Autonomy, Capacity and the Limitations of Liberalism An Exploration of the Law Relating to Treatment Refusal

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Thesis Summary

This thesis explores how the law deals with the patient's right to refuse treatment, evaluating the issue in the context of capable, incapable and involuntary patients. The thesis shows how the consent requirement, and consequently the right to refuse, derives from the law's adherence to the principle of individual autonomy which, this thesis demonstrates, is underpinned by Millian liberal theory. Within this view, the requirement for capacity is fundamental. The thesis shows that capacity acts as gate-keeper for the right of autonomy, determining whether or not the right will be respected in each individual's case. Therefore, an appreciation of the inter-relationship between the principle of autonomy and the requirement for capacity is essential. The thesis uses the term "autonomy paradigm" to describe this inter-relationship. The two components of the autonomy paradigm are set out in the first two chapters of the thesis.

The primary aim of the thesis is to establish the limitations of the autonomy paradigm. It identifies two difficulties with the paradigm. The first is that the paradigm is premised on a binary division of patients into the categories of capable and incapable, with incapable patients regarded as largely irrelevant within the model. The consequences of this aspect of the paradigm are explored in chapters 3 and 4 of the thesis. The second difficulty is that the process of capacity assessment is not the value-free, neutral procedure that the autonomy paradigm requires. In reality, patients are not determined to be capable or incapable without reference to the nature of the decisions they are making and the consequences of these decisions for them. Thus, the autonomy paradigm is based on an idealised view of the capacity requirement which cannot be delivered in practice. For these reasons, a more realistic view of the autonomy paradigm must be taken.

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Introduction

Introduction to the Introduction

In Schloendorff v Society of New York Hospital, Cardozo J famously stated that:

[E] very human being of adult years and sound mind has a right to determine what shall be done with his own body ²

This statement has come to encapsulate the consent requirement in modern healthcare law. Once an individual meets the necessary conditions regarding age and capacity, medical treatment may be provided only if she³ gives her consent to the treatment in question and, consequently, the capable patient has the right to refuse medical treatment.

The consent requirement derives from the law's adherence to the principle of individual autonomy or self-determination. As O'Neill writes, "no themes have become more central in large parts of bioethics, and especially in medical ethics, than the importance of respecting individual rights and individual autonomy." The principle of autonomy has its roots in traditional liberal philosophy, the basis for which may be summarised in John Stuart Mill's famous dictum that "over his own body and mind, the individual is sovereign". The principle of autonomy requires respect to be shown to each individual's choices even if these choices are contrary to societal views of what is sensible, reasonable or in the individual's best interests. In Mill's words, "the only purpose for which power can be rightfully exercised over any member of a civilized

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¹ (1914) 211 NY 125.

² *Ibid*, 128.

For convenience, the female and male pronouns will be used in alternate chapters in this thesis.

Autonomy and Trust in Bioethics (Cambridge: Cambridge University Press, 2002), p 2. For other commentary regarding the prevalence of autonomy, see Schneider The Practice of Autonomy (New York: Oxford University Press, 1998), p 3 ("The law and ethics of medicine are today dominated by one paradigm - the autonomy of the patient."); Wolpe "The Triumph of Autonomy in American Bioethics: A Sociological View" in de Vries and Subedi eds Bioethics and Society: Constructing the Ethical Enterprise (Upper Saddle River, New Jersey: Prentice Hall, 1998), p 43 ("For better or for worse ... autonomy has emerged as the most powerful principle in American bioethics ... and has become the 'default' principle").

On Liberty (London, 1859), p 14. All quotations are taken from Grey ed On Liberty and Other Essays (Oxford: Oxford University Press, 1991).

community, against his will, is to prevent harm to others." The individual's "own good, either physical or moral, is not a sufficient warrant."

The requirement for capacity is fundamental to the liberal principle of autonomy. In *On Liberty*, Mill premised individual freedom from state interference on "all the persons concerned being of full age, and the ordinary amount of understanding." In a modern healthcare context, this means that only capable patients have the right to refuse treatment. Thus, capacity acts as gate-keeper for the right of autonomy, determining whether or not the right will be respected in each individual's case. In the words of leading ethicists, Buchanan and Brock, its function is:

[F]irst and foremost, to sort persons into two classes: (1) those whose voluntary decisions ... must be respected by others and accepted as binding, and (2) those whose decisions, even if uncoerced, will be set aside and for whom others will act as surrogate decision-makers.⁹

Because of its gate-keeper role, the requirement for capacity acts as both a hidden support for and a hidden challenge to the principle of autonomy. It lends support to the principle because it allows a pure version of autonomy to be endorsed by the law while enabling difficult cases to be resolved at an individualised level. However, the capacity requirement may also be used in a way which undercuts the practical application of the principle. For example, the law could allow capable patients an autonomy-based right to refuse treatment and then set the standard for capacity so high that most patients could not meet it. Therefore, an appreciation of the inter-relationship between the principle of autonomy and the requirement for capacity is essential. In this thesis, the term "autonomy paradigm" is used to describe this inter-relationship. Thus, this term as used throughout the thesis signifies the model comprising the principle of autonomy as viewed through the lens of the capacity requirement.

The aim of this thesis is to identify the limitations of the autonomy paradigm with particular reference to the way in which it operates in the context of treatment refusal.

⁶ *Ibid*, p 14.

⁷ Ibid.

⁸ *Ibid*, p 84.

Deciding for Others: The Ethics of Surrogate Decision Making (New York: Cambridge University Press, 1989), p 27.

The term "limitation" in this context is intended to mean any difficulty which prevents the paradigm from providing an appropriate conceptual model for decision-making. Thus, the term covers inadequacies in the application of the paradigm to individual patients' situations as well as inconsistencies within the paradigm itself. This means that the autonomy paradigm is measured against the realities of individual patients' situations and against the liberal principles upon which the paradigm is based.

In these contexts, the thesis identifies two fundamental difficulties with the paradigm. First, the autonomy paradigm is premised on a binary division of patients into the categories of capable and incapable with incapable patients being placed outside the ambit of the autonomy principle and, consequently, regarded as largely irrelevant within the model. This division fails to take account of the complexity of human decision-making and the continuum of human abilities. The second difficulty with the paradigm is that the process of capacity assessment is not the value-free, neutral procedure that the autonomy paradigm requires. In reality, patients are not determined to be capable or incapable without reference to the nature of the decisions they are making and the consequences of these decisions for them. Thus, the autonomy paradigm is based on an idealised view of the capacity requirement which cannot be delivered in practice.

Although it identifies limitations of the autonomy paradigm, the thesis does not argue that the paradigm should be abandoned by the law and, indeed, the thesis will argue that, provided that the limitations of the paradigm are recognised, the autonomy paradigm should be extended to treatment for a mental disorder. Instead, the thesis will present a more realistic picture of the role of autonomy within healthcare law and will show that the law needs to develop a broader human rights framework in relation to incapable patients to complement its endorsement of the right of autonomy.

Part I of this introductory chapter will set out the legal context for the thesis in more detail and Part II will then outline the structure of the chapters to follow.

Part I: The Legal Context for the Thesis

The context for this thesis is the law's response to the refusal of medical treatment by adult patients, whether these patients are capable, incapable, or covered by mental health

legislation. This is the context within which the patient's right of autonomy is most commonly called into action and therefore it enables the limitations of the autonomy paradigm to be most clearly identified.

In modern healthcare jurisprudence, the patient's right to refuse treatment has been consistently upheld as legally enforceable even if the refusal results in the patient's death. The classic cases, through which the law in this area has developed, have involved articulate and strong-minded individuals who were guided by religious or other convictions in reaching the decision to refuse treatment. In these cases, the principle of respect for autonomy supersedes competing principles such as beneficence and the sanctity of life. Furthermore, consistent with the underlying premise of autonomy, it is widely accepted that the patient's reasons for making the decision are irrelevant. In the words of Lord Donaldson MR in *Re T (Adult: Refusal of Treatment)*, a patient may choose to refuse treatment "whether the reasons for making that choice are rational, irrational, unknown or even non-existent."

Judicial commitment to the right to refuse is such that two leading judgments have described the right as "absolute": see Re T (Adult: Refusal of Treatment) [1992] 3 WLR 782, 786 per Lord Donaldson MR; Re MB (An Adult: Medical Treatment) [1997] 2 FCR 541, 549 per Dame Butler-Slogs LI

Treatment refusals in this context are often based on religious beliefs. A Jehovah's Witness may refuse a blood transfusion or any procedure involving blood or blood products, believing these procedures to be forbidden by the Bible. The prohibition on blood transfusions is based on a literal interpretation of biblical commands such as "Only flesh with its soul – its blood – you must not eat" (Genesis 9: 3,4) and "Keep abstaining from ... blood and from things strangled and from fornication" (Acts 15:28, 29): see further Family Care and Medical Management for Jehovah's Witnesses (New York: Watch Tower Biblical and Tract Society, 1995), pp 3-5. A Christian Scientist may refuse surgical and medical intervention, preferring to rely solely on the healing power of God. The fundamental beliefs of Christian Science (or the Church of Christ, Scientist) are set out by its founder, Mary Barker Eddy, in her work Science and Health with Key to the Scriptures (Boston: Christian Science Publishing Company, 1875). A Roman Catholic may refuse an abortion or certain medical treatment whilst pregnant because of the risk posed to the foetus, which Catholic doctrine dictates has an immortal soul from the time of conception. See Declaration on Procured Abortion (Rome: Sacred Congregation for the Doctrine of the Faith, 1974).

The principle of beneficence is discussed further in Chapter 1. In brief, the principle requires the healthcare provider to act in the best interests of the patient.

There is some dispute regarding what the principle of sanctity of life means and this matter is discussed further in Chapter 1. For present purposes, a useful definition of the principle is given by Hoffmann LJ in Airedale NHS Trust v Bland [1993] AC 789, 826 who describes it as a "strong feeling that there is an intrinsic value in human life, irrespective of whether it is valuable to the person concerned or indeed to anyone else."

¹⁴ [1992] 3 WLR 782, 796.

Before a patient may avail herself of the right to refuse treatment, she must be legally capable. In the words of Lord Donaldson MR, "[t]he right to decide one's own fate presupposes a capacity to do so". Because capacity plays this role under the law, the concept has a specific and definable legal meaning. While in ordinary English, an individual's capacity to do something may be represented on a continuum ranging from grossly incapable to highly capable, in the current legal context there is no room for such a continuum. Instead, it is essential that patients who have legal capacity may be clearly differentiated from those who do not. As Buchanan and Brock note, legal capacity is "a threshold concept, not a comparative one." The law sets the required standard for capacity and asks simply whether the patient reaches the designated threshold.

The test for capacity at common law is set out by the Court of Appeal in Re MB (An Adult: Medical Treatment). 18 More recently, a statutory test has been introduced in section 3 (1) of the Mental Capacity Act 2005 (the "MCA 2005"). In both instances, the test for capacity is a functional one, centring on whether or not the patient has certain abilities directly related to the function of making a decision about healthcare. These are, first, the ability to understand and retain relevant information, and, secondly, the ability to use and weigh this information. Under the legal test, the relevant question is whether the patient has these abilities. If she does, then, within a legal framework based on the principle of autonomy, her decision must be respected regardless of its reasonableness or the basis upon which it was made. As explained by Beauchamp, the legal capacity to do something is distinguishable from an individual's capacity in doing something¹⁹ and the law is concerned only with capacity in the former sense. Thus, the only consistent position within a legal framework based on the principle of autonomy is that the nature or consequences of the patient's decision is irrelevant to the assessment of her capacity. Furthermore, provided that the patient has the necessary abilities, any underlying condition she may have, for example a mental disorder or intellectual disability, should play no role in the assessment process.

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¹⁵ Ibid.

Some American commentators (see for example Buchanan and Brock *supra* note 9) use the term "competence" to refer to capacity in this, legal, sense.

Supra note 9, p 27.

¹⁸ [1997] 2 FCR 541, 553-554.

[&]quot;Competence" in Cutter and Shelp eds Competency: A Study of Informal Competency Determinations in Primary Care (Dordrecht: Kluwer, 1991), p 56.

The legal model set out above is internally consistent and conceptually in accordance with the law's liberal underpinnings. It operates effectively and provides certain and defensible answers in the classic treatment refusal cases where the patient's convictions are understandable and accessible to most observers even if the patient's belief structures and the value-judgements she makes are different to those of the observer.²⁰ However, the model becomes more difficult to apply as the reasons for the patient's decision become less understandable or as it becomes less clear whether the patient has reached the designated threshold for capacity. In these situations, the pressures placed on the capacity assessment process are increased, especially if the effect of finding the patient to be capable may result in the patient making a decision that appears to the assessor to be contrary to her best interests.

For patients found incapable, until recently, there has been no adequate conceptual model within which to deal with the issue of treatment refusal. The pervasive influence of the autonomy paradigm meant that the law was primarily interested in whether or not the patient met the standard for capacity in order for the principle of autonomy to apply. If she did not, the law was content to leave the response to treatment refusal by incapable patients largely in the hands of the medical profession, limited only by a general and largely unrestrictive requirement that medical professionals act in the best interests of the patient.²¹ Although the application of the capacity requirement clearly results in a rigid binary division between patients, the law failed to develop a model within which to deal with patients who were legally incapable but still wished to refuse treatment. This has begun to change and the legal framework contained in the MCA 2005 allows for advance treatment refusals made while the patient is still capable to apply if she becomes incapable²² and sets out a model for patient participation in the

Section 24 of the MCA 2005.

See, for example, *Malette* v *Shulman* (1990) 72 OR (2d) 417 (the claimant brought a successful action based on her doctor's failure to respect her advance refusal of a blood transfusion on the basis of her beliefs as a Jehovah's Witness); *St George's Healthcare NHS Trust* v *S* [1998] 3 WLR 936 (the claimant's successful action was based on the defendant hospital's failure to respect her refusal of a caesarean section because of her belief in "letting nature take its course"); *Re B (adult: refusal of medical treatment)* [2002] 2 All ER 449 (the claimant was permitted to refuse ventilation on the basis of her own assessment of her quality of life).

The lack of a conceptual framework is evident in cases such as Re F:(An Adult: Sterilisation) [1990] 2 AC 1 and Re MB (An Adult: Medical Treatment) [1997] 2 FCR 541.

determination of best interests, notwithstanding incapacity.²³ Further, the human rights agenda set by the European Convention on Human Rights (the "ECHR") has had an impact on the legal response to healthcare decision-making in respect of incapable patients. This developing framework provides the context within which the thesis can explore the alternatives to the autonomy paradigm in the case of incapable patients.

The final aspect of the law upon which this thesis builds is legislation relating to patients with mental disorders and, in particular, the Mental Health Act 1983 (the "MHA 1983") which excludes the autonomy paradigm from aspects of treatment for a mental disorder. As the recent demise of the Draft Mental Health Bill 2004 shows, there are enormous challenges in developing an appropriate framework to deal with patients with mental disorders. The MHA 1983, together with United States' legislation and the Irish Mental Health Act 2001, provide the legal context within which to examine the challenges posed for the autonomy paradigm by the issue of treatment for a mental disorder.

The thesis focuses on treatment refusal by adult patients (patients over the age of 18 years²⁴). The thesis does not address the role to be played by the requirement for maturity as a prerequisite for the right to refuse treatment.²⁵ There are two reasons for this. First, the maturity requirement gives rise to specific normative and practical concerns which cannot simply be equated to those raised by the capacity requirement in the context of adults.²⁶ Conceptions of maturity, the role of parents, and the nature of adolescent decision-making must be taken into account in assessing the maturity

²³ Section 4 of the MCA 2005.

²⁴ Although the age of consent for minors is generally set at 16 years (see section 8 (1) of the Family Law Reform Act 1969), in Re W (a minor) (wardship: medical treatment) [1992] 3 WLR 758, the Court of Appeal held that, until a minor has reached the age of 18 years, her right to refuse treatment is circumscribed. Thus, in a treatment refusal context, the relevant age remains the legal age of majority, which is set at 18 years.

²⁵ Under the maturity requirement, famously set out in Gillick v West Norfolk and Wisbech AHA [1986] AC 112, a minor may consent to treatment if sufficiently mature. The requirement itself is described by Lord Scarman (ibid, 189) as follows: "It is not enough that [a minor] should understand the nature of the advice which is being given: she must also have a sufficient maturity to understand what is involved." A maturity requirement is entirely consistent with liberal theory: Mill's requirement for freedom from state interference is premised on the individual being of "full age" (see quote in text to note 8 supra).

²⁶ For a discussion of these concerns, see Rosato "Let's Get Real: Quilting a Principled Approach to Adolescent Empowerment in Health Care Decision-Making" (2002) 51 De Paul L Rev 769; Hartman "Adolescent Decisional Autonomy for Medical Care: Physician Perceptions and Practices" (2001) 8 U Chi L Sch Roundtable 87.

requirement. Secondly, the English courts have effectively rejected the right of minors to refuse treatment unless the refusal has been judicially approved as being in the minor's best interests.²⁷ Therefore, the autonomy paradigm does not apply to minors and a different legal context arises to that explored in this thesis. While the thesis does not deal specifically with minors, in some instances jurisprudence involving minors may be relevant to the discussion of capacity in an adult context and this will be used where it can make a relevant contribution.

In terms of the jurisdictions covered, the thesis will concentrate primarily on the legal position adopted in England and Wales. Since the House of Lords decision in *Re F: (An Adult: Sterilisation)*, ²⁸ a substantial declaratory jurisdiction has developed in England and Wales. This has meant that issues relating to capacity and to the provision of treatment to incapable patients have been the subject of detailed judicial discussion. ²⁹ The issue of capacity has also been examined in some detail by the Law Commission and the law in this area has recently been subject to statutory reform with the signing into law of the MCA 2005. ³¹ In addition, the Report of the Richardson Committee ³² and the ongoing debate relating to the reform of the MHA 1983 provide useful material to inform the discussion of the possible role of the autonomy paradigm in mental health law.

The thesis will also draw on the law of other jurisdictions, in particular the United States and Ireland and on the jurisprudence of the European Court of Human Rights (the "ECtHR"). Courts and legislators in the United States have been to the forefront in

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See Re W (a minor) (wardship: medical treatment) supra note 24. The decision in Re W was controversial and seen by many commentators as overly limiting adolescent autonomy. See Brazier and Bridge "Coercion or Caring: Analysing Adolescent Autonomy" (1996) 16 Legal Studies 84; Bridgeman "Because We Care? The Medical Treatment of Children" in Sheldon and Thompson eds Feminist Perspectives on Health Care Law (London: Cavendish Publishing Ltd, 1998); Douglas "The Retreat from Gillick" (1992) 55 MLR 569; Murphy "Circumscribing the Autonomy of 'Gillick Competent' Children" (1992) 43 NILQ 60. For a defence of the decision, see Lowe and Juss "Medical Treatment – Pragmatism and the Search for Principle" (1993) 56 MLR 865.

²⁸ [1990] 2 AC 1.

Some judges have been especially active in developing the law in this area. As will be evident in the chapters to follow, Dame Butler-Sloss P and Thorpe LJ have had a very significant impact on the direction taken by the law.

A series of Consultations Papers culminated in the *Report on Mental Incapacity* Law Com No 231 (London: HMSO, 1995).

The Act received Royal Assent on April 7, 2005. It is expected to come into force in 2007.

Expert Committee Review of the Mental Health Act 1983 (London: Department of Health, HMSO, 1999) (chaired by Professor Genevra Richardson).

developing the autonomy paradigm and have sought to apply the principle of autonomy notwithstanding that the patient is incapable or that the treatment is for a mental disorder. A study of US law therefore enables some of the limitations of the autonomy paradigm in these contexts to be most clearly demonstrated. Ireland also provides a useful source for comparison. Ireland has long operated within the framework of a written constitutional bill of rights³³ and a consideration of Irish law provides an interesting contrast to the jurisprudence of the ECtHR. Furthermore, the Irish Mental Health Act 2001 extends aspects of the autonomy paradigm to treatment for a mental disorder and provides useful insights into the application of the paradigm in this context.

Part II: Structure of the Thesis

The thesis begins with an exploration of the two components of the autonomy paradigm. Chapter 1 examines the principle of autonomy and Chapter 2 looks at the role and definition of the capacity requirement. Chapter 1 situates the principle of autonomy within liberal theory and explains why liberalism provides the strongest basis for the principle. This chapter then sets out the flaws in the principle as identified by its critics. The chapter argues that autonomy must be recognised as a more complex principle than has traditionally been assumed within liberal theory. However, it also acknowledges the importance of autonomy, especially in the context of treatment refusal, and notes the failure of critics to provide a viable alternative basis for the law in this area. Chapter 1 then explores the law's response to the principle of autonomy. It establishes the elevated status of the legal right of autonomy and notes the courts' reluctance to engage in any overt limiting of the right. The chapter concludes that, as the law stands, the only outlet for a court to make value judgements regarding the appropriateness of treatment refusal in a particular situation is through the application of the capacity requirement. In this way, the law relies on the capacity requirement so as to enable it to endorse a pure form of autonomy in difficult treatment refusal situations.

Chapter 2 examines the role of capacity within the autonomy paradigm. It shows that there is no single, immutable meaning of capacity and that any definition of capacity

Bunreacht na hÉireann (the Irish Constitution) was adopted in 1937.

involves value judgements. Setting the standard for capacity requires a judgement to be made regarding the importance to be accorded to autonomy and to values that conflict with autonomy. The choice of relevant abilities also involves normative judgements. In deciding what kinds of abilities are important, a court is deciding what kinds of people should have their right of autonomy protected. Thus, it decides whether autonomy is the prerogative of the rational patient or whether the right extends to other kinds of patients also. Chapter 2 also shows that capacity is, to an extent, a contingent state rather than an absolute one. As empirical studies show, patients can be made more or less capable depending on the environment in which they are tested and the attitude of the capacity assessor.³⁴ Chapter 2 links the theoretical discussions of capacity with the legal standard for capacity established in *Re MB (An Adult: Medical Treatment)*.³⁵ The chapter concludes that the legal standard is consistent with the principle of autonomy as understood by liberal philosophers. At this level, therefore, the conceptual consistency of the autonomy paradigm is evident.

Having established the theoretical model of the autonomy paradigm, the thesis moves to examine the limitations of the paradigm. Chapters 3 and 4 look at the first limitation identified by exploring the effect of the binary division of patients into the categories of capable and incapable. Chapter 3 considers the situation of patients who fail to reach the standard for capacity. This chapter argues that its adherence to the autonomy paradigm has led the law to neglect the need for a conceptual framework within which to deal with incapable patients. In the absence of such a framework, the traditional response in England and Wales was to shift decision-making power into the hands of the medical profession through the application of a best interest test. In contrast, other jurisdictions, in particular the United States, have attempted to apply the autonomy paradigm notwithstanding incapacity. More recently, the MCA 2005 has developed a new framework, which attempts to apply aspects of the principle of autonomy to decision-making for incapable patients. Chapter 3 argues that the right of autonomy cannot simply be extended to incapable patients. Instead, the chapter favours a broader

See, for example, the work of Gunn et al "Decision Making Capacity" (1999) 7 Medical Law Review 269

³⁵ [1997] 2 FCR 541, 553-554. The test is set out in text to note 18 *supra*.

human rights based approach to decision-making which focuses on the issues of restraint, resistance, liberty, dignity and procedural adequacy as well as autonomy.

