularly in the dual notions of capacity responsibility and prospective responsibility. If this is so, then the inconsistent ascription of responsibility to adolescents in these particular situations would seem not to be justified, and the policy of having a wide gap between the two ages of responsibility to lack a secure jurisprudential basis.

In examining these issues, this paper will largely concern itself with death. I will proceed by analysing, firstly, those adolescent autonomy cases where the likely outcome of treatment refusal would have been fatal had the courts not intervened, and secondly, the criminal law as it pertains to individuals under the age of 18 who have committed the offence of murder. There are two reasons for this. Firstly, in both situations decisions made by the child in question will lead to the death of an individual, and thus, for the purposes of analysis, there is a degree of symmetry between the healthcare and criminal cases. Secondly, the decision to refuse life-saving care is possibly the most serious decision an individual can make. Although the number of cases involving minors is small, they are of enormous relevance as the right to refuse treatment cuts to the very core of what we understand by autonomy and self-determination. Similarly, homicide is the gravest offence an individual can commit, and thus how the courts deal with young people who have killed is likely to

¹¹ However, as these points were not central to her paper it is unsurprising that Hollingsworth did not fully discuss them.

¹² H. Keating. The ‘Responsibility’ of Children in the Criminal Law. *CFLQ* 2007; 19: 183-203.

¹³ D. Archard. 2004. *Children: Rights and Childhood*. New York: Routledge. p127.

¹⁴ Keating (n12) p184.

provide an accurate reflection of how the criminal justice system views the legal and mental capacity of children.

9.2. THE BEIJING RULES¹⁵ AND ADOLESCENT RESPONSIBILITIES

To illustrate these points let us suppose that Mary, a 15 year-old girl of normal intelligence, is found guilty of the murder of V. The perpetrated act was not unreflective but was preceded by deliberation and, as she is found to have had the necessary mental component (*mens rea*) while committing the *actus reus*, Mary is held to be fully responsible for her actions and punished accordingly.¹⁶ While serving her custodial sentence, Mary develops leukaemia. This does not affect her brain, and her intellect is unimpaired. Mary needs chemotherapy and a blood transfusion, and will almost certainly die without treatment, although these therapies are not required immediately and she has time to consider. She refuses to consent. Although she accepts that refusal is likely to result in her death, Mary is adamant that she will not accept the proposed therapies. The medical staff are troubled by this decision and seek the assistance of the court. What will the court decide? If it follows existing case law, then the court will override Mary's decision regardless of her motivation; her wish to be responsible for her healthcare outcome will be denied. Thus, there would appear to be a simultaneous ascription and denial of responsibility to the same child when all that apparently changes is the legal arena she encounters. One way of explaining this discrepancy would be if the term 'responsibility' had a different meaning in each context. Being held liable for historic acts on the one hand, and responsible for making healthcare choices on the other, might express different

¹⁵ United Nations Standard Minimum Rules for the Administration of Juvenile Justice. The rules, generally referred to as the Beijing rules, seek to promote juvenile welfare and minimize intervention by state juvenile justice systems and thus consequent harm. The rules are not binding in international law; states are invited, but not required, to adopt them.

¹⁶ One objection to holding children criminally responsible is they do not deliberate sufficiently to be regarded as fully responsible. However, as Tadros points out, the 'objection ... that we are not as responsible for unreflective actions as we are for reflective actions ... is untrue'. See V. Tadros. *Insanity and the Capacity for Criminal Responsibility*. *Edinburgh L Rev* 2001; 5 325-354. p327. On the other hand, there is a considerable body of literature that supports the view that Mary should be less responsible by virtue of immaturity. For an overview see E.S. Scott & T. Grisso. *The Evolution of Adolescence: A Developmental Perspective on Juvenile Justice Reform*. *J Crim L Crim* 1997; 88: 137-189.

aspects of the notion of ‘responsibility’; the term and its cognates do have a number of context sensitive uses and senses.¹⁷

Against this, the Beijing Rules state that, in general, there should be ‘a close relationship between the notion of responsibility for delinquent or criminal behaviour and other social rights and responsibilities.’¹⁸ In broad terms, this implies that if Mary is old enough to bear the responsibility for her actions when they infringe the criminal law then she is of a sufficient age to claim a variety of rights. While there is no automatic entitlement to possess all possible rights at any particular time, nonetheless it seems reasonable to expect that if society burdens an individual with a legal responsibility then she has a prerogative to claim a correlative legal right. Those who are required to labour under certain responsibilities yet are denied what might be seen as corresponding rights might feel that such an imposition requires a satisfactory explanation. From this it would seem that if there is a significant discrepancy between the age at which Mary becomes criminally responsible and the age at which she comes to possess certain legal rights, then this disparity is in need of some justification. For the purposes of this paper, the social right that Mary wishes to claim is healthcare autonomy, or the right to be responsible for making choices about her personal medical welfare.

9.3. RESPONSIBILITY

In order to develop a sense of Mary’s various responsibilities it is necessary first, to identify what it means to be responsible, or to be held responsible, and second, to examine the relationship between responsibility and autonomy. Etymologically, coming from the Latin *respondeo* or the French *répondre*, to be responsible is to be answerable for an action.¹⁹ Kneale noted that our fundamental idea of responsibility is dependent upon the notion of being held ‘accountable under some rule to a determinate authority for a determinate sphere of action’.²⁰ While he recognised this does not seem to account for several of the ordinary ways in which we use the term, he posited that all other uses of ‘responsibility’ are derivative of the

¹⁷ J.A. Corlett. 2004. *Responsibility and Punishment*. 3rd edn. Dordrecht: Kluwer Academic Publishers. pp10-12.

¹⁸ Official commentary on Article 4(1).

¹⁹ J.R. Lucas. 1993. *Responsibility*. Oxford: Clarendon Press. p5.

²⁰ W. Kneale. 1969. The Responsibility of Criminals. In *The Philosophy of Punishment*. H.B. Acton, ed. London: MacMillan: 172-196. p175.

basic concept.²¹ Hart also argued that accountability underpinned the fundamental meaning of responsibility and classified what he saw as its distinctive connotations under the headings of Role-Responsibility, Causal-Responsibility, Liability-Responsibility and Capacity Responsibility.²² Role responsibility refers to obligations or duties that we have by virtue of the personal or professional roles we hold in an organisation or society at large. We are accountable for any failure to fulfil our acknowledged role responsibilities, and may incur blame, censure or punishment as a consequence.²³ If we excel at our role then we may be praised or subjected to a positive judgment on our actions although, unlike its negative counterpart, this only occurs in a moral rather than a legal sense.²⁴ Causal responsibility, when applied to humans (as opposed to things, events or conditions), entails being responsible for an outcome when some act or failure to act by the individual concerned significantly contributes to that state of affairs. Liability responsibility usually requires causal responsibility, and imputes blameworthiness to an individual and marks her out as someone who may be appropriately subjected to reactive attitudes, sanction or punishment.²⁵ A person may be deemed morally or legally blameworthy depending on a variety of circumstances, most particularly whether her act or omission has breached a legal rule. However, this is only true if the person imputed to be liable has certain mental capacities. For Hart the capacities in question are those of understanding, reasoning and control of conduct, although he concedes that while they constitute ‘the most important criteria of moral liability responsibility’ they are a less important standard for legal responsibility.²⁶

Cane feels that Hart’s account is too narrow, that it is insufficiently concerned with ‘prospective responsibility’.²⁷ Hart is primarily interested in historic or retrospective responsibility and while he acknowledges future-looking responsibility this is only with regard to some duty, role or task that we have to perform. However, Cane argues, prospective responsibility is not solely related to

²¹ Ibid. p176.

²² H.L.A. Hart. 1968. *Punishment and Responsibility*. Oxford: Oxford University Press. p212.

²³ Ibid. pp212-4.

²⁴ Corlett (n17) pp12-4.

²⁵ Ibid. p15.

²⁶ Hart (n22) p227.

²⁷ P. Cane. 2002. *Responsibility in Law and Morality*. Oxford Hart Publishing p32.

roles or tasks, but is also concerned with the notion of being a responsible person.²⁸ In this regard, an ethic of responsibility is partly about ‘what it is to lead a life ... and about the quality and character of that life’,²⁹ a moral virtue that we should aspire to and seek to inculcate and foster in individuals.³⁰ While the law does not concern itself with virtuous or supererogatory behaviour, it retains an interest in prospective responsibility in that it encourages conduct that coheres with our obligations under law, and discourages actions that infringe the law. In an ideal ‘prospectively responsible world’ conformity with our obligations would be maximised, thus limiting our need to invoke liability responsibility or seek remedy for damages incurred.³¹ However, in order to be the kind of person who can have prospective responsibilities we must be individuals who can understand such obligations. As far as the law is concerned we are prospectively responsible for future acts if we are likely to be held liable for their consequences. As Bok put it ‘I will be responsible if things turn out badly’ means that if things turn out badly, ‘it will then be appropriate for me to be held responsible’.³² Prospective responsibility is thus largely concerned with responsible agency. The law seems to believe that children have the capacity for such agency in that it continues to place great store in the deterrent value of punishment as a means of engendering responsible behaviour amongst young people.³³

In briefly outlining these concepts of responsibility, I have made several assumptions, some of which have been vigorously contested in the philosophical literature.³⁴ Most notably I have presumed that, in general, individuals who are subject to assessments of, and reactive attitudes to, their actions freely engage in those actions in the first place; that they have free will to choose between alternate possibilities, that their decisions are not predetermined by genetic or environmental factors, and that such alternate possibilities exist. A full assessment of these issues is

²⁸ Ibid.

²⁹ G. Watson. Two Faces of Responsibility. *Phil Topic* 1996; 24: 227- 248. p229.

³⁰ C.C. Gauthier. The Virtue of Moral Responsibility and the Obligations of Patients. *J Med Phil* 2005; 30: 153–166.

³¹ Cane (n27) p35.

³² H. Bok. 1998. *Freedom and Responsibility*. Princeton, NJ: Princeton University Press. p124.

³³ Criminal Justice and Immigration Act 2008, s 9 (2). ‘Purposes etc. of sentencing: offenders under 18: The court must have regard to - (a) the principal aim of the youth justice system (which is to prevent offending (or re-offending) by persons aged under 18’.

³⁴ Fischer (n7).

well beyond the bounds of this paper, but the position outlined is one that is largely reflective of the law as it stands. In addition, I have assumed that the same fundamental idea of liberal autonomy underpins both criminal and medical law. Although philosophically contestable, this does not seem an unreasonable position, particularly since the stated primary goal of the youth justice system is deterrence. If the Criminal Justice and Immigration Act 2008 is read as a lexical ordering of priorities, then deterrence seems to trump even the welfare principle. The value of deterrence would seem to be particularly dependent upon liberal notions of rational agents engaging (or not) in acts of free will.

9.4. RESPONSIBILITY AND AUTONOMY

Mary, having taken responsibility for her crime now wishes to take responsibility for making decisions about her personal medical welfare. Stated this way, the notion of ‘responsibility for self-determination’ assumes equivalence with that of ‘autonomy’. This is not a new relationship. The antecedents of autonomy are largely religious, originating from Puritan notions of personal responsibility and conscience, and the derivation of self-governance, rights and freedom from natural law.³⁵ Rooted in these precepts, the Anglo-American doctrinal view of healthcare autonomy has tended to emphasise individualistic interests, although as a social reality choices are inevitably not entirely atomistic in nature. However, if an individual engages in acts based upon free and uncoerced decision-making then these might be considered ‘autonomous acts’.³⁶

The legal concept of autonomy, as outlined in *Re T*, entails the right to determine what shall be done with one's own body, including the right to decide whether or not to accept medical treatment.³⁷ The law tends to regard autonomy as a negative rather than a positive right in that a person may refuse but not demand treatment.³⁸ If treatment is refused by a competent individual then this autonomous

³⁵ A.I. Tauber. Sick Autonomy. *Perspectives Biol Med* 2003; 46: 484–495. p485.

³⁶ Ibid. p490.

³⁷ *Re T (Adult: Refusal of Treatment)* [1993] Fam 95 as per Lord Donaldson at 113. However, some judicial decisions appear less than enthusiastic in unequivocally embracing the principle. See J. Coggon. Varied and Principled Understandings of Autonomy in English Law: Justifiable Inconsistency or Blinkered Moralism? *Health Care Analysis* 2007; 15: 235–255. M. Brazier & E. Cave. 2007. *Medicine, Patients and the Law*. 4th edn. London: Penguin. pp99-121.

³⁸ *R (Burke) v General Medical Council* [2005] EWCA Civ 1003.

decision must be respected even if refusal risks permanent injury or death and is based on reasons that appear irrational, ill-considered or even non-existent to an observer. The hallmark of autonomy is thus recognition of an individual's 'right to a life structured by his own values'.³⁹ This right overrides the very strong public interest in preserving the life and health of all citizens, and according to Lord Scarman in *Sidaway* is 'a basic human right protected by the common law.'⁴⁰

The idea of personal responsibility for health has become increasingly prevalent,⁴¹ and the evolving inter-relationship between capacity, autonomy and responsibility has been noted by the law. In 1967, the Latey Committee recommended that the legal age of majority in the United Kingdom be reduced from 21 to 18 years, commenting that 'most people today mature earlier than in the past; ... by 18 most young people are ready for these *responsibilities and rights*'.⁴² Similarly the Court of Appeal in *Gillick v West Norfolk and Wisbech Area Health Authority* stated that: 'it must be determined, in relation to a particular child and a particular matter, whether he or she is of sufficient understanding to make a *responsible and reasonable decision*'.⁴³ To be considered responsible in this sense would seem to require that an individual engages in a form of self-reflection, an evaluation of choices against a background of a structured value system. Wallace calls such responsibility for one's actions 'the condition of autonomy'.⁴⁴ In addition, as Tauber points out, 'autonomous choices bequeath responsibility for those choices.'⁴⁵

The relationship between healthcare autonomy and responsibility thus seems to have both backward- and forward-looking components. The responsible person engages in critical reflection before making an autonomous choice, but also takes

³⁹ R. Dworkin. 1993. *Life's Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom*. New York: Alfred A Knopf. Cited by Lord Steyn in *Chester v Afshar* [2005] 1 AC 134 HL at 144.

⁴⁰ *Sidaway v Board of Governors of the Bethlehem Royal Hospital and the Maudsley Hospital* [1985] AC 871 at 882.

⁴¹ See for example Department of Health. 2009. *The NHS Constitution for England*. London. s2(b); also D. Spruijt-Metz. 1999. *Adolescence, Affect and Health*. London: Psychology Press. pp31-35.

⁴² Home Office. 1967. *Report of the Committee on the Age of Majority*, Cmnd. 3342. London: HMSO. para 518 (my emphasis). This body was referred to as the Latey Committee after its chairperson, throughout Parliamentary and Lord's debates.

⁴³ *Gillick* at 124 as per Parker LJ (my emphasis).

⁴⁴ R.J. Wallace. 1998. *Responsibility and the Moral Sentiments*. Cambridge, MA: Harvard University Press. p53.

⁴⁵ Tauber (n35) p490.

responsibility for preferring this or that option. This is not to say that an individual may necessarily be subject to praise or blame for their healthcare choice, but rather that they must bear the consequences, beneficial or inimical, of their decision; they have liability responsibility for that decision. In the fictional case outlined above, Mary appears willing to assume liability responsibility for her choice, yet is disallowed from doing this by the court. This cannot be because she does not appreciate the idea of liability responsibility given her criminal conviction and sentencing. What then is the denial of Mary's autonomy claim based upon? A review of adolescent autonomy cases might seem to suggest that this rejection has its origins in controversial judicial interpretations of existing legislation and case law.

9.5. A BRIEF HISTORY OF ADOLESCENT AUTONOMY

The Latey Report recommended 'that young people should be able to give consent to medical treatment from the age of 16 onwards.'⁴⁶ The motivation for this proposal appeared to have been entirely practical; to allow those under 18 to access medical care in the absence of their parents, and also to protect doctors from potential charges of battery.⁴⁷ Several relevant bodies had advised the Latey Committee on the issue of adolescent consent. In its submission the British Medical Association (BMA) stated that:

Consent by a person of 16 years or upwards, who appears to the medical practitioner to be capable of understanding what is involved and of expressing his own wishes, should be considered to be a valid consent to medical or surgical treatment without necessity of confirmation by his parent or legal guardian. *Of course the refusal of a person over 16 to undergo treatment should also be respected* providing it appears to the medical practitioner that the person clearly understands the implications of his decision.⁴⁸

The Report continued by noting

This opinion is supported by all the professional bodies who have given evidence to us - The Medical Defence Union, the Medical Protection Society (who, however, suggest that from 16 to 18 the patient should be able to consent but that a refusal could be overridden by parents), the Institute of

⁴⁶ Hansard HC Deb 20 November 1967 vol 754 cc956-1028 at 963.

⁴⁷ Hansard HL Deb 26 November 1968 vol 297 cc1132-98 at 1149.

⁴⁸ Home Office (n42) para 480 (my emphasis).

Hospital Administrators, the Royal College of Nursing and the Ministry of Health.⁴⁹

There is no further comment made on treatment refusal, nor on the disparate views expressed by the Medical Protection Society on the one hand, and the BMA, apparently supported by a variety of bodies, on the other. This lack of elaboration would seem to suggest that the Latey Committee endorsed the stance of the majority, a logical position since, as Kennedy put it, ‘the power to refuse is no more than the obverse of the power to consent and that they are simply twin aspects of the single right to self-determination’.⁵⁰

The Family Law Reform Act 1969 enacted most of the recommendations of the Latey Committee, s 8(1) stating that:

The consent of a minor who has attained the age of sixteen years to any surgical, medical or dental treatment ... shall be as effective as it would be if he were of full age; and where a minor has by virtue of this section given an effective consent to any treatment it shall not be necessary to obtain any consent for it from his parent or guardian.

Twenty years later the Children Act 1989 specifically alluded to the right of a child ‘of sufficient understanding to make an informed decision’ to refuse medical or psychiatric examination, ‘or other assessment’.⁵¹ In between these two pieces of legislation the ruling by the House of Lords (most particularly the judgment of Lord Scarman) in *Gillick* implied that a child of sufficient intellectual and emotional maturity had decision-making capacity, that ‘parental right yields to the child’s right to make his own decisions when he reaches a sufficient understanding and intelligence to be capable of making up his own mind’.⁵² At this juncture it would have appeared safe to state that children could be divided into two groups: (a) those who were incapable of consenting to treatment by virtue of age-related immaturity or mental disability; and (b) those who were capable of consenting due to the fact that they were over 16 years of age, or were under 16 but had sufficient intellectual capacity ‘to enable him or her to understand fully what is proposed’.⁵³ It would also

⁴⁹ Ibid.

⁵⁰ Quoted in E. Jackson. 2006. *Medical Law*. Oxford: Oxford University Press. p245.

⁵¹ s44(7).

⁵² At 186 as per Lord Scarman.

⁵³ Ibid, at 189.

have seemed reasonable to assume that the right to consent entailed the right to refuse, that, as Harris noted,

to understand a proposed treatment well enough to consent to it is to understand the consequences of a refusal. And if the consequences of a refusal are understood well enough to consent to the alternative then the refusal must also be competent.⁵⁴

Thus, assuming Mary is a competent adolescent, she would appear to be in possession of the ultimate right of choice, specifically the power of veto, should her decision be contested.⁵⁵

‘But enter now Lord Donaldson’,⁵⁶ whose judgements in *Re R*⁵⁷ and *Re W* have proven to be enormously influential in defining the limits of adolescent autonomy. *Re R* concerned a 15 year-old girl, in the care of the local authority, who suffered increasingly serious episodes of psychotic illness, but when periodically lucid refused consent to treatment. In *Re W*, a local authority sought leave to treat a 16 year-old girl suffering from anorexia nervosa who was refusing medical treatment. These cases have been discussed extensively elsewhere,⁵⁸ and so I shall dwell only briefly upon their specifics. Although the cases were different, one similarity was that both R and W most likely lacked capacity by virtue of their illness rather than their age.⁵⁹ Despite this, Lord Donaldson used both cases to comment on a minor’s right to refuse treatment. His aim in doing so appears to have been to protect doctors against what otherwise might be unlawful treatment.⁶⁰ Lord Donaldson adjudged that the court, in exercising its inherent jurisdiction, could override a minor’s refusal. For treatment to lawfully proceed a doctor required only a single consent which could be provided by the minor, or if she refused, her parents or the court: ‘No minor of whatever age has power by refusing consent to treatment to override a consent to treatment by someone who has parental responsibility for the

⁵⁴ J. Harris. Consent and End of Life Decisions. *J Med Ethics* 2003; 29: 10-15. p12.

⁵⁵ M. Freeman. Rethinking Gillick. *Int J Child Rights* 2005; 13: 201-217. p202.

⁵⁶ Ian Kennedy, quoted in Jackson (n50) p245.

⁵⁷ *Re R* [1992] Fam 11 CA (hereafter *Re R*).

⁵⁸ See for example Brazier & Bridge (n9); Freeman (n55); A. Bainham. The Judge and the Competent Minor *LQR* 1992; 108: 194-200. G. Douglas. The Retreat from Gillick. *MLR* 1992; 55: 569-576. J. Eekelaar. White Coats or Flak Jackets/ Children and the Courts Again. *LQR* 1993; 182-187. J. Murphy. W(h)ither Adolescent Autonomy? *J Soc Welfare Fam Law* 1992; 14: 529 - 544.

⁵⁹ Brazier & Cave (n37) p405.

⁶⁰ Eekelaar (n58).

minor and *a fortiori* consent by the court'.⁶¹ In order to reach this conclusion, Lord Donaldson firstly interpreted the Latey Committee Report as not recommending that patients aged between 16 and 18 be able to give an effective refusal to medical care.⁶² He cited paragraph 484 which states that 'without prejudice to any consent that may otherwise be lawful, the consent of young persons aged 16 and over to medical or dental treatment shall be as valid as the consent of a person of full age.' The first part of this was translated into section 8(3) of the Family Law Act as 'Nothing in this section shall be construed as making ineffective any consent which would have been effective if this section had not been enacted.' This circumlocutory prose has left commentators uncertain of what it might mean.⁶³ Lord Donaldson's interpretation was that the pre-existing right to consent upheld by section 8(3) was that of those with parental responsibilities.⁶⁴ This explication was criticised by Freeman who suggested that Lord Donaldson's position was incoherent 'because, if section 8(3) is referring to parental rights at common law, these are rights which have dwindled to the point of yielding to the child's right to make his/her own decisions when of sufficient understanding and intelligence.'⁶⁵

Secondly, Lord Donaldson decided that Lord Scarman, in his judgement in *Gillick*, was not saying that a competent child's right to refuse was determinative. Instead he argued

I do not understand Lord Scarman to be saying that ... the parents ceased to have an independent right of consent ... In a case in which the 'Gillick competent' child refuses treatment, but the parents consent, that consent enables treatment to be undertaken lawfully ... If Lord Scarman intended to go further than this and to say that in the case of a 'Gillick competent' child, a parent has no right either to consent or to refuse consent, his remarks were obiter ... Furthermore I consider that they would have been wrong.⁶⁶

Kennedy questioned the legitimacy of Lord Donaldson's 'gloss' on *Gillick*, suggesting that he had interpreted the case in such a way as to achieve a particular end, that a 'party under the age of 18, even though legally competent, would lose the

⁶¹ *Re W* at 639.

⁶² *Ibid* at 634-5.

⁶³ Freeman (n55) p203.

⁶⁴ *Re W* at 634.

⁶⁵ Freeman (n55) p203.

⁶⁶ *Re R* at 23.

most critical element of the right to self-determination, the right to refuse.⁶⁷ Thirdly, Lord Donaldson denied those provisions in the Children Act 1989 that allowed for a sufficiently mature child subject to a supervision order to make an informed choice about proposed examinations or treatment. In his view sections 38(6), 43(8) and 44(7) of that Act ‘all concern interim or supervision orders and do not impinge upon the jurisdiction of the court to make prohibited steps or specific issue orders’.⁶⁸ In all subsequent cases where the refusal of treatment by a minor has been contested the courts have universally taken the position assumed by Lord Donaldson, despite the fact that such judgements may, according to Jackson, ‘permit the Court, in exercising its inherent jurisdiction, to override the express and unambiguous provisions of a statute’.⁶⁹ This may be a reflection of the implicitly undemocratic nature of judicial law-making, but, according to Perry, when ruling on ‘hard cases’ judicial freedom to amend existing legal rules or generate new ones must be constrained. Judges have a responsibility to engage in impartial moral and legal reasoning so that the outcome coheres with the rest of the law.⁷⁰ Whether Lord Donaldson’s judgements in *Re R* or *Re W* adhere to these stipulations has been a subject of intense academic scrutiny,⁷¹ but what is undoubted is that subsequent case law has remained faithful to his interpretation.

In total there have been seven cases pertaining to the refusal of life-sustaining treatment by adolescents which have come before English courts. Two of these concerned minors with anorexia nervosa,⁷² four related to children who rejected blood transfusions because of their religious convictions⁷³ and one involved the refusal of a heart transplant by a 15 year-old girl following an acute illness.⁷⁴ Three of the seven were over 16 years at the time while three more were 15 ½ years old.

⁶⁷ Quoted in Jackson (n50) p245.

⁶⁸ *Re W* at 638.

⁶⁹ Jackson (n50) p245.

⁷⁰ T.D. Perry. 1976. *Moral Reasoning and Truth: An Essay in Philosophy and Jurisprudence*. London: Clarendon Press. pp85-6.

⁷¹ See Brazier & Bridge (n9); Freeman (n55); Bainham (n58); Douglas (n58); Murphy (n58).

⁷² *Re W*; *Re C (Detention: Medical Treatment)* [1997] 2 FLR 180. The life and death nature of *Re W* is debatable as she was not refusing all treatment. I have included the case because of its central nature in defining the limits of adolescent autonomy. In *Re C* there was testimony from a psychiatrist that C was ‘putting herself at risk of collapse and sudden death within 3 to 7 days’. At 187.

⁷³ *Re S* [1995] 1 FCR 604 (hereafter *Re S*); *Re L* [1998] 2 FLR 810 (hereafter *Re L*); *Re E*; *Re P*.

⁷⁴ *Re M* [1999] 2 FCR 577 (hereafter *Re M*).

The child in *Re M* was 14. Some of the minors involved in these cases had been declared competent by physicians⁷⁵ or the courts⁷⁶, or had their general intellect commented upon⁷⁷ in the process of their hearings. None of the children seem to have been of sub-normal intelligence. Thus, on the face of it the majority, if not all, of these minors would appear to have been competent by statute or by the standards set in *Gillick*. The refusal of consent by these adolescents thus required the judiciary to formulate legal devices in order to protect doctors against claims of trespass should they initiate treatment against the will of the patient. In general the courts invoked two principles, which I will term specific incapacity and welfare, in order to override the patient's decision.

9.5.1. *Specific Incapacity*

In a number of cases declarations were made to the effect that, despite their level of intelligence, the adolescents in question lacked the requisite capacity to make the relevant decisions for a variety of reasons. Firstly, in the instance of anorexia it was argued that suffering from this form of mental illness destroyed 'the ability to make an informed choice.'⁷⁸ While this point might be subject to philosophical debate, at least the courts have been consistent in their approach to this problem regardless of the age of the individual.⁷⁹ A second reason for overriding the autonomy of a minor was that the consequences of the decision were of such gravity that the capacity required to exercise proper choice was beyond that possessed by the average (or even highly intelligent) adolescent.⁸⁰ An alternative version of this came when Ward LJ adjudged that E failed to fully understand the consequences of his decision; in particular he was unable to foresee the exact nature of his death.⁸¹ If the

⁷⁵ *Re W* at 640. Dr G. testified: 'basing my view on discussion with [W] ... I am convinced that she has a good intelligence, and understands what is proposed as treatment.'

⁷⁶ *Re W* at 627. Thorpe J held that, although W had sufficient understanding to make an informed decision, he had inherent jurisdiction to make the order sought. Also *Re M* at 581.

⁷⁷ *Re E* at 391: 'I find that A is a boy of sufficient intelligence to be able to take decisions about his own well-being ... Impressed though I was by his obvious intelligence ...'.

⁷⁸ *Re W* as per Balcombe LJ at 640. *Re C* at 195-6.

