



Introduction

Although the law may be far from our minds as we try to make healthcare decisions in circumstances which can be difficult and traumatic, in fact, the law plays a central role in the decision-making process. It provides the framework within which we deliberate; it tells us when we can make decisions for ourselves and when we cannot and it dictates what happens to us when our right to make our own decisions is removed. This book critically evaluates the law's engagement with the process of healthcare decision-making and explores ways in which this might be enhanced.

Since the latter part of the twentieth century, the law's approach to healthcare decision-making has centred on ensuring respect for the principle of individual autonomy. In this, the law reflects the predominant ethical status which has been accorded to the principle.¹ Thus, John Stuart Mill's famous aphorism that '[o]ver himself, over his own body and mind, the individual is sovereign'² might be seen as the defining summation of principle. This principle is given legal effect in Cardozo J's often-cited dictum that 'every human being of adult years and sound mind has a right to determine what shall be done with his own body'³ Yet, the reality has always been more complex than citations of Mill or Cardozo might suggest. The status of autonomy within ethical discourse has been challenged for almost as long as the principle has been revered, while in a legal context the degree of respect accorded to the principle of autonomy has varied depending on the circumstances in which the principle is called into action. The principle has been most influential in respect of treatment refusal, especially where the refusal is based on adherence to religious beliefs. At the same time, however, in many jurisdictions the right of a capable patient to refuse treatment for a mental disorder has

¹ See O. O'Neill, *Autonomy and Trust in Bioethics* (Cambridge University Press, 2002), p. 2.

² J. S. Mill, *On Liberty* (London, 1859) in J. Grey (ed.) *On Liberty and Other Essays* (Oxford University Press, 1991), p. 14.

³ *Schloendorff v. Society of New York Hospital* (1914) 211 NY 125, 128.

been decisively sidelined by mental health legislation. Where the right of autonomy is recognised, the law has relied on the requirement for capacity to act as gatekeeper for the application of the right. Thus, while respect for autonomy provides the principled foundation for the law's approach to decision-making, the question of whether or not each individual's decision will actually be respected is dependent on whether she meets the legal standard for capacity in respect of the decision in question.

The symbiotic relationship between the principle of autonomy and the requirement for capacity has a number of consequences for the law's response to healthcare decision-making. First, the law relies on capacity to deal with difficult cases on an individual basis. This has allowed the law to lend its support to autonomy with little analysis of what the principle actually means or of how conflicts with other principles should be resolved. The law's approach is effectively summarised by Lord Donaldson MR in *Re T (Adult: Refusal of Medical Treatment)*.⁴ Setting out the applicable principle in the strongest terms, Lord Donaldson found that:

An adult patient who ... suffers from no mental incapacity has an absolute right to choose whether to consent to medical treatment, to refuse it or to choose one rather than another of the treatments being offered ... This right of choice ... exists notwithstanding that the reasons for making the choice are rational, irrational, unknown or even non-existent.⁵

However, His Lordship went on to note that the legal recognition of the right to consent to or refuse treatment 'merely shifts the problem ... and calls for a very careful examination of whether, and if so the way in which, the individual is exercising that right'.⁶

Secondly, the law has treated autonomy as the principle-based part of the dyad, with capacity being treated as a simple matter of fact. Yet the capacity requirement is inherently normative. As Allen Buchanan and Dan Brock remind us, '[t]he proper standard of competence must be chosen; it cannot be discovered'.⁷ Whether or not a person has capacity to make a particular decision depends on whether she reaches a designated standard in respect of specified abilities. What is required, both in respect of the standard to be reached and in respect of the necessary abilities, depends on the view of autonomy which we hold. This, in turn, depends on our view of the relationship between the individual and society and the point at which we believe societal duties to protect are implicated.

⁴ [1992] 3 WLR 782. ⁵ *Ibid.*, 786. ⁶ *Ibid.*, 796.