Chapter 4 notes that the right of a patient with a mental disorder to refuse treatment is circumscribed if the patient is subject to the MHA 1983. This chapter explores the basis for the legislative restriction on the application of the autonomy paradigm. It argues that there is no justification in principle for a different approach to treatment refusals simply because the treatment in question is for a mental disorder. However, using comparative material from the United States and Ireland, this chapter demonstrates why a simple extension of the autonomy paradigm to treatment for a mental disorder would provide an inadequate protection for the rights of people with mental disorders and why a broader human rights framework is required.

The remaining three chapters address the second limitation of the autonomy paradigm identified. These chapters set out the reasons why the process of capacity assessment cannot deliver the value-free judgment of capacity or incapacity which the theoretical model of the autonomy paradigm requires (and presumes to be possible). Chapter 5 examines the functional test for capacity in detail and identifies a number of tensions in the test which allow it to be manipulated to achieve the outcome considered most appropriate by the capacity assessor. This chapter also shows that these tensions are enhanced in the case of patients with certain kinds of mental disorders. Chapter 5 also demonstrates that the functional test is inherently incapable of assessing capacity in a way which is free from the influence of external actors.

Chapter 6 examines the role of the assessor and the assessment process. This chapter shows that, in practice, the test for capacity is applied by members of the medical profession. The chapter questions the extent to which members of the medical profession are able to carry out this legal role and identifies the particular pressures placed on medical professionals in assessing capacity in a treatment refusal situation. This chapter also examines the increasingly complex forensic testing mechanisms intended to facilitate medical experts in establishing legal capacity. The best known of these mechanisms is the MacArthur Competence Assessment Tool for Treatment (MacCAT-T), developed by

forensic psychologist Thomas Grisso and psychiatrist Paul Appelbaum.³⁶ This chapter argues that, while a more rigorous approach to capacity assessment by the medical profession is necessary, these forensic mechanisms do not provide the most appropriate way to achieve this.

Chapter 7, the final substantive chapter in the thesis, revisits the role played by the nature of the patient's decision in the capacity assessment process. This chapter argues, in the light of the preceding chapters, that the nature of the patient's decision will inevitably influence the assessment of capacity, especially in grave or serious situations, situations of marginal capacity or where the patient suffers from a mental disorder. This chapter looks in detail at the variable standard for capacity which has been endorsed by a number of English courts since it was first identified by Lord Donaldson MR in *Re T* (Adult: Refusal of Treatment).³⁷ Under this standard, the extent of the abilities required would appear to vary according to the gravity of the patient's decision. For more grave decisions, the patient will have to show greater ability to understand and retain and to use and weigh information than if the decision is a lower risk one. Chapter 7 shows that the variable standard is inconsistent with underlying liberal theory. However, the chapter also asks whether a case may be made for a variable standard as a means of monitoring the inevitable role played by the nature of the patient's decision.

The thesis concludes with a discussion of the implications of the arguments made regarding the limitations of the autonomy paradigm. The Conclusion to the thesis will put forward a number of suggestions for the future development of the law, concentrating in particular on the importance of human rights and the need for a reassessment of what can reasonably be expected from the capacity assessment process.

The MacCAT-T is described in Grisso and Appelbaum Assessing Competence to Consent to Treatment: A Guide for Physicians and Other Health Professionals (New York: Oxford University Press, 1998).

³⁷ Supra note 14, 796.

Chapter 1: Autonomy and the Right to Refuse Medical Treatment

Introduction

This thesis argues that the law uses the requirement for capacity to maintain adherence to a pure form of autonomy and remain conceptually consistent with liberal theory. The autonomy paradigm represents the inter-relationship between the principle of autonomy and the requirement for capacity. This chapter explores the first aspect of the paradigm, examining in detail the principle of autonomy. The chapter establishes the nature of autonomy, both as a philosophical premise and as a legal right, and looks at the right of autonomy in the specific context of treatment refusal. Part 1 of the chapter defines the principle of autonomy and situates this principle within liberal philosophy. This Part of the chapter traces the ascent of the principle of autonomy to assume the primary role within healthcare ethics and the corresponding demotion of principles such as beneficence and the sanctity of life. This Part then sets out critiques of the principle of autonomy and assesses the force of these critiques. It will be argued that, while these critiques have a certain force, autonomy's critics have not been able to produce a viable alternative to the autonomy principle in the context of treatment refusal.

Part II of the chapter looks at the law's endorsement of the right of autonomy in relation to the right to refuse treatment. It explores the right to refuse treatment at common law and under the European Convention on Human Rights and the Irish Constitution. This Part argues that questions relating to the limits on the common law right of autonomy have as yet received little attention from the courts. This has resulted in a judicial endorsement of an "absolute" right to refuse, with the more difficult questions being resolved in the less controversial context of an individualised capacity assessment. Accordingly, the inadequacies and complexities of the autonomy principle are all condensed within the simple question: does this patient have the capacity to make this decision? Part II also looks at the more wide-ranging approach to treatment refusal indicated by the ECHR and the Irish Constitution where the right is not restricted to capable patients only but has a basis in the rights of bodily integrity, dignity and protection from inhuman or degrading treatment.

Part I: The Nature of Autonomy

This Part of the chapter begins with a definition of autonomy. It then sets out the philosophical basis for the principle as applied in the healthcare context and explores a range of critiques of the principle before concluding on the importance of the principle of autonomy in modern healthcare law.

A Definition of Autonomy

While the importance of autonomy to healthcare ethics and law is clear, what the principle of autonomy actually means is less so. Gerald Dworkin comes close to parody in his description of autonomy:

It is equated with dignity, integrity, individuality, independence, responsibility, and self-knowledge. It is identified with qualities of self-assertion, with critical reflection, with freedom from obligation, with absence of external causation, with knowledge of one's own interests It is related to actions, to beliefs, to reasons for acting, to rules, to the will of other persons, to thoughts, and to principles. About the only features held constant from one author to another are that autonomy is a feature of persons and that it is a desirable quality to have.¹

Notwithstanding this potential for definitional breadth, in the context of healthcare ethics, autonomy can be usefully described in Buchanan and Brock's more simple terms as the individual's "interest in making significant decisions about his or her own life" ²

The term "autonomy" is derived from the Greek "auto" (self) and "nomos" (rule or law). As originally used, the term referred to the right of city-states to self-government. However, with the greater importance accorded to the individual within the philosophy of the Enlightenment, the principle of autonomy came to be associated with individuals as well as states and has now come to represent a core right of the individual.

The Theory and Practice of Autonomy (New York: Cambridge University Press, 1988), p 6.

Deciding for Others: The Ethics of Surrogate Decision Making (Cambridge: Cambridge University Press, 1989), p 36.

The Liberal Origins of the Principle of Autonomy

The principle of autonomy, as it arises in healthcare ethics and law, derives in large part from the liberal philosophy of John Stuart Mill.³ Although Mill did not use the term "autonomy",⁴ a respect for individual autonomy is inherent in his view of the principle of individual liberty under which an individual's freedom may be interfered with only in order to prevent harm to others. Mill described this aspect of the liberty principle as follows:

The only part of the conduct of any one, for which he is amenable to society, is that which concerns others. In the part which merely concerns himself, his independence is, of right, absolute. Over himself, over his own body and mind, the individual is sovereign.⁵

Mill defended the principle of individual liberty on the basis that it is through liberty that human individuality can develop. For Mill, the development of individuality was the ultimate goal of the person. In Mill's words:

It is not by wearing down into uniformity all that is individual in themselves, but by cultivating it and calling it forth, within the limits imposed by the rights and interests of others, that human beings become a noble and beautiful object of contemplation. ⁶

In Mill's view, allowing people a sphere of freedom also had other benefits. It encouraged originality and allowed persons of genius to develop.⁷ Allowing freedom also recognised the essential differences between people and ensured that all people had the best chance to achieve happiness and moral growth.⁸

The principle of individual autonomy is central to modern liberal theorists.

Rawls's *Theory of Justice*⁹ is premised on the individual acting autonomously, which Rawls defines as "acting from principles that we would consent to as free and equal

⁷ *Ibid*, pp 71-72.

See, in particular, On Liberty (London, 1859). For a detailed discussion of the linkage between Mill and autonomy (in the sense used in healthcare ethics and law), see O'Neill Autonomy and Trust in Bioethics (Cambridge: Cambridge University Press, 2002), pp 29-34.

O'Neill (*ibid*, p 30) could only find one mention of the term "autonomy" in Mill's work and this was in the context of the autonomy of states rather than of individuals.

On Liberty supra note 3, p 14.

⁶ *Ibid*, p 70.

⁸ *Ibid*, pp 75-76.

⁹ (Cambridge, Massachusetts: Harvard University Press, 1971).

rational beings."¹⁰ Ronald Dworkin echoes Mill in his justification for the elevation of individual autonomy. In *Life's Dominion*, ¹¹ Dworkin argues that:

Recognizing an individual right of autonomy makes self-creation possible. It allows each of us to be responsible for shaping our lives rather than be led along by them, so that each of us can be, to the extent a scheme of rights can make this possible, what we have made of ourselves.¹²

In the healthcare context, this means that, in Dworkin's words, "[w]e allow someone to choose death over radical amputation or a blood transfusion, if that is his informed wish, because we acknowledge his right to a life structured by his own values." ¹³

Like Mill, Dworkin and other modern liberals¹⁴ ascribe an intrinsic or inherent value to autonomy. The autonomous person is in some sense a morally better person. Thus, Dworkin argues:

A good life need not be an especially reflective one; most of the best lives are just lived rather than studied. But there are moments that cry out for self-assertion, when a passive bowing to fate or a mechanical decision out of deference or convenience is treachery, because it forfeits dignity for ease.¹⁵

Even if the non-autonomous individual avoids significant suffering in his life, it is commonly perceived that "[t]he moral texture of such a life is drab". Thus, Gillon describes autonomy as "a prerequisite for all the virtues" because virtues must "be based on deliberated choice if they are to be virtues." People who, in Feinberg's words, have experienced "irksome constraint justified wholly on paternalistic grounds" feel more than mere irritation or frustration but rather feel that "in some way they have been violated, invaded, belittled."

16

Ibid, p 516.

Life's Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom (London: Harper Collins, 1995) (first published (New York: Alfred A Knopf, 1993)).

¹² *Ibid*, p 224.

¹³ Ibid.

See, for example, Feinberg *The Moral Limits of the Criminal Law Vol 3: Harm to Self* (New York: Oxford University Press, 1986), pp 31-44; Silver "Reflections on Determining Competency" (2002) 16 *Bioethics* 454, 465-467.

Life's Dominion supra note 11, pp 239-240.

McCall Smith "Beyond Autonomy" (1997) 14 Journal of Contemporary Health Law and Policy 23, 30.

Gillon Philosophical Medical Ethics (Chicester: John Wiley, 1985), p 66.

¹⁸ Supra note 14, p 27.

Other Philosophical Supports for the Principle of Autonomy

While most obviously associated with Millian liberalism, pro-autonomy theorists may also draw support from other philosophical perspectives. Some theorists¹⁹ take their foundational premises from the work of Immanuel Kant. Kant used the term "autonomy" in his work in a way in which Mill did not. Thus, he wrote that "Autonomy of the will is the sole principle of all moral laws and of duties in keeping with them." In deriving Kantian support for the principle of autonomy in the healthcare context, theorists argue that Kant's fundamental principle of morality, or "Categorical Imperative", is premised on the autonomous individual. One formulation of the Categorical Imperative is that "I ought never to act except in such a way that I could also will that my maxim should become a universal law".²¹ Explaining the relevance of the Universal Law to individual autonomy, Gillon argues:

It is by both rationally recognising the validity of the moral law and willing or choosing to accept it for ourselves that we can be subject to the universal moral law and yet at the same time also authors of it.²²

Thus, unless individuals have a choice about whether or not to accept a universal moral law, they cannot be bound by such a law. In this sense, it might be argued that individual choice (or autonomy) may be regarded as an essential component of Kantian ethics.

Supra note 17, p 64.

See for example Charlesworth *Bioethics in a Liberal Society* (Cambridge: Cambridge University Press, 1993), pp 12-13; Gillon *supra* note 17, p 64. *cf* Beyleveld and Brownsword *Human Dignity in Bioethics and Biolaw* (Oxford: Oxford University Press, 2002) who argue in favour of a right to dignity as empowerment (which prioritises the right of autonomy) on the basis of Gewirth's Principle of Generic Consistency (PGC) which also purports to set out a single fundamental principle of morality (frequently referred to as "Gewirthian") akin to Kant's Categorical Imperative.

Kant Critique of Practical Reason (1785), from Gregor ed Kant, Practical Philosophy (Cambridge: Cambridge University Press, 1996) (original emphasis).

Groundwork of the Metaphysics of Morals (1785), p 402 (reproduced in Gregor ed Cambridge Texts in the History of Philosophy: Kant Groundwork of the Metaphysics of Morals (Cambridge: Cambridge University Press, 1997)). Although there is only one categorical imperative, Kant formulated the categorical imperative in three different ways. In addition to the first formulation set out in the text ("The Formula of Universal Law"), the other two formulations were (ibid, p 429) "Act so that you treat humanity, whether in your own person or in that of any other, always as an end and never as a means only" ("The Formula of the End in Itself") and (ibid, p 436) "All maxims that proceed from our own making of law ought to harmonize with a possible kingdom of ends as a kingdom of nature" ("The Formula of Legislation for a Moral Community": see generally Sullivan An Introduction to Kant's Ethics (Cambridge: Cambridge University Press, 1994).

However, O'Neill shows that this kind of individualistic interpretation of Kant is misconceived. 23 She argues that, in setting out the Categorical Imperative, Kant was not concerned with "any special sort of act of choice, by which each actually chooses laws or principles for everyone else."24 Rather, he was concerned to express a requirement regarding which principles "could be chosen by all, that is to say which principles are univeralisable, or fit to be universal laws."25 As summarised by O'Neill, under the categorical imperative, "individuals can choose to act on principles that meet or that flout the constraints set by the principle of autonomy, but have reasons to act only on those principles that meet those constraints."26 O'Neill uses the terms "individual autonomy" and "principled autonomy" to distinguish the two meanings of autonomy. Individual autonomy is autonomy in the Millian sense; it is concerned with "carving out some particularly independent trajectory in this world".²⁷ Principled autonomy, on the other hand, is an action, the principle for which could be adopted by other people.²⁸ As will be clear in the discussion of treatment refusal, the conception of autonomy relied upon in the healthcare context is individual, rather than principled, autonomy. The basis for the right of autonomy is to allow the individual to develop and live according to his own conception of morality and not to enable an individual to develop principles which could be adopted by others. It would therefore seem that Mill rather than Kant provides a more defensible basis for the principle of autonomy in the treatment refusal context.

The principle of autonomy derives support from sources outside Millian liberalism (although these supports are not inconsistent with a liberal conception of autonomy). Cox White²⁹ defends autonomy on the basis that it is not possible to develop an objective or universal view of what is good without reference to the individual. She sets out three "major contenders" for theories of universal good; these are hedonism, objective goodness, and desire satisfaction. She describes hedonism, which is premised on the view that pleasure is always good and pain always bad, as "implausible" and notes that people frequently do things that do not give them

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²³ Supra note 3, pp 83-86

Ibid, p 84, original emphasis.

²⁵ Ibid.

Ibid.

²⁷ *Ibid*, p 85.

²⁸ Ibid

Competence to Consent (Washington DC: Georgetown University Press, 1994).

pleasure in pursuit of a greater goal.³⁰ The objective goodness theory also fails to convince Cox White. She argues that, in spite of centuries of effort, all attempts have failed to develop a "universally *shared* plausible list of things that are objectively good or evil".³¹ Even the seemingly uncontroversial values that are supported by healthcare professionals, such as life, health and the absence of pain, are not necessarily shared by their patients.³² Cox White concludes that, ultimately, desire satisfaction provides the most plausible statement of a universal good. First, it "fits much better with our observations".³³ People do desire things other than pleasure and goods considered desirable by others. Further, she argues that, unlike objective goods, it is possible to determine a patient's desires by simply asking the patient what he wants.³⁴ Finally, and in a rather circular fashion, she argues that "desire satisfaction theory provides the best fit within the practice of informed consent."³⁵

Atkins'³⁶ work also questions the plausibility of an objective view of what is good. Her argument is based on the essential subjectivity of each individual. In this, she relies on Thomas Nagel's influential essay "What is it Like to Be a Bat?'³⁷ In this essay, Nagel explores the fundamental impossibility of understanding what it is like to be another creature. Even at the farthest reach of our imagination, we, as humans, can only imagine what it would be like for a human to be a bat, but we can never imagine what it would be like for a bat to be a bat. Expanding this point, Nagel argues:

The problem is not confined to exotic cases, however, for it exists between one person and another. The subjective character of the experience of a person deaf and blind from birth is not accessible to me, nor presumably is mine to him.³⁸

Applying Nagel's argument in the context of treatment refusals, Atkins argues that:

³⁰ Supra note 29, p 21.

³¹ *Ibid*, p 22 (original emphasis).

³² Ibid.

³³ *Ibid*, p 23.

³⁴ Ibid.

Ibid. This is unsatisfactory because Cox White is using a practice (informed consent), which was developed from a theory (the right of autonomy) to justify the theory from which it was developed. If the theory cannot stand on its own, then the practice to which it gave rise cannot be used to support it.

[&]quot;Autonomy and the Subjective Character of Experience" (2000) 17 Journal of Applied Philosophy 71. This article was quoted by Dame Butler-Sloss in Re B (An Adult: Medical Treatment) [2002] 2 All ER 449, 469-470.

^{(1974) 83} *The Philosophical Review* 435. (Reprinted in Nagel *Mortal Questions* (Cambridge: Cambridge University Press, 1979), p 165.

Mortal Questions ibid, p 170.

Respect for autonomy is an acknowledgement of the limitations of our knowledge of other people and a willingness to incorporate that understanding into our own world views. When we respect autonomy we don't simply observe another's freedom from a distance, as it were; we accede to our fundamental fallibility and an epistemological humility.³⁹

She argues further that "the more extreme the experience of illness", the more difficult it becomes to understand the subjective experience of another individual. The essence of Atkins' argument is that because, at a fundamental level, we cannot share each others' experiences, we must respect each individual's conception of the world and, consequently, his decisions.

These arguments in support of the principle of autonomy are consistent with, and may be used to lend support to, the liberal view of autonomy. Both Cox White's rejection of objective goods and Atkins' endorsement of individual subjectivity may be accommodated within Millian liberalism, which is ultimately based on each individual assuming responsibility for the way in which he conducts his life.⁴⁰ For this reason, the core support for the principle of autonomy in healthcare ethics and law may still be regarded as deriving from Millian liberalism.

The Nature of Millian Autonomy

Having established the connection between Millian liberalism and the principle of autonomy, it is now necessary to consider briefly the nature of the liberal conception of autonomy. Within liberal theory, it is clear that the principle of autonomy is not absolute. First, Mill premised the basic principle of non-interference on "all the persons concerned being of full age, and the ordinary amount of understanding". 41 As will be seen in the next chapter, this focus on capacity remains a feature of modern liberal theory. Secondly, interference with another person is justified in order to prevent harm to others. In Mill's words, "the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others."42 However, Mill did not consider this limitation to allow a wholesale overriding of the individual's freedom. He noted that "[t]he acts of an

³⁹ Supra note 36, 75.

For Mill, liberty was important because it allowed each individual to achieve his own form of happiness and moral growth. See text to note 8 supra.

⁴¹ Supra note 3, p 84. 42

individual may be hurtful to others, or wanting in due consideration for their welfare, without going the length of violating any of their constituted rights."⁴³ While acknowledging that "no person is an entirely isolated being"⁴⁴ and that an individual's behaviour does impact on the people close to him and to a lesser degree on society at large, Mill argued that a person can be stopped from doing something only if, in doing that thing, he would "violate a distinct and assignable obligation" to others.⁴⁵

While the individual right of autonomy is not absolute, it is clear that within liberal theory, once the right does arise, it is accorded primary status in a hierarchy of values. Other values, such as beneficence or the sanctity of life, must be accorded subordinate status to the principle of autonomy because it is only in this way that the goal of the individual's sovereignty over his own mind and body may be assured. This does not mean that these other values are meaningless or that they cannot coexist with autonomy for most of the time. However, in the case of an ultimate conflict between autonomy and the other values, if the law is to be consistent with liberal theory, decision-making power must be fully situated in the patient regardless of the consequences for the patient's welfare and even for his life. Thus, in Mill's words, "[t]here are good reasons for remonstrating with [an autonomous individual], or reasoning with him, or persuading him, or entreating him, but not for compelling him."

The Role of Autonomy in Healthcare Ethics

For much of the history of medicine, the principle of autonomy has not played any part in the operative ethical framework. ⁴⁸ Instead, the relevant imperatives were doing good for the patient, frequently referred to as beneficence, and the protection of life, often referred to as the sanctity of life principle. A brief overview of these

43 *Ibid*, p 83.

⁴⁴ *Ibid*, p 88.

⁴⁵ *Ibid*, p 90.

See the passage from Mill quoted in text to note 5 supra.

Supra note 3, p 14.

Under the traditional Hippocratic Oath, the physician promised to "use my power to help the sick to the best of my ability and judgment": see *Hippocratic Writings* trans Chadwick and Mann (London: Penguin Books, 1950). For a useful historical perspective, see Engelhardt "Basic Principles in Bioethics: A Historical and Cultural View" in Kemp *et al* eds *Bioethics and Biolaw Vol II: Four Ethical Principles* (Copenhagen: Rhodos International Science and Art Publishers and Centre for Ethics and Law, 2000).

principles is necessary in order to appreciate the impact made on healthcare ethics by the elevation of the principle of autonomy.

The principle of beneficence means simply acting for the good of the patient. As traditionally conceived, this principle did not require consultation with the patient and the doctor's view of what was good was the only relevant factor. This extreme form of beneficence is now usually referred to as paternalism. This is described by Pelligrino and Thomasma as follows:

Paternalism centres on the notion that the physician ... has better insight into the best interests of the patient than does the patient, or that the physician's obligations are such that he is impelled to do what is medically good, even if it is not 'good' in terms of the patient's own value system.⁴⁹

Paternalism, in this sense, may be seen as having defined the relationship between doctor and patient until the latter part of the twentieth century.⁵⁰

This simplistic view of beneficence is challenged by Pelligrino and Thomasma. These commentators suggest a more complex view of the concept of beneficence which takes cognisance of the patient's views and requires the doctor to negotiate and seek to reach a consensus with the patient regarding the appropriate mode of treatment.⁵¹ In this way, the principle of beneficence is not necessarily in conflict with respect for the principle of autonomy but, crucially, if a conflict does arise, the principle of autonomy is not automatically accorded pre-eminent status.