⁷⁹ Mental Health Act 1983, s63 allows for the treatment, including tube feeding, of patients with anorexia against their will. See for example *Re KB (Adult) (Mental Patient: Medical Treatment)* [1994] 19 BMLR 144 as per Ewbank J at 146. Referred to with approval by Hoffmann LJ in *B v Croydon HA* [1995] Fam. 133 at 139.

⁸⁰ A. Grubb. Commentary on *Re L (Medical Treatment: Gillick Competency)*. *Med Law Rev* 1999; 7: 58-61.

⁸¹ *Re E* at 391. See also *Re S* at 615.

validity of consent is predicated upon a precise knowledge of pathological processes then few signed consent forms are likely to be legally meaningful because, as Brazier notes, how many of us ‘enjoy such insight?’⁸² Grubb asserts that by tacking on such requirements to assessments of capacity the courts have created a test that makes it ‘very difficult if not impossible for a teenager ever to be legally competent’.⁸³ The third reason given for denying the capacity of a minor was premised upon the notion that an individual needs to be informed of all relevant risks and benefits in order to give effective consent. In *Re L*, Sir Stephen Brown P remarked that the surgeon ‘did not, however, feel it appropriate – and I can well understand why – to go into detail about the manner of the death.’⁸⁴ As a consequence it was observed that the child did not possess sufficient information about the procedure she was to undergo and so her refusal of consent could not be considered competent.⁸⁵ This reasoning seems specious and if it were law would appear to legitimise the manipulation of anyone’s capacity, regardless of their age or maturity, simply on the basis of non-disclosure of pertinent information by a doctor, an omission that in itself would appear to be negligent.⁸⁶ Finally, in cases where minors refused blood transfusions because of their religious convictions, the courts intimated that the children lacked voluntariness, or were unable to make a free choice because of the undue influence of others.⁸⁷ Coercion entails the deliberate intention to influence another’s decision by the use of a serious, credible and irresistible threat,⁸⁸ while the notion of undue influence involves illegitimate or overbearing persuasion.⁸⁹ It is this latter concept that lead Ward LJ to conclude regarding E:

I find that the influence of the teachings of the Jehovah's Witnesses is strong and powerful ... He is a boy who seeks and needs the love and respect of his parents whom he would wish to honour as the Bible exhorts him to honour them. I am far from satisfied that at the age of 15 his will is fully free ... his volition has been conditioned by the very powerful expressions of faith to which all members of the creed adhere.⁹⁰

⁸² Brazier & Cave (n37) p405.

⁸³ Grubb (n80) p61.

⁸⁴ *Re L* at 811.

⁸⁵ *Re L* at 813.

⁸⁶ Brazier & Cave (n37) pp99-120.

⁸⁷ *Re E* at 393. See also *Re S* at 613.

⁸⁸ R. Faden, et al. 1986. *A History and Theory of Informed Consent*. Oxford: Oxford University Press. p339.

⁸⁹ *Re T* as per Lord Donaldson MR at 113-4.

⁹⁰ *Re E* at 393.

Many people might find religious tenets that demanded the rejection of life-saving therapy as somewhat irrational,⁹¹ but mainstream spiritual beliefs are no less ethereal. The question here was whether, given his religious upbringing, E could make a free choice. One does not have to embrace determinism to appreciate that many aspects of one's upbringing continue to have an influence on our decision-making processes in later life, and there is little evidence to suggest that the views we express with 'the vehemence and conviction of youth'⁹² suddenly abate on reaching the age of majority. The Jesuitical aphorism 'give me the boy until the age of seven, I will give you the man' would seem to have particular resonance here. This was especially true in the tragic case of E who rejected further transfusions upon turning 18 and died soon afterwards.⁹³

9.5.2. *Welfare*

Perhaps a more honest approach by the courts was to declare that the competence of the minor was irrelevant:

there must come a point at which the court, while not disregarding the child's wishes, can override them in the child's own best interests, objectively considered. Clearly such a point will have come if the child is seeking to refuse treatment in circumstances which will in all probability lead to the death of the child.⁹⁴

In essence the courts took the view that adolescents need to be protected from themselves, that their best interests dictated that they have a 'chance to live a precious life'.⁹⁵ According to Nolan LJ it is 'the duty of the court to ensure so far as it can that children survive to attain that age (18)'.⁹⁶ In this context, it might also be argued that healthcare professionals are under an obligation to act only for the well-being of their patients. If this is a primary duty of doctors, which can only be trumped by the clearest exercise of (adult) autonomy, then an adolescent's refusal of care might be regarded as insufficient to negate a physician's basic obligation. This line of reasoning, however, seems excessively paternalistic as it takes no account of individual capacity, and would seem to empower a doctor to override the express

⁹¹ *Re W* as per Lord Donaldson at 637.

⁹² *Re E* at 393.

⁹³ *Re S* at 614.

⁹⁴ *Re W* as per Balcombe LJ at 642. See also *Re P* and *Re C* at 189.

⁹⁵ *Re E* at 393.

⁹⁶ *Re W* as per Nolan LJ at 647.

wishes of a competent young patient in order to uphold values held by the medical profession, rather than those held by the patient herself. While emotively adopting a standpoint that prevents the loss of young lives seems almost irresistible, it must be noted that these arguments construe the prolongation of physical being as the sole worthwhile existential property, and ignore the relevance of psychological, emotional and spiritual elements.

9.6. THE AGE OF CRIMINAL RESPONSIBILITY

While the law's engagement with adolescent autonomy is a particularly recent phenomenon, criminal jurisprudence has a much longer acquaintance with children and has not been so diffident in attributing competence to them. There has generally been recognition that children under a certain age lack the capacity to be criminally culpable, and it is interesting that this has changed little over millennia. The limited sources available from Ancient Greece indicate that while Athenians regarded children as physically, mentally and morally incapable,⁹⁷ they remained liable for homicidal acts.⁹⁸ In Roman civilisation *infantes* (under the age of 7) who caused the death of another were exempted from prosecution under the law on murder as they were deemed incapable of homicidal intent. Those between *infantes* and the age of puberty (14) were also generally seen as being free from criminal intent, but were liable to prosecution, according to Julian, if they were *doli capax*.⁹⁹ Thus, a child's physical and mental capacities and their ability to appreciate wrongdoing were considered before responsibility was attributed.

Under English common law, the age of majority was historically concerned with defining the authoritative relationship between adults and children in a pre-industrial patriarchal social system.¹⁰⁰ Although it was not necessarily related to criminal responsibility, at various times the ages of culpability and majority approximated. Ine, a 7th-century West Saxon king, deemed that by the age of 10, a

⁹⁷ M. Golden. 1990. *Children and Childhood in Classical Athens*. London: Johns Hopkins University Press. p5.

⁹⁸ Ibid. p40.

⁹⁹ 'Capable of evil': B. Rawson. 2003. *Children and Childhood in Roman Italy*. Oxford: Oxford University Press. pp74-5. A more modern judicial translation of the term *doli incapax* is 'incapacity of committing an offence'. See *R v JTB* [2009] UKHL 20 per Lord Phillips at para 8.

¹⁰⁰ D. Gorham. The "Maiden Tribute of Modern Babylon" Re-Examined: Child Prostitution and the Idea of Childhood in Late-Victorian England. *Victorian Studies* 1978; 21: 353-379. p362.

boy could be 'privy to a theft', but contemporary law would also have entitled him to manage his own lands.¹⁰¹ Later, the Laws of Aethelstan (925 AD) specified that only those over 12 could be punished as an adult, while capital punishment should be reserved for those over 15,¹⁰² which was also the age of majority at the time.¹⁰³ By 1215, when the *Magna Carta* was issued, the age of majority increased to 21 for military personnel, although it was less for agricultural tenants.¹⁰⁴ Later, some London Boroughs invoked a rule whereby the 'years of discretion, which brought to a child independent responsibility for crime and trespass, were ... chosen to give the child full legal capacity'.¹⁰⁵ Gradually, however, 21 became the accepted age of majority, where it remained until 1969. By contrast, children were liable to be punished for crime from the age of 7.¹⁰⁶ Blackstone's *Commentaries on the Laws of England* outlined the criminal responsibility of children under the Common Law:

under seven years ... infant cannot be guilty of felony, for then a felonious discretion is almost an impossibility in nature ... at eight ... he may be guilty of felony ... if it appear to the court and jury that he was *doli capax* ... he may be convicted and suffer death.¹⁰⁷

Thus, the courts were not so much guided by 'years and days, as by the strength of the delinquent's understanding and judgment ... *malitia supplet aetatem*.'¹⁰⁸ In the early 19th century the justice system scarcely discriminated between children and adults in terms of criminal procedures or sanctions. Classical free-will theories depicting the criminal as a rational agent choosing crime were heavily influential, and thus responsibility, retribution and deterrence were key parts of a punitive system. Later, a more welfarist approach to juvenile crime saw the creation of separate institutions in which to incarcerate young offenders, while the Children Act 1908 abolished the death penalty for children and established the juvenile court

¹⁰¹ M.S. Kuefler. "A Wryed Existence": Attitudes toward Children in Anglo-Saxon England. *J Soc Hist* 1991; 24: 823-834. p826.

¹⁰² W.B. Sanders ed. 1970. *Juvenile Offenders for a Thousand Years: Selected Readings from Anglo-Saxon Times to 1900*. Chapel Hill, NC: University of North Carolina Press. pp3-4.

¹⁰³ T.E. James. The Age of Majority. *Am J Leg Hist* 1960; 4: 22-33. p25.

¹⁰⁴ Ibid. pp26-30.

¹⁰⁵ Ibid. p23.

¹⁰⁶ I. Pinchbeck. The State and the Child in Sixteenth-Century England - II. *Br J Sociol* 1957; 8: 59-74.

¹⁰⁷ W. Blackstone. 1809. *Commentaries on the Laws of England: Vol. IV: Of Public Wrongs*. 15th edn. London: T. Cadell and W. Davies. pp22-3.

¹⁰⁸ 'Malice supplies age'.

system. The Children and Young Persons Act 1933 changed the minimum age of criminal responsibility from 7 to 8 years, later raised to 10 by the Criminal Justice Act 1963.¹⁰⁹ Fionda argues that the 1990s saw a retreat from the liberal position,¹¹⁰ while Fortin maintains that ‘the last twenty years have seen an increasingly punitive approach to young people who offend, particularly the very young ones.’¹¹¹

Indications of this punitive ideology might be seen in the Criminal Justice and Public Order Act 1994 which reduced the minimum age for detention from 14 to 10 years in the case of grave crimes, and the Crime and Disorder Act 1998, s34 which abolished the presumption of *doli incapax*.¹¹² This centuries-old common law doctrine was enshrined to ensure that an allowance was made for children with immature faculties of reasoning, comprehension and knowledge; that instigating punitive measures against those without developed capacity lacked moral justification.¹¹³ With regard to a defendant (between the ages of 10 and 14) the prosecution thus had to establish

for the purposes of ascertaining criminal responsibility ... not knowledge of unlawfulness but knowledge that what he did was seriously wrong, beyond any measure of mere naughtiness that the child understood his act as seriously wrong rather than merely mischievous or naughty.¹¹⁴

It is uncertain whether the presumption of *doli incapax* actually prevented many prosecutions or convictions.¹¹⁵ While it was, in general, easily rebutted without the need for expert evidence, the presumption still identified this period of a child’s life as a transitional bridge between criminally incapable younger childhood and capable adolescence.¹¹⁶ Walker argued that s34 merely abolished the presumption, but that the defence of *doli incapax* might still be open to children (between 10 and 14 years).¹¹⁷ However, the House of Lords recently denied this possibility, finding that

¹⁰⁹ J. Fionda. 2001. Youth and Justice. In *Legal Concepts of Childhood*. J. Fionda, ed. Oxford: Hart Publishing. pp78-82.

¹¹⁰ Ibid, pp 82-3.

¹¹¹ J. Fortin. 2005. *Children's Rights and the Developing Law*. 2nd edn. Cambridge: Cambridge University Press. p547.

¹¹² R. Arthur. Young Offenders: Children in Need of Protection *Law & Policy* 2004; 26: 309-327. p317.

¹¹³ D. Haydon & P. Scraton. 'Condemn a Little More, Understand a Little Less': The Political Context and Rights Implications of the Domestic and European Rulings in the Venables-Thompson Case. *J Law Soc* 2000; 27: 416-448. p420.

¹¹⁴ *C v DPP* [1994] 3 WLR 888 at 890-891.

¹¹⁵ H. Keating. Reckless Children? *Crim L Rev* 2007: 546-558. p550.

¹¹⁶ Ibid.

¹¹⁷ N. Walker. The End of an Old Song? *NLJ* 1999; 149: 64.

s34 abolished both the presumption and the defence.¹¹⁸ Citing some ‘startling results’ arising from appeal to the defence of *doli incapax*,¹¹⁹ Lord Phillips concurred with the views of Laws J in *C v DPP*: ‘this presumption at the present time is a serious disservice to our law ... It is unreal and contrary to common sense’.¹²⁰ Lord Phillips continued

These ... cases demonstrated that the rebuttable presumption of *doli incapax* was an anachronism. Children in the 20th Century had to go to school where they were, or were supposed to be, taught the difference between right and wrong. In the case of some offences it beggared belief to suggest that young Defendants might not have appreciated that what they were doing was seriously wrong.¹²¹

The abolition of *doli incapax* has meant that a child who has attained the age of 10 years is now subject to be tried using the same principles of criminal law as an adult.¹²²

9.7. RESPONSIBILITY: ADOLESCENT CRIME AND AUTONOMY

What of Mary? Because she was found guilty there was an *ex-post* ascription of causal responsibility and legal liability to her. She breached the criminal code by unlawfully killing another while having the intention either to kill or to do serious harm to V.¹²³ However, causal accountability, by assigning discretion and intention to an individual,¹²⁴ also says something about the mind of that person at the time immediately before the crime was committed. Firstly, Mary had a choice as to whether she would commit the act in question; she had an array of alternate possibilities open to her. Discretion, in part, relates to what Hart termed the ‘idea of

¹¹⁸ *R v JTB* [2009] UKHL 20.

¹¹⁹ The cases referred to were *JBH and JH (Minors) v O’Connell* [1981] Crim LR 632; *IPH v Chief Constable of South Wales* [1987] Crim LR 42.

¹²⁰ *C v DPP* at 894.

¹²¹ *R v JTB* at para 20.

¹²² E. Stokes. 2000. Abolishing the Presumption of *doli incapax*: Reflections on the Death of a Doctrine. In *Youth Justice: Theory and Practice*. J. Pickford, ed. London: Cavendish Publishing. p51.

¹²³ Law Commission. 2006. *Murder, Manslaughter and Infanticide*. London: TSO. s1.13.

¹²⁴ ‘Subject to three exceptions, the crime of murder is committed where a person of sound mind and discretion unlawfully kills any reasonable creature in being and under the Queen’s peace with intent to kill or cause grievous bodily harm’. The exceptions relate to the defences of provocation, diminished responsibility and action in pursuance of a suicide pact. J. Richardson ed. 2000. *Archbold: Criminal Pleading, Evidence and Practice*. London: Sweet & Maxwell. p1622.

obligation'.¹²⁵ The law dictates that we are obligated to perform certain acts and refrain from others; in Mary's case the law placed her under an obligation to refrain from harming V. Mary chose to ignore this restriction on her actions; she made a mental decision to choose a particular course of action from the array of possibilities available to her. In addition, Mary must also have intended to cause serious harm to V, again choosing from the menu of options available to her - from inflicting minor or no harm to serious or fatal harm. In making these choices Mary took prospective responsibility for the crime she was about to commit. In order to find her guilty the court must have believed that Mary had the mental capacity to have taken such choices and assumed prospective responsibility.

The case for the abolition of the defence of *doli incapax* was based on three contentions: that it was archaic, illogical and unfair in practice.¹²⁶ Its outdated nature was purportedly apparent in the fact that

it assumes ... that in general, a child under 14 cannot differentiate right from wrong. ... the notion that the average 10-14 year old does not know right from wrong seems contrary to common sense in an age ... when children seem to develop faster both mentally and physically.¹²⁷

However, as has been noted, that ability to discriminate between right and wrong does not necessarily equate with a capacity to take personal responsibility for acts.¹²⁸ This claim has been repeated, often by those with considerable expertise in psychological and cognitive development.¹²⁹ However, such assertions have largely fallen on deaf ears, the law generally preferring to reinforce the notion that those above the age of responsibility are 'mature enough to be accountable'.¹³⁰ The White Paper *No More Excuses* determined that children should receive a clear signal that they will be held responsible for their actions.¹³¹ As a general philosophy it would

¹²⁵ H.L.A. Hart. 1961. *The Concept of Law*. Oxford: Clarendon Press. pp79-88.

¹²⁶ Home Office. 1997. *Tackling Youth Justice*. London. para 7.

¹²⁷ Ibid. para 8.

¹²⁸ Home Office. 1960. *Report of the Committee on Children and Young Persons, Cmnd 1191*. London: HMSO. para 81. The Ingleby Committee was set up to review the powers and proceedings of juvenile courts and the provisions for preventing cruelty to and neglect of children. See also Keating (n12).

¹²⁹ See for example Royal College of Psychiatrists (n9).

¹³⁰ Home Office. 1997. *No More Excuses – A New Approach to Tackling Youth Crime in England and Wales, Cm 3809*. London: HMSO. p2. Ministry of Justice. 2009. *Murder, Manslaughter and Infanticide: Proposals for Reform of the Law. Summary of Responses and Government Position*. London: TSO. para 100.

¹³¹ Home Office, *ibid*.

seem unfair to ascribe such responsibility to individuals who were not capable of self-government; we do not, as a general rule, assign such agency to animals. It would thus seem reasonable to assume that legislators perceive children who are convicted of criminal acts as responsible agents with regard to those acts. The law thus must implicitly hold certain concepts about young people to be true. With regard to Mary these might include the following: (1) that she was capable of reflecting upon available choices, weighing them up and coming to a decision as to whether to take action X or refrain from act Y; (2) that she understood the notion of risk and dangerous activities; (3) that she had some comprehension of the consequences of such choices, both in terms of outcome for V and her liability with respect to that action; (4) that she had some idea of both a sliding scale of possible harms that might result from her action when perpetrated with different degrees of force, and of the nature of death;¹³² and (5) by virtue of mentally making her choice she assumed prospective responsibility for acting in the way she did.

Sufficient mental capacity is an essential prerequisite of culpability; otherwise the law would not need to set a minimum age of criminal responsibility. This standard of mental capacity is generally regarded as being set at a low level.¹³³ However, there appears to be a tension here as the above analysis would seem to indicate that the law has attributed a level of reasoning to Mary that is more sophisticated than some minimal norm. The criminal courts do not appraise whether this degree of erudition is present, but assume it to be so based on age, particularly since the abolition of *doli incapax*. This presumption of capacity responsibility by the criminal justice system stands in marked contrast with what appears almost as a presumption of incapacity by the courts in other legal arenas. When Mary refuses

¹³² If Mary had only intended to seriously harm V rather than kill him, then it is possible that she could be found guilty of murder without having an understanding of the nature of death. The Homicide Act 1957 required malice aforethought to be established in order for a murder conviction to be secured. This entailed that the defendant had to be at least aware that the harm done was life-threatening. Subsequent court judgments held that a jury could find a defendant guilty of murder even if he or she only intended to cause serious harm. See Law Commission (n123) s1.26-29. For the purposes of this analysis I have assumed that Mary deliberately killed V. In the Bulger murder trial, Venables and Thompson, who were 10 when committing their offence, were deemed by the trial judge, Morland J, to have carried out the abduction of Jamie Bulger for the purpose of killing him. If two young boys can have an understanding of what it means to take a life away, then it seems implausible that a 15 year-old adolescent of normal intelligence would not have a similar, and in all probability, more mature concept of death.

¹³³ Cane (n27) p72.

medical treatment, the court is likely to deny that she is capable of assuming responsibility for her healthcare decision, and may well provide some of the reasons previously invoked in adolescent autonomy cases as a basis for this decision. In a way these reasons might be regarded as grounds for excusing Mary from being responsible. These ‘excusing conditions’ might be summed up as follows: (1) mental illness; (2) lack of foresight, information or knowledge; or (3) undue influence of others. It is unlikely that any of these conditions would excuse Mary from being found guilty of murder. The first, mental illness, is not particularly relevant in this instance. The Homicide Act 1957 allowed for a plea of diminished responsibility in cases where arrested or retarded development, or disease or injury of the mind substantially impaired mental functioning,¹³⁴ while to establish a defence of insanity it needed be demonstrated that ‘the party accused was labouring under such a defect of reason, from disease of the mind, as not to know the nature or quality of the act he was doing, or if he did know it, that he did not know he was doing what was wrong.’¹³⁵ In this instance, Mary suffered from no form of mental illness, and the possibility of diminished responsibility due to adolescent immaturity is not currently recognised under English law.¹³⁶ Apropos of the second condition, in general ignorance does not absolve us from responsibility. In particular, a lack of knowledge of the exact nature of V’s death would not reduce Mary’s culpability. That she might not know, for example, that a stab wound to the chest could result in V’s lungs filling with blood, his gasping for breath followed by progressive hypoxaemia, acute organ failure and death is rightly not germane to her capacity responsibility. If it were, then only healthcare professionals or perhaps even forensic pathologists could be held so responsible. Thirdly, no form of undue influence or duress excuses one from being

¹³⁴ s2. This was amended by the Coroners and Justice Act 2009 (s52). This provides that ‘A person (“D”) who kills or is a party to the killing of another is not to be convicted of murder if D was suffering from an abnormality of mental functioning which—(a) arose from a recognised medical condition, (b) substantially impaired D’s ability to do one or more of the things mentioned in subsection (1A), and (c) provides an explanation for D’s acts and omissions in doing or being a party to the killing.

(1A) Those things are—(a) to understand the nature of D’s conduct; (b) to form a rational judgment; (c) to exercise self-control.’

¹³⁵ *M’Naghten’s Case* [1843] 10 Cl & Fin 200 at 210.

¹³⁶ Law Commission (n123) s5.125-137. Ministry of Justice (n130) paras 99-103.

responsible for murder or attempted murder, no matter how severe the threat.¹³⁷ The Law Commission provides an interesting example of this:

A psychopathic father compels his eleven-year-old son through threats of death to participate in the murder of one of the father's rivals ... It seems to be nothing less than an affront to justice that the father may be convicted only of manslaughter, on the grounds of diminished responsibility (due to his psychopathic disorder), but his son must be convicted of murder if his participation involved knowingly taking part in the killing.¹³⁸

This fictional account provides an interesting contrast with those cases where a particular religious upbringing (presumably by a non-psychopathic family) might be felt to unduly influence an adolescent's decision to reject life-sustaining treatment.

How can we state, as the courts appear to, that Mary had the capacity responsibility to commit a homicidal act but not to refuse medical care? Before she killed V she had to understand that if she chose to act in a particular way then this action might result in serious harm to V or his death. Her range of choices concerning the acceptance or rejection of treatment entailed similar decisional parameters. If the decision D1 to commit act A1 is likely to result in the death of a person (V), and the decision D2 to commit act A2 is also likely to result in the death of a person (herself) then for the courts to discriminate between Mary's abilities to assume responsibility for both decisions there must be some fundamental difference between the mental mechanics required for D1 and D2. The court has already attributed Mary with the capacities of reflection, analysis and decision-making with regard to her crime, and also with a comprehension of consequences, liability and harms (including death). According to Buchanan and Brock the capacities necessary for competent health care decision-making might be generalised as those of communication, understanding, reasoning and deliberation, and 'a set of values or conception of the good.'¹³⁹ There seems nothing in these generic properties that the court does not already presume Mary to possess by virtue of her conviction. There thus seems little difference in the capacities required to be prospectively responsible

¹³⁷ Law Commission. 2005. *A New Homicide Act for England and Wales? Consultation Paper No 177*. London. paras 1.72-1.78; *R v Howe* [1987] 2 WLR 568; *R v Gotts* [1992] 2 AC 412.

¹³⁸ *Ibid.* para 1.78-1.79.

¹³⁹ A. Buchanan & D.W. Brock. Deciding for Others. *Milbank Q* 1986; 64, Supplement 2: 17-94. pp24-26.

for choices or actions that pertain to either criminal acts or one's personal healthcare decisions.

9.8. COHERENCE AND THE LAW

Should we take Mary's problem seriously? Simply put, the criminal justice system has a responsibility to prosecute wrongdoing, while it seems reasonable that the family courts should err on the side of life rather than death. However, the Beijing Rules might suggest that the fair ascription of responsibilities and rights is a matter of justice. The mathematical disparity in respective ages between culpability and autonomy, or responsibility and right, in England is eight years, one of the widest in the European Union.¹⁴⁰ This contrasts markedly with other jurisdictions such as Germany, where the gap is four years, or Belgium, where there is no gap at all,¹⁴¹ and raises questions of fairness and equity. One way of narrowing the gap might be to increase the age of criminal responsibility. A number of organisations have criticised the low age at which criminal culpability starts in the United Kingdom¹⁴² but despite a series of reports and white papers suggesting that it should be increased to 12,¹⁴³ 14¹⁴⁴ or 16,¹⁴⁵ this age has remained at 10 since 1963. Recent political rhetoric on the issue would seem to suggest that this is unlikely to change in the near future.¹⁴⁶ Thus, in general terms, the law denies full autonomy until the age

¹⁴⁰ The UK countries have 'the lowest age of criminal responsibility in western Europe', House of Lords Deb (20 Nov 2007) 731 as per Baroness Miller at 734. See also L. Palme. 1997. No Age of Innocence: Justice for Children IN In *The Progress of Nations*. UNICEF. Accessed on January 8 2009 at <http://www.unicef.org/pon97/p56a.htm>.

¹⁴¹ In Belgium, Art. 388 of the Civil Code, amended by Art. 1 of the Law of 19 January 1990 reduced the civil majority to 18 years. A minor lacks the legal capacity to contract with a physician or a hospital. The age of criminal responsibility is also 18. See Fortin (n111) p550.

¹⁴² See for example Committee on the Rights of the Child. 2008. *Consideration of Reports Submitted by States Parties Under Article 44 of the Convention. Concluding observations: United Kingdom of Great Britain and Northern Ireland*. Geneva: United Nations. para 78; Children's Society. 2008. *Children in Trouble with the Law* London: TCS. R. Allen. 2006. *From Punishment to Problem Solving: A New Approach to Children in Trouble*. London: Centre for Crime and Justice Studies.

¹⁴³ Home Office (n128) para 93.

¹⁴⁴ The Children and Young Persons Act 1969.

¹⁴⁵ Home Office. 1965. *The Child, the Family and the Young Offender*, Cmnd 2742. London: HMSO.

¹⁴⁶ See Ministry of Justice (n856) paras 99-103. See also, for example, the House of Lords debate on 20 November 2007 at <http://www.parliament.the-stationery-office.com/pa/ld200708/ldhansrd/text/71120-0001.htm>, and comments made by both the Home Office and the Shadow Home Affairs minister in response to calls for an increase in the age of criminal responsibility: BBC News 'Criminal age "should be raised"' (22 September 2006) at <http://news.bbc.co.uk/go/pr/fr/-/1/hi/uk/5369274.stm>.

of 18 largely because of presumed incapacity¹⁴⁷ but holds that those above the age of 10 have sufficient decision-making capacity to be held accountable for criminal acts.¹⁴⁸ In Mary's case the courts are likely to have treated her as an adult with respect to the act that brought about the death of another,¹⁴⁹ yet as an incapable child when she refused life-saving treatment.

This seems an incongruous situation and raises questions about the coherence of the law in its dealings with children in that it appears to perceive the views and actions of minors as reflective of immaturity for some legal purposes but of full agency for others. As a general principle legal coherence would seem an important tenet of jurisprudence. Lord Nicholls maintained that:

To be acceptable the law must be coherent. It must be principled. The basis on which one case, or one type of case, is distinguished from another should be transparent and capable of identification. When a decision departs from principles normally applied, the basis for doing so must be rational and justifiable if the decision is to avoid the reproach that hard cases make bad law.¹⁵⁰

However, Cane suggests that while 'consistency and coherence are aspects of justice ... they do not exhaust it.'¹⁵¹ Nevertheless, the law is consistent in its approach to adults. Once over 18 years an individual is presumed to possess the capacity to be either capable or culpable in the healthcare or criminal justice arenas respectively. It is also consistent in dealing with those with mental incapacity. The Law Commission points out that 'it is ... the case that someone aged (say) 20, but with a mental age of ten, can plead diminished responsibility as they suffer from "arrested or retarded development of mind" under ... the Homicide Act 1957'.¹⁵² Individuals with this degree of mental disability are also likely to be deemed incapable of making

¹⁴⁷ Grubb (n80) p60. He suggests that the courts contrive to obfuscate and distort the legal concept of competence, to make 'it very difficult if not impossible for a teenager ever to be legally competent'.