⁷ A. Buchanan and D. Brock. *Deciding for Others: The Ethics of Surrogate Decision Making* (Cambridge University Press, 1989), p. 47.

Normative factors also impact on the day-to-day operation of the capacity requirement. In reality, the law's requirement that capacity be assessed without reference to the nature of the decision the person proposes to make is almost impossible to meet.

Thirdly, the application of the capacity requirement sorts people into those whose voluntary decisions must be respected and those 'whose decisions, even if uncoerced, will be set aside and for whom others will act as surrogate decision-makers'.⁸ Evidently, the impact of this sorting process is not neutral. People with capacity represent the norm. Those who do not are defined in contrast to this norm; they are, in this sense, the 'other'.⁹ As a consequence, legal and ethical discourse in respect of people lacking capacity has been impoverished. Traditionally, the law has tended to ignore the issue of decision-making in this context, behaving as if this did not need a conceptual basis beyond a generalised adherence to an amorphous best interests standard. This position is beginning to change, driven in part by broader human rights agendas, including those set by the European Convention on Human Rights (ECHR) and the United Nations Convention on the Rights of Persons with Disabilities (CRPD).¹⁰ Nonetheless, the legal consequences of a finding of incapacity remain significant.

The scope of the discussion

This book critiques the law's approach to healthcare decision-making and aspects of the liberal foundations upon which this has been based. In doing this, it focuses on three categories of people. These are adults with capacity, adults without capacity and adults who have been made subject to mental health legislation. The book does not attempt to address the particular issues which arise in respect of healthcare decision-making by and for children and young people. Although issues of autonomy, capacity and best interests arise in this context also, the unique nature of the relationship between parents and children gives rise to additional issues which cannot be discussed in sufficient depth in this work.¹¹ However,

⁸ *Ibid.*

⁹ The notion of 'othering' (defining people or groups as different from, and lesser than, a dominant group) is perhaps most closely associated with feminist theory, which identifies the way in which woman is seen as 'Other' in respect of a male norm: see S. de Beauvoir, *The Second Sex* (1949) Parshley, HM trans. (London: Penguin, 1972).

¹⁰ (2006) General Assembly Resolution 61/106.

¹¹ There are various ways of conceptualising the relationship between children and parents. Recent developments have seen a move from notions of parental rights to children's

some aspects of law's approach in respect of children are relevant to the discussion at hand and these will be referred to where appropriate.

In terms of jurisdictions covered, the book focuses primarily on the law in England and Wales. The law in this jurisdiction reflects a range of significant recent developments in terms of case law, policy debate and legislative intervention. The Mental Capacity Act 2005 (MCA) is especially interesting for the purposes of the discussion here because of its efforts to formalise the concept of capacity and to facilitate new approaches to decision-making for people lacking capacity.¹² The protracted reform process which ultimately culminated in the Mental Health Act 2007 (MHA 2007) is also informative from both policy and legal perspectives.¹³ In addition, parts of the book draw heavily on the legal position in the United States, which tends to adhere to a liberal autonomy-based model for decision-making in all circumstances, including incapacity and decisions in respect of treatment for a mental disorder. The book also includes discussion of aspects of the law of particular relevance to the arguments made from a number of other jurisdictions, including Australia, Canada, Ireland, New Zealand and Scotland.

Additionally, the book draws extensively on the jurisprudence of the European Court of Human Rights (ECtHR)¹⁴ and on the domestic

rights: see J. Fortin, 'Children's Rights: Are the Courts Now Taking Them More Seriously?' (2004) 15 *King's College Law Journal* 253. However, additionally, as noted by J. Bridgeman, *Parental Responsibility, Young Children and Healthcare Law* (Cambridge University Press, 2007), p. 228, the issue of parental responsibility arises. For an approach to healthcare decision-making for children based on a conception of relational responsibilities, see Bridgeman, pp. 228–42.