The second dominant ethical principle was the principle of the sanctity of life. This ethical view derives from the Judaeo-Christian tradition whereby life is seen as having an intrinsic value unrelated to the individual's views regarding the value of his own life.⁵² The principle is based, in Ramsey's words, on the fact that,

Every human being is a unique, unrepeatable opportunity to praise God. His life is entirely an ordination, a loan and a stewardship."53

For the Patient's Good (New York: Oxford University Press, 1988), p 7.

The consequences of this kind of relationship have been widely discussed. See generally Donnelly Consent: Bridging the Gap Between Doctor and Patient (Cork: Cork University Press, 2002), pp 5-10.

Pelligrino and Thomasma describe this form of beneficence as "beneficence-in-trust" (see *supra* note 49, Chapter 4).

See the description of the principle in *Airedale NHS Trust* v *Bland* [1993] AC 789, 826 per Hoffmann LJ.

[&]quot;The Morality of Abortion" in Rachels ed Moral Problems: A Collection of Philosophical Essays (New York: Harper & Row, 1971), pp 11-12, cited in Keyserlingk Sanctity of Life or

At its most extreme, adherence to the principle of sanctity of life requires that life be preserved at all costs. The term "vitalism" is used to describe this approach.⁵⁴

A less extreme, and more commonly accepted, approach to the principle acknowledges that there are instances in which life need not be preserved but still holds that human life has an "intrinsic dignity which entitles it to protection from unjust attack". ⁵⁵ Proponents of this view of the sanctity of life accept that the principle does not require a person "to administer or undergo a treatment which is not worthwhile". ⁵⁶ While not so obviously in conflict with the principle of autonomy as the vitalist approach, there is still room for conflict between autonomy and this view of the sanctity of life principle. In particular, autonomy respects the individual's right to refuse treatment not because the treatment is not worthwhile but simply because it is what he wishes to do. Respecting this wish clearly challenges the principle of sanctity of life.

The principles outlined above were, by and large, adhered to by doctors and accepted by patients for much of the history of medicine. By the late 1960s, however, attitudes began to change. Medical ethicists, especially in the United States, began to emphasise the importance of patient autonomy and began to question the presumption that a doctor is in a better position to assess benefits for the patient than the patient himself. ⁵⁷ Robert Veatch, a foremost autonomy theorist, ⁵⁸ describes how medical ethics came to be seen as "a conflict between the old Hippocratic paternalism (having the physician do what he or she thought was best for the patient) and a principle of autonomy". ⁵⁹ Within a remarkably short time, autonomy had, as a theoretical proposition at any rate, "won the day" and patient consent became the

60 Ibid.

Quality of Life in the Context of Ethics, Medicine and Law (Ottawa: Law Reform Commission of Canada, 1979), p 12.

For a description of vitalism, see Keyserlingk *ibid*, pp 19-20.

Keown "Restoring Moral and Intellectual Shape to the Law After *Bland*" (1997) 113 *LQR* 481, 483.

Keown *ibid*, 485. Keown *ibid* describes a treatment as not worthwhile in this sense "either because it offers no reasonable hope of benefit or because, even though it does, the expected benefit would be outweighed by burdens which the treatment would impose, such as excessive pain."

See Veatch "Autonomy's Temporary Triumph" [1984] The Hastings Center Report 38, 38. For a sociological perspective on the shift to autonomy, see Wolpe "The Triumph of Autonomy in American Bioethics: A Sociological View" in de Vries and Subedi eds Bioethics and Society: Constructing the Ethical Enterprise (Upper Saddle River, New Jersey: Prentice Hall, 1998), pp 38-43.

See in particular A Theory of Medical Ethics (New York: Basic Books, 1981).

[&]quot;Autonomy's Temporary Triumph" supra note 57, 38.

central focus in relation to all medical interventions. This occurred especially quickly in the United States, where individual autonomy and freedom from external control had long been regarded as fundamental "American" values.⁶¹

The principle of autonomy now provides the basis for the ethical standards of the medical profession on this side of the Atlantic. In England and Wales, the General Medical Council⁶² and the British Medical Association⁶³ both acknowledge the principle of autonomy and include a statement of the patient's right to refuse treatment in their ethical guidelines. In Ireland, the patient's right to refuse is acknowledged, although with notably less enthusiasm, in the Medical Council's A Guide to Ethical Conduct and Behaviour.⁶⁴

Notwithstanding the recognition of the status of autonomy, there is ongoing debate among healthcare ethicists regarding the proper status for autonomy. In the early 1980s, Veatch made the claim that:

[T]he principle of autonomy is nothing more than a footnote on a full theory of medical ethics dealing with those rare cases where we can pretend that the community is limited to an isolated patient exercising his or her will unbounded by obligations to others. ⁶⁵

Although this claim was clearly premature, there is a growing view that autonomy on its own is an inadequate principle upon which to base an entire system of healthcare ethics. As will be seen below, criticisms of the autonomy principle draw attention to some of the limitations of the principle.

See Seeking Patients' Consent: The Ethical Considerations (London: General Medical Council, 1998); Withholding and Withdrawing Life Prolonging Treatments: Good Practice in Decision-Making (London: General Medical Council, 2002), para 13.

John Wayne's films are often cited as giving cultural expression to this view of the solitary individual living his own life without societal interference; Walt Whitman's "Song of Myself" (from Leaves of Grass (1855)) gives poetic expression to this view. A less complimentary evocation is found in Michael Moore's film "Bowling for Columbine" (United Artists, 2002).

Withholding and Withdrawing Life Prolonging Medical Treatment: Guidance for Decision Making (2nd Ed) (London: British Medical Association, 2001).

^{(6&}lt;sup>th</sup> Ed) (Dublin: Medical Council, 2004), p 31 states "A competent adult patient has the right to refuse treatment". The guide continues "While the decision must be respected, the assessment of competence and the discussion on consent should be carried out in conjunction with a senior colleague."

[&]quot;Autonomy's Temporary Triumph" supra note 57, 39.

Critiques of the Autonomy Principle in Healthcare

The role of autonomy in healthcare ethics has been criticised from a number of different perspectives. For some critics, the autonomous individual is not an appropriate construct to place at the centre of an ethical principle. This critique of autonomy is generally part of a broader critique of liberalism. Other critics focus on the cost to other values arising from the elevation of the autonomy principle while still other critics dispute the presumption that each individual knows best what is suitable for him.

The most sustained critiques of modern liberalism have come from the communitarian perspective⁶⁶ and from feminist theorists. Both communitarians and feminists regard contemporary liberalism as conceiving of the autonomous individual as independent, self-sufficient and unconnected to others.⁶⁷ In contrast to this liberal view, communitarians argue that the individual must be understood in the context of his attachment to the community of which he is a member⁶⁸ and within the historical and inter-generational traditions and practices that underpin his community.⁶⁹ Furthermore, communitarians dispute the view that the independent person (in Glendon's phrase, the "lone rights-bearer") is, in some way, morally superior. Rather, Sandel contends that "[t]o imagine a person incapable of constitutive

This label is associated most closely with the political philosophers Alasdair MacIntyre, Michael Sandel, Charles Taylor and Michael Walzer. However, the label is applied by others (usually critics), rather than having been chosen by these theorists. The broad communitarian critique of liberal theory (in particular as the latter is conceived by Rawls A Theory of Justice (Cambridge, Massachusetts: Harvard University Press, 1971)) is that it fails to take account of the importance of tradition and social context in moral reasoning and in defining the individual and that liberalism undervalues the role of community. See further Mulhall and Swift Liberals and Communitarians (Oxford: Blackwell Publishing, 1992); Bell "Communitarianism", The Stanford Encyclopaedia of Philosophy (Winter 2001 Edition) Zalta ed https://plato.stanford.edu/archives/win2001/entries/communitarianism.

Schmitt Beyond Separateness: The Social Nature of Human Beings – Their Autonomy,
Knowledge, and Power (Boulder: Westview Press, 1995), p 1 describes this individual's
relationships as being based on the contractual model whereby "[e]ach participant in this large
social market-place is expected to be self-sufficient, to take care of herself or himself."

See Sandel "Conclusion: Liberalism and the Limits of Justice" in Liberalism and the Limits of Justice (2nd Ed) (Cambridge University Press, 1997).

See MacIntyre's argument as expressed in *After Virtue: A Study in Moral Theory* (London: Duckworth, 1981), p 221 that "the self has to find its moral identity in and through its membership in communities such as those of the family, the neighbourhood, the city and the tribe".

⁷⁰ Rights Talk: The Impoverishment of Political Discourse (New York: Free Press, 1991), p 47.

attachments ... is not to conceive an ideally free and rational agent, but to imagine a person wholly without character, without moral depth."⁷¹

Feminist critiques of liberalism also dispute the liberal conception of the individual, rejecting "the paradigm of moral subjects as autonomous, rational, independent, and virtually indistinguishable from each other." In Sherwin's words:

In place of the isolated, independent, rational agent of traditional moral theory, feminist ethics appeals to a more realistic and politically accurate notion of a self as socially constructed and complex, defined in the context of relationships with others.⁷³

Feminist theorists also challenge the view of the autonomous or independent person as morally superior. Schmitt argues that autonomy may only be achieved if others take on the burden of caring.⁷⁴ This "work of caring" has traditionally been assigned to women and, feminists argue, has consequently been devalued.⁷⁵ The elevation of the autonomy principle is regarded as part of this devaluation of women's values and is therefore unacceptable to many feminist theorists.

Other critics note the cost to other values arising from the adoption of a liberal conception of autonomy. Callahan argues:

[Autonomy] buys our freedom to be ourselves, and to be free of undue influence by others, at too high a price. It establishes contractual relationships as the principal and highest form of relationships. It elevates isolation and separation as the necessary starting point of human commitments.⁷⁶

In her critique of autonomy, O'Neill argues that the important value of trust between doctors and patients has been lost because of the liberal view of autonomy "simply as

Supra note 67, p 50.

Liberalism and the Limits of Justice supra note 68, p 179.

Sherwin *No Longer Patient: Feminist Ethics and Health Care* (Philadelphia: Temple University Press, 1992), p 53.

⁷³ Ibid.

See Gilligan's research into the impact of gender difference on the level of respect given to "care" values (In a Different Voice: Psychological Theory and Women's Development (Cambridge, Mass: Harvard University Press, 1982). Gilligan's work has been applied in a legal context by West "Jurisprudence and Gender" (1988) 55 University of Chicago Law Review 1 and in relation to autonomy by Nedelsky "Reconceiving Autonomy: Sources, Thoughts and Possibilities" (1989) 1 Yale Journal of Law and Feminism 7. On the development of a separate feminist/feminine ethic, see generally Gatens ed Feminist Ethics (Ashgate: Dartmouth, 1998). For critiques of this approach (also from a feminist perspective), see Scales "The Emergence of Feminist Jurisprudence: An Essay" (1986) 95 Yale Law Journal 1373, 1381; MacKinnon "Feminist Discourse, Moral Values and the Law – A Conversation" (1985) 34 Buffalo Law Review 11, 74.

independence from others".⁷⁷ Contrasting the different features of trust and autonomy, she notes:

Trust is most readily placed in others whom we can rely on to take our interests into account, to fulfil their roles, to keep their parts in bargains. Individual autonomy is most readily expressed when we are least constrained by others and their expectations. Trust flourishes between those who are linked to one another; individual autonomy flourishes where everyone has 'space' to do their own thing.⁷⁸

Because of its association with western, liberal political philosophy, the elevation of autonomy may also have adverse implications for the values of pluralism, tolerance and the recognition of difference and diversity.⁷⁹ Other cultures have different views of the individual and his relationship with society and these may not fit within the individualistic autonomy-based model.⁸⁰ Jennings argues that:

By normalizing and universalizing a particular set of cultural assumptions and privileged behaviours and a class-specific conception of rational moral choice, bioethics makes both a practical and an ethical mistake. Practically, bioethics is unable to give adequate clinical and public policy guidance to professionals who confront culturally diverse patients and citizens Ethically, bioethics fails to respect persons because it erases their particularity and their culturally constituted identities.⁸¹

A number of commentators also challenge the presumption underpinning the autonomy principle that the autonomous individual is in a position to make a free choice. Wolpe, a sociologist, argues that the idea of "free choice" "is itself socially constructed and situated." He points to the inherently coercive nature of serious illness or disease and argues that, in addition, patients' freedom to decide is limited in the following ways:

[&]quot;Autonomy: A Moral Good, Not a Moral Obsession [1984] The Hastings Centre Report 40,

Supra note 3, p 24. Cf Wolpe's argument (supra note 57, pp 50-51) that autonomy flourished because of a lack of trust in the medical profession.

⁷⁸ *Ibid.* p 25.

See Fox Essays in Medical Sociology (2nd ed) (New Brunswick, NJ: Transaction Books, 1987); Gervais "Changing Society, Changing Medicine, Changing Bioethics" and Jennings "Autonomy and Difference: The Travails of Liberalism in Bioethics" in de Vries and Subedi eds, supra note 57.

See, for example, the different approach to autonomy identified in Japan in Kitamura et al "Image of Psychiatric Patients' Competency to Give Informed Consent to Treatment in Japan" (1999) 22 International Journal of Law and Psychiatry 45.

Supra note 79, p 261.

Supra note 57, p 54.

The constellation of structural factors that can add a coercive element to decision making is almost endless; the power and prestige of the medical profession influences people towards physicians' recommendations, even as the erosion of trust makes them wary of physicians' motivations; families or communities often manipulate or coerce their family members into medical decisions; class, race, education, cultural, and religious factors can limit patient options, understandings and perceptions of medical possibilities; life circumstances, such as the need to get back to a job that will not tolerate long medical absences, coerce patients to make certain types of decisions.⁸³

Wells and Schneider make similar arguments from a legal perspective;⁸⁴ in Wells' case, this argument is based on feminist theory⁸⁵ and, in Schneider's case, on an empirical study of patient views.⁸⁶ Wells' articulates her difficulty with the autonomy principle in the context of a patient's refusal of a caesarean section as follows:

To paint a picture of the world in which the decisions and processes leading up to the medical treatment have all involved a series of autonomous steps ... is a serious misrepresentation and the assumption that individuals are not subject to multiple influences in their beliefs or that p/maternalism is unwanted is unproven.⁸⁷

Schneider criticises both lawyers and bioethicists for failing to deal with patients as they really are and instead basing their views of patients' rights on "a bloodless, flat, distant, abstract, depersonalized, impoverished view of the way people think, feel, and act, of the social circumstances in which people live, of the ethical lives they lead". 88 Attempting to confront this, Schneider's research into the practice of autonomy was based on interviews with patients as well as empirical studies of medical care and literary and biographical accounts of illnesses. 89 This led him to conclude that:

⁸³ Ibid.

See also Roger Dworkin's argument "Medical Law and Ethics in the Post-Autonomy Age" (1993) 68 *Indiana Law Journal* 727, 728 that the law's endorsement of autonomy "reduces human beings to their choose-and-act function" thus overemphasising one aspect of humanness.

See "Patients, Consent and Criminal Law" (1994) 16 Journal of Social Welfare and Family Law 65; "On the Outside Looking In: Perspectives on Enforced Caesareans" in Sheldon and Thompson eds Feminist Perspectives on Health Care Law (London: Cavendish Publishing Ltd, 1998).

The Practice of Autonomy (New York: Oxford University Press, 1998).

[&]quot;On the Outside" *supra* note 85, p 255. See also Wells' arguments regarding the possible patriarchal influences of religion in cases of treatment refusal ("Patients, Consent and Criminal Law" *supra* note 85, 69-70).

Supra note 86, p xvii.

Schneider sets out the methodology for his study *ibid*, pp xx-xi.

Some people may behave as autonomists imagine, but an imposing number of them act quite differently. Their desire for information is less equivocal than the model assumes; their taste for rational analysis is less pronounced; their personal beliefs are not as well developed, relevant or strong; and their desire for control is more partial, ambivalent and complex.⁹⁰

In summary, commentators argue from a range of perspectives that the abstract principle of autonomy fails to recognise the range of human experience.⁹¹ The autonomous individual does not exist; instead, the contextualised subject recognised by communitarians, feminists, sociologists and patient-focussed commentators is a much more complicated creation with more complex motivations.92 These critics provide a more accurate portrayal of the human person than the relatively simple individual upon whom the principle of autonomy is premised. They show that, once it is required to move beyond simple situations, the application of the autonomy principle encounters difficulty. Thus, for example, it is easy to see why autonomy should apply in respect of an ardent Jehovah's Witness who, with the support of family and community, has chosen to refuse blood products and can personally offer evidence to this effect. However, once matters become more complex, difficulties arise. What if, as in a recent Irish case, 93 the Jehovah's Witness has become unconscious and evidence is produced showing that she had converted to the religion on her recent marriage in order to please her husband? Or what of the patient who, disheartened by inadequate facilities or depressed by uninterested carers, decides to refuse treatment because he believes that his life is no longer worthwhile?94 Allowing these patients to refuse treatment because they are capable without

Ibid, p 229. In speculating as to why this might be the case, Schneider (pp 48-73) draws attention to the difficulty of making medical decisions, especially when the decision-maker is very sick or is frightened and possibly disoriented by being in hospital or in other unfamiliar surroundings. He also argues that sick people may differ from healthy people and indeed from their healthy selves. Sick people, he argues, (p 75) "often feel frightened, discouraged, dull-witted, abstracted, uninterested and weary."

On the dangers of abstract morality, see Doyal "Medical Ethics and Moral Indeterminacy" (1990) 17 Journal of Law and Society 1.

See Brody Life and Death Decision Making (New York: Oxford University Press, 1988), Chapter 5 for a selection of case studies showing the range of motivations for treatment refusal.

See the facts in JM v Board of Management of St Vincent's Hospital [2003] 1 IR 321 (discussed further in text to note 254 infra).

See Lidz and Arnold "Rethinking Autonomy in Long Term Care" (1993) 47 *University of Miami Law Review* 603 for a discussion of the different issues that arise when autonomy is threatened by a long term situation rather than a single act.

investigating the circumstances that led to their decisions seems a very inadequate response to their situations.

Because of the inadequacies of autonomy in difficult situations, many commentators advocate a more complex ethical model within which the principle of autonomy operates alongside other values including patient welfare. Within this model, doctors and patients attempt to negotiate an agreement based on a holistic view of the individual. Rather than simply accepting a patient's refusal of treatment, the doctor seeks to understand the source of the patient's decision and to alleviate uncertainties and other factors which may impede a patient in reaching the best decision in the circumstances. In light of the critiques of autonomy set out above, the advantages of this approach are clear. A negotiated agreement based on mutual respect between doctor and patient is a preferable ethical model to a simple endorsement of the principle of autonomy.

However, even within this ethical framework, difficult treatment refusal situations will still arise which cannot be resolved by a mutually negotiated agreement. Here, the difference between ethics and law becomes important. Regardless of ethical ideals, the law will have to adjudicate upon the legal rights of a patient who refuses treatment against the advice of his doctor. This lead to the question of whether, in light of the critiques of autonomy set out above, autonomy should remain the determinative principle in the law.

In considering this question, a number of points must be made. Autonomy's critics, as explained above, have provided a persuasive critique of autonomy but have not presented an alternative model for difficult treatment refusal situations. This is understandable; the contextualised subject, clothed with all the complexities inherent in human decision-making, is much harder to fit within a legal framework that, by its nature, requires a single definitive answer to the question of whether the patient should be permitted to refuse a specific treatment. ⁹⁶ Returning to the example of the

In her critique of an autonomy-based approach, Wells *supra* note 87, p 255 concedes that, if the law "listened to women's account of pregnancy, childbirth and the early maternal bond" in considering whether the woman should be permitted to refuse a caesarean section, the

See for example Gerard Dworkin *supra* note 1, p 32, who argues "Autonomy *is* important, but so is the capacity for sympathetic identification with others, or the capacity to reason prudentially, or the virtue of integrity. Similarly, although it is important to respect the autonomy of others, it is also important to respect their welfare, or their liberty, or their rationality". Similar arguments are put forward by Buchanan and Brock *supra* note 2, pp 39-40; Schneider *supra* note 86, p 33.

Jehovah's Witness convert discussed above,⁹⁷ the choices are either to recognise the woman's autonomy and her right to make her own decision or to recognise the complex factors surrounding her decision and make the decision for her. Neither solution is satisfactory. In the first instance, a multitude of factors external to the woman may have led her to make a serious decision which she would not otherwise have made; in the second instance, what is in essence a collective subjectivity (the way in which women would be presumed to behave in this situation) replaces the woman's own subjectivity.

In the absence of a viable alternative model, the vacuum created by a rejection of autonomy would most likely be filled by a return to wholesale paternalism or, as Callaghan terms it, a "return to those good old days that understood doctors to be good old boys who could work out moral problems among themselves in the locker room." Such a return would have a negative impact on healthcare ethics in a number of respects. The principle of autonomy provides the basis for patient involvement in their healthcare decisions. The vast majority of patients are unlikely ever to seek to rely on a right to refuse treatment but they are likely to want to know the nature of their medical conditions and to be consulted in making treatment decisions. The informed consent model has its antecedents in the principle of autonomy just as much as the right to refuse treatment. While, as Harrington notes, the informed consent model is not without flaws or limitations, there are practical and therapeutic benefits arising from the inclusion of patients in healthcare decision-making. Any

"answers would be no easier". However, she argues that the debate would "acquire an integrity it currently lacks".

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See text to note 93 *supra*.

Supra note 76, 42.

This is supported by patient surveys. See for example Meredith et al "Informational Needs of Cancer Patients in West Scotland: Cross Sectional Survey of Patients' Views" (1996) 313

British Medical Journal 724; Tamburini et al "Cancer Patients' Needs During Hospitalisation: A Quantitative and Qualitative Study" (2003) 3 BMC Cancer 12. Cf Schneider (supra note 86, Chapter 2) who argues, based on a range of empirical studies, that patients are very keen to receive information about their conditions although they are sometimes less keen to participate in actual decision-making about their care.

The informed consent model in this context means the "autonomy driven duty to disclose" information relevant to the treatment decision (see Maclean "The Doctrine of Informed Consent: Does it Exist and Has it Crossed the Atlantic?" (2004) 24 Legal Studies 386, 386). "Privileging the Medical Norm: Liberalism, Self-Determination and Refusal of Treatment" (1996) 16 Legal Studies 348.

Research shows that when patients are involved in their treatment, it is more likely to be effective (see Schulman "Active Patients Orientation and Outcomes in Hypertensive Treatment" (1979) 17 Med Care 267) and patients are less likely to suffer from depression and anxiety (see Fallowfield et al "Psychological Outcomes of Different Treatment Policies in Women with Early Breast Cancer Outside a Clinical Trial" (1990) 301 BMJ 575). Some

significant shift away from the autonomy principle in treatment refusal cases may diminish the status of autonomy in this important context. Furthermore, the ideal of the negotiated agreement between doctor and patient could also come under pressure if autonomy were no longer accorded determinative status. Agreements are negotiated in light of the parties' realisation of the alternatives and the whole tenor of a negotiated treatment decision would change if the ultimate power of choice were taken from the patient. For these reasons, any downgrading of the principle of autonomy in treatment refusal cases would have wide-reaching significance within healthcare ethics.