¹⁴⁸ The Crime and Disorder Act 1998, s34.

¹⁴⁹ See S. Bandalli. Abolition of the Presumption of Doli Incapax and the Criminalisation of Children. *Howard J Crim Justice* 1998; 37: 114-123. Stokes (n122).

¹⁵⁰ *Fairchild v Glenhaven Funeral Services Ltd* [2003] 1 AC 32 at 68.

¹⁵¹ Cane (n27) p20.

¹⁵² Law Commission (n137) para 6.75. The Government response to Law Commission proposals to increase the age of criminal responsibility stated that the defence of diminished responsibility should not be available to children over the age of 10 unless they are suffering from a recognised medical condition which would him or her 'substantially less able to understand the nature of their conduct, form a rational judgment or exercise self-control'. Ministry of Justice (n130) para 100.

important decisions about their medical welfare, particularly if their choice was likely to have serious consequences. In contrast with adults and the mentally disabled, children seem not to be dealt with in a consistent manner. The criminal law adjudges the capacity of children to be ‘reflected in the age of criminal responsibility, rather than in the reach of the ‘diminished’ responsibility defence’. Logically, the same defence should apply to children as to the mentally disabled, that ‘someone who is in fact 10 years old should be able to plead ... that their mental age may have substantially impaired their responsibility for the killing.’¹⁵³ But this is not so. Unlike the incompetent adult, the child over 10 is presumed *capax*, and yet unlike the competent, also *incapax* in terms of healthcare decision-making.

9.9. CONCLUSION

Much of the law seems to be dichotomous in nature: guilty/not guilty; liable/not liable; rational/not rational. The court system appears to regard children’s identities in a similarly binary fashion. Mary as a criminally responsible youth must bear responsibility for her choices, while as an adolescent refusing medical treatment she becomes a vulnerable child whose wish to be responsible for her own healthcare decision-making is denied. In some ways this is reminiscent of the Ancient Greek myth of the Procrustean bed. Procrustes had an iron bed into which he lured those passing by. If his victim was too tall he amputated their legs, and if too short they were stretched on the rack until they were long enough. Nobody ever fitted on the bed because it was secretly adjustable. Children of the age of 10 have their capacity stretched on the legislative rack in order to make them ‘responsible’, while in other contexts adolescents have theirs amputated by the courts in order to shrink their decisional competence. This manipulation of capacity unfortunately obscures the fact that children, just like adults, may be divided into those who have capacity responsibility for certain decisions and those who have not. Although the percentage of the population in the former category increases with age there is no biological turning point that acutely renders the incompetent competent.

Honoré suggests that being responsible for the outcome of our conduct is essential for our identity formation; that ‘to deny people’s responsibility for their

¹⁵³ Law Commission (n135) para 6.75.

actions is to strike at their identity.’¹⁵⁴ If children are to be held accountable by the criminal justice system then it seems that we should recognise their capacity to make their own healthcare decisions. We may not like their choices, but if we believe them to have an identity that bears responsibility then we must trust their capacity to exercise their preferences. By contrast, if we disallow children from making autonomous healthcare choices on the basis of decisional incompetence, then the criminal justice system would seem to have little entitlement to hold them responsible for acts that transgress the criminal law. Rather they should be dealt with, as in other jurisdictions, by agencies outside of the criminal law.

¹⁵⁴ T. Honoré. 1999. *Responsibility and Fault*. Oxford: Hart Publishing. p10.

CHAPTER 10

CONCLUSIONS

*People don't like the true and simple; they like fairy tales...*¹

This thesis has as its central concern the performance of healthcare procedures on children which they did not choose for themselves, but rather were authorised by those in a position to exercise power over them. The interventions in question either did not represent a health improving action for the child in question, or were explicitly rejected by the child as not being to his or her overall benefit, usually for spiritual reasons. In each case, despite the child effectively being silent, the process of 'consent' took place. Anxieties about parental authorisation of non-therapeutic interventions are not new, and disagreement about the legal and moral validity of such 'consent' has been longstanding (within the context of the history of bioethics).² In his essay on the subject, Goldstein sought to explore the 'role for law in protecting children from parental exploitation and parents and children within a family from state exploitation in the provision or denial of medical care.'³ For Goldstein, the state should only supervene when the life of the child is at stake, and otherwise should refrain from interference, not only in the right of parents to make medical decisions for their children, but also in 'the reciprocal right of children to have their parents assume responsibility for making such decisions.'⁴ If law, this would create a situation where, so long as the child's life was secure, parents could make all manner of uncontestable healthcare decisions. This does not seem to be a

¹ Attributed to Edmond de Goncourt, *Journal* 2 March 1861.

² For contrasting views on the legality of parental 'consent' to non-therapeutic interventions see M.H. Pappworth. 1967. *Human Guinea Pigs*. London: Routledge & Kegan Paul., and G. Dworkin. Legality of Consent to Nontherapeutic Medical Research on Infants and Young Children. *Arch Dis Child* 1978; 53: 443-446. For opposing positions on the moral right of parents to authorise these procedures see P. Ramsey. The Enforcement of Morals: Nontherapeutic Research on Children. *Hastings Cent Rep* 1976; 6: 21-30 and A.M. Capron. 1982. The Authority of Others to Decide About Biomedical Interventions with Incompetents. In W. Gaylin. 1982. Competence: No Longer All or None. In *Who Speaks for the Child: The Problems of Proxy Consent*. W. Gaylin & R. Macklin, eds. New York: Plenum Press, pp115-152.

³ J. Goldstein. Medical Care for the Child at Risk: On State Supervention of Parental Autonomy. *Yale L J* 1977; 86: 645-670.p647.

⁴ Ibid.

position that many people (overtly at least) appear comfortable to continue to subscribe to. Instead a number of justifications have been constructed in order to endow non-therapeutic interventions with moral and legal authenticity. The novel aspect of this thesis has been to analyse critically these justifications. In so doing I have argued that those who have formulated models have used language, perhaps unintentionally, in a manner that distorts the true picture of what is taking place, which is the exercise of power. I have not suggested that this use of power has been maleficent, but rather that reliance on obfuscatory terminology has prevented proper debate about the acceptability of breaching the bodily integrity of a child in order to satisfy the needs of parents, society or the state.

10.1. CHILDREN, POWER AND INEQUALITY

There is also the broader issue of inequality; of why it is deemed acceptable to take the tissue of the vulnerable incompetent but not the capable adult; of why it is appropriate to impose different tests of mental capacity on the adolescent and the adult, or of competence on the ‘criminal’ child and ‘innocent’ teenager. Inequality exists where there is an imbalance of power between two protagonists. Children are relatively powerless, and these actions by parents and the state represent the exercise of power in both the ‘power over’ and ‘power to’ senses. Parents are invested with power over their children, and also have the power to compel them in certain ways. The state has the power to limit or support parental authority. The first three submitted articles examined how this power was exercised over young children in the context of donation; either of bone marrow to a sick relative, or of biological material or information to researchers. Paper 1 looked at the idea that children legitimately can be donors because they have familial and social obligations. However, analysis revealed that what we mean by ‘obligations’ is different for children and adults, and that this difference relates to personal power to refuse to fulfil those obligations. Paper 2 carried this idea forward and identified that if children and adults were to be treated equally then, with regard to research enrolment, either no unconsenting person could become a research participant, or all persons should have similarly enforceable obligations. This position would also hold for bone marrow donation. It is probable that neither of these positions will come to pass, because the power in the adult-child relationship is vested in the adult. Broadly speaking, adults seem to support the notion of paediatric research, and also that

healthy children should donate their bone marrow to sick siblings. However, the rise of individual autonomy in Anglo-American healthcare would also seem to imply that many adults do not believe that *they should be obliged* to donate their own tissue. Adults therefore have the power of control over their own and their children's tissues, although this power is not unlimited. Paper 3 developed this theme by arguing that this power over tissue is similar to the traditional property-type rights parents historically enjoyed over their children. The fourth paper, while conceptually different, also had as its central focus how adult power affects children's health and healthcare, specifically older children's healthcare choices. I considered the judicial and legislative power to award or deny children's competence with regard to particular acts, and suggested that although the state has the power to act in this manner in order to suit its own ends, it does not seem a particularly fair way to treat children. The common themes of all four papers thus involve the concepts of power, inequality and fairness, and it is clear that these concerns affect children of all ages, although perhaps in different ways. These issues are not isolated to healthcare but are germane to all aspects of parent-child relations. This is a relationship whose characteristics have changed over time, and it seems appropriate to place the matters raised in this thesis in an historical context.

10.1.1. Parents, Power and History

Although history has long been a subject of intellectual interest, it is revealing that the history of childhood is a relatively recent field of academic endeavour; almost all modern thought on the subject having been influenced by Philip Ariès controversial book, *Centuries of Childhood*, published in the 1960s.⁵ The English translation of this work contains the statement that 'in medieval society the idea of childhood did not exist';⁶ that in pre-modern societies children were merely small and undeveloped adults with no special psychological or emotional needs. On Ariès' view, our modern conception of childhood was born in the late 16th century amongst the upper classes, but did not inculcate itself into the attitudes of the lower classes until the end of the 19th century. There were many aspects of pre-modern childhood that apparently bore this contention out, including harsh

⁵ H. Cunningham. *Histories of Childhood*. *Am Hist Rev* 1998; 103: 1195-1208. P. Ariès. 1962. *Centuries of Childhood* London: Jonathan Cape Ltd.

⁶ Ariès, *ibid.* p125. The French version used the term *sentiment*.

discipline, the involvement of young children in physically demanding and dangerous work, and high mortality rates coupled with a propensity to reuse the name of the dead child for subsequent progeny.⁷ However, scholarship over the past forty years has consistently demonstrated that the concept of childhood did exist in the Middle Ages, and that parents invested both material and emotional resources in children.⁸ Indeed, the models of child rearing and education prevalent at this time arguably were more modern and enlightened than the brutality aimed at ‘breaking the will’ of the child that commonly was advocated centuries later.⁹

Children have undergone modest developmental changes since the Early Middle Ages, most notably with regard to their health and educational welfare, but childhood has been transformed. This is because childhood, although containing the universals of growth and development, can have very different content according to how adults construct it. And, as Cunningham points out, children have to live with the consequences of how adults invent, reinvent and imagine childhood, which they do in order to make sense of their own world.¹⁰ Thus, what a child is, and how they should live, study, work and behave have changed through the ages as adult worldviews have varied. As Shahar has observed, ‘Childraising practices ... as well as parent-child relations are determined not solely by biological laws but are also culturally constructed.’¹¹ Changing adult perceptions of childhood have had an immense, and sometimes terrible, influence on the lives of children. Nowhere is this more apparent than with regard to the criminal law.

In the Early Middle Ages,¹² Saxon laws specified that only those aged over 15 years could be subject to capital punishment.¹³ By the time of the Tudor monarchy (which was gruesomely inventive in the manner that they dispatched people convicted of capital offences), children were no longer immune and were not spared the worst forms of execution. Thus, the historical records of the period document cases such as that of Margret Davie, a servant girl (probably about 12 years old), who was accused of poisoning three households. While this crime sounds

⁷ Stearns. p4.

⁸ S. Shahar. 1990. *Childhood in the Middle Ages*. New York: Routledge. p1.

⁹ M.J. Bunge ed. 2001. *The Child in Christian Thought*. Cambridge: Eerdmans. p5.

¹⁰ H. Cunningham. 2006. *The Invention of Childhood*. London: BBC Books. p12.

¹¹ Shahar (n8) p1.

¹² Fifth to tenth centuries.

¹³ M.S. Kuefler. "A Wryed Existence": Attitudes toward Children in Anglo-Saxon England. *J Soc Hist* 1991; 24: 823-834. p827.

implausible to modern ears, she was put to death in 1542 by being ‘boyled in Smithfeild’.¹⁴ Seventeenth century law declared that ‘An infant of eight yeares of age, or above, may commit homicide, and shall be hanged for it’. If children were found guilty of the killing of an individual to whom they might ‘oweth faith, duetie, and obedience’ such as a mistress or a parent (the crime of *Pettie Treason*), then the penalty was to be ‘drawen and hanged’ if male or ‘burned alive’ if female.¹⁵ Blackstone’s *Commentaries* from the 19th century discuss the case of an eight year-old boy who was accused of setting fire to two barns. He was hanged when he was found to have ‘malice, revenge and cunning’.¹⁶ Today, we would react with horror at such treatment, although some of the public sentiments expressed during the trial of Venables and Thompson following the death of James Bulger might lead one to wonder how wide the gap is between contemporary social attitudes and those of our forefathers.¹⁷ Nonetheless, English law has changed (although insufficiently so¹⁸) to recognise some of children’s vulnerabilities.

Parenting, at least according to deMause, has also changed enormously:

The history of childhood is a nightmare from which we have only recently begun to awaken. The further back in history one goes, the lower the level of childcare, and the more likely children are to be killed, abandoned, beaten, terrorized and sexually abused.¹⁹

Critics have argued that this, at best, grossly overstates the case.²⁰ It is difficult to compare parenting across cultures and ages where the lives of individuals are very different. There are also very few, if any, firsthand accounts of childhood from most

¹⁴ C. Wriothesley. 1875. *A Chronicle of England During the Reigns of the Tudors, from A.D. 1485 to 1559*. London: J B Nichols and Sons. p134.

¹⁵ W.B. Sanders ed. 1970. *Juvenile Offenders for a Thousand Years: Selected Readings from Anglo-Saxon Times to 1900*. Chapel Hill, NC: University of North Carolina Press. pp10-11.

¹⁶ W. Blackstone. 1809. *Commentaries on the Laws of England: Vol. IV: Of Public Wrongs*. 15th edn. London: T. Cadell and W. Davies. p24.

¹⁷ B. Franklin. 2002. Children's Rights and Media Wrongs. In *The New Handbook of Children's Rights: Comparative Policy and Practice*. B. Franklin, ed. London: Routledge: 15-44. For a view on retributivism as a justification for punishment in this case see D. Gurnham. The Moral Narrative of Criminal Responsibility and the Principled Justification of Tariffs for Murder: Myra Hindley and Thompson and Venables. *Legal Studies* 2003; 23: 605-623.

¹⁸ See Committee on the Rights of the Child. 2008. *Consideration of Reports Submitted by States Parties Under Article 44 of the Convention. Concluding Observations: United Kingdom of Great Britain and Northern Ireland*. Geneva: United Nations.

¹⁹ L.B. de Mause. 1976. *The History of Childhood*. London Souvenir Press. p1.

²⁰ C. Heywood. 2001. *A History of Childhood*. Cambridge: Polity Press. pp41-42.

eras. Thus, it is not possible to determine their opinions on such matters. Heywood suggests that what we can appreciate is

a growing momentum to social and cultural changes affecting children from the eighteenth century onwards ... an increasing volume of works devoted to childhood ... a range of institutions dedicated to child welfare. Families became smaller and more child-oriented. And schools took over from the farms and workshops as the principal site for the work of children.²¹

The lives of children have changed because parents, and states, have used their power to effect that change. As part of this power paradigm, child-parent relations developed in a proprietorial manner. This is not to make a claim about the quality of intimacy or emotional bonds involved; there is no reason to hold that historic parents did not love their children in the context of their own existence, which was often 'nasty, brutish and short'.²² Nonetheless, the proprietorial model had clear implications for parental decision-making with regard to children's lives. However today, according to Page,

Children are no longer legally the property of their parents, and we find it morally repugnant to think of them as property at all. Clearly attitudes to children have changed ... The liberation of children from the tyranny of parents, schoolteachers and adults generally is well on the way.²³

The focus of this thesis is on adult power rather than tyranny, and I would suggest that most parent-child or state-family relationships in liberal democracies fall well short of the tyrannical. Nonetheless, it is interesting that CS Lewis observed that

Of all tyrannies a tyranny sincerely exercised for the good of its victims may be the most oppressive ... for they do so with the approval of their own conscience.²⁴

10.2. THE SUBMITTED ARTICLES

As outlined earlier, the first three papers in this thesis focused on two interventions in young children – bone marrow donation and research without therapeutic intent. I argued that these interventions are contentious because they

²¹ Ibid. p171.

²² T. Hobbes & C. MacPherson. 1985. *Leviathan*. London: Penguin Classics. p186.

²³ E. Page. Parental Rights. *J Appl Phil* 1984; 1: 187-203. p187.

²⁴ C.S. Lewis. The Humanitarian Theory of Punishment. *Res Judicatae* 1952; 6: 224-230. p228.

breach the child's bodily integrity without having a clear therapeutic purpose with regard to *that* child. Their controversial nature has led to attempts to justify these procedures in a way that avoids an appeal to the no longer acceptable proprietarianism. Academics have sought to fill the void left by the departure of the children-as-property model with a number of ideal-type parent-child relationship theories. I have discussed some of these in the context of healthcare – the best interests principle, the fiduciary model, the intimate obligation thesis, and the 'constrained parental authority' paradigm. The first two of these, while serving as useful political tools to advance the concept of children as beings with independent interests, do not reflect the realities of children's lives. And, as Callahan has argued, when it comes to children's healthcare there is a disparity between what we say and do, that there is 'a kind of soft-hearted sentimentality about children that is not matched by hard deeds'.²⁵ One such sentiment is the appeal to the paramountcy of the child's welfare. This might be seen as what could be termed a 'thin' aspiration. Fraser used the expression 'thin needs' to describe amorphous social or moral objectives that might receive general approbation while they remain indeterminate and inert proposals.²⁶ Rights based concepts such as the 'best interests of the child' might come under the umbrella of 'thin' aspirations. But when these interests generate 'specific goal-directed functional requirements' in order to produce 'thicker' ends, fundamental conflicts of interest may arise that inhibit the fulfilment of these ends.²⁷ As I have argued earlier, this conflict of interests between children, or between the donor child and his parents, means that the welfare principle does not stand up as a justification for using an unconsenting child as a research subject or tissue donor.

10.2.1. Fairy Tales

In fact, in these contexts, Callahan's 'sentimentality' is germane in a different way. Our soft-heartedness is directed not towards the donor (of tissue or research material) but towards the recipient. This emotion drives an obligation to fulfil the

²⁵ D. Callahan. Health Care for Children: A Community Perspective *J Med Phil* 2001; 26: 137-146. p137.

²⁶ N. Fraser. 1990. Struggle over Needs: Outline of a Socialist-Feminist Critical Theory of Late-Capitalist Political Culture. In *Women, the State and Welfare*. L. Gordon, ed. Madison: University of Wisconsin Press: 199-225.

²⁷ Ibid.

needs of the sick child. However, when the transfer of biological material is authorised charges of proprietarianism still must be avoided. In order to elude such claims, a kind of fairy tale is devised in which children are the actors.²⁸ In the context of bone marrow donation between siblings, for there not to be a happy ending to the story there must be some form of moral turpitude, or a failed but heroic attempt at rescue. Parental failure to act resulting in the destruction of a child is almost inconceivable and, as the parents are the authors of the story, something must be done. Thus, one child suddenly has a duty to rescue his sibling; a feat of heroism that is claimed to be in his best interests. Within this tale there is an imperative for the ‘well’ child to act with valour. The young child cannot choose to act so he is placed on the white horse (or hospital trolley) and sent off to battle the dragon. This is a tale that is emotionally appealing, but is still a justificatory fabrication.

The parent has the power to place the child up on the steed and send him into battle, but also the power to decline to mount the horse himself. This is what happened in the case of *McFall v Shimp*, where David Shimp refused to donate his bone marrow to his cousin. Although some comment might be made about the remoteness of the relationship, Shimp could also, as in the case of the Deier brothers,²⁹ have declined to donate to a sibling. However, he could have authorised the transfer of bone marrow between two of his children, or even between one of his children and a cousin.³⁰ It seems an odd concept of family that relational obligations only exist for members under the age of majority. Once over the age of 18, the requirement for family members to provide for each other disappears. In the context of bone marrow donation, parents have the power to compel and the power to refuse, and this power is a source of inequality between adults and children.

Inequality pervades the lives of children, particularly those who are too young to formulate or articulate their wishes. Some of this inequality is necessary for the protection of the child, but where more is demanded of the vulnerable child than the adult, then this inequality requires some justification. As discussed in paper 4, soon to be adults are also affected by inequalities imposed by the legal system. A

²⁸ For a discussion of the relationship between literature, morality and the law particularly with regard to the family see D. Gurnham. 2009. *Memory, Imagination, Justice: Intersections of Law and Literature*. Farnham: Ashgate. Esp. chap 6.

²⁹ See paper 3.

³⁰ The HTA have approved bone marrow donation between child cousins. Information supplied by HTA on 29 October 2010.

brief perusal of the most recent report issued by the Monitoring Committee on the implementation by the United Kingdom of the CRC would seem to suggest that Callahan's contention of unfulfilled soft-heartedness has resonance in many of the areas where society interacts with children.³¹ The Committee was particularly critical of the juvenile justice system and the low age of criminal responsibility, which I have argued is at odds with the denial of adolescent healthcare autonomy. This inconsistency is premised upon another fairy tale which is dependent on notions of childhood innocence. In *Re E* the court chose to label the adolescent in question as an innocent, a child who did not know what he was asking for and was ignorant of the consequences. In so doing, Ward J conjured into being an imaginary entity that was at odds with the corporeal being in front of him. This allowed the court to make a judgment as it did. As Gurnham's reading of the girl's carnality and cannibalism in Millien's *The Grandmother* makes clear, it is difficult to maintain that a child is ignorant in the face of explicit instruction.³² *E* had been a Jehovah's Witness since birth. He was clearly immersed in that faith. To hold that he did not understand the consequences of the one belief that marks out adherents of this particular form of spirituality from other Christian religions is to create a fiction. This narrative, despite Ward LJ's contention that he had always arrived at the right answer in such cases, ultimately turned out to be mythical.

The contradictory notions that the judgments in the Thompson/Venables trial and *Re E* raise can be explained by the creation of two oppositional images of childhood, the representation of the child as an angel, or as a devil. Franklin has suggested that according to the first account children are 'passive, vulnerable and in need of protection', while according to the second they are unruly and out of control. Children are thus either 'victims or villains'.³³ Ennew contended that the western conception of childhood insists on the actors performing 'inside' – 'inside society,

³¹ Committee on the Rights of the Child (n18). The Committee expressed 'regret' about the following failures: incorporation of the Convention in the State party's law (paras 8-9); budgetary allocations (paras 10-11); dissemination and awareness of the Convention (paras 20-21); non-discrimination (paras 22-23); corporal punishment (paras 35-38); education (paras 47-48); asylum-seekers and refugee children (paras 49-50) and juvenile justice (paras 59-62).

³² Gurnham (n28) p100. In the tale the wolf tells the girl what she is eating (her grandmother's teeth), and also instructs her to remove her clothing and get into bed with him. That his motivation is both gastronomic and carnal is evident from the text. In the face of unambiguous instruction it seems impossible to maintain that the girl was innocent.

³³ Franklin (n17) p16.

inside a family, inside a private dwelling'. Street children or 'villains' act 'outside' and thus are placed 'outside childhood'.³⁴ Thus, on this account *E* was vulnerable and in need of adult protection. He was deemed to possess the adult-determined hallmarks of minority: innocence, frailty and dependence. Venables and Thompson existed 'outside of childhood', and could be deemed to be culpable, regardless of the fact that much of their behaviour could be put down to the inadequacies and irresponsible (in)actions of their adult parents. Adults make choices and children must live with the consequences.

10.3. ANALYSING JUSTIFICATIONS

Behind all of these fairy tales are real human lives immersed in private tragedy; true life stories of illness and despair. And parents, or the court in exercise of its' *parens patriae* jurisdiction, must make decisions. This is not in dispute. The contentious nature of any decision comes not so much in the person of the chooser (although this may be subject to query), but in the premises used to justify the choice made. It is the use of the ideal; the best interests principle, the fiduciary model or intimate obligations that is controversial. Ideal-type relational theories, as for much of bioethics, are premised upon a two person paradigm. The first two of these theories have difficulties when decisions have to be made by parents which involve more than the sick child.³⁵ It is obviously in the interest of the sick child to get a donation from his healthy sibling. However, it is impossible to state that it is definitely in the well child's best interests – to do so is to create a fiction. The fiduciary model also has similar problems when two children have competing needs. If the model identified that the parents must always act in the interests of the less well off child this might be an advance, at least in terms of clarity. Then, the discussion could move on to 'what harms is it reasonable for parents to inflict on an individual child for the benefit of another member, or the family unit?'

One limit that the courts have imposed is that children will not be allowed to reject life-saving treatment even if their parents support their decision but the medical profession take a contrary view. In the case of religiously inspired rejection of blood transfusions, there is a clash of visions as to what is in the child's best

³⁴ J. Ennew. 1986. Outside Childhood: Street Children's Rights. In B. Franklin, ed. (n17) 201-214. p202.

³⁵ There are also difficulties when it comes to issues such as innovative or 'Hail Mary' therapies.

interests. The parents take a broader existential view which takes in happiness in the afterlife; the judicial perspective is of the (sometimes imaginary) here and now.³⁶ There is a divergence of opinion as to how far interests should extend. On the fiduciary exemplar, the parents clearly feel that they are doing what is best for the child. The state rejects this perspective. In the middle of all of this is the child, whose parents have programmed him into a state of rigid religious observance, while the courts decline to accept their values. The consequences for the child, as in the case of E who was to refuse further transfusions on reaching the age of majority and die in a sinful state, seem profound. That such an outcome could ever have been in his interests, or the intended product of caring parents and a compassionate state, seems doubtful.

Instead of the interests, obligations and fiduciary paradigms which provide a soft-focus view of family life, I would suggest that the ‘constrained parental autonomy’³⁷ model is closer to the political actualities of childhood. This, similar to Goldstein’s account, proposes that reproduction and rearing are adult projects which should not be interfered with so long as the child’s basic needs are met and the child is not subject to abuse. As an ideal theory of parent-child relations it is an impoverished account, as it articulates an adultcentric primacy and relegates the interests of children to a particularly subordinate role. It also seems not to have moved a great deal from the property model. Ross’ claim that children are not their parent’s property because parents are not allowed to sell or martyr their children³⁸ does not seem much of a defence. This still leaves a lot of scope for parents to act in a proprietorial fashion. Here, I think it is worthwhile to draw a (possibly belated) distinction between being treated as *de jure* property, and being treated in a proprietorial manner. Despite assertions to the contrary, it seems correct to me that ‘proprietaryism casts a long shadow over our thinking about parenthood. Even if parents do not actually own their children, it is almost as if they do.’³⁹ This is not to suggest that parents necessarily construe their children as property, insofar as they ever even consider these matters. But they may treat their children in a proprietorial

³⁶ See for example, Sir Stephen Brown’s comments about the future of the severely burned L: ‘she will return to full health – whether it is in a rugby scrum or on the wings I do not know’.

³⁷ L.F. Ross. 1998. *Children, Families and Healthcare Decision-Making*. Oxford: Clarendon Press.

³⁸ L.F. Ross. Justice for Children: The Child as Organ Donor. *Bioethics* 1994; 8: 105-126.

³⁹ D. Archard. 2010. *The Family: A Liberal Defence*. London: Palgrave MacMillan. p45.

way in particular circumstances. And, although I disagree with the thrust of his overall thesis, I share deMause's scepticism as to whether a parent is able 'to see the child as a person separate from himself'.⁴⁰ deMause put this 'deficiency' down to a lack of 'emotional maturity',⁴¹ and this may be so for some. However, it would also seem plausible to hold that in an intense emotional relationship, particularly where one of the parties is dependent, a blurring of boundaries between persons is almost inevitable.