¹² The MCA became operational over the course of 2007 with the main body of the Act coming into force on 1 October 2007. The MCA places on a statutory footing the law relating to capacity in respect of healthcare and welfare decisions and introduces a new framework for decisions in respect of property and financial affairs. The MCA also establishes a Court of Protection (MCA, s. 45) which has an equivalent status to the High Court (s. 47(1)). The MCA, s. 45(6) abolishes the office of the Supreme Court which had been called the Court of Protection. See generally R. Jones, *Mental Capacity Act Manual* (3rd edn) (London: Sweet and Maxwell, 2009); P. Bartlett, *Blackstone's Guide to the Mental Capacity Act 2005* (2nd edn) (Oxford University Press, 2008).

¹³ The MHA 2007 amends the Mental Health Act 1983 in a number of respects including the introduction of 'supervised community treatment'. The MHA 2007 also amends the MCA, introducing measures covering admission to hospitals or care homes for people lacking capacity in circumstances where the admission constitutes a deprivation of liberty. The main part of the MHA 2007 came into force on 3 November 2008. See generally P. Fennell, *Mental Health: The New Law* (Bristol: Jordans, 2007).

¹⁴ The United Kingdom ratified the ECHR in 1951 and extended the right of individual petition to the ECtHR in 1966. However, prior to domestic incorporation, national courts had no obligation to take account of the jurisprudence of the ECtHR.

application of the ECHR in the case law, which has developed in England and Wales since the commencement of the Human Rights Act 1998 (HRA).¹⁵ The book also refers to other human rights instruments and, in particular, to the CRPD. As will be clear from the discussion, the CRPD is especially important in respect of decisions for patients lacking capacity and patients with a mental disorder. The CRPD entered into force on 3 May 2008, on receipt of its twentieth ratification. As of July 2010, the CRPD has been signed by 146 states and ratified by 88. Of the jurisdictions discussed in this book, the United Kingdom, Australia, Canada and New Zealand have ratified the CRPD while Ireland and the United States have signed the Convention but have not ratified it.¹⁶ The CRPD is especially significant for the discussion in this book because it breaks down traditional distinctions between civil and political rights, which are usually negative, and social and economic rights which are usually positive.¹⁷ An Optional Protocol operates alongside the CRPD. The effect of this is to allow individuals who consider that they have been the victims of a violation by a State Party of the provisions of the CRPD to directly petition the

¹⁵ The HRA incorporated the ECHR into UK law with effect from 2 October 2000. The HRA requires courts or tribunals in determining a question which has arisen in connection with an ECHR right to take account of any judgment, decision, declaration or advisory opinion of the ECtHR (HRA, s. 2(1)). The method of incorporation adopted requires courts to interpret existing legislation ‘in so far as is possible’ in a way which complies with the ECHR (HRA, s. 3(1)). If this is not possible, a declaration of incompatibility may be made (HRA, s. 4(2)); however, a declaration of incompatibility does not affect the validity, continuing operation or enforcement of the provision (HRA, s. 4(6)). All proposed bills must include either a statement of compatibility with the ECHR by the relevant Minister or a statement that the Minister cannot state the Bill’s compatibility but that the Government nonetheless wishes the House to proceed with the Bill (HRA, s. 19(1)). It is unlawful for ‘public authorities’ to act in a way which is incompatible with the ECHR unless they are statutorily bound to do so (HRA, s. 6(2)). For an overview of the HRA, see D. Feldman, *Civil Liberties and Human Rights in England and Wales* (2nd edn) (Oxford University Press, 2002), pp. 80–104; J. Wadham *et al.*, *Blackstone’s Guide to the Human Rights Act 1998* (5th edn) (Oxford University Press, 2009).

¹⁶ Other ratifying States include Italy, Spain, Sweden, South Africa and Mexico as well as a significant number of African and South American states.