In sum, it would seem that, while autonomy's critics usefully draw attention to important drawbacks to the autonomy principle, in the absence of a meaningful alternative, adherence to the principle of autonomy continues to provide the most suitable framework for the law in the context of treatment refusal. However, the flaws in the principle do not go away simply because there is no feasible alternative to autonomy. Nor are courts immune from the pressures on the exercise of the right of autonomy identified in the discussion above. Rather, as will be seen in the next Part, these issues are dealt with by the law through limiting the application of the right of autonomy in individual circumstances and, in particular, through the capacity requirement. Thus, as the next section makes clear, the law's recognition of the principle of autonomy can only be understood within the context of these individualised limits.

Part II: The Principle of Autonomy and the Law

This Part of the chapter will examine the law's response to the principle of autonomy as given effect in the context of the right to refuse treatment. It will also establish other bases for the right to refuse treatment which are not linked to the principle of autonomy. The earliest legal recognition of the right to refuse treatment is found in United States' law and a brief history of the contribution of this jurisdiction provides the introduction to this Part. This will be followed by a discussion of the right of

research ascribes these benefits to the relationship between psychological processes and the central nervous and immune systems, sometimes described as psychoneuroimmunology (see Kaplan "Health-Related Quality of Life in Patient Decision Making" (1991) 47 Journal of Social Issues 69) although this theory has not yet been proven. See further Donnelly supra note 50, pp 17-19.

autonomy at common law and under the ECHR and the Irish Constitution and of the other bases for the right to refuse treatment under these human rights instruments.

The Early Cases: US Jurisprudence on the Right to Refuse

Faden and Beauchamp¹⁰³ cite the 1767 decision in *Slater* v *Baker and Stapleton*¹⁰⁴ as the first judicial recognition of the requirement for consent to medical treatment. However, legal recognition of the requirement is more commonly associated with a number of early twentieth century decisions¹⁰⁵ and in particular with the decision of the Court of Appeals of New York in *Schloendorff* v *Society of New York Hospital*.¹⁰⁶ These decisions concerned an action in battery following a non-consensual medical intervention and it was not until the 1960s that patients began to seek court approval in advance for the refusal of treatment. The decision of the New York Supreme Court in *Erickson* v *Dilgard*¹⁰⁷ is the first time that the right of a patient to refuse treatment in advance was explicitly recognised.¹⁰⁸ Like many of the early cases before the United States' courts,¹⁰⁹ this case concerned the refusal of a blood transfusion by a Jehovah's Witness and was decided on the basis of religious freedom.¹¹⁰

A History and Theory of Informed Consent (New York: Oxford University Press, 1986), p 116.

^{104 (1767) 2} Wils KB 359.

See Mohr v Williams (1905) 95 Minn 261; Pratt v Davies (1906) 224 Ill 300; Rolater v Strain (1913) 39 Okla 572. See further McCoid "A Reappraisal of Liability of Unauthorised Medical Treatment" (1957) 41 Minn Law Rev 381, 387-393.

^{106 (1914) 211} NY 125.

^{(1962) 44} Misc 2d 27. Cf the earlier case of Martin v Industrial Accident Commission (1956) 147 Cal App 2d 137where the Court recognised obiter that an individual was free to refuse a blood transfusion.

Legislation permitting the compulsory sterilisation of people on the basis *inter alia* of criminality was held to be unconstitutional by the United States Supreme Court in *Skinner v Oklahoma* (1942) 316 US 535. However this decision was based on the equal protection clause in the Fourteenth Amendment to the United States Constitution and on the right to reproduce, rather than on the right to refuse treatment. The challenged statute (the Habitual Criminal Sterilization Act 1935) allowed the compulsory sterilisation of both males and females who had been convicted two or more times for crimes "amounting to felonies involving moral turpitude". However, certain crimes such as revenue offences and embezzlement, which were punishable as felonies, were excluded from the ambit of the Act. In the view of the majority of the Supreme Court, this distinction was discriminatory.

See also In re Brooks' Estate (1965) 32 III 2d 361; Matter of Melideo (1976) 88 Misc 2d 974; St Mary's Hospital v Ramsey (1985) 465 So 2d 666; Wons v Public Health Trust (1989) 541 So 2d 96. See generally Karnezis "Patient's Right to Refuse Treatment Allegedly Necessary to Sustain Life" (1979) 93 ALR 3d 67; Anon "Medical Technology and the Law" (1990) 103 Harv L Rev 1520, 1643-1646.

The right to freedom of religion is protected by the First Amendment to the US Constitution.

As jurisprudence in the area developed, patients successfully relied on the right of autonomy (which was regarded as part of the individual right of privacy)¹¹¹ as the basis for the right to refuse treatment.¹¹² Typically, these patients were elderly and suffering from terminal conditions.¹¹³ In later cases, the privacy-based right to refuse was extended to patients who were not terminally ill¹¹⁴ and to patients who were no longer capable.¹¹⁵ The right to refuse treatment was confirmed by the United States Supreme Court¹¹⁶ in *Cruzan* v *Director*, *Missouri Department of Health*.¹¹⁷ The Supreme Court held that the right was grounded in the individual's liberty interest,¹¹⁸ as opposed to the right to privacy favoured by the majority of courts at state level.¹¹⁹ This constituted a downgrading of the status of the right because, under the US Bill of Rights, the right of privacy is a fundamental right which may not be interfered with without a compelling reason whereas the liberty interest may be balanced against state interests.¹²⁰

Although the term "privacy" is not mentioned in the United States Bill of Rights, in *Griswold* v *Connecticut* (1965) 381 US 479, 484 the right to privacy was held to be protected by the "penumbras" of the first, third, fourth, fifth and ninth amendments. For further discussion of the United States Supreme Court's approach to the development of this right, see Rubenfeld "The Right to Privacy" (1989) 102 *Harv L Rev* 737.

See for example *Re Quackenbush* (1978) 156 NJ Super 282; *Salz v Perlmutter* (1978) 362 So 2d 160; *Re Yetter* (1973) 62 Pa D and C 2d 619; *Lane v Candura* (1978) 376 NE 2d 1232.

The plaintiff in *Re Quackenbush (ibid)* was 72 and suffering from gangrene; the plaintiff in *Salz* v *Perlmutter (ibid)* was 73 and suffering from Lou Gehrig's disease which required ongoing dependence on a respirator; the plaintiff in *Re Yetter (ibid)* was in her 60s and suffering from cancer.

Bouvia v Superior Court (1986) 179 Cal App 3d 1127. The Court of Appeal of California upheld the request of a 28 year-old woman with severe cerebral palsy to have her feeding tube removed although her condition was not terminal and her life expectancy was at least another 15 to 20 years.

See Re Quinlan (1976) 70 NJ 10 (this issue is considered further in Chapter 2).

The right to refuse treatment has also been recognised by the Supreme Court of Canada in Rodriguez v British Columbia (AG) [1993] 3 SCR 519 (although the Court by a 5-4 majority rejected the right to have assistance in ending life) and by the Quebec Superior Court in Nancy B v Hôtel-Dieu de Québec (1992) 86 DLR (4th) 385.

^{(1990) 497} US 261.

The liberty interest is encompassed in the guarantee of due process contained in the Fourteenth Amendment which provides that no State shall "deprive any person of life, liberty or property without due process of law." The majority opinion did not consider the extent of the individual's liberty interest in the case before it and proceeded on the basis of a presumption that (*ibid*, 279) the "United States Constitution would grant a competent person a constitutionally protected right to refuse lifesaving hydration and nutrition."

Rehnquist CJ noted (*ibid*, 279, note 5a) "[a]lthough many state courts have held that a right to refuse treatment is encompassed by a generalized constitutional right of privacy, we have never so held."

The minority, *ibid*, 302 *per* Brennan J (with whom Marshall and Blackmun JJ joined), confirmed the applicability of the liberty interest, although they regarded the liberty interest in the case in question as a fundamental one which in this case could not be outweighed by the interests of the state. The minority did accept (*ibid*, 312) that state interests could justify interference with the right in some circumstances.

As is clear from the decision in Cruzan, the right to refuse treatment is not an absolute right under US law. In setting out limits for the application of the right, courts have focussed on the individual's obligations to others. Thus, in some of the earlier cases, the individual's right to refuse treatment was limited because the exercise of the right would affect foetal interests;¹²¹ or leave the individual's minor children without a parent; 122 or leave the individual's family reliant on state support. 123 In Superintendent of Belchertown v Saikewicz, 124 the Supreme Judicial Court of Massachusetts identified four relevant state interests which could limit the individual's right to refuse. 125 These were, first, "the preservation of life"; secondly, "the protection of the interests of innocent third parties"; thirdly, "the prevention of suicide"; and fourthly, "maintaining the ethical integrity of the medical profession." 126

In recent years, however, and notwithstanding the approach of the Supreme Court in Cruzan, US courts appear to have taken a more robust approach to the right to refuse and the limits set out in Saikewicz have mainly been cited in cases where they have been held not to apply to the case in question. 127 There has also been a change in attitude to the question of foetal rights¹²⁸ and, in Re AC, ¹²⁹ the District of

¹²¹ The decision of the Supreme Court of Georgia in Jefferson v Griffin Spalding County Hospital (1981) 274 SE 2d 457 is typical of early decisions in this regard. Here, the Court held that the state's interest in preserving foetal life took priority over the woman's right to selfdetermination. See also Raleigh Fitkin-Paul Morgan Memorial Hospital v Anderson (1964) 42 NJ 421; In re Jamaica Hospital (1985) 128 Misc 2d 1006; Crouse Irving Memorial Hospital. Inc v Paddock (1985) 127 Misc 2d 101 (a blood transfusion was ordered for a pregnant Jehovah's Witnesses on the basis of the state's interest in preserving the life of the foetus).

¹²² See In the Application of President and Directors of Georgetown College Inc (1964) 118 App DC 90 (the case concerned a mother and a very young child); Holmes v Silver Cross Hospital (1972) 340 F Supp 125. In a number of other cases, the absence of dependant children was cited as a relevant factor in allowing individuals to exercise their right to refuse treatment. See, for example, Re Yetter (1973) 62 Pa D and C2d 619; Salz v Perlmutter (1978) 362 So 2d 160.

¹²³ See United States v George (1965) 239 F Supp 752 (a father of four children could not refuse treatment); Norwood Hospital v Munoz (1991) 564 NE 2d 1017 (the other parent would support the child and therefore the right to refuse was upheld).

¹²⁴ (1977) 370 NE 2d 417. 125

See also the Canadian case of Malette v Shulman et al (1990) 72 OR (2d) 417, 429 where Robins JA recognised a possible state right to require individuals to submit to medical procedures "in order to eliminate a health threat to the community". 126

Supra note 124, 425.

¹²⁷ See Satz v Perlmutter (1978) 362 So 2d 160, 162; upheld (1980) 379 So 2d 359; Bouvia v Superior Court (1986) 179 Cal App 3d 1127, 1142 (the criteria are cited but there is no specific reference to Saikewicz). Judicial application of the Saikewicz criteria can sometimes tend towards the formulaic: see, for example, the application of the Saikewicz criteria in Satz v Perlmutter ibid, 162-163.

¹²⁸ Although note the 2004 decision by state prosecutors in the State of Utah to prosecute for murder a woman who refused a caesarean section, allegedly for cosmetic reasons, leading to the death of one of the twins she was carrying. In April 2004, the woman was sentenced to 18 months probation having pleaded guilty to the lesser charge of child endangerment. (Details

Columbia Court of Appeals stated that it would require "an extraordinary case indeed" before a court would be justified in overriding a patient's wishes and ordering the performance of a major surgical intervention such as a caesarean section. ¹³⁰

The Right of Autonomy at Common Law

Courts in England and Wales, ¹³¹ Ireland ¹³² and the United States ¹³³ have held a right of autonomy (which is sometimes also referred to as a right of self-determination) to exist at common law and, on the basis of this right, have upheld the right of a capable patient to refuse medical treatment even if this will lead to his death. The right was first applied ¹³⁴ by the Court of Appeal in *Re T (Adult: Refusal of Medical Treatment)*. ¹³⁵ Like the early American cases, *Re T* concerned the refusal of a blood transfusion by a young woman who had been brought up as a Jehovah's Witness (although she had not been practicing her religion prior to her illness). ¹³⁶ The Court of Appeal unanimously recognised the right to refuse treatment and Lord Donaldson MR described the right in the following terms:

An adult patient who, like Miss T, 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 is not limited to decisions which others might regard as sensible. It exists notwithstanding that the reasons for making the choice are rational, irrational, unknown or even non-existent.¹³⁷

obtained from <u>www.cbsnews.com/stories/2004/03/12/national/main605537.shtml</u> (last viewed July 26, 2006)).

^{(1990) 573} A 2d 1235.

¹³⁰ *Ibid*, 1252.

See S v McC (orse S) and M (DS intervener); W v W [1972] AC 24, 43 per Lord Reid; Sidaway v Board of Governors of the Bethlem Royal Hospital [1985] AC 871, 882 per Lord Scarman; ibid, 897 per Lord Bridge; ibid, 904 per Lord Templeman; Re F (Mental Patient: Sterilisation) [1990] 2 AC 1, 73 per Lord Goff.

See In re a Ward of Court [1996] 2 IR 79, 156 per Denham J.

Cruzan v Director, Missouri Department of Health (1990) 497 US 261, 270 per Rehnquist CJ for the majority; ibid, 306 per Brennan J for the the majority. The common law basis for the right was also recognised in Stamford Hospital v Vega (1996) 236 Conn 646, 666 (see further Hankins "The Common Law Right of Bodily Self-Determination in Connecticut: Life and Death After Stamford Hospital v Vega" (1997) 29 Conn L Rev 945); Fosmire v Nicoleau (1990) 551 NE 2d 77, 80-81; Matter of Christopher (1998) 177 Misc 2d 352.

Although the House of Lords had recognised the right to refuse treatment in principle in Sidaway v Board of Governors of the Bethlem Royal Hospital [1985] AC 871, 904 per Lord Templeman.

¹³⁵ [1992] 3 WLR 782.

¹³⁶ *Ibid*, 788.

¹³⁷ *Ibid*, 786.

Lord Donaldson MR noted the patient's "right to self-determination – his right to live his own life how he wishes". Although this conflicted with society's interest in "upholding the concept that all human life is sacred", his Lordship concluded that "in the ultimate the right of the individual is paramount. His Lordship recognised only one "possible qualification" on the "absolute" right to refuse which he suggested might arise where viable foetal life was at risk. The right to refuse treatment was affirmed by the House of Lords in *Airedale NHS* v *Bland* and applied in a number of subsequent cases. Lord Donaldson's description of the right as "absolute" was re-iterated by Butler-Sloss LJ in *Re MB* (An Adult: Refusal of Treatment).

As Lord Donaldson MR recognised in *Re T*, however, the recognition of the right to refuse treatment does not conclude the matter. In his Lordship's words:

[T]his merely shifts the problem where the conflict occurs and calls for a very careful examination of whether, and if so the way in which, the individual is exercising that right. In cases of doubt, that doubt falls to be resolved in favour of the preservation of life, for if the individual is to override the public interest he must do so in clear terms.¹⁴⁴

In the case in question, the Court held that T's refusal should not be respected because her will had been overborne due to the undue influence exercised by her mother and because she had been misinformed by the hospital regarding the consequences of her refusal. Re T is representative of most early decisions in relation to the right to refuse where courts typically combined a strong statement of the right of autonomy with a finding that the right did not apply in the circumstances before the court. 146

¹³⁸ *Ibid*, 796.

¹³⁹ *Ibid*.

¹⁴⁰ *Ibid*, 786.

^[1993] AC 789, 864 per Lord Goff; *ibid*, 857 per Lord Keith.

See inter alia Re C (adult: refusal of medical treatment) [1994] 1 WLR 290; St George's Healthcare NHS Trust v S [1998] 3 WLR 936; Re AK (Medical Treatment: Consent) [2001] 1 FLR 129; Re B (adult: refusal of medical treatment) [2002] 2 All ER 449. Cf Secretary of State for the Home Department v Robb [1995] 2 WLR 722 where the Family Division of the High Court held in the context of a hunger strike that the right of self-determination of a convicted prisoner took priority over any countervailing interests of the state.

¹⁴³ [1997] 2 FCR 541, 549.

¹⁴⁴ [1992] 3 WLR 782, 796.

The patient gave a first, oral refusal following a private discussion with her mother (who was a practicing Jehovah's Witness) and subsequently signed a form to this effect, following a further private discussion with her mother. At this time, it appeared unlikely that a blood transfusion would be required and her medical carers gave the patient assurances in this regard.

See generally Harrington *supra* note 101, 357-361. One exception to the early trend is the decision in *Re C (adult: refusal of medical treatment)* [1994] 1 WLR 290 where Thorpe J

While in *Re T*, this was because of undue influence and misrepresentation, in general, the reason the right has not applied has been because the patient was judged to be incapable. ¹⁴⁷ In this way, the capacity requirement acted as a safety-valve for the right to refuse, allowing for the judicial endorsement of a pure form of the right of autonomy without actually having to apply the right in the case in question.

In two later cases, St George's Healthcare NHS Trust v S¹⁴⁸ and Re B (adult: refusal of medical treatment), ¹⁴⁹ the courts have upheld the patient's right to refuse treatment and have not sought to impose an individualised limit on the application of the right. ¹⁵⁰ In St George's Healthcare NHS Trust, the Court of Appeal awarded damages in trespass¹⁵¹ (as well as granting declaratory relief) to a woman who had had a caesarean section performed on her without her consent¹⁵² while, in Re B, Dame

upheld the claimant's right to make an advance refusal of a leg amputation. However, it is noteworthy that, by the time of the decision, C's life was no longer in immediate danger and that the refusal in question would only become relevant if C's medical problem recurred.

See in particular the body of cases in which women refused to have medically indicated caesarean sections: Re MB (An Adult: Refusal of Treatment) [1997] 2 FCR 541; Tameside and Glossop Acute Services Trust v CH [1996] 1 FCR 753; Re L (An Adult: Non-consensual Treatment) [1997] 1 FCR 609; Rochdale Healthcare (NHS) Trust v C [1997] 1 FCR 274; Norfolk and Norwich Healthcare (NHS) Trust v W [1997] 1 FCR 269. In some of these cases, although the woman was found to be incapable, the treatment was imposed on the basis of section 63 of the Mental Health Act 1983 and not because of her incapacity.

[1998] 3 WLR 936. See Bailey-Harris "Pregnancy, Autonomy and the Refusal of Treatment" (1998) 114 LQR 550.

[2002] 2 All ER 449. See Huxtable "A Right to Die Or Is it Right to Die?" (2002) 14 Child and Family Law Quarterly 341.

See also the vigorous approach to the right to refuse treatment taken by Dame Butler-Sloss in Re W [2002] MHLR 411 where she upheld the right of a capable prisoner who suffered from an untreatable psychopathic disorder (and who therefore was not subject to compulsion under the Mental Health Act 1983) to refuse treatment even though the prisoner's injuries were self-inflicted and the prisoner was using the situation to force his transfer to hospital.

This was the first award of damages for wrongful interference with the right to refuse treatment. In Re T [1992] 3 WLR 782, 803, Staughton LJ had recognised the possibility of such an award. However, he expressed doubts regarding the likelihood of an English court making an award of damages such as that awarded in the Canadian decision of Malette v Shulman (1990) 72 OR (2d) 417. See Oddi "The Tort of Interference with the Right to Die: The Wrongful Living Cause of Action" (1986) 75 Georgetown Law Journal 625 for a consideration of the policy issues that arise from the award of damages as opposed to declaratory relief.

The claimant suffered from pre-eclampsia which, according to medical opinion, necessitated an immediate caesarean section in order to save the plaintiff's life and that of the foetus. When she indicated her refusal to have the caesarean section, because she believed in natural childbirth, the claimant was compulsorily detained in a psychiatric hospital "for assessment" under section 2 of the Mental Health Act 1983. She was then moved to the appellant general hospital and a High Court declaration was obtained that it was lawful to proceed with medical treatment notwithstanding her refusal. The judge was not informed that the patient was thought to be capable and appears to have assumed that she was incapable. The caesarean section was performed and, after a period of recovery, the respondent was returned to the psychiatric hospital where she was assessed as showing no evidence of mental disorder and released the following day. The Court of Appeal held that, in these circumstances, the fact

Butler-Sloss permitted a 43 year-old paralysed woman to have artificial ventilation removed¹⁵³ although this would most likely (and ultimately did¹⁵⁴) lead to her death. While these cases do show that the courts are prepared to eschew the safety-valve afforded by capacity requirement in some instances, their importance in this regard should not be over-estimated. The claimants in both cases were clearly capable and fully aware of the import of their decisions.¹⁵⁵ In this regard, they did not present any significant difficulty for the application of the right of autonomy.

Limits on the Right of Autonomy at Common Law

From the above, it is clear that the English courts take the common law right to refuse treatment very seriously, with judges in two leading cases describing the right as absolute. While describing the right as absolute seems rather extreme, it is true that, to date, outside of the individualised findings of incapacity or, in the case of *Re T* undue influence and misrepresentation, the courts have yet to set a limit on the right to refuse treatment. Lord Donaldson's identification of a possible limit based on foetal interests¹⁵⁶ was firmly rejected by the Court of Appeal in *St George's Healthcare NHS Trust*.¹⁵⁷ In Judge LJ's words, "while pregnancy increases the personal responsibilities of a woman it does not diminish her entitlement to decide whether or

that there was a judicial declaration permitting the treatment did not protect the defendants from liability in trespass.

In addition, Ms B was awarded nominal damages in trespass because the hospital had stopped her from exercising the right. (Ms B had sought nominal damages only [2002] 2 All ER 449, 455).

Ms B died on April 24 2002 (see *The Guardian* April 30 2002) having been moved from her original hospital where the staff could not bring themselves to give effect to her decision.

As Morris notes "Once Upon a Time in a Hospital ... The Cautionary Tale of St George's Healthcare NHS Trust v S, R v Collins and Others ex parte S [1998] 3 All ER 673" (1999) 7 Feminist Legal Studies 75, 83, the plaintiff in St Georges Healthcare was unusual in the clarity and vigour with which she opposed the caesarean section. In Re B [2002] 2 All ER 449, 473 Dame Butler-Sloss described the claimant as a "splendid" person with "great courage, strength of will and determination".

See text to note 140 supra.