10.4. THE FUTURE

It is an interesting paradox that at a time when the disavowal of the property model is more vehement than ever, increasing amounts of money are spent on the acquisition of children through adoption and reproductive technologies.⁴² It is arguable that we are at a transition point which may see a radical shift in the concept of childhood. For the first time procreation is no longer linked to sex and intimacy. There is also a growing disjunction between reproduction, rearing and responsibility. Our idea of what constitutes a family is the subject of serious debate between those for whom the traditional and 'natural' model of male and female parents with children is the sole acceptable paradigm, and those for whom the family can take a variety of gendered and other forms as long as it consists of 'adults who take primary custodial responsibility for the dependent children'.⁴³ Emerging technologies raise many questions about the status of families, the role of children within the new technofamily, and the kind of children these changes might produce. Whether these are private family matters or issues requiring public oversight and intervention is of considerable importance.⁴⁴

This thesis has sought to question the legitimacy of the models employed to justify the imposition of unasked for healthcare burdens on children. One aspect of this has related to non-therapeutic interventions, and biotechnological advances raise the possibility of the development of a number of interventions in children which will 'improve' them, although not necessarily in a narrow therapeutic sense. There is

⁴⁰ de Mause (n19) p17.

⁴¹ Ibid.

⁴² B. Lyons. Book Review. Baby Markets: Money and the New Politics of Creating Families (ed. Michele Bratcher Goodwin) *EJHL* 2011; 18: 112-118.

⁴³ Archard (n39) p10.

⁴⁴ Ibid. pp17-25.

already a moral debate in progress about whether biological enhancement would be in children's interests,⁴⁵ or not,⁴⁶ or even whether this is any different to the kind of environmental enhancement we currently engage in.⁴⁷ These arguments, however, still rehearse the justifications that I have suggested serve to obscure many of the real issues. It is also worth remembering, as Heywood observed apropos of all the changes to childhood wrought of adult concerns, 'How far young people benefited from these developments is a moot point.'⁴⁸

10.5. CONCLUDING REMARKS

There is a number of things that this dissertation has not addressed directly. It has aimed at analysing existing justifications for acts and examining prominent child-parent relationship theories. However, it only discusses these issues in the context of western liberal democracies, and perhaps even more narrowly from a particularly Anglo-American doctrinal perspective. It has not considered Eastern philosophies, some of which, such as Confucianism, have a strict hierarchical view of the family, and might take a contrary view to some of what I have had to say about familial relationships. In addition, although I have offered a critical review of parent-child relationship theories and justificatory paradigms, I have not proposed any of my own. But my aim in this thesis was to analyse the *de facto* position; the extant situation in which children find themselves in a world populated by real, and fallible, human actors. My emphasis has been on UK law as it stands, rather than on the more conceptual question of what the law might look like in an ideal world, or in other possible worlds. To address these issues would require another thesis.

Ideal theories inform us of how we might like people to behave, but tell us nothing about their actual behaviour, or why they act in the way they do. In the abstract, such models may be useful in advancing the political status of children but, when employed in legitimising actual non-therapeutic healthcare acts on a child, only serve to justify adult behaviour in a manner that nullifies any moral concerns that treating *that* child in an instrumental and inequitable manner may have elicited. If we

⁴⁵ J. Savulescu & G. Kahane. The Moral Obligation to Create Children with the Best Chance of the Best Life. *Bioethics* 2009; 23: 274-290.

⁴⁶ M. Sandel. 2009. *The Case Against Perfection*. Harvard: Belknap Press.

⁴⁷ E. Malmqvist. Reprogenetics and the "Parents Have always Done It" Argument. *Hastings Cent Rep* 2011; 41: 43-49.

⁴⁸ Heywood (n20) p42.

hold that children are morally relevant beings deserving of respect then it would seem reasonable to suggest that debates about matters that concern them should take place using language that avoids obfuscation and the cloaking of adult interests. In addition, if we believe that the vulnerable should be protected then it seems odd that sometimes we deliberately decline to do so – that we expect more from incompetent children than we do from competent adults. Without proper and transparent consideration of what we inflict on children then we risk, what Trilling termed, the ‘corruption of benevolence’:

*‘Some paradox of our nature leads us ... when once we have made our fellow man the object of our enlightened interest, to go on and make him the object of our pity, then our wisdom, ultimately of our coercion.’*⁴⁹

⁴⁹ L. Trilling. 1950. *The Liberal Imagination: Essays on Literature and Society*. New York: Viking Press. p215.

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APPENDIX

PUBLISHED PAPERS

1. Obliging Children. *Med Law Rev* 2011; 19: 55-85.
2. Dying to be Responsible: Adolescence, Autonomy and Responsibility. *Legal Studies* 2010; 30: 257-27.

OBLIGING CHILDREN[†]

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Children may sometimes undergo healthcare procedures that are not intended to improve their health status. Such interventions might include the use of young children as bone marrow donors or their enrolment in non-therapeutic research. One of the justifications used to legitimise these interventions is the premise that children have obligations to others; to their family in the case of related bone

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[†] The term ‘children’ generally denotes those individuals who are less than eighteen years of age. This paper specifically deals with a subgroup of the child population: those who are too young to, or by virtue of a learning disability, are unable to meaningfully engage in the process of consent or assent, and the opinions of whose parents are taken to be determinative. While there is no specific age limit to this group with regard to medical research, the Royal College of Paediatrics states that ‘researchers should obtain the assent or agreement of school age children to their involvement in the research, and should always ensure that the child does not object’: Child Health Ethics Advisory Committee, ‘Guidelines for the Ethical Conduct of Medical Research involving Children’ (2000) 82 Arch Dis Child 177, 180. In the United States, the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, supported by the American Academy of Pediatrics, state that young children (under an intellectual age of seven years) are not capable of providing assent and thus need not be asked: *Report and Recommendations: Research Involving Children* (Government Printing Office, Washington 1977); American Academy of Pediatrics Committee on Drugs, ‘Guidelines for the Ethical Conduct of Studies to Evaluate Drugs in Pediatric Population’ (1995) 95 Pediatrics 286. Alderson advises that age-stage theories under- or overestimate many children’s abilities, and indicates that some children below the age of five with chronic healthcare problems are capable of making informed decisions; P Alderson, K Sutcliffe and K Curtis, ‘Children as Partners with Adults in their Medical Care’ (2006) 91 Arch Dis Child 300. I agree with Alderson. Accordingly, this article explicitly relates to children under school-going age (or those who have profound learning disability and are under sixteen years) who lack the competence to assent to specific healthcare procedures or research. Incompetent adults may be treated similarly to children in many respects but, although occasionally alluded to in the text, a full discussion of any differences is beyond the remit of this paper. In addition, although other jurisdictions are mentioned, this paper refers specifically to the laws of England and Wales.

marrow transplantation, and to wider society in the case of non-therapeutic research. However, this 'obligation model' (the notion that children possess positive obligations to advance the health status of others) fails as a justificatory paradigm because it is based upon a confusion, identified by Hart, between two notions; that of 'being under an obligation to do something' and that of 'being obliged to do something'. Instead the 'obligation model' is a device employed to put a justificatory gloss upon a consequentialist decision-making process; removing the legitimising gloss allows for a more transparent look at the conflict between parental rights and an individual child's right to bodily integrity.

I cannot thinke my Sister in the least Would faile her Obligation.¹

I. INTRODUCTION

Most contacts children have with healthcare professionals are uncontroversial. Child C with disease X needs investigation Y and treatment Z in order to improve her health status, and parental consent to allow this care to proceed falls readily under standard notions of medical beneficence and parental duty.² If, for example, C is a two-year old child who develops leukaemia, and needs bone marrow analysis in order to plan appropriate treatment, then parental consent will be sought, and almost invariably given, so that the medical staff can lawfully proceed with the necessary investigation.³ This position seems reasonably straightforward, but some decisions are less clear cut. Supposing C is a healthy two-year old child whose bone marrow is being harvested in order to donate it to a sick sibling, the proposed operation is obviously not going to improve C's health. Or perhaps C does have leukaemia and the doctors wish to perform an extra bone marrow aspiration at the end of a chemotherapy cycle, not as part of C's treatment plan, but as part of a research protocol designed to enhance scientific knowledge about the disease. In either case, C has been exposed to potential risks through medical procedures that convey no healthcare benefit to her.⁴ These

¹ W Shakespeare, 'King Lear' in *Complete Works of William Shakespeare* (Wordsworth Editions, Oxford 2007) II, iv, 140.

² In general, the responsibility to make healthcare decisions on behalf of incompetent children falls onto parents. See Children Act 1989 s 3(1): 'In this Act "parental responsibility" means all the rights, duties, powers, responsibilities and authority which by law a parent of a child has in relation to the child and his property'.

³ Where the intended treatment is clearly medically beneficial to the child, parental consent to such care is largely unproblematic in practice. See M Brazier and E Cave, *Medicine, Patients and the Law* (4th edn Penguin, London 2007) 395.

⁴ The potential risks are not just physical in nature, but may also include exposure to psychological and emotional harms.

procedures might be considered non-beneficent interventions (NBI), a term that encompasses any medical (physical, mental, social, or emotional) infringement of an individual's integrity without intent to advance the health of that person. Physical investigations or interventions without therapeutic intent may include:

- (1) Procedures that promote the health status of others through the direct transfer of tissue (e.g. peripheral blood stem cell, bone marrow, or solid organ donation);
- (2) Procedures that promote the health status of others by advancing scientific knowledge and understanding. Children may participate in non-therapeutic research by contributing biological material or by undergoing some novel procedure.⁵
- (3) Procedures that promote the social acceptance of the child, including interventions such as ritual circumcision and 'cosmetic' procedures that affect the child's appearance.⁶

This paper concerns itself specifically with the use of young children as bone marrow donors or their enrolment in non-therapeutic research.⁷ In these instances, the child accrues no healthcare advantage from the intervention, and thus parental or proxy consent to such infringements of the child's bodily integrity might be seen to be legally or ethically questionable. Historically children were considered the property of their parents and such decisions would have required little justification beyond parental

⁵ Although the distinction between therapeutic and non-therapeutic research was dropped by the Declaration of Helsinki revision of 2000 following criticism that it failed to distinguish levels of risk, nonetheless the notion of research without therapeutic intent (RWTI) remains a useful concept, and is one that I shall utilise throughout this paper. It is arguable that children involved in research which comes under the Medicines for Human Use (Clinical Trials) Regulations 2004 could be included under this concept. Although Part 4 s 10 states that there must be some direct benefit for the group of patients involved in the clinical trial, there is no guarantee that a particular child will profit. If it was known that an individual child would derive benefit and suffer no harm from an intervention then there would be no need for research on this proposed therapy. By its very nature, the outcome of research is uncertain. However, the difference between research conducted under the Clinical Trials Regulations and RWTI is that the former holds out some possibility of direct benefit which is absent from the latter.

⁶ An example of 'cosmetic' surgery was described by Ouellette when she discussed eye surgery on Asian infants in order to westernise their appearance. A Ouellette, 'Eyes Wide Open: Surgery to Westernize the Eyes of an Asian Child' (2009) 39 *Hastings Cent* 15.

⁷ While some of the arguments contained in this paper may be extended to 'procedures that promote the social acceptance of the child', a full discussion of this group of interventions would require engagement with models of parental authority and religious or cultural freedoms. This is beyond the scope of this paper.

agreement.⁸ Today the exercise of parental authority based on a claim of property rights in the child would seem to be unacceptable.⁹ Thus, an alternative basis on which to justify the legitimacy of parental consent in these circumstances must be found. In the first instance, the welfare principle, as enshrined in the Children Act 1989, is frequently invoked as it articulates the view that in all matters pertaining to a child's upbringing, his or her best interests should have a determining influence on any decisions made.¹⁰ However, the applicability of the welfare principle in the context of paediatric healthcare decision-making has been the subject of criticism on a variety of grounds.¹¹ A second justification argues that, as they are part of a family or of a larger community, children possess obligations to other members of these social groups.¹² Thus, parental consent to NBI simply allows a child to fulfil her obligations. This claim has been subjected to far less scrutiny than the standard best interests approach, and so this paper seeks to evaluate the assertion that children possess obligations to improve the health of others.¹³

My aim in this paper is to rebut the claims of those who propose the 'obligation model', the notion that children possess positive obligations to advance the health status of others. This is not an objection to particular NBI; rather my problem is with the justifications employed to

⁸ In many cultures, including England up until late Victorian times, parents (particularly fathers) had dominion over almost all aspects of a child's life. See W Blackstone, *Commentaries on the Laws of England, Vol1* (Harper & Brothers 1850) 452–3; D Archard and CM Macleod (eds), *The Moral and Political Status of Children* (OUP, Oxford 2002) 1; AP Derdeyn, 'Child Custody Conflicts in Historical Perspective' (1976) 113 Am J Psychiat 1369.

⁹ Archard and Macleod, *ibid*, 1–4.
¹⁰ s 1(1).

¹¹ For an overview of the relevant arguments, see S Elliston, *The Best Interests of the Child in Healthcare* (Routledge-Cavendish, London 2007).

¹² See for example J Dwyer and E Vig, 'Rethinking Transplantation between Siblings' (1995) 25 Hastings Cent Rep 7; LA Jansen, 'Child Organ Donation, Family Autonomy, and Intimate Attachments' (2004) 13 Camb Q Healthc Ethic 133; TF Ackerman, 'Nontherapeutic Research Procedures Involving Children with Cancer' (1994) 11 J Pediatr Oncol Nurs 134; DW Brock, 'Ethical Issues in Exposing Children to Risks in Research' in MA Grodin and LH Glantz (eds), *Children as Research Subjects: Science, Ethics & Law* (OUP, Oxford 1994) 81–102.

¹³ There are other models besides 'best interests' and the 'obligation' thesis which might be used to justify NBI. These include the 'parental discretion' and the 'not against the best interests of the child' arguments. An examination of these is beyond the scope of this article. An example of the former is Ross' 'constrained parental autonomy' model: see LF Ross, *Children, Families and Healthcare Decision-Making* (Clarendon Press, Oxford 1998), and a critique by Michael Freeman, 'Whose Life is it Anyway?' (2001) 9 Med L R 259. For a review of the 'not against the best interests of the child' standard see Elliston (n 12).

legitimise them. With regard to the 'obligation model', this paper finds that it fails as a justificatory paradigm because it is based upon a confusion between the notion of 'being under an obligation to do something' and that of 'being obliged to do something'.¹⁴ Instead the 'obligation model' is similar to the 'best interests' concept in that it is a device employed to put a justificatory gloss upon a consequentialist decision-making process. Removing the 'legitimising' gloss might allow for a more transparent debate about parental rights and the relationship between such rights and an individual child's right to bodily integrity.

II. JUSTIFYING NON-BENEFICENT HEALTHCARE INTERVENTIONS

Children are different to adults. The Anglo-American doctrinal position emphasises the sovereignty of adult autonomy: any trespass on the integrity of a competent person can only be carried out with their explicit and uncoerced consent.¹⁵ Rational adults can decide whether a proposed investigation, treatment, or research protocol is likely to be desirable or undesirable for themselves, as they subjectively and holistically perceive their lives.¹⁶ However, this possibility is not open to incompetent children. And, as Buchanan and Brock observed, legal and moral philosophers have not over-extended themselves in elucidating mechanisms that guide decision-making on behalf of incompetent individuals in general, on what (and when) paternalistic interventions are allowable in the medical lives of such persons.¹⁷ One suggestion, proffered by Mill, was that we could only allow for interference with the liberty of those persons who are not competent to decide for themselves in order to advance their welfare or prevent self-harm.¹⁸ If this view is applied to young children, then C could not be a bone-marrow donor,

¹⁴ HLA Hart, *The Concept of Law* (Clarendon Press, Oxford 1961) 80.

¹⁵ This principle was classically outlined by J Cardozo in *Schloendorff v Society of New York Hospital* (1914) 211 NY 125: 'Every human being of adult years and sound mind has a right to determine what shall be done with his own body: and a surgeon who performs an operation without his consent commits an assault'. See also *Sidaway v Board of Governors of the Bethlem Royal Hospital* [1985] AC 871, 882: 'A doctor who operates without the consent of his patient is, save in cases of emergency or mental disability, guilty of the civil wrong of trespass to the person: he is also guilty of the criminal offence of assault'.

¹⁶ *Re T (Adult: Refusal of Treatment)* [1993] Fam 95, 113 (Lord Donaldson): '...the patient's right of choice exists whether the reasons for making that choice are rational, irrational, unknown or even non-existent'.

¹⁷ AE Buchanan and DW Brock, *Deciding for Others: The Ethics of Surrogate Decision Making* (CUP, Cambridge 1989) 3.

¹⁸ JS Mill, *On Liberty* (Alex Catalogue, Raleigh, NC 1859).

or participant in non-therapeutic research, unless it could be argued that these NBI somehow promoted her wellbeing.¹⁹

It is by invoking a welfare principle that the law and bioethics have frequently sought to justify living tissue or organ donation by incapacitated individuals.²⁰ In England, although the harvesting of bone marrow from healthy children has been described as ‘relatively routine’,²¹ and solid organ donation from minors has occurred,²² the courts have never specifically considered these procedures. In the only case to touch on this subject, *Re Y*, Connell J approved the donation of bone marrow from a mentally incapacitated adult who lived in residential care, to her sister who had a pre-leukaemic condition.²³ Drawing on the American case of *Curran v Bosze*,²⁴ the court ruled that for Y to donate would be in her best interest, although the process of reasoning used to arrive at this end has been described as ‘convoluted’,²⁵ the benefit to Y seeming ‘somewhat remote on the facts of the case’.²⁶ Subsequent Department of Health guidance suggested that bone marrow donation is a ‘more than “minimal burden”’ which ‘to be lawful... must be in the child’s best interests’.²⁷ The Human Tissue Authority (HTA) code of practice for England and Wales indicates that parents can consent on behalf of their incompetent children

...if the donation is assessed as being in the child’s overall best interests, taking into account not only the medical but also

¹⁹ Some research trials may compare standard treatments with innovative or new therapies. In such instances, there is the possibility of direct benefit. This paper is not concerned with these cases.

²⁰ J Herring, ‘Giving, Selling and Sharing Bodies’ in A Bainham, S Day Sclater and M Richards (eds), *Body Lore and Laws* (Hart Publishing, Oxford 2002) 43–62; Elliston (n 12) 243–71.

²¹ Human Fertilisation and Embryology Authority, *Preimplantation Tissue Typing* (London 2004) para 26.

²² NJ Webb and P-M Fortune, ‘Should Children Ever Be Living Kidney Donors?’ (2006) 10 *Pediatr Transplant* 851.

²³ *Re Y (Mental Patient: Bone Marrow Donation)* [1996] 2 FLR 787.

²⁴ (1990) 566 NE 2d 1319.

²⁵ SE Mumford, ‘Donation without Consent? Legal Developments in Bone Marrow Transplantation’ (1998) 101 *British Journal of Haematology* 599. The putative benefits accruing to Y were largely psychological in nature. According to Connell J, if Y’s sister died then Y’s mother would be less available to visit her because (a) she would be emotionally distraught, and (b) she would be occupied in minding Y’s niece. On the other hand, should Y donate and her sister survive, then this would enhance the relationship between Y and her mother.

²⁶ *Brazier and Cave* (n 4) 455.

²⁷ Department of Health, *Seeking Consent: Working with Young People* (TSO, London 2001) 25.

emotional, psychological and social aspects of the donation, as well as the risks. The consent of only one person with parental responsibility is necessary.²⁸

Parental authorisation for the transfer of bone marrow from one sibling to another has thus far proceeded without judicial oversight, although since 2006 the HTA must approve all donations made by children who are not competent to give consent.²⁹ However, as the HTA has never turned down a proposed child donor³⁰ it would seem that, once the donation has medical legitimacy,³¹ the decision for one sibling to donate to another is one that generally falls within the purview of parental rights. These rights are more limited when it comes to non-regenerative tissues. In *Re Y*, Connell J did not believe that his judgment could 'act as a useful precedent in cases where the surgery involved is more intrusive',³² such as live solid, or non-regenerative, organ donation. The British Transplant Society suggests that minors should rarely be considered live kidney donors,³³ a view supported by the British Medical Association,³⁴ and internationally by the Amsterdam Forum.³⁵ Guidance on the Human Tissue Act 2004 indicates that children can be considered living organ donors in rare circumstances,

²⁸ HTA, *Code of Practice 6: Donation of Allogeneic Bone Marrow and Peripheral Blood Stem Cells for Transplantation* (TSO, London 2009) s 77–81.

²⁹ Unlike children, in cases where the potential donor is an adult lacking capacity to consent, the case must be referred to a court for a declaration that the proposed intervention is lawful. Only then can it be referred to the HTA for a decision on the donation. *Ibid.*, s 93.

³⁰ Since the HTA began regulating in September 2006, there have been no cases of proposed adult donors lacking the capacity to consent. Between September 2006 and the end of March 2010, 258 incompetent children have been proposed as donors of either bone marrow or peripheral blood stem cells. Thus far, all paediatric donors have been approved. In a number of cases, however, the HTA has requested that further support be given to the child (e.g. further play therapy) before approving the donation. Information provided by HTA on 12 August 2010.

³¹ That the bone marrow donation is a medically viable treatment for the disease process in question has some possibility of success and the bone marrow of the proposed donor has the inherent qualities required for a successful donation.

³² *Re Y* at 794. However, see obiter remarks by Lord Donaldson in *Re W* [1992] 4 All ER 627 at 635 which suggest that a parent could consent to organ donation by a minor.

³³ British Transplantation Society, *United Kingdom Guidelines for Living Donor Kidney Transplants* (2nd ed, 2005) s 3.5 <<http://www.bts.org.uk>> accessed 26 January 2010.

³⁴ British Medical Association, *Consent, Rights and Choices in Health Care for Children and Young People* (BMJ Books, London 2001) 165.

³⁵ The Ethics Committee of the Transplantation Society, 'The Consensus Statement of the Amsterdam Forum on the Care of the Live Kidney Donor' (2004) 78 *Transplantation* 491.

subject to parental consent, court approval, and the agreement of an HTA panel.³⁶

Recently, in the USA, the American Academy of Pediatrics reaffirmed that children could act as live donors of non-regenerative organs, albeit within specific and limited circumstances.³⁷ Courts in the USA have dealt with a number of living-related kidney donation cases involving minors as donors, and have approved them on the basis that it was in the donor's best interest to donate.³⁸ As any tissue or organ donation, *prima facie*, cannot serve the donor's healthcare interest, then the courts must believe there to be other non-medical benefits accruing to the child,³⁹ and that these are sufficient in magnitude to offset any risks.⁴⁰ The factors that purportedly tip the risk/benefit scales in a positive direction tend to be psychological or emotional in nature, and are largely related to enhanced self-esteem or status in the family,⁴¹ or the security or companionship afforded by the continuing existence of the surviving recipient.⁴² According to Price, the courts use of putative psychological benefits to justify organ donation by minors has sometimes been seen as being reliant upon 'incredible feats of mental gymnastics'.⁴³

The best interests standard has also been applied to enrolling children in research projects.⁴⁴ However, as set out in the Report of the International Bioethics Committee of UNESCO, this is not necessarily a valid yardstick in the context of children entered into RWTI:

Research activities involving children are carried out to learn more about the nature of paediatric development, disease and potential treatments. Though one might hope that it will in some cases be beneficial to the research participant, the activity cannot be said to be specifically designed for this purpose

³⁶ HTA, *Code of Practice 2: Donation of Solid Organs for Transplantation* (TSO, London 2009) ss 47–8.

³⁷ LF Ross, JR Thistlethwaite, Jr and the Committee on Bioethics, 'Minors as Living Solid-Organ Donors' (2008) 122 *Pediatrics* 454.

³⁸ *Strunk v Strunk* (1969) 445 SW 2d 145, Ky; *Hart v Brown* (1972) 29 Conn. Supp. 368, 289 A.2d 386, Super. Ct.; *Little v Little* (1979) 576 SW (2d) 493, Tex.

³⁹ In the context of incompetent adults see *Re MB* [1997] BMLR 175, 188 (Butler Sloss LJ): 'Best interests are not limited to medical best interests'.

⁴⁰ A Spital, 'Donor Benefit Is the Key to Justified Living Organ Donation' (2004) 13 *Camb Q Healthc Ethic* 105.

⁴¹ *Little v Little*, 499 (Cadena CJ).

⁴² *Strunk v Strunk*, 149; *Re Y*, 793.

⁴³ DP Price, *Legal and Ethical Aspects of Organ Transplantation* (CUP, Cambridge 2000) 351.

⁴⁴ P Allmark and others, 'Is It in a Neonate's Best Interest to Enter a Randomised Controlled Trial?' (2001) 27 *J Med Ethics* 110. For an overview, see Elliston (n 12) 191–242.

because of the nature of the research question. Here it differs from clinical treatment *per se*. As a result, parents cannot consent their children into research simply on the basis of the assumption that they are the ones who have the best interests of their child at heart, for the research procedures are not aimed specifically to ensure the best interests of their child. We do not know at this stage whether they are likely to be beneficial or not – indeed that is the research question being asked. Those who stand to benefit are future children for whom the results of the research will be valuable in informing their treatment.⁴⁵

It is not the purpose of this paper to critique the best interests standard. This has been done effectively by Elliston in her book *The Best Interests of the Child in Healthcare*.⁴⁶ Elliston challenges the value of the standard in the context of medical interventions and, finding it wanting in a number of regards, proposes that it is replaced with an assessment of the reasonableness of parental decisions and the potential harms that may accrue from such decisions. I am in broad agreement with her thesis. With regard to the specific concerns of this paper, the lack of utility of the best interests principle in the context of paediatric research has been articulated by the International Bioethics Committee,⁴⁷ and its inherent vagueness, speculative nature, and inapplicability to young children expressed by a number of advocates of live paediatric organ donation.⁴⁸

Instead, this paper is concerned with an alternative justification for the practice of some NBI. This rationalisation contends that, as members of a family, children have ‘obligations that are implicit in relationships’,⁴⁹ and that in the correct circumstances these inherent familial obligations may justify the risk of tissue or organ donation by a child. In addition, it has been suggested that the obligations of children extend beyond immediate family, and into wider society. Some commentators have contended that these broader

⁴⁵ Report of the International Bioethics Committee of UNESCO. *On Consent* (UNESCO, Paris 2008) III.2.2.87.

⁴⁶ Above, n 12.

⁴⁷ Above, n 46.

⁴⁸ LF Ross, ‘Moral Grounding for the Participation of Children as Organ Donors’ (1993) 21 J Law Med Ethics 251; RA Crouch and C Elliott, ‘Moral Agency and the Family: The Case of Living Related Organ Transplantation’ (2000) 8 Camb Q Healthc Ethic 275; D Steinberg, ‘Kidney Transplants from Young Children and the Mentally Retarded’ (2004) 25 Theor Med Bioeth 229; Dwyer and Vig (n 13); Jansen (n 13).

⁴⁹ Dwyer and Vig (n 13).

obligations serve as a basis for the enrolment of children into research trials.⁵⁰

III. THE NATURE OF OBLIGATIONS

Before evaluating these claims, it would first seem reasonable to examine what the term 'obligation' might mean. The Oxford English Dictionary defines an obligation as the 'action of constraining oneself by oath, promise, or contract to a particular course of action; a mutually binding agreement'. With regard to the law, it is 'a binding agreement committing a person to a payment or other action'.⁵¹ Brandt suggests that the word 'obligation' paradigmatically points to talk about promises or agreements, observing that to 'say "I have an obligation" will, unless the context points explicitly in another direction, imply or suggest that I have either promised or accepted a favour'.⁵² This is unsurprising given the historical derivation of the family members of 'oblige' from *ob* and *ligare*, meaning 'to bind'.⁵³

Hart argued that any statements about obligations presuppose the existence of social rules. The purpose of these rules is to set the standards of behaviour expected in order to meet a particular obligation, and also to articulate the potential consequences of failing to meet it.⁵⁴ Obligation imposing rules have several features that distinguish them from other social rules. They are 'necessary to the maintenance of social life'; are supported by serious social pressure (such as the application of physical or psychological sanctions) in the event of deviations from the rule; and as they impose behaviour contrary to what we may actually wish to do, characteristically involve 'sacrifice or renunciation'.⁵⁵ Moral and legal rules of obligation and duty have significant similarities, and their main differences lie in the specific nature of legal rules, and the form of sanction applied in the case of non-conformity. In the case of moral rules, disapproval is expressed in an attempt to elicit guilt, shame, or remorse, and possibly a change in behaviour, while in the legal case specific penalties may be imposed.⁵⁶ However, in the case of moral obligations, sanctions will generally only be applied in the event of a volitional violation of a rule; this

⁵⁰ Brock (n 13).