¹⁷ On the CRPD generally, see A. Hendricks, ‘UN Convention on the Rights of Persons With Disabilities’ (2007) 14 *European Journal of Health Law* 272; A. Lawson ‘The United Nations Convention on the Rights of Persons With Disabilities: New Era or False Dawn?’ (2006–2007) 34 *Syracuse Journal of International Law and Commerce* 563; D. MacKay, ‘The United Nations Convention on the Rights of Persons With Disabilities’ (2006–2007) 34 *Syracuse Journal of International Law and Commerce* 323; R. Kayess and P. French, ‘Out of Darkness into Light? Introducing the Convention on the Rights of Persons With Disabilities’ (2008) 8 *Human Rights Law Review* 1.

Committee on the Rights of Persons with Disabilities.¹⁸ Of the jurisdictions discussed in this book, only Australia and the United Kingdom have acceded to the Optional Protocol.¹⁹

A final point relates to the terminology used in the book. First, in the interests of convenience, except where a specific gender-related point is under discussion, the book adopts the female pronoun throughout. Secondly, the book uses the term ‘capacity’ to mean both legal capacity and capacity in a more general sense. In this, it is consistent with the use of the term in the MCA but departs from the practice of some American commentators, who use the term ‘competence’ to describe legal capacity and the term ‘capacity’ for capacity in a general sense.²⁰ Thirdly, although, where possible, the book uses the term ‘person,’ it is sometimes necessary for clarity to use the term ‘patient’. This is done with some discomfort, recognising the extent to which this usage serves to limit our view of the person who is currently in the position of patient.

The format for discussion

The issues arising are considered over six substantive chapters. In broad terms, the first two chapters are concerned with autonomy; the second two are concerned with capacity and the remaining two chapters are concerned respectively with decisions by and for people lacking capacity and with treatment for a mental disorder.

Chapter 1 investigates the principle of autonomy as a theoretical construct. This chapter differs from the rest of the book in that it makes limited reference to the law. Rather, its role is to lay down the theoretical foundations for the discussion to follow. By examining the diversity of views regarding the nature of autonomy, Chapter 1 shows that

¹⁸ The Committee is established under Article 34 of the CRPD and is the key enforcement mechanism for the CRPD. States Parties that have ratified the CRPD must submit reports to the Committee within two years of entry into force of the CRPD for the State in question and every four years thereafter (Art. 35). The Committee may make such general recommendations and suggestions on the reports submitted as it considers appropriate and these are forwarded to the State Party in question (Art. 36). For States which have acceded to the Optional Protocol, the Committee must consider any individual petition brought (provided the matter is considered admissible under Art. 2 of the Optional Protocol) and communicate its suggestions and recommendations, if any, to the State Party in question and to the petitioner (Art. 5 of the Optional Protocol).

¹⁹ The Optional Protocol has been signed by 89 States and acceded to by 54. Among the acceding states are South Africa, Spain, Sweden, Mexico and many South American countries.

²⁰ See, for example, Buchanan and Brock, *Deciding for Others*.

autonomy is a more complex and nuanced concept than the law has typically assumed. The chapter explores the philosophical bases for respect for autonomy, identifying the predominant influence of Millian liberal principles of non-interference on modern legal conceptions of autonomy. The chapter also explores a range of critiques of autonomy, focusing in particular on critiques relating to the issue of agency and on critiques of the limited scope of a view of autonomy as non-interference. It uses the work of Joseph Raz²¹ and of feminist ‘relational’ theorists²² as the basis for an exploration of alternative conceptions of autonomy which focus on empowerment rather than non-interference. The chapter argues that these conceptions of autonomy can provide a better basis for the law’s approach to the principle.

Chapter 2 explores the law’s treatment of the autonomy principle. As will be evident from the discussion in this chapter, to date most legal discussion of autonomy has occurred in the context of treatment refusal. The right of autonomy has been conceptualised largely as a negative right to reject treatment choices made by professionals. There has been limited exploration of the question of limits on this right and relatively little legal discussion of a view of autonomy focused on empowerment. Chapter 2 argues that the ongoing status of autonomy in the law is dependent on the adoption of a more robust legal approach to the concept. This requires better legal analysis of both the issue of limits and of positive obligations to facilitate autonomy.