^{[1998] 3} WLR 936. Prior to this, the foetal exception was applied by Sir Stephen Brown P In re S (Adult: Refusal of Treatment) [1993] Fam 123. This decision evoked wide criticism: see de Gama "Court Ordered Obstetrical Intervention: Adult's Refusal to Give Consent on Religious Grounds" (1993) 15 Journal of Social Welfare and Family Law 147; Morgan "Whatever Happened to Consent?" (1992) 142 NLJ 1448; Stern "Court-ordered Caesarean Sections: In Whose Interests?" (1993) 56 MLR 238; Thompson "After Re S" (1994) 2 Med L Rev 127. For an exploration of the ethical issues to which treatment refusal in this context gives rise, see Scott "The Pregnant Woman and the Good Samaritan: Can a Woman Have a Duty to Undergo a Caesarean Section?" (2000) 20 OJLS 407.

not to undergo medical treatment". The possibility of a limit based on the sanctity of life principle or on the concerns of the medical profession was rejected in *Re B* (adult: refusal of medical treatment). Dame Butler-Sloss favoured the "personal autonomy of the severely disabled patient" over concerns expressed by the medical professionals caring for Ms B. 160

The courts have not yet had to consider the extent to which the interests of others (outside of the specific context of foetal interests) would justify limiting the right to refuse treatment. As noted above, it is consistent with liberal theory to interfere with an individual's autonomy in order to prevent harm to others.¹⁶¹ A possible basis for such interference could arise in the context of contagious diseases.¹⁶² Section 13 of the Public Health (Control of Diseases) Act 1984 permits the Secretary of State to make regulations "with a view to the treatment of persons affected with any epidemic, endemic or infectious disease and for preventing the spread of such diseases".¹⁶³ Although no such regulations have been made, ¹⁶⁴ the possibility of introducing provisions in this regard has been mooted.¹⁶⁵ Obviously, in order to be consistent with liberal theory, a significant level of risk to others would have to be

158 Ibid, 957. In Re MB (An Adult: Medical Treatment) [1997] 2 FCR 541, the Court of Appeal, had, obiter, earlier dismissed the relevance of foetal interests in relation to a purported refusal of a caesarean section.

¹⁵⁹ [2002] 2 All ER 449.

¹⁶⁰ Ibid, 472. Ms B's doctors (ibid, 463) could not "bring themselves to contemplate that they should be a part of bringing Ms B's life to an end". One doctor also argued (ibid, 465) that Ms B had not had the opportunity to experience life outside of the confines of the ICU since her illness and that she should have this experience in order to make an informed decision about her future.

See discussion in text to note 42 *supra*.

See arguments made in Gibson "A Shot in the Arm for the Military: Consent to Immunisation Against Biological Warfare Agents" (2002) 5 Medical Law International 161.

The Act is mainly concerned with removing people with certain "notifiable" diseases from the public rather than with the question of treatment. See the similar position pertaining in Ireland where section 31(1) of the Health Act 1947 allows the Minister for Health to make regulations providing for "the prevention of the spread of an infectious disease ... and for the treatment of persons suffering therefrom."

Grubb Kennedy and Grubb Medical Law (3rd Ed) (London: Butterworths, 2000), p 909 argues that, if such regulations permitted compulsory treatment, they could be *ultra vires* the Act. According to this argument, the Act does not clearly grant the Secretary of State the power to make such a provision and because of this ambiguity, the section must be read in a way which does not affect fundamental rights.

According to a report in the *Guardian* May 9 2005, the Health Protection Agency was expected to report "within months" on difficulties in the present law and possible remedies arising from the right of patients with contagious diseases to refuse treatment. The *Guardian* article noted concerns relating to a situation where a man with tuberculosis infected 12 other people because of his refusal to take the antibiotic treatment. To the author's knowledge, there have been no further developments in this regard.

established before provisions of this kind could be introduced¹⁶⁶ and any move in this direction would have to be approached with great care lest it completely undermine patients' rights.¹⁶⁷ For the present, however, there has been no general limit of this kind on the right to refuse treatment at common law.

Instead of adopting general limits on the right to refuse, the courts have relied on individualised limits to protect some patients from the consequences of exercising their right of autonomy. As noted earlier, finding the patient to be incapable has been by far the most common mechanism relied upon. In addition, two other individualised limits were identified by the Court in *Re T (Adult: Refusal of Medical Treatment)*. Although these have not yet been used to any extent, they may play a greater role in the application of the right to refuse in the future. The first of these limits is based on the invalidating effect of undue influence on the patient's consent and the second is based on the category of "cases of doubt" identified by Lord Donaldson.

(i) Undue Influence as a Limit on the Right of Autonomy

The necessity for voluntary consent to medical treatment was affirmed by the Court of Appeal in *Freeman* v *Home Office*. Therefore, an interference with the patient's freedom to decide may render his consent invalid. As noted above, in *Re T*, the Court held that the patient's refusal of a blood transfusion was not binding because she had been unduly influenced by her mother. In the words of Lord Donaldson MR:

The real question in each such case is 'Does the patient really mean what he says or is he merely saying it for a quiet life, to satisfy someone else or

For discussion of the level of risk required, see Chapter 4 at text to note 127.

See Coker "Public Health, Civil Liberties and Tuberculosis" (1999) 318 BMJ 1434.

¹⁶⁸ [1992] 3 WLR 782.

^{[1984] 2} WLR 130 (QB); [1984] 2 WLR 802 (CA). This case concerned allegations by a prisoner that he had been physically restrained and that medical treatment had been forcibly imposed on him without his consent. Both the trial judge and the Court of Appeal held that there was no evidence to support this contention. The Court of Appeal, *ibid*, 813, accepted that some situations, including the provision of medical treatment in a prison setting, require a closer examination of consent for the purposes of establishing voluntariness. However, the Court rejected the argument that the very fact of imprisonment rendered a patient unable to give a voluntary consent.

Supra note 168, 795 per Lord Donaldson; 803 per Butler-Sloss LJ. The young woman's mother was a Jehovah's Witness and both her initial oral refusal and her later written refusal came after the young woman had spent a period alone with her mother. At the hearing, the mother declined to give evidence of what had passed between her and her daughter during these times (ibid, 789) and the daughter was unconscious at this point.

because the advice and persuasion to which he has been subjected is such that he can no longer think and decide for himself?'¹⁷¹

Perhaps surprisingly, given the breadth of Lord Donaldson MR's "real question" in Re T, the issue of undue influence in a medical context has only come before the courts once since Re T. In Mrs U v Centre for Reproductive Medicine, 172 the claimant sought to overturn her husband's signed refusal of consent to the posthumous use of his sperm on the basis that her husband's refusal was as a result of undue influence by a staff member at the infertility clinic. In the High Court, Dame Butler-Sloss P accepted that the staff member in question would have been a "formidable" presence and that there was clearly pressure on the applicant's husband to refuse his consent.¹⁷³ However, applying Lord Donaldson's test from Re T, she concluded that it was not possible to conclude that these pressures were such that "an able, intelligent, educated man of 47, with a responsible job and in good health" had had his will overborne to such an extent that it would constitute undue influence. 174 This finding was upheld by the Court of Appeal. As will be seen in Chapter 5, the issue of undue influence does play a role in relation to the establishment of capacity.¹⁷⁵ However, to date, undue influence as an independent issue has been of very little relevance in treatment refusal cases.

(ii) "Cases of Doubt" as a Limit on the Right of Autonomy

The second limiting factor identified in *Re T* arises where a situation falls within the category of "cases of doubt" identified by Lord Donaldson MR where there is doubt regarding "whether, and if so the way in which, the individual is exercising [the right

Ibid, 797. Butler-Sloss and Staughton LJJ did not offer any views on the appropriate question to be asked although both judges found that the young woman's decision was invalidated because of the possibility of undue influence (ibid, 803 per Butler-Sloss LJ; 804 per Staughton LJ). Both judges also stated that judicial precedent from the law of equity was not of assistance in this situation although they did not indicate why this was the case.

^[2002] EWHC 36 (Fam) (sub nom Centre for Reproductive Medicine v U); [2002] EWCA Civ 565 (CA). See Pattinson "Undue Influence in the Context of Medical Treatment" (2002) 5 Medical Law International 305.

^[2002] EWHC 36 (Fam), [25]. Dame Butler-Sloss accepted that the claimant's husband had been persuaded to change his original consent to the posthumous use of his sperm because of his belief that the couple's fertility treatment would be interrupted if the consent form were not changed.

¹⁷⁴ *Ibid*, [28].

See Chapter 5, text to note 84.

to refuse]".¹⁷⁶ His Lordship was clear that in such cases of doubt, any doubt "falls to be resolved in favour of the preservation of life".¹⁷⁷ His Lordship gave little further indication regarding the factors which cause a situation to fall into this category. In *Re T* itself, the patient had been given misleading, reassuring information by her doctors regarding the consequences of an advance refusal of blood products and it would seem that she did not know she was exercising her right to refuse in a situation where the refusal could realistically lead to her death.¹⁷⁸ Because the patient was unconscious when the case came before the Court, it was not possible to ascertain what she would have done if she had known the level of risk involved and the case may fairly easily be categorised as one of doubt.

The range of the category of "cases of doubt" was not discussed further in *Re* T^{179} and the issue was not taken up in subsequent cases until the decision of Munby J in *HE* v *A Hospital NHS Trust*. ¹⁸⁰ In this case, Munby J relied on Lord Donaldson's categorisation in the context of an advance refusal of treatment and interpreted his Lordship's injunction to mean that the burden of proof must lie with the person seeking to uphold the advance refusal so that, in the event of doubt, the "doubt falls to be resolved in favour of the preservation of life." Proof in this instance must be clear and convincing and "[w]here, as here, life is at stake, the evidence must be scrutinised with especial care." As will be seen in Chapter 3, such a requirement could have significant implications for the circumstances in which an advance right to refuse is recognised. ¹⁸⁴

Both Re T and HE involved advance refusals and this could reasonably be taken to suggest that this limit would apply only in this context. However, it is

¹⁷⁶ [1992] 3 WLR 782, 796. For the passage in full, see text to note 144 *supra*.

For the circumstances of her refusal, see note 145 *supra*.

¹⁷⁷ Ibid

Lord Donaldson MR's categorisation received little attention from commentators although cf Mason, "Master of the Balancers; Non-Voluntary Therapy Under the Mantle of Lord Donaldson" (1993) 2 Juridical Review 115.

¹⁸⁰ [2003] 2 FLR 408.

The patient was a Jehovah's Witness who had executed a standard advance refusal of blood products and who was unconscious at the time of the hearing. Her father petitioned the Court for a declaration that she should receive a blood transfusion notwithstanding her advance refusal on the basis that she had ceased to practice as a Jehovah's Witness on her engagement to a Muslim and that she had committed to becoming a Muslim on her marriage.

Supra note 180, 415. Munby J (*ibid*, 416) cited the passage from Lord Donaldson MR's judgment quoted in the text to note 144 supra.

¹⁸³ *Ibid*, 415.

See further Michalowski "Advance Refusals of Life-Sustaining Medical Treatment: The Relativity of the Absolute Right" (2005) 68 MLR 958, 971. See discussion in Chapter 3 at text to note 44.

noteworthy that in *R* (*Burke*) v the General Medical Council and Others, ¹⁸⁵ Munby J appeared to take a broader interpretation of the category, referring to doubts regarding a refusal arising where it is not clear that "we are in fact dealing with a competent patient or a patient who has competently expressed his wishes in a binding and effective advance directive." ¹⁸⁶ If the existence of doubts regarding a patient's capacity pushed the situation into the category of "cases of doubt" within which the preservation of life becomes the relevant factor, this could significantly displace the autonomy principle. However, it is difficult to see how this could arise given that the presumption of capacity, which was accepted by Lord Donaldson MR in *Re T*, ¹⁸⁷ means that cases of doubt regarding capacity must be resolved in favour of a finding of capacity. Munby J's suggestion (if it was such) that the category of cases of doubt extends beyond advance situations would therefore seem inconsistent with the position of the Court of Appeal.

On the basis of the preceding discussion, it is clear that although other limits, both general and individualised, on the right of autonomy may be envisaged (and could yet develop), at the present time, the capacity requirement is the primary limit on the right of autonomy at common law.

Human Rights Instruments, the Right of Autonomy and the Right to Refuse

This section will examine the way in which the right of autonomy and the right to refuse treatment have been treated under the ECHR and the Irish Constitution and ask what, if anything, these instruments add to the extensive common law protection. The ECHR has been incorporated into the domestic legal systems of the United Kingdom and of Ireland since 2000¹⁸⁸ and 2003¹⁸⁹ respectively. Pecause jurisprudence arising

¹⁸⁵ [2004] 2 FLR 1121.

¹⁸⁶ *Ibid*, 1151.

¹⁸⁷ [1992] 3 WLR 782, 796.

The Human Rights Act 1998 incorporated the ECHR into UK law with effect from January 2000. For an overview of the Act, see Feldman Civil Liberties and Human Rights in England and Wales (2nd ed) (Oxford: OUP, 2002), pp 80-104; Wadham et al Blackstone's Guide to the Human Rights Act 1998 (3rd Ed) (Oxford: Oxford University Press, 2003).

The European Convention on Human Rights Act 2003 incorporated the ECHR into Irish law with effect from December 30 2003. See further O'Connell "The ECHR Act 2003: A Critical Perspective" and Hogan "Incorporation of the ECHR: Some Issues of Methodology and Process" in Kilkelly ed ECHR and Irish Law (Bristol: Jordan Publishing Ltd, 2004).

Both the UK and Ireland have a dualist approach to international treaties. Thus, prior to incorporation into the domestic legal systems, the ECHR did not provide remedies for individual citizens in a national court. Further, national courts had no obligation to take

under the ECHR is relevant to a number of matters addressed in this thesis, it is useful at this point to discuss in brief the legal framework brought about by the incorporation of the ECHR into domestic law. Both the UK and Ireland adopted an indirect or interpretative method of incorporation whereby existing legislation must be interpreted in a way that complies with the Convention. ¹⁹¹ In both jurisdictions, a superior court may make a declaration of incompatibility; however, this does not have an invalidating effect on the legislation in question. ¹⁹² Under the Human Rights Act 1998, new legislation must include either a statement of compatibility with the ECHR by the Minister in charge of the Bill 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. ¹⁹³ There is no equivalent requirement in the European Convention on Human Rights Act 2003 in respect of Irish legislation.

In both jurisdictions, the ECHR also applies to the activities of public bodies and offers individuals a means of redress against such bodies which fail to uphold their rights under the ECHR. Section 6 of the Human Rights Act 1998 states that it is it unlawful for a public authority¹⁹⁴ to act in a way which is incompatible with the

account of jurisprudence arising under the ECHR in making decisions. However, prior to incorporation, individuals had a right of individual petition regarding the State's failure to uphold their ECHR rights (the right of individual petition was extended to individuals in Ireland in 1953 and in the UK in 1966). Petitions were initially made to the European Commission of Human Rights for a finding regarding admissibility and, if admissible, were then heard by the ECtHR in Strasbourg. The Committee of Ministers of the Council of Europe also played an adjudicative role. The Eleventh Protocol to the ECHR, which came into force on November 1 1998, streamlined the procedures for individual petitions. The Commission was abolished and the Committee of Ministers was removed from the adjudicative process. Since this time, all petitions go directly to the ECtHR. See further Feldman, *supra* note 188, pp 45-50 (procedural aspects of petition) and pp 73-74 (dualist approach).

Section 3(1) of the Human Rights Act 1998 states that, so far as possible, "primary legislation and subordinate legislation" must be "read and given effect in a way which is compatible with the Convention rights." Section 2 of the European Convention on Human Rights Act 2003 requires courts "in so far as is possible" to interpret and apply "any statutory provision or rule of law" in accordance with the State's obligations under the Convention.

Section 4(6) of the Human Rights Act 1998 states that a declaration of incompatibility does not affect the validity of the provision, nor is it binding on the parties to the proceedings. A distinction may be made between primary and secondary legislation in this regard. While primary legislation is not invalid (section 3(2)(b)), secondary legislation is not invalid only if "primary legislation prevents the removal of the incompatibility" (section 3 (2)(c)). Section 5 of the European Convention on Human Rights Act 2003 states that a declaration of incompatibility does not affect the validity or continuing operation of the incompatible provision although the section does require the Taoiseach to bring a copy of the order before each House of the Oireachtas within 21 days (on which the Oireachtas is in session).

Section 19(1) of the Human Rights Act 1998.

The term "public authority" includes a court or tribunal and any person who carries out functions of a public nature (section 6(3)); however, this is not an exhaustive definition. See Feldman *supra* note 188, pp 95-96 for discussion of the possible ambit of the definition.

Convention, unless it is statutorily bound to do so.¹⁹⁵ If a court finds that a public authority has acted or proposes to act in an unlawful way, it may grant such relief or remedy or make such order within its powers as it considers appropriate.¹⁹⁶ This includes the award of damages.¹⁹⁷ In Ireland, section 3(1) of the European Convention on Human Rights Act 2003 requires every "organ of the state," subject to any existing statutory provision or rule of law, to perform its functions in accordance with the provisions of the Convention. However, the Act adopts a rather restrictive approach to the remedies available to claimants for breach of their rights by an organ of the state.¹⁹⁹ This restrictive approach to remedies would seem to be premised on the view that ECHR rights are a largely unnecessary addition to the existing constitutional protections afforded to individual rights.²⁰⁰

In addition to allowing the enforcement of remedies in a domestic court, the other important effect of incorporation is the elevation of the importance of the jurisprudence of the European Court of Human Rights (ECtHR). The implementing legislation in both the UK and Ireland includes a requirement that domestic courts take account of the jurisprudence of the ECtHR, the Commission and the Committee of Ministers.²⁰¹

The incorporation of the ECHR into UK law has had a marked impact on the way in which the Anglo-Welsh courts deal with issues of rights²⁰² and this will be evident throughout this thesis. In Ireland, to date, the impact has been much less

¹⁹⁵ Section 6(2)

¹⁹⁶ Section 8(1).

Damages may be awarded provided that the court in question has the power to award damages or to order the payment of compensation (section 8(2)) and provided that the court is satisfied that an award of damages is necessary in addition to any other relief in order "to afford just satisfaction" to the victim (section 8(3)).

The term "organ of the state" is not exhaustively defined but courts are expressly excluded from the category (see section 1(1)).

Section 3(2) of the Act states that a claimant who suffers injury, loss or damage as a result of a contravention of his Convention rights by an organ of the state may institute proceedings for damages. However, the section states that this remedy arises only where no other remedy in damages is available. Although the section does not expressly say so and the matter has not yet been judicially confirmed, it seems to be the case that remedies other than damages may also be available under section 3(2) (although presumably, these would also be limited to cases where no other remedy is available).

The leading Irish constitutional law text, Hogan and Whyte JM Kelly: The Irish Constitution (4th Ed) (Dublin: Lexis Nexis Butterworths), p 1320, regards the ECHR as adding little to the protections afforded by the Constitution. This attitude also meant that Ireland was the last Member State of the Council of Europe to incorporate the ECHR into domestic law (see Hogan supra note 189, p 13).

Section 2 (1) of the Human Rights Act 1998 and section 4 of the European Convention on Human Rights Act 2003.

See Wadham *supra* note 188, pp xi-xvi.

apparent although it may still be that case that the ECHR will carve out a significant place for itself in Irish rights jurisprudence.²⁰³ Having established the legal framework within which ECHR jurisprudence operates, it is now possible to explore the treatment of the right of autonomy and the right to refuse treatment under the ECHR.

ECHR Jurisprudence on Autonomy and Treatment Refusal

The text of the ECHR does not expressly recognise either a right of autonomy or a right to refuse treatment. ²⁰⁴ However, both rights have been recognised by the ECtHR as deriving from the rights protected by the ECHR. Four Articles are of possible relevance in this context. Of these, Articles 3 and 8 are the most important and their application will be discussed in detail in the thesis. Two other articles may also be relevant, although in more limited circumstances than Articles 3 and 8. If the patient seeks to refuse treatment for reasons of religious belief, the Article 9 protection of freedom of thought, conscience and religion may apply. ²⁰⁵ Support for the right to refuse a sterilisation or an abortion might also be found in the Article 12 protection of the right to found a family. ²⁰⁶

Early jurisprudence of the Commission and the ECtHR found in favour of a right to refuse a medical intervention on the basis of the Article 8 protection of the right to respect for private and family life.²⁰⁷ The Article 8 protection was held to

Some commentators see the ECHR as having the potential to impact significantly on Irish law in a range of areas. See further Kilkelly ed *supra* note 189.

On the right to refuse treatment under the ECHR, see generally Wicks "The Right to Refuse Medical Treatment Under the European Convention on Human Rights" (2001) 9 Medical Law Review 17.

In Hoffmann v Austria (1993) 17 EHRR 293, the Court accepted that the refusal of blood transfusions by a Jehovah's Witness was a matter of religious belief. This suggests that the right to refuse this form of treatment would have a prima facie entitlement to protection under Article 9. However, in Hoffmann, the Court did not base its decision on Article 9 but instead relied on the Article 8 respect for family life and the Article 14 prohibition on discrimination to determine whether it was contrary to the ECHR to refuse custody to a Jehovah's Witness parent because of inter alia the health risk to the children arising from the possibility that she would refuse blood transfusions on their behalf. See generally Harris, O'Boyle and Warbrick Law of the European Convention on Human Rights (London: Butterworths, 1995), p 369; Wicks supra note 204, 30-31.

Although as Wicks *supra* note 204, 36 notes, the protection of this right is "far from absolute". See X v Austria (1980) 18 DR 154, 156 where the Commission considered that "a compulsory medical intervention, even if it is of minor importance" may be an interference with the individual's rights as guaranteed by Article 8. This case concerned a blood test in order to establish paternity. This position was confirmed by the ECtHR in Peters v The Netherlands App No 21132/93; 77A (E/B DR 75) which concerned a urine test.

extend to "the physical and psychological integrity" of an individual.²⁰⁸ The right of autonomy was first recognised in *Pretty* v *United Kingdom*²⁰⁹ where it was considered in the context of a patient's claim of a right to assisted suicide. Here, the ECtHR affirmed that the right of autonomy came within the protection of Article 8, stating that "the notion of personal autonomy is an important principle underlying the interpretation of its guarantees".²¹⁰ The right permitted the refusal of medical treatment even if this would lead to the death of a patient.²¹¹ The ECtHR held that the imposition of treatment on a capable, adult patient without consent "would quite clearly interfere with a person's physical integrity in a manner capable of engaging the rights protected under art 8(1) of the Convention."²¹² The ECtHR also held that the legislative prevention of assisted suicide could constitute an interference with Article 8 rights (although it held that, if this were the case, Article 8(2) would permit such interference on the basis of public interest).²¹³

The right to refuse treatment as protected under Article 8 has a scope beyond the right of autonomy. It is clear in the decision in *Glass* v *UK*²¹⁴ that the right of physical integrity is not restricted to capable people.²¹⁵ This broader basis for the right to refuse was in evidence in the recent case of *Storck* v *Germany*.²¹⁶ Here, the ECtHR held that Article 8 had been breached by the administration of medication to the applicant against her will while she was detained, also against her will, at a private clinic. The Court "recall[ed] that even a minor interference with the physical integrity of an individual must be regarded as an interference with the right to respect for private life under Article 8, if it is carried out against the individual's will".²¹⁷ The ECtHR focussed on the fact that the treatment was carried out contrary to the patient's

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X and Y v Netherlands (1986) 8 EHRR 235, para 22.

²⁰⁹ [2002] ECHR 2346/02.

Ibid, para 61. The Court confirmed this principle in Goodwin v UK [2002] ECHR 2978/02, para 90; I v UK [2002] ECHR 2979, para 70.

This contrasts with the narrow view of Article 8 taken by Lord Bingham and Lord Steyn in *R* (*Pretty*) v *DPP* [2002] 1 AC 800. Both Lords regarded Article 8 as protecting autonomy in life but not in relation to the ending of life. See Lord Bingham, *ibid*, 821; Lord Steyn *ibid*, 835.