⁵¹ J Simpson and E Weiner, *Oxford English Dictionary* (2nd edn Clarendon Press, Oxford 1989).

⁵² RB Brandt, 'The Concepts of Obligation and Duty' (1964) 73 *Mind* 374, 386.

⁵³ *Ibid.*

⁵⁴ Hart (n 15) 82.

⁵⁵ *Ibid.*, 83–5.

⁵⁶ *Ibid.*, 165–76.

may not always be true of breaches of legal rules.⁵⁷ Hart contended that the facility to fulfil one's moral and legal obligations is 'within the capacity of any normal adult',⁵⁸ but made no comment on the ability of children to discharge obligations. This raises the question of whether children are the kind of entities that can bear obligations.

IV. THE LEGAL OBLIGATIONS OF CHILDREN

Despite Hart's allusion to the notion of capacity, children do appear to be subject to a number of legal obligations. Once over the age of 10 years, they are under an obligation to obey the criminal law at the risk of the imposition of sanctions should they infringe it.⁵⁹ Children under 10, although apparently *incapax*, may still be subject to safety or curfew orders should they engage in anti-social behaviour.⁶⁰ Even younger children are under an obligation to obey school rules or face the possibility of an exclusion order.⁶¹ Children also have obligations under the law of contract. Although the Family Law Reform Act 1969 set the age of capacity for entering into contracts at 18 years, the Minors' Contracts Act 1987 retains the provision that contracts for 'necessaries'⁶² and contracts of apprenticeship, education, and service are enforceable regardless of age. Other contracts may be made by minors, but are voidable should they choose to repudiate them. However, it has been questioned whether 'a very young child has the mental capacity to enter a contract, even where the contract is of a type which would normally be held valid'.⁶³ In *R v Oldham MBC Ex p. G*, Scott LJ noted

⁵⁷ Ibid, 173.

⁵⁸ Ibid, 167.

⁵⁹ Children and Young Persons Act 1963 s 16.

⁶⁰ The Crime and Disorder Act 1998, ss 11–5.

⁶¹ Office for Standards in Education, *The exclusion from school of children aged four to seven* (2009) <<http://www.ofsted.gov.uk/Ofsted-home/Publications-and-research/Browse-all-by/Documents-by-type/Thematic-reports/The-exclusion-from-school-of-children-aged-four-to-seven>> accessed 30 December 2009.

⁶² According to *Chitty on Contracts* necessities are: 'Such things as relate immediately to the person of the minor, as his necessary food, drink, clothing, lodging and medicine, are clearly necessities for which he is liable. But the term is not confined to such matters only as are positively essential to the minor's personal subsistence or support; it is also employed to denote articles purchased for real use, so long as they are not merely ornamental, or are used as matters of comfort or convenience only, and it is a relative term to be construed with reference to the minor's age and station in life. The burden of showing that the goods supplied are necessities is always on the supplier'. H Beale (ed), *Chitty on Contracts* (30th edn Sweet & Maxwell, London 2008) Vol 1, Pt 3, Chap 8, s 2, 8-008.

⁶³ Ibid, 8-003.

If a minor is to enter into a contract with the limited efficacy that the law allows, the minor must at least be old enough to understand the nature of the transaction and, if the transaction involves obligations on the minor of a continuing nature, the nature of those obligations.⁶⁴

To some extent, this reflects the observations of Lord Kenyon CJ in *Jennings v Rundall*:

The law of England has very wisely protected infants against their liability in cases of contract... where an infant has made an improvident contract with a person who has been wicked enough to contract with him, such person cannot resort to a Court of Law to enforce such contract.⁶⁵

In theory, children 'of all ages are subject to the same tort obligations as adults',⁶⁶ there being no set minimum age below which tortious liability does not exist. The liability of an individual is simply dependent upon whether the requirements of the tort in question have been fulfilled, but the capacity of the defendant may be pertinent in establishing whether those conditions are, in fact, satisfied.⁶⁷ As indicated in *Jennings*, a child cannot be sued in tort as a means of enforcing a contract which would be otherwise voidable because of the age of the minor.⁶⁸ In addition, the standard of behaviour expected of a minor is not that of an adult, but rather that of a prudent and reasonable child of similar age in the particular situation. *Mullin v Richards*⁶⁹ concerned two fifteen-year-old schoolgirls who were fencing with plastic rulers, an activity which resulted in one sustaining a permanent eye injury. The Court of Appeal, drawing on the Australian case of *McHale v Watson*,⁷⁰ declined to attribute negligence. In *McHale*, Owen J held that 'the standard by which... conduct is to be measured is... that reasonably to be expected of a child of the same age, intelligence and experience'.⁷¹

Thus, although children do bear obligations under law, the age and capacity of the child appears relevant to her liability. In particular, the legal obligations of young children would seem to be especially limited. Despite this, those that propose the obligation model argue

⁶⁴ *R v Oldham MBC Ex p. G* [1992] 24 HLR 726, 742.

⁶⁵ [1799] 101 ER 1419, 1421–2.

⁶⁶ R Bagshaw, 'Children Through Tort' in J Fionda (ed), *Legal Concepts of Childhood* (Hart Publishing, Oxford 2001) 127.

⁶⁷ K Oliphant, 'Children as Tortfeasors under the Law of England and Wales' in M Martin-Casals (ed), *Children in Tort Law. Part I: Children as Tortfeasors* (Springer, Vienna 2006) 153.

⁶⁸ At 1420.

⁶⁹ [1998] 1 WLR 1304.

⁷⁰ [1966] 115 CLR 199.

⁷¹ *Ibid*, 234.

that such individuals do possess significant and potentially burdensome moral obligations with regard to healthcare.⁷²

V. MORAL OBLIGATIONS, CHILDREN, AND HEALTHCARE

A. *Moral Obligations to Family*

Rather than a conglomeration of atomistic individuals who merely occupy similar earthly orbits, Crouch and Elliot suggest that it might be more fruitful to regard the family as a moral unit.⁷³ This is best construed as a collective entity without internal moral boundaries. In this morally diffused union, the interests of one member become a shared interest of all through the promotion of an 'other-' rather than a 'self-regarding' ethic. In such an environment, it becomes permissible and even obligatory on occasion, for individuals to sacrifice their personal interest for the good of another member.⁷⁴ Dwyer and Vig contend that this is reasonable when the sacrificial risk taken by one member is commensurate with both the strength of relationship, and the benefit to be accrued by the recipient.⁷⁵ When extended to the decision-making process about whether a child should be a donor or not, they also suggest that the determination should take account of moral interests. This would not be the simple addition of 'moral feelings' into the best interests' calculus, but rather 'the injunction to do the right thing, all things considered'.⁷⁶ They continue:

Donating tissue to a sibling is not what we normally think of as altruism ... There are obligations to those to whom we are related in complex ways: our parents, children, siblings, friends, and neighbors. We can simply think of obligations as important aspects of various relationships.⁷⁷

Assuming that potentially substantial benefits will accrue to the recipient, and allowing (for the moment) that such obligations exist, there is a moral expectation that family members undertake some risk in donating. For Dwyer and Vig, this allows for 'parents to undergo

⁷² It is arguable that incompetent adults are subject to the same obligations. In England, the Human Tissue Act 2004 (see guidance n 29, s 93) and the Mental Capacity Act 2005 (ss 30–3) may provide additional safeguards in the contexts of tissue donation and medical research.

⁷³ *Crouch and Elliot* (n 49).

⁷⁴ T John and others, 'Children's Consent and Paediatric Research: Is It Appropriate for Healthy Children to be the Decision-makers in Clinical Research?' (2008) 93 *Arch Dis Child* 379, 382.

⁷⁵ Dwyer and Vig (n 13).

⁷⁶ *Ibid.*, 9.

⁷⁷ *Ibid.*

significant risks, siblings to undergo some risks, and strangers (at least occasionally) to undergo slight risks'.⁷⁸ While they admit that it may appear strange to speak of young children having obligations or duties, this is only so if we believe that 'all duties must be grounded in voluntary action or consent', rather than there being a natural duty to assist others.⁷⁹ Pentz et al concur that obligations to family serve as 'the moral justification for allowing young children to be donors'⁸⁰ but do not analyse the basis of this obligation.

There are a number of possible objections to 'intra-familial obligation' arguments. First, the question arises as to whether individual family members actually do have obligations towards each other. English has claimed that adult children do not owe their parents anything; there are no vertical intergenerational obligations that flow from child to parent, rather the obligations flow the other way.⁸¹ Parents choose to have children and thus take on the duties associated with parenthood.⁸² Children do not choose to be born, do not contract with their parents, and so incur no debt towards them. While this might seem an impoverished view of parent-child relations, it does not argue that there are not many things that children should want to do for their parents, but rather that these acts are based upon desire borne out of mutual respect rather than the presence of filial obligation. As Callahan has pointed out, the real world picture of family life may differ significantly from the ideal version:

Just as not all children are lovable, neither do all parents give the welfare of their children their serious attention and highest priority. Many children do not find their parents lovable and feel no special sense of duty toward them. Many parents are not happy with the way their children turn out, or with the kind of lives they live, and do not seek to remain intertwined with them.⁸³

⁷⁸ Ibid, 11.

⁷⁹ Ibid, 10.

⁸⁰ RD Pentz and others, 'Designing an Ethical Policy for Bone Marrow Donation by Minors and Others Lacking Capacity' (2004) 13 *Camb Q Healthc Ethic* 149, 150.

⁸¹ J English, 'What Do Grown Children Owe Their Parents?' in O O'Neill and W Ruddick (eds), *Having Children* (OUP, New York 1979) 351–6.

⁸² In theory this would mean that a parent would be under an obligation to donate an organ to an offspring who needed it. But this is not an enforceable duty. As a court in Washington State noted: 'I would not have the right to require the woman to donate an organ to one of her other children, if that child were dying'. Quoted in VEB Kolder, J Gallagher and MT Parsons, 'Court-Ordered Obstetrical Interventions' (1987) 316 *NEJM* 1192, 1194.

⁸³ D Callahan, 'What Do Children Owe Elderly Parents?' (1985) 15 *Hastings Cent Rep* 32.

If children do not have obligations towards their parents, then there seems no reason to hold that they have obligations to siblings, other family members, or to the family unit as a whole. There may be things that children are compelled to do on behalf of their family, and others that they do because they wish to, but these actions confer no legitimacy on the obligation model.

Secondly, this model fails to take account of the imbalance of power that naturally exists in the family unit, particularly when children are young. Parents are the assessors of interests, and when there are competing interests between siblings, or between parents and children, the authority to choose which interest should predominate resides with them. Thus, while the 'intra-familial obligation' paradigm might seem to suggest that each individual's interests are taken account of, in reality the entirely reasonable preoccupation parents have with a terribly ill leukaemic child might well result in them attributing less weight to the potentially conflicting interests of a donor child. It is understandable if parental loyalties are divided between the sick child and the potential donor, and equally comprehensible if that division is not equal. If we take the case of the previously mentioned C (aged 2) and her sick sibling (S), it is likely that C's parents will consent to the medical removal of some of her bone marrow and its transfer to her sister. To them, the burden placed on one child may well seem acceptable in light of the possible benefits accruing to the other and, assuming the procedure is medically indicated, they can authorise the procedure because they are invested with the power to do so, albeit subject to HTA approval.

It is also possible to argue that S's parents may perceive themselves as having a responsibility to provide her with appropriate medical treatment, and might construe as neglectful any failure to do so when a matching donor (C) is available. The point is that most parents love and cherish their children and will do whatever it takes to enable their offspring to fight illness and survive. However, unrestricted parental power in this regard could pose a substantial threat to the rights of some family members (particularly young ones), rights which might be significantly infringed in the name of the parental vision of 'doing the right thing'.⁸⁴ The issue then becomes one of the permissible extent to which the bodily integrity of a child might be impinged upon for the benefit of another family member, and in the case of non-regenerative organs this becomes a matter for the courts to consider.⁸⁵

While the obligation thesis seems to present intra-familial obligations as something a child acquires passively on being born, Harris and Holm

⁸⁴ Jansen (n 13) 135.

⁸⁵ HTA (n 37).

take an alternative view. They also hold that we have a fundamental moral obligation to help other people in need, but rather than assuming a 'non-voluntary' grounding for the attribution of obligations to children, they base their theory firmly in agency: '(I)f children are moral agents, and most of them, except very young infants are, then they have both obligations and rights; and it will be difficult to find any obligations that are more basic than the obligation to help others in need'.⁸⁶ They continue by asserting that parents must take the moral agency of their children seriously, and thus must make decisions on their offspring's behalf that are commensurate with that child discharging her moral obligations. Although Harris and Holm were concerned specifically with the obligation of children to participate in scientific research, it seems reasonable that their argument might be extended to sibling tissue donation. Thus (on this broadened view of Harris and Holm's argument), if C's sister S has leukaemia and needs a bone marrow donation, and C is the best HLA match for S, then C's parents would seem to have no great decision to make. S is in need and C has the capability to help her. Hence, C has a moral obligation to help S and C's parents ought to consent to the donation, regardless of the actual or possible preferences of C.⁸⁷

This, however, is not as straightforward as it might seem. On the one hand, children exhibit moral behaviour towards other beings from an early age,⁸⁸ and Alderson has demonstrated that even young children are capable of making appropriate healthcare decisions, and of considering the moral dimensions of these choices.⁸⁹ On the other hand, societal and legal recognition of the scope of children's agency is severely limited. Whatever the possibility of a Gillick-competent minor's agency being acknowledged,⁹⁰ it is unlikely that a two-

⁸⁶ J Harris and S Holm, 'Should we presume moral turpitude in our children? – Small children and consent to medical research' (2003) 24 *Theor Med Bioeth* 121, 125. Infants who are not yet moral agents are described as moral agents *in spe* (in-waiting). The authors do not say what obligations such infants might have to bear.

⁸⁷ If C has an obligation to donate to S then her parents' views would appear to be irrelevant. If, for example, C's parents actually love her more than S and refuse to consent to the inter-sibling donation in order to avoid C becoming upset, should the parents' views carry any weight? If C truly has an obligation then should this not be enforced regardless of parental wishes?

⁸⁸ CA Brownell and CB Kopp (eds), *Socioemotional Development in the Toddler Years: Transitions and Transformations* (Guilford Press, New York 2007).

⁸⁹ P Alderson and J Montgomery, *Health Care Choices: Making Decisions with Children* (IPPR, London 1996).

⁹⁰ Lord Scarman refers to a 'child's right to make his own decisions when he reaches a sufficient understanding and intelligence to be capable of making up his own mind': *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] AC 112, [1985] 3 All ER 402 (HL) 420.

three-, or four-year-old child will be ascribed agency if, in this instance, agency means having the decision-making capacity to choose whether or not one will fulfil one's obligations. May has argued that, as a child is not a moral agent, he could not be a bearer of moral obligations, even presumptive ones.⁹¹ In general terms, agency entails making life choices and carrying out an action plan based upon the choices made. It seems a rather peculiar conception of agency where all decisions are taken by another rather than the actor herself, as in the instance in C and her parents above. In the case of bone marrow donation, C's parents are making a decision which she has to abide by. Thus, while C is undoubtedly a moral being—and possibly an agent in other aspects of her life—she is not a moral agent in this scenario. It might be stated that C's parents are teaching her to behave in a prescribed moral manner, but while such educative processes may result in a child developing a particular moral outlook, this does not equate with actual agency in relation to this particular act.

B. Moral Obligations to Society

In the celebrated Ramsey–McCormick debate on whether children should ever be enrolled in RWTI, Ramsey argued in accordance with the Nuremberg Code: that non-therapeutic experimentation on children or the incompetent was illegitimate because of the absence and impossibility of their voluntary consent.⁹² McCormick's contrary position was that parental consent to RWTI was 'morally valid precisely insofar as it is a reasonable presumption of the child's wishes'.⁹³ This presumption was premised on the belief that the child's wishes were inextricably linked to what the child *ought* to do. Thus, with regard to medical treatment the child, if competent, would choose the treatment 'because he ought to choose the good of his life'. McCormick posits that there are other goods 'definitive of his growth and flourishing', besides physical wellbeing, that a child ought to want:

To pursue the good that is human life means not only to choose and support this value in one's own case, but also in the case of others when the opportunity arises. . . . It can be good for one to pursue and support this good in others If this is true of all of us up to a point and within limits, it is no less true of the infant.⁹⁴

⁹¹ WE May, 'Experimenting on Human Subjects' (1974) 41 *Linacre Q* 238.

⁹² P Ramsey, 'The Enforcement of Morals: Nontherapeutic Research on Children' (1976) 6 *Hastings Cent Rep* 21.

⁹³ R McCormick, 'Proxy Consent in the Experimental Situation' (1974) 18 *Perspectives in Biology and Medicine* 2, 12.

⁹⁴ *Ibid.*

Thus, parents could legitimately consent to their child's participation in RWTI, because this is what the child ought to want to do. McCormick denied Ramsey's claim that his language of ought was 'implying or imputing moral obligation and moral agency' to an infant,⁹⁵ but this refutation appears undermined by his contention that his concerns lie with minimal social duties: 'our willingness to experiment on children (and fetuses) when risk, discomfort, and pain are minimal or nonexistent points to a duty that we all have to be willing to bear our fair share that all may prosper'.⁹⁶ Bartholome, although disagreeing with Ramsey, had little doubt that McCormick's idea of duties implied obligation.⁹⁷

In the context of medical research, it has been argued that not only does a child apparently have obligations to existing children, but they also have duties to past and future generations.⁹⁸ The basis for these obligations is that children benefit from medical progress which has only been possible through the sacrifices of previous generations of children; the moral obligation is thus grounded in a duty to fairness.⁹⁹ Although Brock acknowledges that children do not 'freely participate' in choosing which medical care they undergo, he suggests we can presume upon their hypothetical consent to participate in research studies. If children were rational self-interested beings, then they would realise that 'the expected benefits of such research over time exceed ... its burdens' and therefore would agree to participate in and accept the benefits of research.¹⁰⁰ Ignoring for the moment Litton's argument that it is impossible to wrong either children of the past or the future in this context,¹⁰¹ Brock's contention remains that, as each child hypothetically consents to the benefits accruing from research, then they have an obligation to other generations of children to participate in research in order to distribute fairly any burdens and benefits.¹⁰²

⁹⁵ RA McCormick, 'Experimentation in Children: Sharing in Sociality' (1976) 6 *Hastings Cent Rep* 41, 42.

⁹⁶ RA McCormick, 'Experimental Subjects: Who Should They Be?' (1976) 235 *JAMA* 2197.

⁹⁷ WG Bartholome, 'Parents, Children, and the Moral Benefits of Research' (1976) 6 *Hastings Cent Rep* 44.

⁹⁸ Brock (n 13). It is uncertain whether Brock, or any other commentator, holds that children with a specific illness have a particular duty towards other children who suffer from the same disease process, or whether the obligation is to society in general.

⁹⁹ For opposing views on whether or not this duty exists for adults see: J Harris, 'Scientific Research Is a Moral Duty' (2005) 31 *J Med Ethics* 242; I Brassington, 'John Harris' Argument for a Duty to Research' (2007) 21 *Bioethics* 160.

¹⁰⁰ Brock (n 13) 92.

¹⁰¹ P Litton, 'Non-Beneficial Pediatric Research and the Best Interests Standard: A Legal and Ethical Reconciliation' (2008) 8 *Yale J Health Policy Law Ethics* 359, 406.

¹⁰² Brock (n 13) 92.

In sum, the position outlined by Ramsey states that as medical science has treated vulnerable individuals badly in the past, such persons require protection. Therefore, non-therapeutic research should not be carried out upon anybody who is not capable of giving explicit consent. The contrary thesis argues that (a) children ought to contribute to scientific research because it is a social good; or (b) because they do, or will, derive healthcare benefit from prior research, they have a duty born out of justice to contribute to future research. As a consequence, it can be presumed that children, if they were capable, would consent to being a research subject, because that is what they ought to do. These latter claims, however, appear subject to a number of problems.

First, there appears an underlying assumption that medical research necessarily will result in good things and thus children would choose to participate. While some research undoubtedly has brought about life-extending or enhancing therapies, some has significantly harmed research participants.¹⁰³ Sometimes the risks are not apparent until after the event,¹⁰⁴ and occasionally researchers act without beneficent intent.¹⁰⁵ It has also been claimed that many clinical trials are not completed or published,¹⁰⁶ and that the results of many research publications are, in fact, false.¹⁰⁷ While these latter issues result in a less tangible form of harm to research participants,¹⁰⁸ it seems unlikely that competent individuals would willingly consent to be part of a research project that would never yield meaningful results, or might be published in a misleading fashion. All of this might lead the rational actor to question whether he should participate in a clinical trial, and sometimes a substantial number of competent adults do refuse to become research subjects.¹⁰⁹ Given this, there seems no good reason

¹⁰³ RS Saver, 'Medical Research and Intangible Harm' (2006) 74 U Cin Law Rev 941.

¹⁰⁴ News Roundup, 'Healthy Woman Dies in Research Experiment' (2001) 322 Br Med J 1565.

¹⁰⁵ In 2007, the Office of Research Integrity assessed 222 complaints of professional misconduct with regard to research. See Office of Research Integrity, *Annual Report 2007* (DHHS, Washington, DC 2007).

¹⁰⁶ One study identified that over half of all FDA approved trials were not published within 5 years: K Lee, P Bacchetti and I Sim, 'Publication of Clinical Trials Supporting Successful New Drug Applications: A Literature Analysis' (2008) 5 PLoS Med e191. See also MK Krzyzanowska, M Pintilie and IF Tannock, 'Factors Associated with Failure to Publish Large Randomized Trials Presented at an Oncology Meeting' (2003) 290 JAMA 495.

¹⁰⁷ JPA Ioannidis, 'Why Most Published Research Findings Are False' (2005) 2 PLoS Med e124.

¹⁰⁸ RS Saver (n 104).

¹⁰⁹ See for example: NS Abraham, JM Young and MJ Solomon, 'A Systematic Review of Reasons for Nonentry of Eligible Patients into Surgical Randomized Controlled Trials' (2006) 139 Surgery 469.

to hold that it can be presumed that children would automatically consent if they were competent.

Secondly, even if one lived in a society where there existed a legal obligation to assist others in need, there are no grounds to presume that such an obligation would require a person to undertake risks, both concrete and intangible, by participating in medical research. To date, no duty-to-rescue laws have been enacted in England, while only three US states (Minnesota, Rhode Island, and Vermont) impose any liability for 'bad Samaritanism'.¹¹⁰ Thus, any such obligation remains largely a moral rather than a legal matter.¹¹¹ Barth observed that the biblical Good Samaritan cared for the beaten and robbed traveler 'but he did not put himself in any peril by doing so. Perhaps this is about as much as can be reasonably asked of the ordinary mortal man'.¹¹² Being a research subject naturally exposes a person to risk, although the level of 'peril' may often be small. While competent adults have a choice about whether or not to place themselves in jeopardy by participating in medical research, young children do not. Conventional legal and ethical wisdom suggest that the difference between adults and children lies in the inherent vulnerability of the latter, and that, in general, the response to this defencelessness should be protective. However, if children are expected to be research Samaritans, a risk which competent adults can choose to avoid, then this suggests that the primary response to children's vulnerability is not always protective.

Thirdly, young children do not voluntarily derive the benefits of prior medical research. They do not consent to the medical care they receive, nor do they choose what kind of therapy it is. It has been argued those who benefit from medical research without contributing to future research are acting as 'free-riders', and that such behaviour is contrary to the principle of fairness.¹¹³ Harris and Holm contend that children should 'share the obligation to participate in medical research'.¹¹⁴ Can children who do not participate in research be free-riders? Whatever the merits of the free-rider argument,¹¹⁵ it would seem that in order to be a free-rider one would have to choose to avail of medical care and opt to contribute nothing (or an insufficient amount) in

¹¹⁰ K Levy, 'Killing, Letting Die, and the Case for Mildly Punishing Bad Samaritanism' (2010) 44 Georgia Law Rev 607.

¹¹¹ S Harnay and A Marciano, 'Should I help My Neighbor? Self-interest, Altruism and Economic Analyses of Rescue Laws' (2009) 28 Eur J Law Econ 103, 105.

¹¹² A Barth, 'The Vanishing Samaritan' in JM Ratcliffe (ed), *The Good Samaritan and the Law* (Anchor Books, New York 1966) 159.

¹¹³ Harris (n 100).

¹¹⁴ Harris and Holm (n 87) 125.

¹¹⁵ For an analysis see Brassington (n 100).

return. If, for example, one wished, but was unable for some reason, to contribute to research then it would seem unfair to be labelled a free-rider. Similarly, if one eschewed all standard western medical care for an illness, while at the same time refusing to participate in research, then one could hardly be a free-rider. Young children have little choice in either their medical care or research participation. If they were competent they might reject either, or both. It thus makes little sense to speak of their presumed or hypothetical consent in this regard. Rather Brock has fabricated a fiction of children's presumed consent in order to shoehorn them into a position where they are under a putative obligation to participate in research, to not be a free-rider. But since young children are without choice, then Brock's argument would appear to be without foundation.

Alternatively, Ackerman has proposed that 'the rights of individuals must be balanced against societal needs' and that a denial of 'the moral authority of parents and health professionals to involve children in activities that do not promote their own welfare' might be seen to be 'excessively individualistic'.¹¹⁶ In order to fulfil these societal needs, and in particular the needs of the gravely ill, everyone is under an obligation to concede their own interests in order to advance the interests of others. The obligations of children might include 'participation in research involving non-therapeutic procedures which might promote the welfare of other children who suffer from catastrophic diseases'.¹¹⁷ While Ackerman might rail against 'excessive' individualism, the hallmark of autonomy in liberal societies is the recognition of an individual's 'right to a life structured by his own values'.¹¹⁸ These values may, or may not, entail a commitment to medical research. Those with the capacity to exercise their autonomy may make health-care choices that are individualistic regardless of societal need, and to perform research on an unconsenting autonomous subject would constitute a breach of ethical principles and infringe the criminal law.¹¹⁹ It does not seem unreasonable that decisions concerning children's health-care issues would be made according to the same criterion. However Ackerman, by imposing obligations on children, is appealing for choices concerning them to be made according to a different, communal norm. It is arguable that the standard to which Ackerman is appealing is a double one.

¹¹⁶ Ackerman (n 13) 134.

¹¹⁷ Ibid, 135.

¹¹⁸ R Dworkin, *Life's Dominion: An Argument about Abortion, Euthanasia, and Individual Freedom* (Alfred A Knopf, New York 1993) cited by Lord Steyn in *Chester v Afshar* [2005] 1 AC 134 (HL) 144.

¹¹⁹ n 16.

VI. OBLIGING CHILDREN

Hart has argued that sometimes there is confusion between 'the assertion that someone was obliged to do something and the assertion that he had an obligation to do it'.¹²⁰ The statement 'he had an obligation' does not tell us anything about the fulfilment of the obligation; the presence of the obligation is independent of whether the relevant individual acted in accordance with the obligation or not.¹²¹ In contrast, according to Hart, 'the statement that someone was obliged to do something, normally carries the implication that he did' it.¹²² The essential difference between the two statements lies in the notion of coercion. Being obliged to do something occurs when the coerced individual is subjected to a real threat of serious harm if he does not comply with the demand issued to him. Hart's interest lay in the behaviour of the rational adult, and his notion of the coercive mechanism underlying 'being obliged' might not seem to be particularly germane to the present discussion. It might thus be useful to think in terms of compulsion rather than coercion. On Hart's reading, the difference between the notions of 'being under an obligation' and 'being obliged' hinges on the concept of voluntariness. Whether an adult fulfils any moral or legal obligations he is under, or not, is down to choice. If he chooses not to perform an act when under an obligation to do so, he faces reactive attitudes and possible sanction. If, on the other hand, an individual is obliged to perform an act, then he will be coerced or compelled to do so.

In order to illustrate this point, we might return to two-year-old C, who is about to be a bone marrow donor for her sister S. The reality is that C has no choice in this matter, and even if she objects to any part of the procedure at the time (and many two-year-old children might), she will be obliged to donate (unless her parents change her mind).¹²³ This is in contrast with the case of Robert McFall, a

¹²⁰ Hart (n 15) 80.

¹²¹ Ibid, 81.

¹²² Ibid.