Chapter 3 explores normative aspects of the concept of capacity within an autonomy-based legal framework. It outlines the features of capacity as set out in the MCA and shows that these are largely in accordance with a liberal conception of the requirement. This chapter then identifies flaws in the liberal account of capacity. It argues that this account inappropriately conceptualises capacity as based solely on the workings of each individual’s internal decision-making processes. People are seen as having or lacking capacity without reference to the context in which assessment takes place or to the factors external to the person, which impact on the

²¹ In particular J. Raz, *The Morality of Freedom* (Oxford: Clarendon Press, 1986) and *Ethics in the Public Domain: Essays in the Morality of Law and Politics* (Oxford: Clarendon Press, 1994).

²² C. Mackenzie and N. Stoljar, ‘Autonomy Reconfigured’ in C. Mackenzie and N. Stoljar (eds.) *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self* (New York: Oxford University Press, 2000), p. 4, describe relational autonomy as an ‘umbrella term’ to describe a range of related perspectives that seek to recognise the socially embedded nature of the individual within a framework which retains respect for autonomy at its core.

assessment process. The chapter also argues that the liberal account of capacity fails to recognise the epistemological fallibility inherent in the operation of the capacity requirement and to deal with the normative consequences to which this gives rise. Accordingly, the chapter argues in favour of a relational approach to capacity and a more realistic approach to the role played by the nature of the decision made in the operation of the capacity requirement.

Chapter 4 provides a detailed evaluation of how capacity assessment operates in practice. It considers the components of the applicable standard under the MCA and identifies the tensions to which this standard gives rise when applied in practice and the resulting challenges faced by capacity assessors. This chapter also addresses the reality that, most of the time, legal capacity is not assessed by lawyers or courts but by healthcare professionals, most typically medical professionals. Chapter 4 explores the implications of this delegation of capacity assessment to the healthcare profession. While Chapter 4 makes a number of suggestions regarding how the capacity assessment process might be improved in practice, as with Chapter 3, a core conclusion emerging from Chapter 4 is that capacity is a less reliable ‘sorting’ mechanism than liberal theorists have assumed.

Chapter 5 is concerned with people who lack the capacity to make a healthcare decision and who, as a result, are sidelined by a framework focused on autonomy. The chapter identifies the flaws in the two traditional approaches to decision-making in this context, the best interests standard, which has been favoured in England and Wales, and the substituted judgment standard, which has been adopted in jurisdictions in the United States. It evaluates the efforts of the MCA to provide a blend of the two standards, which recognises the past and present wishes of the person lacking capacity within a framework that remains centred on best interests. Having assessed the possibilities offered by the MCA, Chapter 5 argues that the MCA cannot, of itself, provide a complete legal framework for decision-making. Consequently, the chapter explores the role of rights other than autonomy and assesses the potential contribution of the ECHR and the CRPD in this respect.

Chapter 6 evaluates the legal position in respect of treatment for a mental disorder. As the chapter shows, in many jurisdictions, including England and Wales, once a person has been brought within the ambit of mental health legislation, her right to refuse treatment for her mental disorder is significantly restricted, regardless of her decision-making capacity. Chapter 6 argues that this differential treatment is discriminatory

and that it contributes to the stigmatisation of people with mental disorders. However, the chapter also draws on the legal position in the United States and Canada to argue that the difficult issues that arise in respect of treatment for a mental disorder cannot be addressed simply by extending a traditional right of autonomy as non-interference to this context. Instead, Chapter 6 argues in favour of legal measures to facilitate greater empowerment of patients with a mental disorder, regardless of whether or not they have decision-making capacity. This chapter also argues that the potentially abusive nature of treatment for a mental disorder requires a higher degree of protection for patients in this context.

The book concludes by identifying a number of key themes which have emerged from the discussion and exploring some of the broader implications of these for the future development of the law in respect of healthcare decision-making.