Supra note 209, para 63.

See discussion in text to note 225 *infra*.

^[2004] ECHR 102 Application No 61827/00. The ECtHR held that the decision of healthcare professionals to treat a child with severe mental and physical disabilities contrary to the wishes of his mother was a violation of the child's right to physical integrity under Article 8. See commentary in Huxtable "Glass v United Kingdom: Maternal Instinct v Medical Opinion" (2004) 16 Child and Family Law Quarterly 339.

²¹⁵ *Ibid*, para 70.

²¹⁶ [2005] ECHR 406.

²¹⁷ *Ibid*, para 143.

will, that she had constantly resisted the imposition of medical treatment and that medication had at all times been administered by force.²¹⁸ The question of the applicant's capacity was not central, although it does seem to have been assumed by the Court that the applicant had been capable at least at the time of her admission to the hospital.²¹⁹

In addition to the protection afforded by Article 8, the right to refuse treatment may in some instances be protected by Article 3 of the ECHR, which contains an absolute prohibition on torture and on inhuman or degrading treatment. In *Herczegfalvy* v *Austria*, ²²⁰ the ECtHR found that treatment imposed against a patient's will could, depending on the circumstances, be contrary to Article 3. ²²¹ Like the protection afforded by Article 8, the Article 3 right is not limited to capable patients. In *Herczgafalvey*, the ECtHR confirmed that Article 3 could apply to treatment for a mental disorder, which in this case had been forcibly imposed contrary to the wishes of an incapable, involuntary patient. Thus, both Articles 3 and 8 protect the rights of incapable patients as well as those of patients who are capable. Their application in the context of incapable patients will be discussed further in Chapter 3, where it will be argued that this kind of rights-based protection provides an important alternative framework to the autonomy paradigm.

A second, and related, contribution to be made by ECHR jurisprudence relates to the obligation placed on a state to protect the right. The common law right of autonomy is effectively self-starting. It is called into action by the capable individual and, if he does not take steps in this direction, there is no obligation on the state to take steps on his behalf. In contrast, in *Storck* v *Germany*,²²² the ECtHR found that the interference with the applicant's private life could be imputed to the state, notwithstanding that this interference had taken place in a private institution.²²³ The state was under a duty to "exercise supervision and control" over private psychiatric

218 *Ibid*, para 144

²²⁰ (1992) 15 EHRR 437.

The Court *ibid*, para 76 presumed the applicant to have been capable of consenting to admission at the time she was admitted against her will although it also acknowledged the possibility that, having been medicated, she may have lost capacity.

The requirements for the application of Article 3 are discussed in detail in Chapter 3 at text to note 173.

²²² Supra note 216.

²²³ *Ibid*, para 145.

institutions.²²⁴ Thus, the ECHR protection may have more practical benefit than the common law right of autonomy, which must be actively exercised by the individual.

While in the regards set out above, the protection of the right to refuse afforded by the ECHR is more extensive than the autonomy-based common law right, in other respects, the protection of the right of autonomy and of the right to refuse under the ECHR would seem to be more limited than the "absolute" protection afforded by the common law. ²²⁵ Article 8 (2) permits interference with rights protected under Article 8 provided that this is:

In accordance with the law and is necessary in a democratic society 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.

These limits on Article 8 are stated in broad terms and would seem to allow relatively extensive interference with the individual's rights. As noted above, in *Pretty*, it was held that the interference with the applicant's rights arising from the prohibition on assisted suicide would be justified under Article 8(2) in order to protect the rights of others. This justification was used in the context of medical interventions in *X* v *Austria*, ²²⁶ where the Commission held that the imposition of a blood test to establish paternity was justified for the protection of the rights of others, and in *Acmanne* v *Belgium*, ²²⁷ where the Commission held that compulsory screening for tuberculosis was justified in order to protect public health. ²²⁸

In R (Mumjaz) v Mersey Care NHS Trust,²²⁹ the House of Lords adopted a relatively broad interpretation of Article 8(2). In particular, the House of Lords held that Article 8(2) could justify the seclusion of a patient with a mental disorder in order to protect the interests of others.²³⁰ The Court also held that the requirement under Article 8 (2) that the interference with the rights protected must be "in accordance

²²⁴ *Ibid*, para 150.

Although, as noted in text to note 162 *supra*, the extent to which the common law permits limits on the right of autonomy is still not fully clear.

²²⁶ (1980) 18 DR 154.

²²⁷ (1984) 40 DR 251.

²²⁸ Cf YF v Turkey App No 24209/94; unpublished 2003 ECHR 3607 where a forced gynaecological examination on a female detainee was held not to be "in accordance with the law" and therefore the issue of whether it could be justified under the Article 8(2) grounds did not arise.

²²⁹ [2005] 3 WLR 793.

Ibid, 808 per Lord Bingham; 826 per Lord Steyn; 826 per Lord Hope.

with the law" did not require the interfering measure to be contained in statute or regulations but that it could, as in this case, be set out in the written policy of a high security psychiatric hospital. Although the hospital policy was not in compliance with the relevant statutory Code of Practice, ²³¹ this did not take the policy outside of the ambit of Article 8(2). In Lord Steyn's words, the relevant question was whether the limiting measure was "formulated with sufficient precision and ... sufficiently accessible to satisfy the criterion of foreseeability." Thus, while the precise ambit of Article 8(2) has not been decided, it does seem that courts have taken a relatively permissive approach to this aspect of Article 8

From the preceding discussion, it is clear that the ECHR can make an important contribution to the law relating to treatment refusal especially because, unlike the common law right of autonomy, the rights protected by the ECHR are not restricted to capable patients only. A similar, although less developed, picture emerges from jurisprudence arising under the Irish Constitution.

The Contribution of Irish Constitutional Jurisprudence

Jurisprudence arising under the Irish Constitution recognises both the individual right of autonomy and the right to refuse treatment and, like the ECHR, does not regard the right to refuse treatment as co-extensive with the right of autonomy. The right of autonomy is one of the unenumerated personal rights of "the citizen" protected by Article 40.3.1 of the Irish Constitution.²³³ The right was first recognised by the Irish

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The Code of Practice to the Mental Health Act 1983 Revised in 1999 (London: Stationary Office, 1999) (Health Service Circular HSC 1999/050; Local Authority Circular LAC (99) 11) was published by the Secretary of State for Health under section 118 of the Mental Health Act 1983. The Code sets out guidance for hospitals on the use of seclusion for detained patients including statements that seclusion should be used as a last resort and that there should be an ongoing review of seclusion every two hours by two nurses and every four hours by a doctor. The claimant in this case was placed in seclusion for long periods of time in accordance with the hospital's seclusion policy which set out a reduced review procedure once a patient has been secluded for more than 24 hours.

Supra note 229, 826-827.

Article 40.3.1 states that "The State guarantees in its laws to respect, and, as far as practicable, by its laws to defend and vindicate the personal rights of the citizen" and has been judicially interpreted, in a series of cases beginning with Ryan v Attorney General [1965] IR 294, to extend protection to a category of unenumerated (or unstated) rights which follow from "the Christian and democratic nature of the State." Hogan and White supra note 200, p 1413 regard the development of unenumerated personal rights as "one of the most significant developments in contemporary [Irish] constitutional jurisprudence".

Supreme Court in *In Re a Ward of Court*.²³⁴ Here, the Court allowed the withdrawal of hydration and nutrition from a woman who had been in a near persistent vegetative state for the previous 23 years. Two members of the Court identified the woman's right of autonomy as relevant to the matter. Hamilton CJ viewed the right of autonomy as part of the right to privacy²³⁵ while Denham J regarded the right as a separate constitutional right.²³⁶ The existence of the right of autonomy as a separate right was affirmed *obiter* by two members of the Supreme Court in *North Western Health Board* v *HW and CW*.²³⁷

The right to refuse treatment is also protected by other constitutional rights in addition to the right of autonomy. In *In Re a Ward of Court*,²³⁸ the right to refuse treatment was regarded as coming within the ambit of the right to bodily integrity,²³⁹ the right to dignity,²⁴⁰ and the right to life.²⁴¹ As with rights arising under the ECHR, the notable feature of this aspect of Irish constitutional jurisprudence is that these rights are not restricted to capable patients only. Indeed, in *In Re a Ward of Court*, the Supreme Court expressly held²⁴² that these rights extended to incapable patients on the basis of the constitutional guarantee of equality.²⁴³ The failure to extend the rights in this way would, in the words of O'Flaherty J, "operate as an invidious discrimination between the well and the infirm."²⁴⁴ The Supreme Court did not expand further on the implications of extending the right to refuse to incapable patients and did not attempt to develop a framework within which to give effect to the

^{[1996] 2} IR 79. See generally Harrington "Withdrawal of Treatment from an Incompetent Patient" (1995) 17 DULJ 120; Keown "Life and Death in Dublin" [1996] CLJ 6; Tomkin and McAuley "Re a Ward of Court: Legal Analysis" [1995] Medico-Legal Journal of Ireland 45.

²³⁵ Ibid, 126. This was also the view of Costello J (writing extra-judicially) "The Terminally Ill: The Law's Concerns" (1986) 21 Irish Jurist 35, 42.

²³⁶ *Ibid*, 167.

^{[2001] 3} IR 622, 717 per Denham J; 746-751 per Hardiman J. This case was primarily concerned with the scope of parental rights to make decisions for their children under Article 42.5 of the Irish Constitution (specifically the parental right to refuse the PKU or "heel" test, which enables certain congenital disabilities to be detected in newborn babies).

²³⁸ [1996] 2 IR 79.

Ibid, 124-125 per Hamilton CJ who described the treatment in question (the surgical insertion of a feeding tube into the ward's stomach) as "intrusive" and as constituting "an interference with the integrity of [the ward's] body"; see also *ibid*, 129-130 per O'Flaherty J; *ibid*, 163 per Denham J.

Ibid, 163-164 *per* Denham J.

Article 40.3.2 provides express protection for the right to life. According to Hamilton CJ *ibid*, 124, the right to life "necessarily implies the right to have nature take its course and to die a natural death". See also *ibid*, 160 per Denham J.

Ibid, 126 per Hamilton CJ; ibid, 130, per O'Flaherty J; ibid, 159 per Denham J.

As set out in Article 40.1 of the Constitution.

²⁴⁴ [1996] 2 IR 79, 130.

right.²⁴⁵ However, at a theoretical level, it is clear that, as with jurisprudence arising under the ECHR, Irish constitutional jurisprudence on the right to refuse has a broader basis that simply the right of autonomy.

As with the ECHR, the protection afforded to the right to refuse under the Irish Constitution is not absolute. In *In re a Ward of Court*, Denham J noted "a few rare exceptions to [the right to refuse treatment] e.g., in regard to contagious diseases or in a medical emergency where the patient is unable to communicate." Hardiman J in *North Western Health Board* v *HW and CW* set out a wider range of possible exceptions, which he listed as "the case of infectious diseases," exceptions "based on social need", and exceptions "specifically identified by law."

Although the issue of foetal interests as an exception to the right to refuse has not come before the Irish courts, ²⁴⁸ should the question arise, Article 40.3.3 of the Constitution will undoubtedly play a role in its resolution. This Article states:

The State acknowledges the right to life of the unborn and, with due respect to the equal right to life of the mother, guarantees in its laws to respect, and, as far as practicable, by its laws to defend and vindicate that right. ²⁴⁹

Article 40.3.3 could be used to limit a woman's right of autonomy if the effect of respecting that right would interfere with the State's obligation to defend and vindicate the right to life of "the unborn". In the only relevant decision to date, Attorney General v X, a majority of the Supreme Court held that, while a woman's right to life could be protected at a cost to the right to life of the unborn, similar protection would not be afforded to the woman's right to travel (which in this case was for the purpose of procuring an abortion). If the woman's right of autonomy were accorded a similar status to the right to travel, it might be expected that this right

In fact, the Court did little more than list the rights implicated and provided no analysis of how they operated and interacted with each other and with the principle of sanctity of life. The decision has been criticised for its lack of conceptual coherence: see critique in Keown supra note 234; Hogan and Whyte supra note 200, pp 1397-1401.

²⁴⁶ [1996] 2 IR 79, 156.

²⁴⁷ [2001] 3 IR 622, 748.

Nor was this situation included within the possible exceptions identified by Denham and Hardiman JJ and discussed in the text prior to this note.

The provision was inserted as the Eighth Amendment to the Constitution following a referendum in 1983.

²⁵⁰ [1992] 1 IR 1.

Ibid, 57 per Finlay CJ; ibid, 73 per Hederman J; ibid, 92 per Egan J. This position was subsequently amended by referendum and, following the Thirteenth Amendment to the Constitution, Article 40.3.3 now expressly states that it does not limit freedom to travel between the State and another state.

would also be subordinate to the right to life of the unborn. However, this outcome is far from certain. The Irish courts have shown some discomfort with the use of Article 40.3.3 to enable the right to life of the unborn to trump all of a pregnant woman's rights other than the right to life.²⁵² Further, Hogan and Whyte²⁵³ argue that the State's obligation is only to do what is "practicable" to vindicate the life of the unborn and suggest that the process of forcing a caesarean section on a resisting woman might not be regarded as "practicable".

The Irish courts have had much less exposure to actual treatment refusal cases than the courts in England and Wales. The only reported decision, other than In Re a Ward of Court, is the decision of the President of the High Court in JM v Board of Management of St Vincent's Hospital.²⁵⁴ In this case, Finnegan P affirmed the existence of a right to refuse treatment (in this case dealing with the advance refusal of a blood transfusion by a Jehovah's Witness who had subsequently become unconscious). He noted that the right to refuse was not absolute but considered that, in the case of "the terminally ill", it would be "very difficult" to envisage circumstances in which the right of a capable patient could be interfered with.²⁵⁵ In the case in question, however, the woman's decision was not binding because she had not made a "clear final decision to have, or not to have, the treatment." This was on the basis that the woman, who had become a Jehovah's Witness on her marriage, was African and that it was part of her culture to adopt her husband's religion on marriage. 257 The woman's decision to refuse treatment was taken "because of her cultural background and her desire to please her husband and not offend his sensibilities". 258 Although Finnegan P did not actually say so, presumably this cultural conclusion was based on evidence presented to the Court, possibly by the woman's husband who had petitioned the Court to allow the blood transfusion to be given.

Finnegan P may have been showing an element of self-justification when he described the decision in *JM* as "an easy decision". ²⁵⁹ In reality, the decision raises

See Society for the Protection of Unborn Children (Ireland) Ltd v Grogan (No 5) [1998] 4 IR 343, 375 per Denham J; ibid, 389-390 per Keane J.

Supra note 200, p 1523.

²⁵⁴ [2003] 1 IR 321.

²⁵⁵ *Ibid*, 324.

²⁵⁶ *Ibid*, 325.

²⁵⁷ *Ibid*, 324.

²⁵⁸ *Ibid*, 325.

Ibid, 325. Finnegan P noted that the woman had a child and a loving husband and that the transfusion would give her a 60% chance of survival.

very difficult questions regarding both the nature of the autonomy principle²⁶⁰ and the status of the right of autonomy in Irish law. The decision also shows the inherent difficulty in giving effect to the patient's right of autonomy in high-risk, uncertain situations. As with Lord Donaldson MR's "cases of doubt",²⁶¹ JM serves as a useful reminder of the judicial instinct to protect life and well-being at the expense of autonomy in high-risk situations.

Conclusion

This chapter has looked at the theoretical basis for the autonomy principle and at its application by the law. It has shown that the principle of autonomy, as recognised in healthcare law and ethics, has its primary philosophical basis in Millian liberalism. The chapter argued that, although the autonomy principle has important flaws and a more complex ethical framework is required, the principle is still an essential component of the law in the context of treatment refusal.

The survey of the legal treatment of the right of autonomy shows that the common law affords a significant level of protection to the right. To date, the courts in England and Wales have not had to adjudicate a conflict between the individual's right of autonomy and the rights and interests of others and therefore judicial statements regarding the "absolute" nature of the right have not been put to the test. The chapter showed that the only limits on the right to date have come in the individualised contexts of undue influence, doubts regarding the patient's intentions and, most importantly, the patient's incapacity. The chapter also investigated the level of protection afforded to the right of autonomy under the ECHR and the Irish Constitution and showed that the right of autonomy in this context is very clearly not an absolute right. However, the important contribution of these human rights instruments is that the individual's right to refuse treatment does not arise simply from the right of autonomy but has a basis in other rights which are not so dependent on the patient being capable.

The ultimate conclusion of this chapter is that, as the law currently stands, the only real limit on the patient's right of autonomy is the requirement that the patient be

See discussion in text to note 93 supra.

See discussion in text following note 176 supra.

capable. A closer examination of the capacity requirement is therefore necessary in order to understand the autonomy paradigm. This examination provides the basis for the next chapter.

Chapter 2: Defining Capacity

Introduction

It is clear from the previous chapter that the capacity requirement is an essential part of the autonomy paradigm. The purpose of this chapter is to examine this requirement and its role within the autonomy paradigm. The chapter is concerned with capacity as a legal and theoretical concept rather than in the applied context of individual treatment refusal situations. The theoretical position must first be understood in order to present a full picture of the autonomy paradigm and to allow the practical application of the capacity requirement to be examined in later chapters.

Two premises underlie this chapter. The first is that there is no single, immutable meaning of capacity and that the choice of a standard for capacity is dependent on value judgements. As Buchanan and Brock state, "[t]he proper standard of competence must be chosen; it cannot be discovered." The United States President's Commission sets out the nature of the choice as follows:

[A] conclusion about a patient's decisionmaking capacity necessarily reflects a balancing of two important, sometimes competing objectives: to enhance the patient's well-being and to respect the person as a self-determining individual.²

In choosing the proper standard for capacity, a court (or legislature) makes a trade-off between values.³ As Gunn notes, "[t]he challenge is to choose the right level to set as the gateway to decision-making and respect for persons and autonomy."⁴ On the one hand, respect for patient autonomy might suggest that the standard for capacity should be set at a relatively low level so as to ensure that as many patients as possible will be permitted to make decisions for themselves. On the other hand, concern for values such as beneficence or the sanctity of life might dictate a higher standard of capacity so that patients who are most at risk are protected against the consequences of their

Deciding for Others: The Ethics of Surrogate Decision Making (New York: Cambridge University Press, 1989), p 47.

President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research Making Health Care Decisions: A Report on the Ethical and Legal Implications of Informed Consent in the Patient-Practitioner Relationship (Washington DC: US Superintendent of Documents, 1982), p 57.

See generally Kopelman "On the Evaluative Nature of Competency and Capacity Judgments" (1990) 13 International Journal of Law and Psychiatry 309.

[&]quot;The Meaning of Incapacity" (1994) 2 Med Law Rev 8, 14.

decisions. However, the choice of a standard for capacity is more complex than this. In setting the standard, a court or legislature is deciding which kinds of abilities should be relevant. In privileging certain abilities, a court is determining what characteristics an individual should possess in order to justify a respect for her right of autonomy. In effect, it is addressing the core question of why the principle of autonomy is important.

The second premise underlying this chapter is that the choice of a standard for capacity must be consistent with the liberal underpinnings of healthcare law. The law cannot endorse the patient's right of autonomy on the one hand and then apply the capacity requirement in a way which is inconsistent with the theoretical basis for the right. At a general level, a capacity requirement is fully consistent with liberal theory. Mill premised the principle of freedom from state interference on "all the persons concerned being of full age, and the ordinary amount of understanding." While capacity retains a central role in modern liberal theory, liberal theorists have dedicated relatively little attention to the question of which conception of capacity is most consistent with the liberal principle of autonomy. This chapter will seek to identify the view of capacity which most clearly coheres with liberal theory so as to be able to evaluate the internal consistency of the autonomy paradigm.

Part I of the chapter looks at the legal test for capacity in healthcare decision making. This Part examines the development of the common law test for capacity and presents the current test in outline. It then examines the work of Law Commission⁷ which has led to the legislative test for capacity contained in the Mental Capacity Act 2005. It will be clear that, as a result of these developments, the basic legal test for

On Liberty (London, 1859), p 84. A capacity requirement is also implicit in Mill's famous wayfarer example which he uses (*ibid*, p 107) to indicate when interference with another person is permitted. The example relates to a wayfarer attempting to cross an unsafe bridge but unaware of the danger. If there is no time to warn the wayfarer of the danger, it is justifiable to seize him until he has been informed of the danger. Thereafter, continued intervention is permissible only if the wayfarer is "a child, or delirious, or in some state of excitement or absorption incompatible with the full use of the reflecting faculty."

Rawls's Theory of Justice (Cambridge, Massachusetts: Harvard University Press, 1971) is premised on individuals having the capacity to act as (*ibid*, p 516) "free and equal rational beings." See also Feinberg's classic liberal treatise on the criminal law The Moral Limits of the Criminal Law Vol 3: Harm to Self (New York: Oxford University Press, 1986), p 28. See Mentally Incapacitated Adults and Decision-Making: An Overview Consultation Paper No

^{119 (}London: HMSO, 1991); Mentally Incapacitated Adults and Decision-Making: A New Jurisdiction Consultation Paper No 128 (London: HMSO, 1993); Mentally Incapacitated Adults and Decision-Making: Medical Treatment and Research Consultation Paper No 129 (London: HMSO, 1993); Mentally Incapacitated and Other Vulnerable Adults: Public Law Protection Consultation Paper No 130 (London: HMSO, 1993); Report on Mental Incapacity Law Com No 231 (London: HMSO, 1995).

capacity is now "clear and easily to be understood by lawyers." This Part then uses jurisprudence relating to capacity across a number of areas of the law in order to place the issues that arise in the healthcare context within a broader legal context.

Having established the legal position, Part II will relate the legal test for capacity to theoretical discussions of capacity. This Part explores a range of views regarding the appropriate standard for capacity and the value judgements that influence the choice of a standard for capacity. It will be argued that a view of capacity which centres on the individual's ability to understand relevant information and to make authentic choices is most consistent with the principle of autonomy. It will also be argued that any modern conception of capacity must take account of the fact that capacity is, to an extent, a contingent rather than an absolute state. Although this view of capacity does not play a role within traditional liberal theory, it will be argued that an acceptance of this view of capacity is essential if the law is to provide meaningful protection for the principle of autonomy.

Part I: The Legal Test for Capacity

It is only in relatively recent years, and in the wake of its recognition of the principle of autonomy, that the law has had to develop a test for capacity in the healthcare context. A 1977 article by American psychiatrists, Roth, Meisel and Lidz, provides the earliest attempt to categorise the abilities required to establish legal capacity in this context (although these commentators despaired of finding a single standard for capacity, which they described as "a search for the holy grail"). In 1991, the Law Commission issued a Preliminary Consultation Paper relating to mentally incapable adults and, although the matter had not yet been resolved by the courts, the

Per Dame Butler Sloss P in Re B (adult: refusal of medical treatment) [2002] 2 All ER 449, 455.