¹²³ In general, the HTA's accredited assessor (AA) interviews the potential donor (at a level appropriate to their age and understanding) to assess whether the HTA requirements have been met. However, 'where the potential donor is a very young child and not able to comprehend information about the planned procedure, the AA's discussion should be held with the person/s consenting on the donor's behalf – in most cases, this is likely to be the person/s with parental responsibility'. (n 29) ss 55–6. No mention is made of the younger child who protests at hospitalisation or anaesthesia, most likely because oppositional behaviour is often reactive rather than the product of reflective choice. Even where children are older and capable of articulating reasoned choices, empirical data identify that many paediatric donors experience emotional distress. In part, this is because they 'believe that they did not have a choice about whether to serve as a marrow

thirty-nine-year-old asbestos worker who suffered from aplastic anaemia. His adult cousin, David Shimp, was a matching donor, but refused to donate his bone marrow. He stated that his immediate family responsibilities outweighed his obligation to assist his cousin. In summing up Flaherty Jr, J stated: ‘...one human being is under no legal compulsion to give aid or to take action to save another human being. ... [Yet,] in the view of the courts, the refusal of the defendant is morally indefensible’.¹²⁴

Regardless of sanctions, obligations involve choice and require agency to exercise that preference. One can refuse to fulfil one’s obligations, moral or legal, and face the opprobrium of the court or society, or punishment. Being obliged to do something is premised on the notion that that thing *will* be done. In England, there is no obligation to rescue imposed on capable adults.¹²⁵ Assuming that an individual has not brought about the event and owes no duty of care, then that individual cannot be prosecuted for standing by and not undertaking a risk in order to save a drowning person. Similar considerations pertain to illness. Although it may be a moral ideal to donate an organ to a critically ill relative, a capable adult cannot be obliged to do so.¹²⁶ Again in *McFall*, the judgment maintained

For our law to compel the defendant to submit to an intrusion of his body would change every concept and principle upon which our society is founded. To do so would defeat the sanctity of the individual, and would impose a rule which would know no limits... For a society, which respects the rights of one individual, to sink its teeth into the jugular vein or neck of one of its members and suck from it the sustenance for another member, is revolting to our hard wrought concepts of jurisprudence.¹²⁷

In reviewing the case Meisel and Roth concurred with these latter sentiments:

No matter how idiosyncratic Shimp’s reasons for refusal, his mere wish not to donate marrow should not be overridden... It is he who would have had to bear the risks of donation, even if they were relatively slight, and it is he who now bears the costs of refusing –

donor’. American Academy of Pediatrics Committee on Bioethics, ‘Children as Hematopoietic Stem Cell Donors’ (2010) 125 *Pediatrics* 392, 395.

¹²⁴ *McFall v Shrimp* (1978) 10 Pa. D.&C 3d 90 Allegheny County Court, 90.

¹²⁵ There is no legal duty to act as a Good Samaritan, regardless of how grave the need of another, nor how simple it might be to assist them. See *Dorset Yacht Co Ltd v Home Office* [1970] AC 1004, 1061 (Lord Diplock): ‘the priest and the Levite would have incurred no civil liability in English law’.

¹²⁶ Steinberg (n 48) 229.

¹²⁷ *McFall* (n 125) 90.

public notoriety, guilt, family discord. These are inherently personal choices. Who is to say that the death of a cousin is inherently more serious than the breakup of one's marriage or the chance of one's own death or incapacitation from general anesthesia? Shimp decided that, placed in this obviously difficult situation, the costs of donation were greater than the costs of refusing to be a donor. His choice must be honored.¹²⁸

It does seem peculiar that vulnerable young children can be obliged to undertake the very risks that Shimp rejected, resoundingly supported by some commentators at least. In a nutshell, it would seem that young children are not the bearers of moral obligations that commit them to voluntary participation in tissue donation or research programmes. Rather, they are in a position where they may be obliged or compelled to do so.

Against this, it might be argued that while children may not be fully fledged moral agents, parents have a duty to educate their child to recognise, and discharge their obligations to others. Battaglia asked the question:

If parents say yes to those medical procedures which are 'therapeutic' - that is, the procedures are directed at improving the growth and development of the child, a form of 'biologic good' - can the parents then say yes to those actions which they believe enable the child to participate in his or her 'moral good'?¹²⁹

Many parents who do enrol their children in medical research studies claim to do so for altruistic reasons; in order to benefit other children in society.¹³⁰ Advancing the moral good of the child might seem an irresistible prospect. However, if children are *obliged* to participate in RWTI or tissue donation, then the process would seem to be more about the exercise of power than education. The oft repeated case described by Gaylin is illustrative of this point. A researcher sought permission to take some blood from a child in the context of a non-therapeutic research study. The child, afraid of needles, dissented but was overruled by his father who stated:

This is my child. I was less concerned about the research involved than with the kind of boy I was raising. I'll be damned if I was

¹²⁸ A Meisel and LH Roth, 'Must a Man Be His Cousin's Keeper?' (1978) 8 Hastings Cent Rep 5, 6.

¹²⁹ Cited in Ramsey (n 93) 23.

¹³⁰ SC Harth and YH Thong, 'Sociodemographic and Motivational Characteristics of Parents who Volunteer Their Children for Clinical Research: A Controlled Study' (1990) 300 Br Med J 1372.

going to allow my child, because of some idiotic concept of children's rights, to assume he was entitled to be a selfish, narcissistic little bastard.¹³¹

Leaving aside concerns about the ability of small children, or severely learning-disabled individuals, to comprehend and assimilate the appropriate moral messages allegedly inherent in such procedures, the course of action itself seems peculiar. Altruism concerns actions that are 'motivated solely or primarily by regard for others'.¹³² Nagel defined it as the 'willingness to act in consideration of the interests of persons, without the need of ulterior motives'.¹³³ The altruistic extent of an act is generally judged by the amount of risk or self-sacrifice an individual endures in its performance.¹³⁴ Given that it is the child who suffers whatever harms there are, then clearly the parent is not engaged in an altruistic act, unless we regard the child as a possession or extension of the parent. Neither is the child engaged in an altruistic act because, as has been pointed out, 'forced altruism is not altruism'.¹³⁵

The case described by Gaylin does raise questions about research participation and the dissenting younger child. If research involvement is a moral obligation then, unless it is a weak duty, it would seem that parents should 'encourage' objecting children to participate regardless of remonstrations. However, a number of guidelines suggest that 'children and young people should not usually be involved in research if they object or appear to object in either words or actions, even if their parents consent'.¹³⁶ The Royal College of Paediatrics asserts that researchers 'should always ensure that the child does not object' but seem to limit their discussion to the child of school-going age.¹³⁷ Such assertions seem to tacitly

¹³¹ W Gaylin, 'Competence: No Longer All or None' in W Gaylin and R Macklin (eds), *Who Speaks for the Child: The Problems of Proxy Consent* (Plenum Press, New York 1982) 94.

¹³² W Glannon and LF Ross, 'Do Genetic Relations Create Moral Obligations in Organ Transplantation?' (2002) 11 *Camb Q Healthc Ethic* 153.

¹³³ T Nagel, *The Possibility of Altruism* (Princeton University Press, New Jersey 1970) 78.

¹³⁴ Glannon and Ross (n 133) 154.

¹³⁵ S Zink and SL Wertlieb, 'Forced Altruism is not Altruism' (2004) 4 *Am J Bioethics* 29.

¹³⁶ General Medical Council, Council of Europe, *0–18 years: guidance for all doctors* (GMC, London 2007) para 38. See also Council of Europe, *The Additional Protocol to the Convention on Human Rights and Biomedicine* 15.1(v) and 15.2. <<http://conventions.coe.int/treaty/en/treaties/html/195.htm>> accessed 10 June 2010.

¹³⁷ Royal College of Paediatrics and Child Health, 'Guidelines for the Ethical Conduct of Medical Research Involving Children' (2000) 82 *Arch Dis Child* 177, 182.

equate non-dissent with assent. However, this seems suspect as children often go along with their parents' wishes regardless of their personal preferences. For example, in the context of bone marrow transplantation, many paediatric donors believe they have little choice about whether they will donate or not, and feel compelled to do so.¹³⁸ The Medical Research Council guidelines state that a 'child's refusal to participate or continue in research should always be respected',¹³⁹ but later indicates that any objection should be *deliberate*.¹⁴⁰ Whether the actions of particularly young children are indicative of reflective rejection or general unhappiness may be difficult to decipher on occasion. In addition, as Cave observes, while the Clinical Trials Regulations 2004 'require that a minor's explicit wishes are "considered"', they do not give his views or wishes any legal force'.¹⁴¹ It is difficult to know how these guidelines are implemented in practice, when a researcher is faced with consenting parents but a dissenting young child. Regardless, a distinction must be made between children being obliged to participate in a medical endeavour that they have not chosen, and children being forced, screaming, to donate a blood sample for the purposes of research. Just because a parent has the power to enrol a child in a non-therapeutic research study does not mean that his or her power is, or should be, unlimited in this respect.

VII. THE CALCULUS OF CHILDHOOD MUNIFICENCE

The 'obligation model' is no more successful than the 'best interests' concept in justifying NBI. In reality, such interventions happen as the product of a fundamentally consequentialist decision-making process. Children who become tissue donors or research subjects are members of captive populations.¹⁴² A parent does not volunteer a child to become a tissue donor simply because that child is seen to be morally impoverished and in need of ethical enhancement, or has low self-esteem and tissue donation is being used as a means of boosting self-regard.¹⁴³ Rather, the child has a relative who needs a tissue donation in order to

¹³⁸ Above, n 123.

¹³⁹ *Medical Research Involving Children* (MRC, London 2004) 1.3.

¹⁴⁰ 5.1.6.

¹⁴¹ E Cave, 'Seen But Not Heard? Children in Clinical Trials' (2010) 18 Med L R 1, 9.

¹⁴² This term is used by Ross in the context of some forms of research. See LF Ross, *Children in Medical Research: Access versus Protection* (OUP, Oxford 2006) 6.

¹⁴³ D Steinberg, 'Response to (CQ Vol 13, No 2): A Critique' (2005) 14 Camb Q Healthc Ethic 301.

treat some disease process, and the child is the best, or only, match.¹⁴⁴ Any justification is secondary to the primary fact of underlying need.

On a naïve utilitarian calculus, bone marrow transplantation might appear a net good. A child may be a tissue donor for her sibling because on a harm-benefit analysis the greatest good is likely to be achieved by sacrificing the integrity of one child in order to sustain the life of another. Bone marrow harvesting allegedly provides a small risk to a child and some temporary discomfort.¹⁴⁵ As the procedure is relatively common, it would appear that most parents (and doctors) deem this a reasonable price to pay for the potential to save the life of another of their offspring. Savulescu suggests that sibling bone marrow donation is ‘about distributing benefits and burdens within a family’.¹⁴⁶

Most children who become participants in a non-therapeutic research project are also members of a captive population; they suffer from some illness, or are part of a particular community which is the object of scientific scrutiny. Their enrolment into a study straightforwardly is to address a deficit in scientific knowledge which researchers feel is to the detriment of children generally. Pence referred to this as the ‘Good-of-Others View’ of medical research:

It is important to understand that most research involving children is intended to benefit other children, albeit children who may not yet have been born or children who have no relation to the subjects...

On this (utilitarian) view, a small risk to any particular child is justified through its expected contribution to the good of most children.¹⁴⁷

The brief of the Amici Curiae of the Association of American Medical Colleges and others, submitted to the Maryland Court of Appeal in the case of *Grimes*, echoed this point, although it was bolstered with an unproven empirical claim:

The overall cost of such a rule in terms of lost advances in medical and health knowledge (and ultimately lost opportunities to cure diseases and prevent suffering and the loss of life) will far outweigh the asserted advantage of protecting individual rights.¹⁴⁸

¹⁴⁴ The Supreme Court of Illinois ruled that the donor should have ‘an existing, close relationship with the recipient’, although it declined to define what might constitute such a relationship. *Curran v Bosze* (n 25) 1345.

¹⁴⁵ Although the risk of death is approximately 1/10,000. American Academy of Pediatrics (n 124) 394.

¹⁴⁶ J Savulescu, ‘Substantial Harm but Substantial Benefit’ (1996) 312 Br Med J 241.

¹⁴⁷ GE Pence, ‘Children’s Dissent to Research: A Minor Matter?’ (1980) 2 IRB 1, 2.

¹⁴⁸ Brief of Amici Curiae. Association of American Medical Colleges, Association of American Universities, Johns Hopkins University and University

On this view, the frequently articulated mantra of 'a child's interests should always prevail over society and science'¹⁴⁹ is simply untrue in trials that involve children who are incompetent because of age or illness, and who will derive no healthcare benefit from the research project. Instead the child is enrolled with the principal aim of affecting the future care of other children. This is a laudable aspiration entailing a morally uncertain process. As Kopelman points out, paediatric research is in a moral bind.¹⁵⁰ Policies that aim to protect children by not allowing any subject to participate in a study without their explicit informed and competent consent obviously exclude most children. However, unless some research is carried out on children, there will be little progress made in paediatric healthcare.¹⁵¹ Notwithstanding this, from the perspective of the ill or the impoverished, participation in research which entails some cost on their behalf may seem like a case of double jeopardy.

There are clear advantages to admitting the consequentialist motivation behind NBI, not least that it would provide for a more honest and transparent debate. Primarily, it would focus attention on the legitimacy of proxy authorisation when a child or incompetent individual is obliged to undergo procedures that are not of medical benefit to her. In general, terms consent holds only between the consenting party and the recipient of the consent. Thus, consent to inflict harm on a third party is not necessarily a sufficient justification.¹⁵² Brownsword expresses the issue thus:

Suppose, for example, that when the ... child is about a year old a bone marrow transplant for the sake of the ailing sibling is proposed. Currently, if the couple endorse this course of action, no awkward questions are likely to be asked. Yet, can it be right that a couple, simply by consenting to this procedure to be carried out on their donor child, cover it with legitimacy? If the child had authorised its parents to act as its proxy, the consent would be traceable to the will of the child and the integrity of

of Maryland Medical System Corporation in support of appellees motion for reconsideration. *Grimes v Kennedy Krieger Inst Inc* (2001) CA Md 128.

¹⁴⁹ H Sammons, 'Ethical Issues of Clinical Trials in Children: A European Perspective' (2009) 94 Arch Dis Child 474, 475.

¹⁵⁰ LM Kopelman, 'Children as Research Subjects: Moral Disputes, Regulatory Guidance, and Recent Court Decisions' (2006) 73 Mt Sinai J Med 596, 603.

¹⁵¹ This, of course, assumes that a lack of 'progress' in the field of medical science is a bad thing, a view that has been contested. See for example I Illich, *Medical Nemesis: The Expropriation of Health* (Calder and Boyars, London 1975).

¹⁵² R Brownsword, 'Happy Families, Consenting Couples, and Children with Dignity: Sex Selection and Saviour Siblings' (2005) 17 Child Fam Law Q 1, 4.

the child's rights (assuming that the child is conceded, at this time, to be a rights-holder in relation to its own bone marrow) would be maintained. However, without any suggestion of a proxy authorisation, it is wholly unclear why the consent of the couple should be thought to cast a justified burden on the rights-holding child.¹⁵³

One answer to this apparent dilemma is that the state entrusts parents with a broad discretion to raise their children as they see fit, including decisions which may expose the child to risks.¹⁵⁴ Such parental authority seems to entail the right to require one child to donate tissue to benefit another, or to participate in a research project to the advantage of present or future members of a community.¹⁵⁵ However, it is arguable that this seems to license parents to treat their unconsenting child as a means to an end in some healthcare contexts, a position that is very different to the jealously guarded right to bodily integrity enjoyed by themselves, as autonomous adults.¹⁵⁶

VIII. CONCLUSIONS

This paper is not a polemic against either bone marrow donation by young children or their participation in RWTI; both are important interventions that may save the lives of some children and improve the lot of others. It is an argument against the 'obligation model' as a justification for these procedures. It also seeks to question why there is a necessity to defend these interventions by stating that they are in a child's best interest, or that they allow children to fulfil their obligations to their family or society. A need for justification would seem to indicate some discomfort around the legitimacy of the procedures. I suggest that there are two reasons for this uneasiness. First, there have been a number of instances in the past when vulnerable persons have been treated badly by medicine and science, and so there is a need to defend interventions lacking

¹⁵³ Ibid.

¹⁵⁴ N Fost, 'Ethical Issues in Research and Innovative Therapy in Children with Mood Disorders' (2001) 49 *Biol Psychiat* 1015, 1019; LF Ross, 'Informed Consent in Pediatric Research' (2004) 13 *Camb Q Healthc Ethic* 346, 348; Buchanan and Brock (n 18) 239.

¹⁵⁵ F Schoeman, 'Parental Discretion and Children's Rights: Background and Implications for Medical Decision Making' (1985) 10 *Journal of Medicine and Philosophy* 45; Buchanan and Brock (n 18) 233; Ross, *ibid*; Fost, *ibid*.

¹⁵⁶ Although the courts have not always dealt with adult autonomy in a consistent manner. See J Coggon, 'Varied and Principled Understandings of Autonomy in English Law: Justifiable Inconsistency or Blinkered Moralism?' (2007) 15 *Health Care Anal* 235.

direct benefit in these populations.¹⁵⁷ Secondly, 'obliging' unconsenting children, but not rational adults, might indicate some inequality between the way children and adults are treated.

It does not seem unreasonable to suggest that all persons¹⁵⁸ should be treated in a similar fashion unless there is a compelling reason to behave differently towards one group when compared with others. As things stand, children can be obliged to act as donors of tissue or scientific information, whereas competent adults cannot. One argument that could be made in favour of preserving this position is that it serves a social function that outweighs a child's right to the equal protection of the law;¹⁵⁹ that the purpose is sufficient to override the right to bodily integrity of children but insufficient to breach that of adults. In order for this to be so, it would seem that it should hold that there is a far greater social need for children to be medical Samaritans than adults. It is uncertain that this is the case, as there is also a significant deficit of adult research volunteers¹⁶⁰ and tissue donors.¹⁶¹ It is possible to suggest that there are special claims on children because, for example, the paucity of prior research has meant that many drugs used in paediatrics have never been tested on children.¹⁶² Thus, if pharmaceutical trials do not involve children who are too young to consent, then improper drug administration may occur leading to harm to other children. However, adults are not free from similar claims. A lack of adult volunteers may inhibit or retard the development of new treatments, which also causes harm to others. In both instances, a failure of 'volunteerism' will lead to suboptimal therapy delivery and consequential harm.

If, with regard to NBI, children were to be treated in a similar fashion to adults, then this would leave us with two basic

¹⁵⁷ See for example MA Grodin and LH Glantz (eds), *Children as Research Subjects: Science, Ethics & Law* (OUP, Oxford 1994).

¹⁵⁸ This assumes, as the dictum of Dame Elizabeth Butler-Sloss stated, that the 'child is a person'. E Butler-Sloss, *Report of Inquiry into Child Abuse in Cleveland* (HMSO, London 1988) 245.

¹⁵⁹ McGillivray examined and dismissed this argument in the context of domestic corporal punishment. See A McGillivray, 'Child Physical Assault: Law, Equality and Intervention' (2004) 30 *Manitoba Law J* 133.

¹⁶⁰ See for example A Mathur, 'Should Patients Have to Agree to Medical Research?' *BBC News* (12 December 2009) <<http://news.bbc.co.uk/go/pr/fr/-/2/hi/health/8399763.stm>> accessed 30 December 2009.

¹⁶¹ Anthony Nolan Trust, 'Why Join the Donor Register?' <<http://www.anthonynolan.org.uk/donating/>> accessed 30 December 2009. See also Statistics and Audit Directorate, *Transplant Activity in the UK 2008–2009* (NHS Blood and Transplant, London 2009) 4.

¹⁶² PHY Caldwell and others, 'Clinical Trials in Children' (2004) 364 *Lancet* 803.

possibilities. The first position would preclude NBI from being performed on any individual without their express consent. This 'integrity model' would mean that no young child could act as a research participant in a non-therapeutic trial or be a tissue donor. The second position (the 'obligation model') would suggest that all persons would have, as a minimum duty, a requirement to be a research subject or tissue donor in certain circumstances (for example, situations where the need is great and the cost to the individual small). Neither of these paradigms might seem attractive to some;¹⁶³ the 'integrity model' would lead to a slow down in some scientific advancement, while the 'obligation model' clearly impinges on adult autonomy. Thus, the extant position is the one that is likely to continue. Adults have the power to oblige children, but not other rational adults to undergo NBIs, regardless of need. Despite devising principles that indicate the contrary, the practice of both law and bioethics appear to offer greater protection to competent adults than incompetent children.

¹⁶³ A full discussion of the merits of either of these positions is beyond the scope of this paper.

Dying to be responsible: adolescence, autonomy and responsibility

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The United Nations Standard Minimum Rules for the Administration of Juvenile Justice state that there should be 'a close relationship between the notion of responsibility for delinquent or criminal behaviour and other social rights and responsibilities'. If healthcare autonomy, or the 'right to be responsible for making decisions about our own medical welfare', is accepted as one of these social rights then, in England, the age gap between criminal responsibility and healthcare right is considerable. It has been suggested that this age difference might be explained in terms of the attribution of responsibility; in essence that there is a difference in the timing and nature of the responsibility being ascribed. The aim of this paper is to examine the concept of responsibility, particularly as it relates to adolescent decisions concerning death; the refusal of life-saving treatment, on the one hand, and the commission of homicidal acts, on the other. It would appear that there is considerable overlap in the types of responsibility alluded to in both situations, most particularly in the notions of capacity responsibility and prospective responsibility. If this is so, then having a wide gap between the two ages of responsibility would seem to lack a secure jurisprudential basis.

INTRODUCTION

In September 1990, a hospital authority sought leave to administer blood to a Jehovah's Witness, aged 15³/₄, who was refusing life-saving transfusions. Ward J found that while the adolescent was intelligent enough to take decisions about his own well-being, he failed to appreciate the full implications (especially regarding the exact nature of his death) of his choice, and the authority was granted leave to give the required treatment.¹ Three years later, two 11-year-old boys, one of whom was psychologically and emotionally immature,² were found guilty of murder at Preston Crown Court following an 'act of unparalleled evil and barbarity' committed when they were just 10.³ Taken together, these two cases seem to indicate that one can have a sufficient comprehension of the character and consequences of fatal actions to be deemed culpable of murder at the age of 10, yet lack this same understanding when significantly older should the act in question create a risk of harm to self, rather than to others. In essence, legislation and case-law in England indicates that should E have committed a homicide, he could be held criminally responsible for that act from the

1. *Re E (A Minor) (Medical Treatment)* [1993] 1 FLR 386 (*Re E*). Although the adolescent in question was referred to as 'A' throughout the case, in this paper I shall refer to him as E to avoid confusion.

2. *V v UK* (2000) 30 EHRR 121 at 134.

3. Cited in *R v Secretary of State for the Home Department ex parte Venables and Thompson* [1998] AC 407 at 439.

age of 10.⁴ In contrast, the age at which he could legally become fully responsible for making choices about his personal medical welfare,⁵ and in particular refusing life-saving treatment, is 18.⁶ Thus, as a 10 or 15 year-old he is held to be simultaneously capax and incapax, to have the capacity to be criminally culpable on the one hand, but to be ultimately incapable of making serious healthcare decisions on the other. This discrepancy, that the courts treat children differently depending on whether they are accused of a criminal offence or are appealing to be allowed to make decisions concerning their own healthcare, has been noted before⁷ but is a dichotomy that appears not to have been subjected to detailed analysis.

Hollingsworth suggests that the age difference between criminal culpability and medical autonomy might be explained in terms of the attribution of responsibility; that there is a difference in the timing and nature of the responsibility being ascribed:

‘conferring responsibility on a child to consent or refuse medical treatment is a pre-condition to the actual decision-making act itself. Responsibility must be conferred before the child can (in a legal sense) make the decision, and the child’s capacity affects whether or not they are given that responsibility in the first place. But where a child is being held legally *liable*, the action or decision has already been taken by the child (the offence . . . has already been committed), and he is then being held responsible in an ex post manner.’⁸

This might seem a reasonable account but is, I believe, deficient in unpacking the issues surrounding both the ascription and meaning of responsibility in the context of both criminal law and autonomy.⁹ The main aim of this paper is to explore the referents of ‘responsibility’ and how they are applied in the two different legal situations in question.

Keating has recently contrasted the different approaches taken by criminal law and family law with regard to the age at which children are held to be responsible, and suggested that, in these contexts, ‘the concept of responsibility itself is being manipulated’.¹⁰ While it might be argued that the law should not set a uniform age of

4. Children and Young Persons Act 1963, s 16.

5. The relationship between responsibility and autonomy is a complex one and has been the subject of recent philosophical debate; see J Fischer ‘Recent work on moral responsibility’ (1999) 110 *Ethics* 93 at 98. In this paper I will assume equivalence between the notions of ‘responsibility for self-determination’ and ‘autonomy’ as applied to healthcare decision making. This is a position I will discuss later.

6. Nolan LJ has argued that the courts would not countenance the refusal of lifesaving treatment by an adolescent. See *Re W (A Minor) (Medical Treatment)* [1992] 4 All ER 627 at 647 (*Re W*). It is clear from *Johnson J in Re P* that the judgement in *Re W* defines the law on this subject: *Re P (Medical Treatment: Best Interests)* [2004] 2 FLR 1117 (*Re P*). However, the Mental Capacity Act 2005 indicates that there should be a presumption that all adults (aged 16 or over) have full legal capacity to make decisions for themselves. How the courts might interpret this in future cases that concern adolescent refusal of treatment is uncertain.

7. See, eg, M Brazier and C Bridge ‘Coercion or caring: analysing adolescent autonomy’ (1996) 16 *LS* 84; K Hollingsworth ‘Responsibility and rights: children and their parents in the youth justice system’ (2007) 21 *Int J Law Policy Family* 190; Royal College of Psychiatrists (RCP) *Child Defendants* (Occasional paper OP56) (London: RCPsych, 2006).

8. Hollingsworth, *ibid*, at 195 (original emphasis).

9. However, as these points were not central to her paper it is unsurprising that Hollingsworth did not fully discuss them.

10. H Keating ‘The “responsibility” of children in the criminal law’ (2007) 19 *CFLQ* 183.

responsibility across all legal domains in order to comply with some 'unadorned principle of consistency',¹¹ nonetheless, it seems reasonable that any lack of consistency be justifiable.¹² I believe that there is considerable overlap in the types of responsibility alluded to when we refer to 'criminal responsibility' and 'responsibility for healthcare decision-making', most particularly in the dual notions of capacity responsibility and prospective responsibility. If this is so, then the inconsistent ascription of responsibility to adolescents in these particular situations would seem not to be justified, and the policy of having a wide gap between the two ages of responsibility to lack a secure jurisprudential basis.

In examining these issues, this paper will largely concern itself with death. I will proceed by analysing, first, those adolescent autonomy cases where the likely outcome of treatment refusal would have been fatal had the courts not intervened, and, secondly, the criminal law as it pertains to individuals under the age of 18 who have committed the offence of murder. There are two reasons for this. First, in both situations decisions made by the child in question will lead to the death of an individual, and, thus, for the purposes of analysis, there is a degree of symmetry between the healthcare and criminal cases. Secondly, the decision to refuse life-saving care is possibly the most serious decision an individual can make. Although the number of cases involving minors is small, they are of enormous relevance as the right to refuse treatment cuts to the very core of what we understand by autonomy and self-determination. Similarly, homicide is the gravest offence an individual can commit, and thus how the courts deal with young people who have killed is likely to provide an accurate reflection of how the criminal justice system views the legal and mental capacity of children.

THE BEIJING RULES¹³ AND ADOLESCENT RESPONSIBILITIES

To illustrate these points, let us suppose that Mary, a 15-year-old girl of normal intelligence, is found guilty of the murder of V. The perpetrated act was not unreflective but was preceded by deliberation, and as she is found to have had the necessary mental component (*mens rea*) while committing the *actus reus*, Mary is held to be fully responsible for her actions and punished accordingly.¹⁴ While serving her custodial sentence, Mary develops leukaemia. This does not affect her brain, and her intellect is unimpaired. Mary needs chemotherapy and a blood transfusion, and will almost certainly die without treatment, although these therapies are not required

11. D Archard *Children: Rights and Childhood* (New York: Routledge, 2004) p 127.

12. Keating, above n 10, at 184.

13. United Nations Standard Minimum Rules for the Administration of Juvenile Justice. The rules, generally referred to as the Beijing Rules, seek to promote juvenile welfare and minimise intervention by state juvenile justice systems and thus consequent harm. The rules are not binding in international law; states are invited, but not required, to adopt them.