[&]quot;Tests of Competency to Consent to Treatment" (1977) 134 American Journal of Psychiatry 279. The work of Roth et al was developed further by Appelbaum and Roth "Competency to Consent to Research: A Psychiatric Overview" (1982) 39 Archives of General Psychiatry 951; Appelbaum and Grisso "Assessing Patients' Capacities to Consent to Treatment" (1988) 319 New England Journal of Medicine 1635. See also Annas and Densberger "Competence to Refuse Medical Treatment: Autonomy and Paternalism" (1984) 15 Toledo Law Review 561 (one of the earliest assessments from a legal standpoint).

[&]quot;Tests of Competency" *ibid*, 283.

Commission described the approach to capacity in English law as task-specific¹² and requiring an individualised inquiry which must ask "does [the patient] understand the general nature and likely consequences of what he is deciding and can he communicate his decision?"¹³

Developing a Standard for Capacity

Although the issue of capacity was not central in *Re T (Adult: Refusal of Medical Treatment)*, ¹⁴ Lord Donaldson MR made two important *obiter* contributions regarding the test for capacity. First, his Lordship stated that a presumption of capacity applies to all adults. ¹⁵ Secondly, his Lordship stated that "[t]he more serious the decision, the greater the capacity required." This comment suggests a variable standard for capacity whereby the required level of capacity rises or falls depending on the level of risk involved with more serious outcomes requiring patients to be meet a higher standard. The meaning of his Lordship's comments and the appropriateness of a variable standard for capacity within the autonomy paradigm will be discussed in detail in Chapter 7 of the thesis.

The first significant analysis of the abilities required for capacity¹⁷ is found in *Re C (adult: refusal of medical treatment)*. ¹⁸ Here, Thorpe J adopted a functional,

See Gillick v West Norfolk and Wisbech AHA [1986] AC 112, where the House of Lords had preferred a task-specific, individualised approach to minors' capacity.

Supra note 7, p 52. Case law at this time contained a number of obiter statements regarding the abilities required for capacity. In Re F (Mental Patient: Sterilisation) [1990] 2 AC 1, 52, Lord Bridge referred to the capacity "to make or communicate rational decisions" and in Gillick supra note 12, 189, Lord Scarman noted that: "It is not enough that [a minor] should understand the nature of the advice which is being given: she must also have a sufficient maturity to understand what is involved".

^{[1992] 3} WLR 782. Only Lord Donaldson MR departed from the trial judge's conclusion that the young woman had the capacity to make the advance refusal, concluding (*ibid*, 795) that there was "abundant evidence" that Ms T was not in a "physical or mental condition which enabled her to reach a decision." His Lordship's conclusion in this regard is suspect given that he seems to have relied on medical evidence which was subsequently retracted by the expert witness.

¹⁵ *Ibid*, 796.

¹⁶ *Ibid*, 796.

The issue of capacity had been considered by the Court of Appeal in two cases concerning minors, namely Re R (a minor) (wardship: medical treatment) [1991] 4 All ER 177 and Re W (a minor) (wardship: medical treatment) [1992] 3 WLR 758. However, the Court's comments were obiter (in both cases, the Court concluded that capable minors did not have the right to refuse treatment) and the Court did not attempt to address the matter of capacity in any detail. In Re T [1992] 3 WLR 783, 786 Lord Donaldson MR described the comments of the Court in Re R as restricted to the context of minors only.

¹⁸ [1994] 1 WLR 290.

task-specific assessment of capacity based on a three-part test.¹⁹ Under this test, a patient is capable if the patient can: first, comprehend and retain the information relevant to the decision in question; secondly, believe that information; and, thirdly, weigh that information in the balance to arrive at a choice.²⁰ In the case in question, Thorpe J held the plaintiff to be capable of refusing a potentially life-saving, below-the-knee amputation notwithstanding his schizophrenia, his "grandiose delusion that he was a doctor" and his persecutory delusions.²¹ Thorpe J's test was adopted in a number of subsequent decisions²² and has been incorporated into guidance for the medical profession.²³ The test was approved in principle by the Court of Appeal in *Re MB (an adult: medical treatment)*,²⁴ although the Court restated some aspects of the test and, insofar as there is a difference between the two,²⁵ the test in *Re MB* now prevails.²⁶

The test corresponded with the test for capacity set out by the Law Commission in its Report on Mental Incapacity) (considered further at text following note 31 infra). According to Fennell Treatment Without Consent: Law, Psychiatry and the Treatment of Mentally Disordered People since 1845 (London: Routledge, 1995), p 256, the forensic psychiatrist who testified in Re C and upon whose expert evidence the test is based, set out the test for capacity based on his recollection of the Law Commission's proposals.

Supra note 18, 295.

Contrary expert opinion had argued (*ibid*, 293) that the plaintiff was not capable on the basis of these last two characteristics.

See for example the High Court decisions in Tameside and Glossop Acute Services Trust v CH [1996] 1 FCR 753; Re L (An Adult: Non-Consensual Treatment) [1997] 1 FCR 609; R v Collins and another, ex parte Brady [2000] 58 BMLR 173; Re JT (adult: refusal of medical treatment) [1998] 2 FCR 662; Re AK (Medical Treatment: Consent) [2001] 1 FLR 129. The test is also implicitly adopted, although the case is not cited, in Rochdale Healthcare (NHS) Trust v C [1997] 1 FCR 274 and Norfolk and Norwich Healthcare (NHS) Trust v W [1997] 1 FCR 269.

The test is referred to in the joint publication of the British Medical Association and the Law Society Assessment of Mental Capacity (London: BMA, 1995). The test also provides the basis for the Department of Health Guidance Notes Seeking Consent: Working with Children (London: Department of Health, 2001); Seeking Consent: Working with Older People (London: Department of Health, 2001).

²⁴ (1997) 2 FCR 541.

Although it is not clear that judges recognise the differences between the two tests. In Re B (adult: refusal of medical treatment) [2002] 2 All ER 449, 459 Dame Butler-Sloss P applied the test in Re MB but stated that this test involved the Court adopting the criteria laid out by Thorpe J in Re C.

See the Practice Direction (Declaratory Proceedings: Incapacitated Adults) [2002] 1 WLR 325. Although there has been no judicial confirmation to this effect, the test is also likely to be adopted by the Irish courts. The Law Reform Commission Consultation Paper on Vulnerable Adults and the Law: Capacity (LRC CP 37-2005) (Dublin: LRC, 2005) assumes that the test would be applicable in Ireland. On a practical level, it is noteworthy that Irish psychiatrists are members of the Royal College of Psychiatrists. In providing expert evidence, they are likely to be influenced by the practice guidelines issued by the Royal College (see The Psychological Care of Medical Patients: A Practical Guide (2nd Ed) (Royal College of Physicians and Royal College of Psychiatrists, 2003)) which are based on the English legal position.

In *Re MB*, the patient refused her consent to a caesarean section because her phobic fear of needles prevented her from consenting to the necessary anaesthetic. The Court confirmed the existence of a presumption of capacity²⁷ but held that, in the circumstances of this case, the woman lacked capacity because of her dominating fear of needles.²⁸ Butler-Sloss LJ set out the following two-part test for capacity, expressed in negative terms:

A person lacks capacity if some impairment or disturbance of mental functioning renders the person unable to make a decision whether to consent to or to refuse treatment. That inability to make a decision will occur when:

- (a) The patient is unable to comprehend and retain the information which is material to the decision, especially as to the likely consequences of having or not having the treatment in question;
- (b) The patient is unable to use the information and weigh it in the balance as part of the process of arriving at the decision.²⁹

The test in *Re MB* contains a number of refinements on the *Re C* test. First, the Court in *Re MB* required that the individual's inability to make a decision must have arisen because of an "impairment or disturbance of mental functioning." This causal requirement links the patient's inabilities to an underlying source. Secondly, the test emphasises certain information, namely the "likely consequences" of having or not having the treatment in question. Thirdly, the Court subsumed the "ability to believe" requirement form the *Re C* test into the requirement that the patient be able to "use and weigh" information. Finally, at an earlier point in her judgment, Butler-Sloss LJ reiterated the view first expressed by Lord Donaldson in *Re T* that the standard of capacity is dependent on the seriousness of the decisions to be made. The test in *Re MB* will be discussed in detail in Chapter 5. Next, however, it is necessary to examine the legislative test for capacity which developed alongside the common law test in England and Wales.

Supra note 24, 553.

²⁸ *Ibid*, 554.

²⁹ *Ibid*, 553-554.

³⁰ *Ibid*, 553.

Developing a Legislative Test for Capacity

In a series of Consultation Papers, leading up to the publication of a final Report on Mental Incapacity in 1995, 31 the Law Commission addressed a range of issues relating to the legal treatment of mentally incapable adults, including the appropriate test for capacity. The Law Commission recommended the adoption of a task-specific, functional test for capacity.³² The Law Commission regarded the individual's legal status, for example the fact that she had been admitted to wardship, as irrelevant to the assessment of capacity on the basis that this would be "quite out of tune with the policy aim of enabling and encouraging people to take for themselves any decision which they have the capacity to take".33 The Law Commission also rejected any role in the determination of capacity for the nature of the decision made, arguing that a focus on the nature of the decision "penalises individuality and demands conformity at the expense of personal autonomy."³⁴ To emphasise this, the Law Commission recommended that legislation should state that a person should not be regarded as incapable merely because she makes a decision that would not be made by a person of ordinary prudence³⁵ and that legislation should include an express statement of the presumption of capacity.36

More controversially, the Law Commission recommended the inclusion of a "diagnostic threshold" in defining capacity.³⁷ The Commission recommended that, before someone could be found incapable, she must be shown to suffer from a mental disability. A "mental disability" was defined as meaning "any disability or disorder of the mind or brain, whether permanent or temporary, which results in an impairment or disturbance of mental functioning." Justifying its adoption of this threshold, the

For full details of these publications, see note 7 supra.

Report on Mental Incapacity supra note 7, p 33.

³³ *Ibid*, p 33.

³⁴ Ibid.

³⁵ *Ibid*, pp 39-40

³⁶ *Ibid*, p 32.

³⁷ *Ibid*, pp 34-36.

Ibid, p 36. The inclusion of the term "mental disability" marked a departure from the Law Commission's original "diagnostic threshold" (Consultation Paper No 128 supra note 7, paras 3.10-3.14) which had been based on the presence of a "mental disorder" (as defined in section 1(2) of the Mental Health Act 1983). Following extensive criticism (see in particular Carson "Disabling Progress: The Law Commission's Proposals on Mentally Incapacitated Adults' Decision-Making" (1993) 15 Journal of Social Welfare and Family Law 304; Fennell

Law Commission argued that the "diagnostic hurdle" was necessary in order to ensure that the test for capacity "is stringent enough *not* to catch large numbers of people who make unusual or unwise decisions".³⁹ The diagnostic threshold was the only way to get the "right" decision in relation to people with mental disabilities without overly interfering with the autonomy of people without mental disabilities.

Finally, the Law Commission recommended that the test for capacity should be based on the ability to understand and retain relevant information, 40 to "make a decision based on the information relevant to the decision" ⁴¹ and to communicate the decision made.⁴² It recommended that a person should not be regarded as unable to understand information if she could understand an explanation of the relevant information in broad terms and simple language. In this way, the Law Commission sought to import the patient's right to comprehensible information "by implication into the test for capacity."43 The Law Commission's reference to the ability to "make a decision based on the information" had been the cause of some controversy. As initially proposed, this had required that a patient be able to make a "true choice" relating to the information.⁴⁴ This requirement was intended to cover compulsion arising from a mental disorder⁴⁵ as well as the situation of "those whose mental disorders render them particularly susceptible to the influence of others."46 The term "true choice" was not used in the final Report in response to criticisms of the "elusiveness of the concept of 'true choice". 47 However, the Commission held firm to the view of capacity implicit in the true choice requirement, reiterating its view that a "decision based on a compulsion, the overpowering will of a third party or any other

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[&]quot;Statutory Authority to Treat, Relatives and Treatment Proxies" (1994) 2 Med L Rev 30), the Law Commission (Report on Mental Incapacity supra note 7, p 36) changed to a threshold based on "mental disability" in order to avoid the "mind-set" associated with mental disorder.

Ibid, p 16 (relevant information was defined as including information about the reasonably foreseeable consequences of taking or refusing the treatment).

⁴¹ *Ibid*, p 39.

⁴² *Ibid*, p 40.

The Law Commission *ibid*, p 39 agreed with this assessment by Fennell "Statutory Authority to Treat" *supra* note 38, 39 of their intention in including this requirement in the test for capacity.

Consultation Paper No 129 supra note 7, pp 20-21.

As discussed in note 38 *supra*, the Law Commission later replaced the term "mental disorder" with "mental disability".

Consultation Paper No 129 *supra* note 7, p 20.

See the *Report on Mental Incapacity supra* note 7, p 37.

inability to act on relevant information as a result of mental disability is not a decision made by a person with decision-making capacity."48

Some ten years after the publication of the Law Commission's Report, the MCA 2005 was finally enacted. The Act received Royal Assent in April 2005 and is expected to come into force in 2007. The MCA 2005 will be supplemented by a Code of Practice and a Draft Code of Practice was circulated by the Department of Constitutional Affairs in September 2004.⁴⁹ As will be seen in Chapter 3, the MCA 2005 provides a detailed framework for decision-making in relation to mentally incapable adults. Crucially, the Act sets out an individualised, task-specific, functional test for capacity, which is to be applied separately in the context of each decision to be made, and does not permit determinations of a general incapacity to make decisions.⁵⁰ The approach to capacity in the MCA 2005 takes on board many of the recommendations of the Law Commission and is largely in accordance with the common law approach in *Re MB (an adult: medical treatment)*.⁵¹ Insofar as there is a difference with the common law test, the legislative definition will be determinative once the Act comes into force.

The MCA 2005 gives legislative status to the presumption of capacity⁵² and confirms the inappropriateness of deciding capacity on the basis of the nature of the decision made, stating that a person is not to be treated as unable to make a decision merely because a decision made is unwise.⁵³ A person is defined as lacking capacity in relation to a matter "if at the material time he is unable to make a decision for

⁴⁸ *Ibid*, p 39.

A Consultation Paper on the Code of Practice (CP 05/06) was published by the Department for Constitutional Affairs on March 9 2006 (see

www.dca.gov.uk/consult/codepractise/draftcode0506a.pdf).

Contrast the position under section 47 of the Adults with Incapacity (Scotland) Act 2000 which states that, if a medical practitioner primarily responsible for the medical treatment of an adult is of the opinion that the adult is incapable of making a decision about medical treatment, she must certify that the patient is incapable. This certificate must specify the period for which it remains in force, but it may not exceed one year (section 47(5)). This certification requirement caused some concern to medical professionals in terms of the administrative burden it placed on them and in July 2004, the Minister for Health introduced changes to allow healthcare professionals, other than medical doctors, to issue the necessary certificates. Contrast also the approach suggested by the Irish Law Reform Commission supra note 26, para 2.40 which recommended the adoption of a "predominantly" functional approach to capacity but stated that, if incapacity is "profound and enduring," a new functional determination should not be required in every situation.

^{(1997) 2} FCR 541. See discussion in text following note 24 *supra*.

Section 1(2). Decisions regarding capacity are to be based on the balance of probabilities (section 2(4)).

⁵³ Section 1(4).

himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain."54 The impairment may be permanent or temporary. 55 In this, the legislation adopts the causal requirement set out in Re MB (an adult: medical treatment), 56 rather than the threshold based on "mental disability" recommended by the Law Commission.⁵⁷ Under the MCA 2005, a person is unable to make a decision if unable:

- (a) to understand the information relevant to the decision,
- (b) to retain that information,
- (c) to use or weigh that information as part of the process of making the decision, or
- (d) to communicate his decision (whether by talking, using sign language or any other means).58

Unlike the common law, the MCA 2005 does not expressly require a different level of capacity depending on the seriousness of the decision. The MCA 2005 provides that a person is not to be regarded as unable to understand relevant information if "he is able to understand an explanation of it given to him in a way that is appropriate to his circumstances". 59 The MCA 2005 also requires that a person is not to be treated as unable to make a decision unless "all practicable steps to help the person have been taken without success".60

It is clear from this overview of the MCA 2005 that, in general terms, the legislative test for capacity does not diverge significantly from the test at common law. While the legal standard for capacity is clear, the relationship between the legal test and the liberal conception of capacity requires further discussion and will be the subject of Part II of this chapter. Before this, however, it is helpful to consider capacity to make healthcare decisions within the context of jurisprudence on capacity in other civil contexts. 61 A study of testamentary capacity, capacity to contract and

⁵⁴ Section 2(1).

⁵⁵ Section 2(2).

⁵⁶ (1997) 2 FCR 541. See text to note 29 supra. 57

See discussion in text to note 37 supra.

⁵⁸ Section 3(1).

⁵⁹ Section 3(2). There is no equivalent provision in the Adults with Incapacity (Scotland) Act 2000 nor is there any recommendation for such a provision in the Irish Law Reform Commission's proposals.

⁶⁰ Section 1(3).

While the issue of capacity also arises in a criminal context, the treatment of the concept in a civil context provides a more suitable basis for this comparison because the issue of capacity in a civil context generally relates to the individual's right to do something whereas in a criminal context, it relates to the ascription of responsibility for an action already done.

capacity to marry allows certain common themes to be identified, which are sometimes overlooked in discussions regarding the ethical complexities of capacity in a healthcare context.⁶² While it might be argued that medical treatment raises issues of autonomy and protection more immediately than, say, testamentary capacity or freedom to contract, it is important to remember that much of the case law in these areas comes from a time when freedom to contract or to dispose of property were regarded as far more important than the freedom to make healthcare decisions.⁶³

Themes in the Broader Law Relating to Capacity

In many regards, capacity in a healthcare context operates on the basis of the same principles as capacity in other civil contexts. Thus, courts in all civil contexts proceed on the basis of a presumption of capacity, prefer a functional or task-specific approach to capacity, and expressly reject any role for the nature of the patient's decision in the assessment of capacity. However, as will emerge from the following discussion, the practical reality may sometimes diverge from these general principles.

(i) A Presumption of Capacity

The law has long accepted a presumption of capacity. Writing in 1833, Shelford described the presumption and its basis as follows:

Reason, being the common gift to man, raises the general presumption that every man is in a state of sanity, and that *insanity* ought to be proved; and in favour of liberty and of that dominion which, by the law of nature, men are entitled to exercise over their own persons and properties, it is a presumption of the law of England, that every person, who has attained the age of discretion, is of sound mind until the contrary is proven: and this holds as well in civil as in criminal cases.⁶⁴

Because psychiatrists, medical ethicists and other medical personnel have played a significant role in the debate relating to capacity in a healthcare context, healthcare capacity can sometimes be discussed in a vacuum and lessons to be learned from the law's treatment of capacity in other areas can be ignored.

One crucial difference between healthcare capacity and capacity to contract or testamentary capacity is that the issue of capacity in the latter contexts is most likely to arise after the event through an attempt by a third party to "undo" a particular decision.

Shelford Practical Treatise on the Law Concerning Lunatics, Idiots, and Persons of Unsound Mind (Philadelphia: JS Littell,1833), p 23. Original emphasis.

However, this presumption was reversed where an individual had been made a ward of court⁶⁵ and instead, a presumption of continuance applied to the effect that, once an individual has been found incapable, she continues to be so. The presumption of continuance appears to have remained a feature of the law until it was rejected by the Court of Appeal in *Masterman-Lister* v *Brutton & Co.*⁶⁶ Kennedy LJ held that "if there is clear evidence of incapacity for a considerable period of time then the burden of proof may be more easily discharged".⁶⁷ However, he insisted that the presumption of capacity remains intact and the burden remains on the party asserting incapacity.

(ii) A Task-Specific Approach to Capacity

The law adopts a task-specific, or functional, approach to capacity in civil law contexts. With a functional approach, an individual's capacity is related to the function she has to perform. It is clear from the case law that different tasks may require different levels of capacity. Capacity to contract and capacity to execute a deed both require the party to understand the nature of the transaction entered into. Capacity to marry is also based on understanding the nature of the contract of marriage and the responsibilities that the married state entails. The test for testamentary capacity is higher, requiring that the testator shall be able to "understand the nature of the act and its effects; shall understand the extent of the property of

Shelford *ibid*, p 32 noted that, if an individual had been subject to a commission in lunacy, "the burthen of proof shewing sanity is thrown upon those who seek to establish a lucid interval, or the soundness of his understanding." See *Cartwright* v *Cartwright* (1793) 1 Phillim 100; *White* v *Driver* (1809) 1 Phillim 84.

^[2002] EWCA Civ 1889, [17]. The claimant sought to have a personal injuries settlement overturned on the basis of his own incapacity. He had suffered from a head injury some twenty years previously. In 1997, he had obtained the opinion of a consultant in neuropsychiatric rehabilitation that he was, and since the accident had been, "incapable by reason of mental disorder of managing and administering his property and affairs" (within the terms of section 94(2) of the Mental Health Act 1983).

Ibid, [17].
 See Halsbury's Laws of England (4th Ed) (London: Butterworths, 1992), p 719 which cites Boughton v Knight (1873) LR 3 P & D 64, 72 as authority for this proposition in relation to the capacity to contract. In relation to capacity to execute a deed, see Ball v Mannin (1829) 3 Bli NS 1, 22 where a person was held to be capable of executing a deed if he "is capable of understanding what he does by executing the deed ... when its general purport has been fully explained to him"

Re Park's Estate, Park v Park [1953] 2 All ER 1411, 1430 per Singleton LJ. On the question of what the (modern) marriage contract entails, see Sheffield City Council v E and Anor [2004] EWHC 2808 (Fam), [109]-[132]. This case also (ibid, [85]) held that the test is a general one and is not based on capacity to understand the implications of a particular marriage.

which he is disposing, shall be able to comprehend and appreciate the claims to which he ought to give effect."⁷⁰ Capacity to litigate also requires a high level of abilities.⁷¹ This variation in tests depending on the context means that a person may be capable of performing one legal function and not another. Thus, for example, in *Re Park's Estate*, *Park* v *Park*,⁷² a man was held to lack testamentary capacity but to have had the capacity to marry a few hours before making the putative will.

An essential attribute of the task-specific approach to capacity is that an individualised assessment of capacity must be undertaken in each instance. It cannot be presumed that the fact that a person is unable to perform one task makes him incapable of performing another. This approach may be seen in *Banks* v *Goodfellow*⁷³ in the context of testamentary capacity. The Court rejected the view that any degree of "mental unsoundness," even if unconnected with the testamentary disposition, rendered the testator incapable. Instead the question for the court was whether the testator met the functional test for testamentary capacity. While the requirement for an individualised assessment was generally accepted, the need for an individualised test was displaced if the individual had been admitted to wardship. However, in *Masterman-Lister* v *Brutton & Co*, the Court of Appeal held that the fact that an individual was incapable of "managing and administering his property and affairs" did not displace the requirement for a functional, task-specific test for capacity in

Banks v Goodfellow (1870) LR 5 QB 549, 565 per Cockburn CJ.

See Masterman-Lister supra note 66, [26] where the requirements for capacity to litigate were set out in identical terms to those for the capacity to consent to medical treatment.

^{[1953] 2} All ER 1411.

Supra note 70.