14. One objection to holding children criminally responsible is they do not deliberate sufficiently to be regarded as fully responsible. However, as Tadros points out the 'objection . . . that we are not as responsible for unreflective actions as we are for reflective actions . . . is untrue'. See V Tadros 'Insanity and the capacity for criminal responsibility' (2001) 5 ELR 325 at 327. There is, however, a considerable body of literature that supports the view that Mary should be less responsible by virtue of immaturity. For an overview, see ES Scott and T Grisso 'The evolution of adolescence: a developmental perspective on juvenile justice reform' (1997) 88 J Crim Law Crim 137.

immediately and she has time to consider. She refuses to consent. Although she accepts that refusal is likely to result in her death, Mary is adamant that she will not accept the proposed therapies. The medical staff are troubled by this decision and seek the assistance of the court. What will the court decide? If it follows existing case-law, then the court will override Mary's decision regardless of her motivation; her wish to be responsible for her healthcare outcome will be denied. Thus, there would appear to be a simultaneous ascription and denial of responsibility to the same child when all that apparently changes is the legal arena she encounters. One way of explaining this discrepancy would be if the term 'responsibility' had a different meaning in each context. Being held liable for historic acts, on the one hand, and responsible for making healthcare choices, on the other, might express different aspects of the notion of 'responsibility'; the term and its cognates do have a number of context-sensitive uses and senses.¹⁵

Against this, the Beijing Rules state that, in general, there should be 'a close relationship between the notion of responsibility for delinquent or criminal behaviour and other social rights and responsibilities'.¹⁶ In broad terms, this implies that if Mary is old enough to bear the responsibility for her actions when they infringe the criminal law, then she is of a sufficient age to claim a variety of rights. While there is no automatic entitlement to possess all possible rights at any particular time, nonetheless it seems reasonable to expect that if society burdens an individual with a legal responsibility then she has a prerogative to claim a correlative legal right. Those who are required to labour under certain responsibilities yet are denied what might be seen as corresponding rights might feel that such an imposition requires a satisfactory explanation. From this it would seem that if there is a significant discrepancy between the age at which Mary becomes criminally responsible and the age at which she comes to possess certain legal rights, then this disparity is in need of some justification. For the purposes of this paper, the social right that Mary wishes to claim is healthcare autonomy, or the right to be responsible for making choices about her personal medical welfare.

RESPONSIBILITY

In order to develop a sense of Mary's various responsibilities it is necessary, first, to identify what it means to be responsible, or to be held responsible, and, secondly, to examine the relationship between responsibility and autonomy. Etymologically, coming from the Latin *respondeo* or the French *répondre*, to be responsible is to be answerable for an action.¹⁷ Kneale noted that our fundamental idea of responsibility is dependent upon the notion of being held 'accountable under some rule to a determinate authority for a determinate sphere of action'.¹⁸ While he recognised this does not seem to account for several of the ordinary ways in which we use the term, he posited that all other uses of 'responsibility' are derivative of the basic concept.¹⁹ Hart also

15. J Corlett *Responsibility and Punishment* (Dordrecht: Kluwer Academic Publishers, 2004) pp 10–12.

16. Official commentary on Art 4(1).

17. JR Lucas *Responsibility* (Oxford: Clarendon Press, 1993) p 5.

18. W Kneale 'The responsibility of criminals' in HB Acton (ed) *The Philosophy of Punishment* (London: Macmillan, 1969) p 175.

19. Ibid, p 176.

argued that accountability underpinned the fundamental meaning of responsibility and classified what he saw as its distinctive connotations under the headings of Role Responsibility, Causal Responsibility, Liability Responsibility and Capacity Responsibility.²⁰ Role responsibility refers to obligations or duties that we have by virtue of the personal or professional roles we hold in an organisation or society at large. We are accountable for any failure to fulfil our acknowledged role responsibilities, and may incur blame, censure or punishment as a consequence.²¹ If we excel at our role then we may be praised or subjected to a positive judgement on our actions, although, unlike its negative counterpart, this only occurs in a moral rather than a legal sense.²² Causal responsibility, when applied to humans (as opposed to things, events or conditions), entails being responsible for an outcome when some act or failure to act by the individual concerned significantly contributes to that state of affairs. Liability responsibility usually requires causal responsibility and imputes blameworthiness to an individual and marks her out as someone who may be appropriately subjected to reactive attitudes, sanction or punishment.²³ A person may be deemed morally or legally blameworthy depending on a variety of circumstances, most particularly whether her act or omission has breached a legal rule. However, this is only true if the person imputed to be liable has certain mental capacities. For Hart, the capacities in question are those of understanding, reasoning and control of conduct, although he concedes that while they constitute 'the most important criteria of moral liability responsibility' they are a less important standard for legal responsibility.²⁴

Cane feels that Hart's account is too narrow, that it is insufficiently concerned with 'prospective responsibility'.²⁵ Hart is primarily interested in historic or retrospective responsibility and, while he acknowledges future-looking responsibility, this is only with regard to some duty, role or task that we have to perform. However, Cane argues that prospective responsibility is not solely related to roles or tasks, but is also concerned with the notion of being a responsible person.²⁶ In this regard, an ethic of responsibility is partly about 'what it is to lead a life . . . and about the quality and character of that life',²⁷ a moral virtue that we should aspire to and seek to inculcate and foster in individuals.²⁸ While the law does not concern itself with virtuous or supererogatory behaviour, it retains an interest in prospective responsibility in that it encourages conduct that coheres with our obligations under law, and discourages actions that infringe the law. In an ideal 'prospectively responsible world', conformity with our obligations would be maximised, thus limiting our need to invoke liability responsibility or seek remedy for damages incurred.²⁹ However, in order to be the kind of person who can have prospective responsibilities, we must be individuals who can understand such obligations. As far as the law is concerned, we are prospectively responsible for future acts if we are likely to be held liable for their consequences. As Bok put it, 'I will be responsible if things turn out badly' means that if things turn out

20. HLA Hart *Punishment and Responsibility* (Oxford: Clarendon Press, 1968) p 212.

21. *Ibid*, pp 212–214.

22. Corlett, above n 15, pp 12–14.

23. *Ibid*, p 15.

24. Hart, above n 20, p 227.

25. P Cane *Responsibility in Law and Morality* (Oxford: Hart Publishing, 2002) p 32.

26. *Ibid*.

27. G Watson 'Two faces of responsibility' (1996) 24 *Phil Topics* 227 at 229.

28. CC Gauthier 'The virtue of moral responsibility and the obligations of patients' (2005) 30 *J Med Phil* 153.

29. Cane, above n 25, p 35.

badly, 'it will then be appropriate for me to be held responsible'.³⁰ Prospective responsibility is thus largely concerned with responsible agency. The law seems to believe that children have the capacity for such agency in that it continues to place great store in the deterrent value of punishment as a means of engendering responsible behaviour amongst young people.³¹

In briefly outlining these concepts of responsibility, I have made several assumptions, some of which have been vigorously contested in the philosophical literature.³² Most notably, I have presumed that, in general, individuals who are subject to assessments of, and reactive attitudes to, their actions freely engage in those actions in the first place; that they have free will to choose between alternate possibilities, that their decisions are not predetermined by genetic or environmental factors, and that such alternate possibilities exist. A full assessment of these issues is well beyond the bounds of this paper, but the position outlined is one that is largely reflective of the law as it stands. In addition, I have assumed that the same fundamental idea of liberal autonomy underpins both criminal and medical law. Although philosophically contestable, this does not seem an unreasonable position, particularly since the stated primary goal of the youth justice system is deterrence. If the Criminal Justice and Immigration Act 2008 is read as a lexical ordering of priorities, then deterrence seems to trump even the welfare principle. The value of deterrence would seem to be particularly dependent upon liberal notions of rational agents engaging (or not) in acts of free will.

RESPONSIBILITY AND AUTONOMY

Mary, having taken responsibility for her crime, now wishes to take responsibility for making decisions about her personal medical welfare. Stated this way, the notion of 'responsibility for self-determination' assumes equivalence with that of 'autonomy'. This is not a new relationship. The antecedents of autonomy are largely religious, originating from Puritan notions of personal responsibility and conscience, and the derivation of self-governance, rights and freedom from natural law.³³ Rooted in these precepts, the Anglo-American doctrinal view of healthcare autonomy has tended to emphasise individualistic interests, although as a social reality choices are inevitably not entirely atomistic in nature. However, if an individual engages in acts based upon free and uncoerced decision making then these might be considered 'autonomous acts'.³⁴

The legal concept of autonomy, as outlined in *Re T*, entails the right to determine what shall be done with one's own body, including the right to decide whether or not to accept medical treatment.³⁵ The law tends to regard autonomy as a negative rather

30. H Bok *Freedom and Responsibility* (Princeton, NJ: Princeton University Press, 1998) p 124.

31. Criminal Justice and Immigration Act 2008, s 9 (2): 'Purposes etc. of sentencing: offenders under 18: The court must have regard to – (a) the principal aim of the youth justice system (which is to prevent offending (or re-offending) by persons aged under 18'.

32. Fischer, above n 5.

33. AI Tauber 'Sick autonomy' (2003) 46 *Perspect Biol Med* 484 at 485.

34. *Ibid*, at 490.

35. *Re T (Adult: Refusal of Treatment)* [1993] Fam 95 as per Lord Donaldson at 113 (*Re T*). However, some judicial decisions appear less than enthusiastic in unequivocally embracing the

than a positive right in that a person may refuse but not demand treatment.³⁶ If treatment is refused by a competent individual then this autonomous decision must be respected, even if refusal risks permanent injury or death and is based on reasons that appear irrational, ill-considered or even non-existent to an observer. The hallmark of autonomy is thus recognition of an individual's 'right to a life structured by his own values'.³⁷ This right overrides the very strong public interest in preserving the life and health of all citizens, and according to Lord Scarman in *Sidaway* is 'a basic human right protected by the common law'.³⁸

The idea of personal responsibility for health has become increasingly prevalent,³⁹ and the evolving inter-relationship between capacity, autonomy and responsibility has been noted by the law. In 1967, the Latey Committee recommended that the legal age of majority in the UK be reduced from 21 to 18 years, commenting that 'most people today mature earlier than in the past; . . . by 18 most young people are ready for these responsibilities and rights'.⁴⁰ Similarly, the Court of Appeal in *Gillick v West Norfolk and Wisbech Area Health Authority* stated that 'it must be determined, in relation to a particular child and a particular matter, whether he or she is of sufficient understanding to make a responsible and reasonable decision'.⁴¹ To be considered responsible in this sense would seem to require that an individual engages in a form of self-reflection, an evaluation of choices against a background of a structured value system. Wallace calls such responsibility for one's actions 'the condition of autonomy'.⁴² In addition, as Tauber points out, 'autonomous choices bequeath responsibility for those choices'.⁴³

The relationship between healthcare autonomy and responsibility thus seems to have both backward- and forward-looking components. The responsible person engages in critical reflection before making an autonomous choice, but also takes responsibility for preferring this or that option. This is not to say that an individual may necessarily be subject to praise or blame for their healthcare choice, but rather that they must bear the consequences, beneficial or inimical, of their decision; they have liability responsibility for that decision. In the fictional case outlined above, Mary appears willing to assume liability responsibility for her choice, yet is disallowed from doing this by the court. This cannot be because she does not appreciate the

principle. See J Coggon 'Varied and principled understandings of autonomy in English law: justifiable inconsistency or blinkered moralism?' (2007) 15 Health Care Anal 235; also M Brazier and E Cave *Medicine, Patients and the Law* (London: Penguin, 4th edn, 2007) pp 99–121.

36. *R (Burke) v General Medical Council* [2005] EWCA Civ 1003, [2006] QB 273.

37. R Dworkin. *Life's Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom* (New York: Alfred A Knopf, 1993) cited by Lord Steyn in *Chester v Afshar* [2005] 1 AC 134 at 144.

38. *Sidaway v Board of Governors of the Bethlehem Royal Hospital and the Maudsley Hospital* [1985] AC 871 at 882.

39. See, eg, Department of Health *The NHS Constitution for England* (London: TSO, 2009) s 2(b); also D Spruijt-Metz *Adolescence, Affect and Health* (Hove: Psychology Press, 1999) pp 31–35.

40. Home Office *Report of the Committee on the Age of Majority* Cmnd 3342 (London: HMSO, 1967) at para 518 (emphasis added). This body was referred to as the Latey Committee after its chairperson, throughout parliamentary and Lord's debates.

41. [1986] AC 112 (*Gillick*) as per Parker LJ at 124 (emphasis added).

42. RJ Wallace *Responsibility and the Moral Sentiments* (Cambridge, MA: Harvard University Press, 1998) p 53.

43. Tauber, above n 33, at 490.

idea of liability responsibility given her criminal conviction and sentencing. What then is the denial of Mary's autonomy claim based upon? A review of adolescent autonomy cases might seem to suggest that this rejection has its origins in controversial judicial interpretations of existing legislation and case-law.

A BRIEF HISTORY OF ADOLESCENT AUTONOMY

The Latey Report recommended 'that young people should be able to give consent to medical treatment from the age of 16 onwards'.⁴⁴ The motivation for this proposal appeared to have been entirely practical: to allow those under 18 to access medical care in the absence of their parents, and also to protect doctors from potential charges of battery.⁴⁵ Several relevant bodies had advised the Latey Committee on the issue of adolescent consent. In its submission, the British Medical Association (BMA) stated that:

'(C)onsent by a person of 16 years or upwards, who appears to the medical practitioner to be capable of understanding what is involved and of expressing his own wishes, should be considered to be a valid consent to medical or surgical treatment without necessity of confirmation by his parent or legal guardian. *Of course the refusal of a person over 16 to undergo treatment should also be respected* providing it appears to the medical practitioner that the person clearly understands the implications of his decision.'⁴⁶

The Report continued by noting:

'(T)his opinion is supported by all the professional bodies who have given evidence to us – The Medical Defence Union, the Medical Protection Society (who, however, suggest that from 16 to 18 the patient should be able to consent but that a refusal could be overridden by parents), the Institute of Hospital Administrators, the Royal College of Nursing and the Ministry of Health.'⁴⁷

There is no further comment made on treatment refusal, nor on the disparate views expressed by the Medical Protection Society, on the one hand, and the BMA, apparently supported by a variety of bodies, on the other. This lack of elaboration would seem to suggest that the Latey Committee endorsed the stance of the majority, a logical position since, as Kennedy put it, 'the power to refuse is no more than the obverse of the power to consent and that they are simply twin aspects of the single right to self-determination'.⁴⁸

The Family Law Reform Act 1969 enacted most of the recommendations of the Latey Committee, s 8(1) stating that:

'(T)he consent of a minor who has attained the age of sixteen years to any surgical, medical or dental treatment . . . shall be as effective as it would be if he were of full age; and where a minor has by virtue of this section given an effective consent to any treatment it shall not be necessary to obtain any consent for it from his parent or guardian.'

44. *Hansard* HC Deb, 20 November 1967, vol 754 cols 956–1028 at col 963.

45. *Hansard* HL Deb, 26 November 1968, vol 297, cols 1132–1198 at 1149.

46. Home Office, above n 40, para 480 (emphasis added).

47. *Ibid.*

48. Quoted in E Jackson *Medical Law* (Oxford: Oxford University Press, 2006) p 245.

Twenty years later the Children Act 1989 specifically alluded to the right of a child 'of sufficient understanding to make an informed decision' to refuse medical or psychiatric examination, 'or other assessment'.⁴⁹ In between these two pieces of legislation the ruling by the House of Lords (most particularly the judgment of Lord Scarman) in *Gillick* implied that a child of sufficient intellectual and emotional maturity had decision-making capacity, that 'parental right yields to the child's right to make his own decisions when he reaches a sufficient understanding and intelligence to be capable of making up his own mind'.⁵⁰ At this juncture it would have appeared safe to state that children could be divided into two groups: (a) those who were incapable of consenting to treatment by virtue of age-related immaturity or mental disability; and (b) those who were capable of consenting due to the fact that they were over 16 years of age, or were under 16 but had sufficient intellectual capacity 'to enable him or her to understand fully what is proposed'.⁵¹ It would also have seemed reasonable to assume that the right to consent entailed the right to refuse, that, as Harris noted, 'to understand a proposed treatment well enough to consent to it is to understand the consequences of a refusal. And if the consequences of a refusal are understood well enough to consent to the alternative then the refusal must also be competent'.⁵² Thus, assuming Mary is a competent adolescent, she would appear to be in possession of the ultimate right of choice, specifically the power of veto, should her decision be contested.⁵³

'But enter now Lord Donaldson',⁵⁴ whose judgments in *Re R*⁵⁵ and *Re W* have proven to be enormously influential in defining the limits of adolescent autonomy. *Re R* concerned a 15-year-old girl, in the care of the local authority, who suffered increasingly serious episodes of psychotic illness, but when periodically lucid refused consent to treatment. In *Re W*, a local authority sought leave to treat a 16-year-old girl suffering from anorexia nervosa who was refusing medical treatment. These cases have been discussed extensively elsewhere,⁵⁶ and so I shall dwell only briefly upon their specifics. Although the cases were different, one similarity was that both R and W most likely lacked capacity by virtue of their illness rather than their age.⁵⁷ Despite this, Lord Donaldson used both cases to comment on a minor's right to refuse treatment. His aim in doing so appears to have been to protect doctors against what otherwise might be unlawful treatment.⁵⁸ Lord Donaldson adjudged that the court, in exercising its inherent jurisdiction, could override a minor's refusal. For treatment to proceed lawfully a doctor required only a single consent which could be provided by the minor, or if she refused, her parents or the court: '(N)o minor of whatever age has power by refusing consent to treatment to override a consent to treatment by someone

49. Section 44(7).

50. At 186 per Lord Scarman.

51. Ibid, at 189.

52. J Harris 'Consent and end of life decisions' (2003) 29 J Med Ethics 10 at 12.

53. M Freeman 'Rethinking Gillick' (2005) 13 Int J Child Rights 201 at 202.

54. Ian Kennedy, quoted in Jackson, above n 48.

55. *Re R (A Minor) (Wardship: Consent to Treatment)* [1992] Fam 11 CA (*Re R*).

56. See, eg, A Bainham 'The judge and the competent minor' (1992) 108 LQR 194; Brazier and Bridge, above n 7; G Douglas 'The retreat from Gillick' (1992) 55 MLR 569; J Eekelaar 'White coats or flak jackets/ doctors, children and the courts – again' (1993) 109 LQR 182; J Murphy 'W(h)ither adolescent autonomy?' (1992) 14 J Soc Welfare Fam Law 529; Freeman, above n 53.

57. Brazier and Cave, above n 35, p 405.

58. Eekelaar, above n 56.

who has parental responsibility for the minor and *a fortiori* consent by the court'.⁵⁹ In order to reach this conclusion, Lord Donaldson first interpreted the Latey Committee Report as not recommending that patients aged between 16 and 18 be able to give an effective refusal to medical care.⁶⁰ He cited para 484 which states that 'without prejudice to any consent that may otherwise be lawful, the consent of young persons aged 16 and over to medical or dental treatment shall be as valid as the consent of a person of full age'. The first part of this was translated into s 8(3) of the Family Law Act as '(N)othing in this section shall be construed as making ineffective any consent which would have been effective if this section had not been enacted'. This circumlocutory prose has left commentators uncertain of what it might mean.⁶¹ Lord Donaldson's interpretation was that the pre-existing right to consent upheld by s 8(3) was that of those with parental responsibilities.⁶² This explication was criticised by Freeman who suggested that Lord Donaldson's position was incoherent 'because, if section 8(3) is referring to parental rights at common law, these are rights which have dwindled to the point of yielding to the child's right to make his/her own decisions when of sufficient understanding and intelligence'.⁶³

Secondly, Lord Donaldson decided that Lord Scarman, in his judgement in *Gillick*, was not saying that a competent child's right to refuse was determinative. Instead he argued:

'I do not understand Lord Scarman to be saying that . . . the parents ceased to have an independent right of consent . . . In a case in which the "Gillick competent" child refuses treatment, but the parents consent, that consent enables treatment to be undertaken lawfully . . . If Lord Scarman intended to go further than this and to say that in the case of a "Gillick competent" child, a parent has no right either to consent or to refuse consent, his remarks were obiter . . . Furthermore I consider that they would have been wrong.'⁶⁴

Kennedy questioned the legitimacy of Lord Donaldson's 'gloss' on *Gillick*, suggesting that he had interpreted the case in such a way as to achieve a particular end, that a 'party under the age of 18, even though legally competent, would lose the most critical element of the right to self-determination, the right to refuse'.⁶⁵ Thirdly, Lord Donaldson denied those provisions in the Children Act 1989 that allowed for a sufficiently mature child subject to a supervision order to make an informed choice about proposed examinations or treatment. In his view ss 38(6), 43(8) and 44(7) of that Act 'all concern interim or supervision orders and do not impinge upon the jurisdiction of the court to make prohibited steps or specific issue orders'.⁶⁶ In all subsequent cases where the refusal of treatment by a minor has been contested, the courts have universally taken the position assumed by Lord Donaldson, despite the fact that such judgments may, according to Jackson, 'permit the Court, in exercising its inherent jurisdiction, to override the express and unambiguous provisions of a statute'.⁶⁷ This

59. *Re W*, above n 6, at 639.

60. *Ibid*, at 634–635.

61. Freeman, above n 53, at 203.

62. *Re W*, above n 6, at 634.

63. Freeman, above n 53, at 203.

64. *Re R*, above n 55, at 23.

65. Quoted in Jackson, above n 48.

66. *Re W*, above n 6, at 638.

67. Jackson, above n 48.

may be a reflection of the implicitly undemocratic nature of judicial law making, but, according to Perry, when ruling on 'hard cases' judicial freedom to amend existing legal rules or generate new ones must be constrained. Judges have a responsibility to engage in impartial moral and legal reasoning so that the outcome coheres with the rest of the law.⁶⁸ Whether Lord Donaldson's judgments in *Re R* or *Re W* adhere to these stipulations has been a subject of intense academic scrutiny,⁶⁹ but what is undoubted is that subsequent case-law has remained faithful to his interpretation.

In total there have been seven cases pertaining to the refusal of life-sustaining treatment by adolescents that have come before English courts. Two of these concerned minors with anorexia nervosa,⁷⁰ four related to children who rejected blood transfusions because of their religious convictions⁷¹ and one involved the refusal of a heart transplant by a 15-year-old girl following an acute illness.⁷² Three of the seven were over 16 years at the time, while three more were 15½ years old. The child in *Re M* was 14. Some of the minors involved in these cases had been declared competent by physicians⁷³ or the courts,⁷⁴ or had their general intellect commented upon⁷⁵ in the process of their hearings. None of the children seem to have been of sub-normal intelligence. Thus, on the face of it, the majority, if not all, of these minors would appear to have been competent by statute or by the standards set in *Gillick*. The refusal of consent by these adolescents thus required the judiciary to formulate legal devices in order to protect doctors against claims of trespass should they initiate treatment against the will of the patient. In general, the courts invoked two principles, which I will term specific incapacity and welfare, in order to override the patient's decision.

Specific incapacity

In a number of cases declarations were made to the effect that, despite their level of intelligence, the adolescents in question lacked the requisite capacity to make the relevant decisions for a variety of reasons. First, in the instance of anorexia it was argued that suffering from this form of mental illness destroyed 'the ability to make an informed choice'.⁷⁶ While this point might be subject to philosophical debate, at least

68. TD Perry *Moral Reasoning and Truth: An Essay in Philosophy and Jurisprudence* (London: Clarendon Press, 1976) pp 85–86.

69. See n 56.

70. *Re W*, above n 6; *Re C (Detention: Medical Treatment)* [1997] 2 FLR 180 (*Re C*). The life and death nature of *Re W* is debatable as she was not refusing all treatment. I have included the case because of its central nature in defining the limits of adolescent autonomy. In *Re C* there was testimony from a psychiatrist that C was 'putting herself at risk of collapse and sudden death within 3 to 7 days'; at 187.

71. *Re S (A Minor) (Refusal of Medical Treatment)* [1995] 1 FCR 604 (*Re S*); *Re L (Medical Treatment: Gillick Competency)* [1998] 2 FLR 810 (*Re L*); *Re E*, above n 1; *Re P*, above n 6.

72. *Re M (A Child: Refusal of Medical Treatment)* [1999] 2 FCR 577 (*Re M*).

73. *Re W*, above n 6, at 640. Dr G testified: 'basing my view on discussion with [W] . . . I am convinced that she has a good intelligence, and understands what is proposed as treatment'.

74. *Ibid.*, at 627. Thorpe J held that, although W had sufficient understanding to make an informed decision, he had inherent jurisdiction to make the order sought. See also *Re M*, above n 72, at 581.

75. *Re E*, above n 1, at 391: 'I find that A is a boy of sufficient intelligence to be able to take decisions about his own well-being . . . Impressed though I was by his obvious intelligence . . . '.

76. *Re W*, above n 6, per Balcombe LJ at 640. *Re C*, above n 70, at 195–196.

the courts have been consistent in their approach to this problem regardless of the age of the individual.⁷⁷ A second reason for overriding the autonomy of a minor was that the consequences of the decision were of such gravity that the capacity required to exercise proper choice was beyond that possessed by the average (or even highly intelligent) adolescent.⁷⁸ An alternative version of this came when Ward LJ adjudged that E failed to understand fully the consequences of his decision; in particular he was unable to foresee the exact nature of his death.⁷⁹ If the validity of consent is predicated upon a precise knowledge of pathological processes then few signed consent forms are likely to be legally meaningful because, as Brazier notes, how many of us 'enjoy such insight?'⁸⁰ Grubb asserts that by tacking on such requirements to assessments of capacity the courts have created a test that makes it 'very difficult if not impossible for a teenager ever to be legally competent'.⁸¹ The third reason given for denying the capacity of a minor was premised upon the notion that an individual needs to be informed of all relevant risks and benefits in order to give effective consent. In *Re L*, Sir Stephen Brown P remarked that the surgeon 'did not, however, feel it appropriate – and I can well understand why – to go into detail about the manner of the death'.⁸² As a consequence, it was observed that the child did not possess sufficient information about the procedure she was to undergo and so her refusal of consent could not be considered competent.⁸³ This reasoning seems specious and if it were law would appear to legitimise the manipulation of anyone's capacity, regardless of their age or maturity, simply on the basis of non-disclosure of pertinent information by a doctor, an omission that in itself would appear to be negligent.⁸⁴ Finally, in cases where minors refused blood transfusions because of their religious convictions, the courts intimated that the children lacked voluntariness, or were unable to make a free choice because of the undue influence of others.⁸⁵ Coercion entails the deliberate intention to influence another's decision by the use of a serious, credible and irresistible threat,⁸⁶ while the notion of undue influence involves illegitimate or overbearing persuasion.⁸⁷ It is this latter concept that led Ward LJ to conclude regarding E:

'I find that the influence of the teachings of the Jehovah's Witnesses is strong and powerful . . . He is a boy who seeks and needs the love and respect of his parents whom he would wish to honour as the Bible exhorts him to honour them. I am far from satisfied that at the age of 15 his will is fully free . . . his volition has been conditioned by the very powerful expressions of faith to which all members of the creed adhere.'⁸⁸

77. Mental Health Act 1983, s 63 allows for the treatment, including tube feeding, of patients with anorexia against their will. See, eg, *Re KB (Adult) (Mental Patient: Medical Treatment)* [1994] 19 BMLR 144 per Ewbank J at 146. Referred to with approval by Hoffmann LJ in *B v Croydon HA* [1995] Fam 133 at 139.

78. A Grubb 'Commentary on *Re L*' (1999) 7 Med Law Rev 58.

79. *Re E*, above n 1, at 391. See also *Re S*, above n 71, at 615.

80. Brazier and Cave, above n 35, p 405.

81. Grubb, above n 78, at 61.

82. *Re L*, above n 71 at 811.

83. *Ibid*, at 813.

84. Brazier and Cave, above n 35, pp 99–120.

85. *Re E*, above n 1, at 393. See also *Re S*, above n 71, at 613.

86. R Faden, T Beauchamp and N King *A History and Theory of Informed Consent* (Oxford: Oxford University Press, 1986) p 339.

87. *Re T*, above n 35, per Lord Donaldson MR at 113–114.

88. *Re E*, above n 1, at 393.

Many people might find religious tenets that demanded the rejection of life-saving therapy as somewhat irrational,⁸⁹ but mainstream spiritual beliefs are no less ethereal. The question here was whether, given his religious upbringing, E could make a free choice. One does not have to embrace determinism to appreciate that many aspects of one's upbringing continue to have an influence on our decision-making processes in later life, and there is little evidence to suggest that the views we express with 'the vehemence and conviction of youth'⁹⁰ suddenly abate on reaching the age of majority. The Jesuitical aphorism 'give me the boy until the age of seven, I will give you the man' would seem to have particular resonance here. This was especially true in the tragic case of E who rejected further transfusions upon turning 18 and died soon afterwards.⁹¹

Welfare

Perhaps a more honest approach by the courts was to declare that the competence of the minor was irrelevant:

'there must come a point at which the court, while not disregarding the child's wishes, can override them in the child's own best interests, objectively considered. Clearly such a point will have come if the child is seeking to refuse treatment in circumstances which will in all probability lead to the death of the child.'⁹²

In essence the courts took the view that adolescents need to be protected from themselves, that their best interests dictated that they have a 'chance to live a precious life'.⁹³ According to Nolan LJ, it is 'the duty of the court to ensure so far as it can that children survive to attain that age (18)'.⁹⁴ In this context, it might also be argued that healthcare professionals are under an obligation to act only for the well-being of their patients. If this is a primary duty of doctors, which can only be trumped by the clearest exercise of (adult) autonomy, then an adolescent's refusal of care might be regarded as insufficient to negate a physician's basic obligation. This line of reasoning, however, seems excessively paternalistic as it takes no account of individual capacity, and would seem to empower a doctor to override the express wishes of a competent young patient in order to uphold values held by the medical profession, rather than those held by the patient herself. While emotively adopting a standpoint that prevents the loss of young lives seems almost irresistible, it must be noted that these arguments construe the prolongation of physical being as the sole worthwhile existential property, and ignore the relevance of psychological, emotional and spiritual elements.

THE AGE OF CRIMINAL RESPONSIBILITY

While the law's engagement with adolescent autonomy is a particularly recent phenomenon, criminal jurisprudence has a much longer acquaintance with children and

89. *Re W*, above n 6, per Lord Donaldson at 637.

90. *Re E*, above n 1, at 393.

91. *Re S*, above n 71, at 614.

92. *Re W*, above n 6, per Balcombe LJ at 642. See also *Re P*, above n 6, and *Re C*, above n 70, at 189.

93. *Re E*, above n 1, at 393.

94. *Re W*, above n 6, per Nolan LJ at 647.

has not been so diffident in attributing competence to them. There has generally been recognition that children under a certain age lack the capacity to be criminally culpable, and it is interesting that this has changed little over millennia. The limited sources available from Ancient Greece indicate that while Athenians regarded children as physically, mentally and morally incapable,⁹⁵ they remained liable for homicidal acts.⁹⁶ In Roman civilisation *infantes* (under the age of 7) who caused the death of another were exempted from prosecution under the law on murder as they were deemed incapable of homicidal intent. Those between *infantes* and the age of puberty (14) were also generally seen as being free from criminal intent, but were liable to prosecution, according to Julian, if they were *doli capax*.⁹⁷ Thus, a child's physical and mental capacities and their ability to appreciate wrongdoing were considered before responsibility was attributed.

Under English common law, the age of majority was historically concerned with defining the authoritative relationship between adults and children in a pre-industrial patriarchal social system.⁹⁸ Although it was not necessarily related to criminal responsibility, at various times the ages of culpability and majority approximated. Ine, a seventh-century West Saxon king, deemed that by the age of 10, a boy could be 'privy to a theft', but contemporary law would also have entitled him to manage his own lands.⁹⁹ Later, the Laws of Aethelstan (925 AD) specified that only those over 12 could be punished as an adult, while capital punishment should be reserved for those over 15,¹⁰⁰ which was also the age of majority at the time.¹⁰¹ By 1215, when the *Magna Carta* was issued, the age of majority increased to 21 for military personnel, although it was less for agricultural tenants.¹⁰² Later, some London Boroughs invoked a rule whereby the 'years of discretion, which brought to a child independent responsibility for crime and trespass, were . . . chosen to give the child full legal capacity'.¹⁰³ Gradually, however, 21 became the accepted age of majority, where it remained until 1969. By contrast, children were liable to be punished for crime from the age of 7.¹⁰⁴ Blackstone's *Commentaries on the Laws of England* outlined the criminal responsibility of children under the common law:

95. M Golden *Children and Childhood in Classical Athens* (Baltimore: Johns Hopkins University Press, 1993) p 5.

96. *Ibid*, p 40.

97. 'Capable of evil': B Rawson *Children and Childhood in Roman Italy* (Oxford: Oxford University Press, 2003) pp 74–75. A more modern judicial translation of the term *doli incapax* is 'incapacity of committing an offence'. See *R v JTB* [2009] UKHL 20, [2009] 1 AC 1310 per Lord Phillips at [8].

98. D Gorham 'The "Maiden Tribute of Modern Babylon" re-examined: child prostitution and the idea of childhood in late-Victorian England' (1978) 21 *Victorian Studies* 353 at 362.

99. MS Kuefler "'A Wryed Existence": attitudes toward children in Anglo-Saxon England' (1991) 24 *J Soc Hist* 823 at 826.

100. WB Sanders (ed) *Juvenile Offenders for a Thousand Years: Selected Readings from Anglo-Saxon Times to 1900* (Chapel Hill, NC: University of North Carolina Press, 1970) pp 3–4.

101. TE James 'The age of majority' (1960) 4 *Am J Legal Hist* 22 at 25.

102. *Ibid*, at 26–30.

103. *Ibid*, at 23.

104. I Pinchbeck 'The state and the child in sixteenth-century England – II' (1957) 8 *Brit J Sociol* 59.

‘under seven years . . . infant cannot be guilty of felony, for then a felonious discretion is almost an impossibility in nature . . . at eight . . . he may be guilty of felony . . . if it appear to the court and jury that he was *doli capax* . . . he may be convicted and suffer death.’¹⁰⁵

Thus, the courts were not so much guided by ‘years and days, as by the strength of the delinquent’s understanding and judgment . . . *malitia supplet aetatem*’.¹⁰⁶ In the early nineteenth century the justice system scarcely discriminated between children and adults in terms of criminal procedures or sanctions. Classical free-will theories depicting the criminal as a rational agent choosing crime were heavily influential, and thus responsibility, retribution and deterrence were key parts of a punitive system. Later, a more welfarist approach to juvenile crime saw the creation of separate institutions in which to incarcerate young offenders, while the Children Act 1908 abolished the death penalty for children and established the juvenile court system. The Children and Young Persons Act 1933 changed the minimum age of criminal responsibility from 7 to 8 years, later raised to 10 by the Criminal Justice Act 1963.¹⁰⁷ Fionda argues that the 1990s saw a retreat from the liberal position,¹⁰⁸ while Fortin maintains that ‘the last twenty years have seen an increasingly punitive approach to young people who offend, particularly the very young ones’.¹⁰⁹ Indications of this punitive ideology might be seen in the Criminal Justice and Public Order Act 1994, which reduced the minimum age for detention from 14 to 10 years in the case of grave crimes, and the Crime and Disorder Act 1998, s 34, which abolished the presumption of *doli incapax*.¹¹⁰ This centuries-old common-law doctrine was enshrined to ensure that an allowance was made for children with immature faculties of reasoning, comprehension and knowledge; that instigating punitive measures against those without developed capacity lacked moral justification.¹¹¹ With regard to a defendant (between the ages of 10 and 14) the prosecution thus had to establish:

‘for the purposes of ascertaining criminal responsibility . . . not knowledge of unlawfulness but knowledge that what he did was seriously wrong, beyond any measure of mere naughtiness that the child understood his act as seriously wrong rather than merely mischievous or naughty.’¹¹²

It is uncertain whether the presumption of *doli incapax* actually prevented many prosecutions or convictions.¹¹³ While it was, in general, easily rebutted without the need for expert evidence, the presumption still identified this period of a child’s life as

105. W Blackstone *Commentaries on the Laws of England: In Four Books. Vol. IV: Of Public Wrongs* (London: T Cadell and W Davies, 1809) pp 22–23.

106. Malice supplies age.

107. J Fionda ‘Youth and justice’ in J Fionda (ed) *Legal Concepts of Childhood* (Oxford: Hart Publishing, 2001) pp 78–82.

108. Ibid, pp 82–83.

109. J Fortin *Children’s Rights and the Developing Law* (Cambridge: Cambridge University Press, 2005) p 547.

110. R Arthur ‘Young offenders: children in need of protection’ (2004) 26 Law & Policy 309 at 317.

111. D Haydon and P Scraton “‘Condemn a little more, understand a little less’: the political context and rights implications of the domestic and European rulings in the Venables-Thompson case’ (2000) 27 J Law Society 416 at 420.

112. *C v DPP* [1994] 3 WLR 888 at 890–891.

113. H Keating ‘Reckless children?’ (2007) Crim L R 546 at 550.

a transitional bridge between criminally incapable younger childhood and capable adolescence.¹¹⁴ Walker argued that s 34 merely abolished the presumption, but that the defence of *doli incapax* might still be open to children (between 10 and 14 years).¹¹⁵ However, the House of Lords recently denied this possibility, finding that s 34 abolished both the presumption and the defence.¹¹⁶ Citing some ‘startling results’ arising from appeal to the defence of *doli incapax*,¹¹⁷ Lord Phillips concurred with the views of Laws J in *C v DPP*: ‘this presumption at the present time is a serious disservice to our law . . . It is unreal and contrary to common sense’.¹¹⁸ Lord Phillips continued:

‘These . . . cases demonstrated that the rebuttable presumption of *doli incapax* was an anachronism. Children in the 20th Century had to go to school where they were, or were supposed to be, taught the difference between right and wrong. In the case of some offences it beggared belief to suggest that young Defendants might not have appreciated that what they were doing was seriously wrong.’¹¹⁹

The abolition of *doli incapax* has meant that a child who has attained the age of 10 years is now subject to be tried using the same principles of criminal law as an adult.¹²⁰

RESPONSIBILITY: ADOLESCENT CRIME AND AUTONOMY

What of Mary? Because she was found guilty there was an ex-post ascription of causal responsibility and legal liability to her. She breached the criminal code by unlawfully killing another while having the intention either to kill or to do serious harm to V.¹²¹ However, causal accountability, by assigning discretion and intention to an individual,¹²² also says something about the mind of that person at the time immediately before the crime was committed. First, Mary had a choice as to whether she would commit the act in question; she had an array of alternate possibilities open to her. Discretion, in part, relates to what Hart termed the ‘idea of obligation’.¹²³ The law dictates that we are obligated to perform certain acts and refrain from others; in Mary’s case the law placed her under an obligation to refrain from harming V. Mary

114. Ibid.

115. N Walker ‘The end of an old song?’ (1999) 149 NLJ 64.

116. *R v JTB*, above n 97.

117. The cases referred to were *JBH and JH (Minors) v O’Connell* [1981] Crim LR 632; *IPH v Chief Constable of South Wales* [1987] Crim LR 42.

118. *C v DPP*, above n 112, at 894.

119. *R v JTB*, above n 97, at [20].

120. E Stokes ‘Abolishing the presumption of *doli incapax*: reflections on the death of a doctrine’ in J Pickford (ed) *Youth Justice: Theory and Practice* (London: Cavendish Publishing, 2000) p 51.

121. Law Commission *Murder, Manslaughter and Infanticide* (London: TSO, 2006) s 1.13.

122. ‘Subject to three exceptions, the crime of murder is committed where a person of sound mind and discretion unlawfully kills any reasonable creature in being and under the Queen’s peace with intent to kill or cause grievous bodily harm’. The exceptions relate to the defences of provocation, diminished responsibility and action in pursuance of a suicide pact: J Richardson (ed) *Archbold: Criminal Pleading, Evidence and Practice* (London: Sweet & Maxwell, 2000) p 1622.

123. HLA Hart *The Concept of Law* (Oxford: Clarendon Press, 1961) pp 79–88.

chose to ignore this restriction on her actions; she made a mental decision to choose a particular course of action from the array of possibilities available to her. In addition, Mary must also have intended to cause serious harm to V, again choosing from the menu of options available to her – from inflicting minor or no harm to serious or fatal harm. In making these choices Mary took prospective responsibility for the crime she was about to commit. In order to find her guilty, the court must have believed that Mary had the mental capacity to have taken such choices and assumed prospective responsibility.

The case for the abolition of the defence of *doli incapax* was based on three contentions: that it was archaic, illogical and unfair in practice.¹²⁴ Its outdated nature was purportedly apparent in the fact that:

‘it assumes . . . that in general, a child under 14 cannot differentiate right from wrong . . . the notion that the average 10–14 year old does not know right from wrong seems contrary to common sense in an age . . . when children seem to develop faster both mentally and physically.’¹²⁵

However, as has been noted, that ability to discriminate between right and wrong does not necessarily equate with a capacity to take personal responsibility for acts.¹²⁶ This claim has been repeated, often by those with considerable expertise in psychological and cognitive development.¹²⁷ However, such assertions have largely fallen on deaf ears, the law generally preferring to reinforce the notion that those above the age of responsibility are ‘mature enough to be accountable’.¹²⁸ The White Paper *No More Excuses* determined that children should receive a clear signal that they will be held responsible for their actions.¹²⁹ As a general philosophy it would seem unfair to ascribe such responsibility to individuals who were not capable of self-government; we do not, as a general rule, assign such agency to animals. It would thus seem reasonable to assume that legislators perceive children who are convicted of criminal acts as responsible agents with regard to those acts. The law thus must implicitly hold certain concepts about young people to be true. With regard to Mary these might include the following: (1) that she was capable of reflecting upon available choices, weighing them up and coming to a decision as to whether to take action X or refrain from act Y; (2) that she understood the notion of risk and dangerous activities; (3) that she had some comprehension of the consequences of such choices, both in terms of outcome for V and her liability with respect to that action; (4) that she had some idea of both a sliding scale of possible harms that might result from her action when

124. Home Office *Consultation: Tackling Youth Justice* (London, HMSO, 1997) para 7.

125. *Ibid.*, para 8.

126. Home Office *Report of the Committee on Children and Young Persons* Cmnd 1191 (London: HMSO, 1960) para 81. The Ingleby Committee was set up to review the powers and proceedings of juvenile courts and the provisions for preventing cruelty to and neglect of children. See also Keating, above n 10, at 189–190.

127. See, eg, Royal College of Psychiatrists, above n 7.

128. Home Office *No More Excuses – A New Approach to Tackling Youth Crime in England and Wales* Cm 3809 (London: HMSO, 1997) p 2. Ministry of Justice *Murder, Manslaughter and Infanticide: Proposals for Reform of the Law. Summary of Responses and Government Position* (London: TSO, 2009) para 100.

129. Home Office, *ibid.*

perpetrated with different degrees of force, and of the nature of death;¹³⁰ and (5) by virtue of mentally making her choice she assumed prospective responsibility for acting in the way she did.

Sufficient mental capacity is an essential prerequisite of culpability; otherwise the law would not need to set a minimum age of criminal responsibility. This standard of mental capacity is generally regarded as being set at a low level.¹³¹ However, there appears to be a tension here as the above analysis would seem to indicate that the law has attributed a level of reasoning to Mary that is more sophisticated than some minimal norm. The criminal courts do not appraise whether this degree of erudition is present, but assume it to be so based on age, particularly since the abolition of *doli incapax*. This presumption of capacity responsibility by the criminal justice system stands in marked contrast with what appears almost as a presumption of incapacity by the courts in other legal arenas. When Mary refuses medical treatment, the court is likely to deny that she is capable of assuming responsibility for her healthcare decision, and may well provide some of the reasons previously invoked in adolescent autonomy cases as a basis for this decision. In a way these reasons might be regarded as grounds for excusing Mary from being responsible. These 'excusing conditions' might be summed up as follows: (1) mental illness; (2) lack of foresight, information or knowledge; or (3) undue influence of others. It is unlikely that any of these conditions would excuse Mary from being found guilty of murder. The first, mental illness, is not particularly relevant in this instance. The Homicide Act 1957 allows for a plea of diminished responsibility in cases where arrested or retarded development, or disease or injury of the mind substantially impairs mental functioning,¹³² while to establish a defence of insanity it must be demonstrated that 'the party accused was labouring under such a defect of reason, from disease of the mind, as not to know the nature or quality of the act he was doing, or if he did know it, that he did not know he was doing what was wrong'.¹³³ In this instance, Mary suffered from no form of mental illness, and the possibility of diminished responsibility due to adolescent immaturity is not currently recognised under English law.¹³⁴ Apropos of the second condition, in general ignorance does not absolve us from responsibility. In particular, a lack of knowledge of the exact nature of V's death would not reduce Mary's culpability. That she might not know, for example, that a stab wound to the chest could result in V's

130. If Mary had only intended to harm V seriously rather than kill him, then it is possible that she could be found guilty of murder without having an understanding of the nature of death. The Homicide Act 1957 required malice aforethought to be established in order for a murder conviction to be secured. This entailed that the defendant had to be at least aware that the harm done was life-threatening. Subsequent court judgments held that a jury could find a defendant guilty of murder even if he or she only intended to cause serious harm. See Law Commission, above n 121, s 1.26–1.29. For the purposes of this analysis I have assumed that Mary deliberately killed V. In the Bulger murder trial, Venables and Thompson, who were 10 when committing their offence, were deemed by the trial judge, Morland J, to have carried out the abduction of Jamie Bulger for the purpose of killing him, n 3 above. If two young boys can have an understanding of what it means to take a life away, then it seems implausible that a 15-year-old adolescent of normal intelligence would not have a similar, and in all probability, more mature concept of death.

131. Cane, above n 25, p 72.

132. Section 2.

133. *M'Naghten's Case* [1843] 10 Cl & Fin 200 at 210.

134. Law Commission, above n 121, s 5.125–5.137. Ministry of Justice, above n 128, paras 99–103.

lungs filling with blood, his gasping for breath followed by progressive hypoxaemia, acute organ failure and death is rightly not germane to her capacity responsibility. If it were, then only healthcare professionals or perhaps even forensic pathologists could be held so responsible. Thirdly, no form of undue influence or duress excuses one from being responsible for murder or attempted murder, no matter how severe the threat.¹³⁵ The Law Commission provides an interesting example of this:

‘A psychopathic father compels his eleven-year-old son through threats of death to participate in the murder of one of the father’s rivals . . . It seems to be nothing less than an affront to justice that the father may be convicted only of manslaughter, on the grounds of diminished responsibility (due to his psychopathic disorder), but his son must be convicted of murder if his participation involved knowingly taking part in the killing.’¹³⁶

This fictional account provides an interesting contrast with those cases where a particular religious upbringing (presumably by a non-psychopathic family) might be felt to influence unduly an adolescent’s decision to reject life-sustaining treatment.

How can we state, as the courts appear to, that Mary had the capacity responsibility to commit a homicidal act but not to refuse medical care? Before she killed V she had to understand that if she chose to act in a particular way then this action might result in serious harm to V or his death. Her range of choices concerning the acceptance or rejection of treatment entailed similar decisional parameters. If the decision D1 to commit act A1 is likely to result in the death of a person (V), and the decision D2 to commit act A2 is also likely to result in the death of a person (herself), then for the courts to discriminate between Mary’s abilities to assume responsibility for both decisions there must be some fundamental difference between the mental mechanics required for D1 and D2. The court has already attributed Mary with the capacities of reflection, analysis and decision making with regard to her crime, and also with a comprehension of consequences, liability and harms (including death). According to Buchanan and Brock, the capacities necessary for competent healthcare decision making might be generalised as those of communication, understanding, reasoning and deliberation, and ‘a set of values or conception of the good’.¹³⁷ There seems nothing in these generic properties that the court does not already presume Mary to possess by virtue of her conviction. There thus seems little difference in the capacities required to be prospectively responsible for choices or actions that pertain to either criminal acts or one’s personal healthcare decisions.

COHERENCE AND THE LAW

Should we take Mary’s problem seriously? Simply put, the criminal justice system has a responsibility to prosecute wrongdoing, while it seems reasonable that the family courts should err on the side of life rather than death. However, the Beijing Rules

135. Law Commission *A New Homicide Act for England and Wales? Consultation Paper No 177* (London: TSO, 2005) paras 1.72–1.78; *R v Howe* [1987] 2 WLR 568; *R v Gotts* [1992] 2 AC 412.

136. Law Commission, *ibid*, paras 1.78–1.79.

137. A Buchanan and DW Brock ‘Deciding for others’ (1986) 64 Supplement 2 Milbank Q 17 at 24–26.

might suggest that the fair ascription of responsibilities and rights is a matter of justice. The mathematical disparity in respective ages between culpability and autonomy, or responsibility and right, in England is 8 years, one of the widest in the European Union.¹³⁸ This contrasts markedly with other jurisdictions such as Germany, where the gap is 4 years, or Belgium, where there is no gap at all,¹³⁹ and raises questions of fairness and equity. One way of narrowing the gap might be to increase the age of criminal responsibility. A number of organisations have criticised the low age at which criminal culpability starts in the UK¹⁴⁰ but, despite a series of reports and white papers suggesting that it should be increased to 12,¹⁴¹ 14¹⁴² or 16,¹⁴³ this age has remained at 10 since 1963. Recent political rhetoric on the issue would seem to suggest that this is unlikely to change in the near future.¹⁴⁴ Thus, in general terms, the law denies full autonomy until the age of 18 largely because of presumed incapacity¹⁴⁵ but holds that those above the age of 10 have sufficient decision-making capacity to be held accountable for criminal acts.¹⁴⁶ In Mary's case, the courts are likely to have treated her as an adult with respect to the act that brought about the death of another,¹⁴⁷ yet as an incapable child when she refused life-saving treatment.

This seems an incongruous situation and raises questions about the coherence of the law in its dealings with children in that it appears to perceive the views and actions of minors as reflective of immaturity for some legal purposes but of full agency for others. As a general principle, legal coherence would seem an important tenet of jurisprudence. Lord Nicholls maintained that:

138. The UK countries have 'the lowest age of criminal responsibility in western Europe': *House of Lords Debates* 20 November 2007, 731 as per Baroness Miller at 734. See also L Palme 'No age of innocence: justice for children' in *The Progress of Nations* (New York: UNICEF, 1997).

139. In Belgium, Art 388 of the Civil Code, amended by Art 1 of the Law of 19 January 1990 reduced the civil majority to 18 years. A minor lacks the legal capacity to contract with a physician or a hospital. The age of criminal responsibility is also 18. See Fortin, above n 109, p 550.

140. See, eg, Committee on the Rights of the Child *Consideration of Reports Submitted by States Parties Under Article 44 of the Convention. Concluding Observations: United Kingdom of Great Britain and Northern Ireland* (Geneva: United Nations, 2008) para 78; The Children's Society *Children in Trouble with the Law* (London: TCS, 2008); R Allen *From Punishment to Problem Solving: A New Approach to Children in Trouble* (London: Centre for Crime and Justice Studies, 2006).

141. Home Office, above n 126, para 93.

142. Children and Young Persons Act 1969.

143. Home Office *The Child, the Family and the Young Offender* Cmnd 2742 (London: HMSO, 1965).

144. See Ministry of Justice, above n 128, paras 99–103. See also, eg, the House of Lords debate on 20 November 2007, available at <http://www.parliament.the-stationery-office.com/pa/ld200708/ldhansrd/text/71120-0001.htm>, and comments made by both the Home Office and the Shadow Home Affairs Minister in response to calls for an increase in the age of criminal responsibility: BBC News 'Criminal age "should be raised"' (22 September 2006), available at <http://news.bbc.co.uk/go/pr/fr/-/1/hi/uk/5369274.stm>.

145. Grubb, above n 78, at 60, suggests that the courts contrive to obfuscate and distort the legal concept of competence, to make 'it very difficult if not impossible for a teenager ever to be legally competent'.

146. Crime and Disorder Act 1998, s 34.

147. See S Bandalli 'Abolition of the presumption of doli incapax and the criminalisation of children' (1998) 37 *Howard J Crim Just* 114, and Stokes, above n 120.

‘(T)o be acceptable the law must be coherent. It must be principled. The basis on which one case, or one type of case, is distinguished from another should be transparent and capable of identification. When a decision departs from principles normally applied, the basis for doing so must be rational and justifiable if the decision is to avoid the reproach that hard cases make bad law.’¹⁴⁸

However, Cane suggests that while ‘consistency and coherence are aspects of justice . . . they do not exhaust it’.¹⁴⁹ Nevertheless, the law is consistent in its approach to adults. Once over 18 years an individual is presumed to possess the capacity to be either capable or culpable in the healthcare or criminal justice arenas, respectively. It is also consistent in dealing with those with mental incapacity. The Law Commission points out that ‘it is . . . the case that someone aged (say) 20, but with a mental age of ten, can plead diminished responsibility as they suffer from “arrested or retarded development of mind” under . . . the Homicide Act 1957’.¹⁵⁰ Individuals with this degree of mental disability are also likely to be deemed incapable of making important decisions about their medical welfare, particularly if their choice was likely to have serious consequences. In contrast with adults and the mentally disabled, children seem not to be dealt with in a consistent manner. The criminal law adjudges the capacity of children to be ‘reflected in the age of criminal responsibility, rather than in the reach of the “diminished” responsibility defence’.¹⁵¹ Logically, the same defence should apply to children as to the mentally disabled, that ‘someone who is in fact 10 years old should be able to plead . . . that their mental age may have substantially impaired their responsibility for the killing’.¹⁵² But this is not so. Unlike the incompetent adult, the child over 10 is presumed capax, and yet unlike the competent, also incapax in terms of healthcare decision making.

CONCLUSION

Much of the law seems to be dichotomous in nature: guilty/not guilty; liable/not liable; rational/not rational. The court system appears to regard children’s identities in a similarly binary fashion. Mary as a criminally responsible youth must bear responsibility for her choices, while as an adolescent refusing medical treatment she becomes a vulnerable child whose wish to be responsible for her own healthcare decision making is denied. In some ways, this is reminiscent of the Ancient Greek myth of the Procrustean bed. Procrustes had an iron bed into which he lured those passing by. If his victim was too tall he amputated their legs, and if too short they were stretched on the rack until they were long enough. Nobody ever fitted on the bed because it was secretly adjustable. Children of the age of 10 have their capacity stretched on the legislative rack in order to make them ‘responsible’, while in other contexts

148. *Fairchild v Glenhaven Funeral Services Ltd* [2003] 1 AC 32 at 68.

149. Cane, above n 25, at 20.

150. Law Commission, above n 135, para 6.75. The government response to Law Commission proposals to increase the age of criminal responsibility stated that the defence of diminished responsibility should not be available to children over the age of 10 unless they are suffering from a recognised medical condition which would make him or her ‘substantially less able to understand the nature of their conduct, form a rational judgment or exercise self-control’: Ministry of Justice, above n 128, para 100.

151. Law Commission, *ibid*, para 6.74

152. *Ibid*, para 6.75.

adolescents have theirs amputated by the courts in order to shrink their decisional competence. This manipulation of capacity unfortunately obscures the fact that children, just like adults, may be divided into those who have capacity responsibility for certain decisions and those who have not. Although the percentage of the population in the former category increases with age there is no biological turning point that acutely renders the incompetent competent.

Honoré suggests that being responsible for the outcome of our conduct is essential for our identity formation; that 'to deny people's responsibility for their actions is to strike at their identity'.¹⁵³ If children are to be held accountable by the criminal justice system then it seems that we should recognise their capacity to make their own healthcare decisions. We may not like their choices, but if we believe them to have an identity that bears responsibility then we must trust their capacity to exercise their preferences. By contrast, if we disallow children from making autonomous healthcare choices on the basis of decisional incompetence, then the criminal justice system would seem to have little entitlement to hold them responsible for acts that transgress the criminal law. Rather, they should be dealt with, as in other jurisdictions, by agencies outside of the criminal law.

153. T Honoré *Responsibility and Fault* (Oxford: Hart Publishing, 1999) p 10.