The testator had been confined to an institution in 1841 (some 24 years before his death) and had remained delusional after his release. The subject of his delusion was that he was pursued by devils and evil spirits and by (the deceased) Featherstone Alexander. He was however capable of conducting his business affairs and was described as being careful with money. At trial, the jury found him to have the necessary testamentary capacity. This verdict was upheld by the Court of Appeal, Queen's Bench Division.

See also Jenkins v Morris (1880) 14 Ch D 674 where an individual who was subject to insane delusions was held to have the legal capacity to execute a lease once he could be shown to be capable of understanding the effect of the deed. A functional approach also applied to capacity to contract. See Theobald The Law Relating to Lunacy (London: Stevens and Sons, 1924), p 217.

See *Re Walker (a Lunatic so found)* [1905] 1 Ch 160 where a ward, by virtue of his legal status, was automatically deemed to be legally incapable of executing a deed. A ward was also statutorily deemed to be incapable of marrying under the Marriage of Lunatics Act 1811. However, the functional test for testamentary capacity continued to apply notwithstanding the testator's admission to wardship (see *Roe v Nix* [1893] P 55).

⁷⁷ [2002] EWCA Civ 1889.

This is the test for admission to the modern equivalent of wardship (as *per* section 94(2) of the Mental Health Act 1983).

other regards. A person may have the capacity to make one decision and not another and a decision as to capacity in one context does not bind the court regarding capacity in another. Rennedy LJ noted that the effect of a finding of incapacity was to deprive the incapable person of her rights and that, following the decision of the ECtHR in Winterwerp v Netherlands, the question of capacity should be separately investigated in each relevant instance.

(iii) Capacity and the Role Played by the Patient's Decision

Courts have long rejected the view that the nature of the decision made by a person is relevant in determining that person's capacity.⁸² In upholding a testator's will in *In re Glynn Deceased*, McCarthy J summed up the accepted position as follows:

It is a fundamental matter of public policy that a testator's wishes should be carried out however, at times, bizarre, eccentric or whimsical they may appear to be. One man's whimsy is another man's logic.⁸³

This approach is entirely consistent with the principles of autonomy and of freedom of contract.

However, the reality is not so straightforward and there appears to be some tension between the courts' rejection of a role for the decision made, on the one hand, and the way in which they apply the functional test for capacity, on the other. In his study of American jurisprudence on capacity in the first half of the twentieth century, Green⁸⁴ concluded that the wisdom of the transaction was the "inarticulate standard" operative in capacity assessments. He argued that:

Supra note 77, [29] per Kennedy LJ; see also Chadwick LJ ibid, [74].

^{[1979] 2} EHRR 387. In this case, the claimant successfully argued (paras 74-77) that his involuntary detention in a psychiatric hospital had also deprived him of the right to conduct his affairs and that he was entitled to a "fair hearing" within the meaning of Article 6 in this regard.

⁸¹ Supra note 77, [17].

⁸² See Austen v Graham (1854) 8 Moo PCC 282.

⁸³ [1990] 2 IR 326, 340.

[&]quot;Proof of Mental Incompetency and the Unexpressed Major Premise" (1944) 53 Yale Law Journal 271, 306. Green focused his study on capacity to contract and to make testamentary dispositions.

Although he was only able to identify a small number of cases where the courts had actually articulated a standard of capacity based on the wisdom of the transaction, Green (*ibid*, 310) suggests that, in most instances, the courts instinctively looked to the outcome of the

[S]ince, both in unconscious desire and in articulate effort, the court is seeking evidence on whether mental incompetency has affected the particular transaction, the dominant factor in the evidence is whether the court sees the particular transaction in its result as that which a reasonably competent man might have made.⁸⁶

While the validity of Green's contention has not been tested by modern studies, his argument has a certain force especially given that capacity assessment outside the healthcare context will often take place after the event when there may be little basis for a conclusion other than the actual nature of the transaction itself.

There are also indications in the case law that courts look to the seriousness of the decision in choosing the appropriate standard for capacity for a specific task. As noted above, different tasks require different levels of capacity. While this variation sometimes relates to the greater complexity of the task at hand, ⁸⁷ the complexity argument does not hold in all contexts. ⁸⁸ Some decisions require a higher level of capacity because of the courts' view of their gravity. ⁸⁹ In *Re Beaney*, ⁹⁰ Nourse QC (sitting as a Deputy High Court judge) held that the outcome of a particular contractual transaction was so serious as to require raising the standard for capacity above the normal one used. He set out the following basis for deciding on the appropriate standard for capacity:

[I]f the subject matter and value of a gift are trivial in relation to the donor's other assets, a low degree of understanding will suffice. But, at the other

transaction while in fact believing that they were basing their assessment on the individual's understanding.

⁸⁶ *Ibid*, 307 (original emphasis).

See Boughton v Knight (1873) LR 3 P & D 64, 72 where Sir James Hannen justified a high standard for testamentary capacity because a testamentary disposition required a wide "survey of facts and things." See also Sheffield City Council v E and Anor [2004] EWHC 2808 (Fam) where Munby J found that a lower standard should apply to capacity to marry than that applied to capacity to consent to medical treatment or capacity to litigate because inter alia (ibid, [87]), unlike medical treatment and litigation, marriage does not require the intervention of experts and (ibid, [89]) the contract of marriage is a very simple one which does not require an expert's "prognosis, diagnosis and advice."

As noted by Singleton LJ in *Re Park's Estate supra* note 72, 1426, although the standard for testamentary capacity is the highest, some wills are extremely simple and require a very limited survey of facts.

Correspondingly, for reasons of social utility, some decisions may require an especially low standard of capacity. In *Sheffield City Council v E and Anor* [2004] EWHC 2808 (Fam), [143] Munby J noted that the status of marriage carried with it a range of "legal, social and fiscal advantages" and that there are many people in society who may be of borderline capacity whose "lives are immensely enriched by marriage." For this reason, he found (*ibid*, [144]) that the test for capacity to marry should not be set too high "lest it operate as an unfair, unnecessary and indeed discriminatory bar against the mentally disabled."

[1978] 1 WLR 770.

extreme, if its effect is to dispose of the donor's only asset of value ... the degree of understanding required is as high as that required for a will". 91

The relative gravity of the outcome may also explain the higher standard for testamentary capacity, which accords with the primary importance traditionally accorded to land ownership and inheritance by the English and Irish courts.⁹²

(iv) Lessons from the Treatment of Capacity in a Civil Context

The above discussion provides a number of insights relevant in the healthcare context. First, it shows that judicial perceptions of societal interests influence the choice of standard for capacity and that the standard for healthcare capacity is among the highest standards required by the civil law. Secondly, it shows the importance of individualised assessment and the dangers of using a finding of incapacity in one situation in another situation where different requirements may be appropriate. Thirdly, it shows that capacity assessment in other civil contexts also gives rise to tension between the ideal of assessing capacity without reference to the decision made and the reality of actually doing this in practice.

Perhaps most importantly, an understanding of the broader law on capacity serves as a reminder that the test for healthcare capacity is not simply an ethical or philosophical construct but must also operate as a functioning legal mechanism and that it must come to terms with the compromises and inadequacies which are inevitable in such a role. In light of this, the next Part of the chapter looks at theoretical models of capacity and asks whether the law adopts a consistent approach to the two aspects of the autonomy paradigm (i.e. the principle of autonomy and the requirement for capacity).

Ibid 774.

The Victorian concern with property inheritance is evident in any Jane Austen novel. In an interesting cultural contrast, courts in the United States have held that a testamentary disposition requires less capacity than is required to enter into a contract. One case cited by Green "Judicial Tests of Mental Incompetency" (1941) 6 Missouri Law Review 141, 158-159 suggests that a "mere glimmering of reason would be sufficient to sustain a will". Meiklejohn "Contractual and Donative Capacity" (1989) 39 Case Western Reserve Law Review 307, 324-5 suggests that the reason the US standard of capacity for wills is lower is because capacity as understood by the courts takes account of the relational context in which the transaction takes place. Wills require a lower level of capacity because of a "shared intuition that, in general, relationships have more to do with wills than with contracts."

Part II: Conceptions of Capacity

This Part will explore a range of conceptions of capacity and set out the view of capacity which is most consistent with the law's endorsement of the principle of autonomy. Four basic conceptions of capacity will be explored and their consistency with the liberal philosophy which underpins the autonomy principle will be assessed. These conceptions are first, capacity based on the ability to understand, secondly, capacity based on the ability to act rationally, and thirdly, capacity based on the ability to make consistent or authentic choices. The fourth conception of capacity has more recently emerged from the literature. This conception challenges the view that possession of any of the relevant abilities is an immutable fact and argues instead that capacity and incapacity are, to an extent, contingent states.

In addition to the issues of principle raised by the choice of a standard for capacity, the choice also has important practical consequences for the numbers of patients found to be incapable. Appelbaum and Grisso's MacArthur Treatment Competence Study⁹³ showed a significant difference in rates of incapacity depending on the type of test employed. This was especially significant for patients with mental illnesses. Grisso and Appelbaum tested patients with mental illnesses (schizophrenia and depression) and physical illness (angina)⁹⁴ for understanding, reasoning ability and the ability to make authentic or consistent decisions.⁹⁵ When patients were tested for understanding only, approximately 28% of patients with schizophrenia were found

The study is reported in Appelbaum and Grisso "The MacArthur Treatment Competence Study I: Mental Illness and Competence to Consent to Treatment" (1995) 19 Law and Human Behaviour 105; Grisso, Appelbaum, Mulvey and Fletcher "The MacArthur Treatment Competence Study II: Measures of Abilities Related to Competence to Consent to Treatment" (1995) 19 Law and Human Behaviour 127; Grisso and Appelbaum "The MacArthur Treatment Competence Study III: Abilities of Patients to Consent to Psychiatric and Medical Treatments" (1995) 19 Law and Human Behaviour 149.

The patients with illnesses were all hospitalised. In addition, Appelbaum and Grisso used a control group of people who had no illness at the time of testing. The control group was matched to the hospitalised groups in terms of age (within 5 years), gender, race, education (within 2 years) and socio-economic status (based on highest lifetime occupation on an eightpoint scale). See further "The MacArthur Treatment Competence Study III" supra note 93, 150-153.

The authors' term this a test for "appreciation."

to be incapable. However, when the test was for all three abilities, approximately 50% of patients with schizophrenia were found to be incapable. This difference in impact was confirmed by the results obtained in patients with depression. For patients with physical illness, the test adopted had a less obvious impact, although there was an increase in the numbers of patients found to be incapable when all the test standards were used. While it is hardly surprising that increasing the number of requirements will lead to more findings of incapacity, the scale of the increase is significant and shows the practical importance of the choice of a standard.

Capacity as Understanding

The ability to understand information relating to the healthcare decision to be made is almost universally regarded as a minimum requirement for capacity. ¹⁰⁰ Very few commentators, however, regard this ability as sufficient. Jones and Keywood present one of the few arguments in favour of a test for capacity based solely on understanding. ¹⁰¹ They contend that the understanding-based test is "more respectful of patient autonomy and more consistent with established legal principles." ¹⁰² For this reason, they argue that the patient "whether mentally disabled or otherwise, who is

See the MacArthur Treatment Competence Study III" *supra* note 93, 168.

⁹⁷ Ihid

If anything, the results were more dramatic in this context. 5.4% of patients with depression were found to be incapable on the basis of a test for understanding alone while almost 25% of the same patients were categorised as incapable when tested across the three categories (*ibid*).

7.3% of patients with physical illness (angina) were found to be incapable based on the

understanding test and 12.2% were found incapable when measured across the three categories (*ibid*).

One commentator who sets a standard lower than understanding is Drane "The Many Faces of Competency" (1985) 15 Hastings Center Report 17. Drane advocates the adoption of a sliding scale for capacity depending on the level of risk involved. For low risk options, he advocates (*ibid*, 18) that a patient be held capable if she is aware of her situation and has assented to the proposed treatment.

[&]quot;Assessing the Patient's Competence to Consent to Medical Treatment" (1996) 2 Medical Law International 107. See also Culver and Gert "The Inadequacy of Incompetence" (1990) 68 The Milbank Quarterly 619, 620 who define capacity primarily in terms of the ability to understand information. However, these commentators also argue (ibid, 632) that, regardless of capacity, it is morally justified to overrule patients' refusals in circumstances where "the patient faces death or serious and permanent physical or mental disability without treatment" and the reasons for the refusal are "seriously irrational." This would mean that capacity as conceived by these commentators would play a wholly different role to that which it plays within the autonomy paradigm.

¹⁰² *Ibid*, 134.

able to understand the treatment issues, should be competent to consent [to] or to reject medical treatment."¹⁰³

On its face, a test for capacity based solely on understanding appears to protect patient autonomy (provided that the level of understanding required is not set at too high a level). It is presumably for this reason that Jones and Keywood argue that this test is consistent with legal principles. However, this is not necessarily the case. The law's endorsement of autonomy does not, of itself, require the lowest standard of capacity to be adopted. Rather it requires that the standard be consistent with the principles underlying the right of autonomy.

A test based solely on understanding is premised on a limited and unsophisticated conception of the way in which people make decisions. It does not attempt to address the factors that influence an individual in applying information to her own situation. For example, a test based on understanding alone does not accord any recognition to the effect of compulsion (whether internal, arising from some forms of mental illness, or external, arising from pressures placed on a patient) on an individual's capacity to make decisions. This constitutes a significant deficiency in this kind of test. Jones and Keywood admit that the test that they advocate will "inevitably be used to deal with complex medical conditions such as compulsive mental disabilities". 104 They argue however that "it is far better to acknowledge these complexities and not sweep them under the carpet by introducing a catch-all provision to deal with patients with mental disabilities who make apparently unwise choices."105 While the importance of acknowledging complexity cannot be disputed, a test based on understanding alone fails to do precisely this. It purports to respect autonomy but without engaging with the philosophical basis upon which the principle of autonomy rests.

¹⁰³ *Ibid*, 137.

¹⁰⁴ *Ibid.* 138.

¹bid. Referring to the specific instance of an anorexic patient, Jones and Keywood argue (ibid) that such a patient should not be found incapable simply because "we cannot understand why she chooses not to eat and because we believe her choice to be irrational". This skates over the issue of how compulsion should be dealt with, focusing the criticism instead on the rationality-based test for capacity.

Capacity as Reasoning Ability/Rationality

A requirement for rationality is central to two influential attempts to formulate a standard for capacity in the context of healthcare decision making. 106 The United States President's Commission considered that decision-making capacity was based inter alia on "the ability to reason and to deliberate about one's choices". 107 This ability to "manipulate information rationally" was also fundamental to the MacArthur Competence Assessment Tool for Treatment (the MacCAT-T) developed by Grisso and Appelbaum. 108

The President's Commission and the authors of the MacCAT-T were careful to distinguish their requirement that a capable person have the ability to reason from an approach which decides capacity on the basis of whether the decision made by the person is a rational one. The President's Commission defined the ability to reason as the "ability to employ probabilistic reasoning about uncertain outcomes" and expressly differentiated this ability from a requirement that the patient must reach a

Supra note 2, p 60.

The linkage between rationality and autonomy has a significant philosophical pedigree. Rationality is associated with autonomy in a Kantian sense (see Groundwork of the Metaphysics of Morals (1875), p 412 (reproduced in Gregor ed Cambridge Texts in the History of Philosophy: Kant Groundwork of the Metaphysics of Morals (Cambridge: Cambridge University Press, 1997) where Kant argued that "[o]nly a rational being has the capacity to act in accordance with the representation of laws, that is, in accordance with principles, or has a will' (original emphasis). However, as noted in Chapter 1, autonomy in the individualistic healthcare context is more closely derived from Millian liberalism than from Kant. From a liberal perspective, rationality is central to Rawls' theory of justice which is premised on the autonomous actor as both rational and objective (see Theory of Justice (Cambridge, Massachusetts: Harvard University Press, 1971), p 516). See also the role accorded to rationality in Harris The Value of Life (London: Routledge and Keegan Paul, 1985), p 201 and Belvyeld and Brownsword Human Dignity in Bioethics and Biolaw (Oxford: Oxford University Press, 2002) who argue in favour of a right to dignity (which they see as prioritising the right of autonomy) premised on the bearer of the right showing (ibid, p 117) "[b]ehaviour that exhibits rationality" which they define as "value-guided behaviour." 107

Supra note 2, p 57. The full requirements for capacity, as set out by the President's Commission were: "(1) possession of a set of values and goals; (2) the ability to communicate and to understand information; (3) the ability to reason and to deliberate about one's choices." See the similar test suggested by Buchanan and Brock supra note 1, p 23.

¹⁰⁸ See Grisso and Appelbaum Assessing Competence to Consent to Treatment: A Guide for Physicians and Other Health Professionals (Oxford University Press, 1998), Chapter 3. The four abilities tested under the MacCAT-T, are first, the ability to express a choice; secondly, the ability to understand relevant information; thirdly, the ability to appreciate the situation and its consequences; and finally, the ability to manipulate information rationally. 109

rational or "objectively correct" decision. ¹¹⁰ Grisso and Appelbaum also clarify their view of this distinction. They note that it is possible to process an irrational belief in a logical or rational way ¹¹¹ and to process information in a logical and rational way but still reach a conclusion that is eccentric or unpopular. ¹¹² In both instances, the individual will have the necessary reasoning ability ¹¹³ (although in the first situation, she may run into difficulties with other aspects of capacity). ¹¹⁴

The incorporation of a requirement for reasoning ability into the test for capacity has been criticised from a number of perspectives. For some critics, the difficulty is that the requirement is inadequate because it fails to take account of other important aspects of decision-making. Other critics argue that the requirement is inappropriate and that rationality should play no role in capacity assessment. In identifying the inadequacy of the rationality requirement, a number of commentators have argued that the requirement fails to take account of the importance of the individual's affective (or emotional) abilities.¹¹⁵ Charland argues that, in traditional work on capacity, emotion has wrongly been regarded as a negative factor which limits a person's ability to make decisions.¹¹⁶ Drawing on broader developments in emotion theory,¹¹⁷ he suggests that individuals may be able to perform perfectly in

110 *Ibid*, p 61.

An example may be found in *In re Maida Yetter* (1973) 62 Pa D & C 2d 619 where the patient refused surgery for breast cancer because it would interfere with her ability to have children and with her career as a movie actress. The woman was 60 years old and did not have a career as an actress. However, if the bases upon which she made her decision had been true, her conclusions might have followed logically.

An example may found in *St George's Healthcare NHS Trust* v *S* [1998] 3 WLR 936 where the patient refused a caesarean section because of her belief in letting nature take its course.

Supra note 108, p 53.

Interestingly, in *Re Maida Yetter supra* note 111, the patient was held to be capable because she had other reasons for refusing the surgery unconnected to the delusions set out in note 111 (her aunt had died following similar surgery some years previously).

In addition to the work of Charland, considered in the text following this note, see also Somerville "Refusal of Medical Treatment in 'Captive' Circumstances" (1985) 63 Canadian Bar Review 59, 65-68; Glass "Refining Definitions and Devising Instruments: Two Decades of Assessing Mental Competence" (1997) 20 International Journal of Law and Psychiatry 5, 20-23. See also the evidence presented by Dr Zigmond on behalf of the Royal College of Psychiatrists to the Joint Committee on the Draft Mental Health Bill (Report of the Joint Committee on the Draft Mental Health Bill (HL Paper 79-1; HC 95-1) (London: Stationery Office, 2005), para 153).

[&]quot;Is Mr Spock Mentally Competent?: Competence to Consent and Emotion" (1998) 5

Philosophy, Psychiatry and Psychology 67; "Appreciation and Emotion: Theoretical

Reflections on the MacArthur Treatment Competence Study" (1999) 8 Kennedy Institute of

Ethics Journal 359.

In this regard, Charland ("Is Mr Spock Mentally Competent? supra note 116, 73) relies heavily on Damasio's study (Descartes' Error: Emotion, Reason and the Human Brain (New York: Grosset/Putnam, 1994)) which investigated the effect of damage to the part of the brain that deals with emotions (the ventromedial region of the frontal lobe) on individuals'

tests based on understanding and rationality but "without emotions they appear unable to cope successfully with real life decision making." Cox White explores why emotion is important for decision-making. She argues that affective capacity is necessary in order for patients to recognise a conflict in their first-order desires. For example, a patient who wants to refuse life sustaining treatment but who also wants to continue to live will be aware of the conflict through "negative felt and cognitive emotions". These emotions motivate people to assess and evaluate their desires and to monitor their evaluation. In other words, for most people, it is only if a decision "feels" wrong that they will re-examine the basis on which the decision is made.

Affective capacity cannot be incorporated into a rationality based test and, therefore, Charland favours developing mechanisms to "operationalize and test how emotions contribute to appreciation" which would operate alongside a rationality test. This would increase the range of abilities necessary for capacity and would require the development of mechanisms to test for emotional ability. The difficulty with this, as Appelbaum notes, is that emotional experience has an "intrinsically subjective nature". While Appelbaum acknowledges that a capacity to feel emotions may be relevant to "good" decision-making, he argues that the difficulties with testing for emotions may lead to unreliable measurement, which in turn will lead to high error rates in capacity assessment with "many people unfairly excluded from making treatment decisions."

cognition, memory and behaviour. The study found that, while people in this situation could understand and memorise without difficulty, they were unable to plan for the future, could not maintain healthy relationships and behaved in self-destructive ways. See also the arguments made by Elliot *Bioethics, Culture and Identity: A Philosophical Disease* (New York: Routledge, 1999), Chapter 5 and Rudnick "Depression and Competence to Refuse Psychiatric Treatment" (2002) 28 *Journal of Medical Ethics* 155 relating to patients with depression who may have difficulty experiencing emotion because they have ceased to care what happens to them and have become passive in the face of their illness.

"Is Mr Spock Mentally Competent?" *supra* note 116, 73.

Competence to Consent (Washington DC: Georgetown University Press, 1994).

¹²⁰ *Ibid*, p 132.

¹²¹ *Ibid*.

[&]quot;Appreciation and Emotion" supra note 116, 372.

¹²³ *Ibid*.

Appelbaum "Ought We to Require Emotional Capacity as a Part of Decisional Competence?" (1999) 8 Kennedy Institute of Ethics Journal 377, 385.

¹²⁵ *Ibid*, 386.

Ibid, 385. See also the concerns raised by Somerville supra note 115, 67 and Glass supra note 115, 22-23.

Cox White puts forward a more achievable way of dealing with emotional incapacity. She argues that, rather than requiring a general test for emotional capacity, an individual's emotional capacity should be questioned only when the way in which the individual is dealing with a particular situation is inconsistent with her past behaviour. Thus, she argues that "a person who usually perceives and attends to his emotions but in a particular situation is doing neither, is not competent." This approach imports emotional capacity into a test for authenticity or consistency rather than giving it a status of its own. Under this formulation, the test measures the individual, not against the "right" emotional response, but against her own prior responses. The way in which this kind of personalised test might work will be considered in more detail in the next section.

In addition to the inadequacy argument set out above, some critics argue that a test based on rationality (or the ability to reason) is inappropriate. First, a test based on the ability to reason invites error. The careful distinction made by the President's Commission and the authors of the MacCATT-T between testing for reasoning ability and deciding capacity on the basis of the rationality of the decision, 128 is convincing at a theoretical level. However, applying the distinction in practice may be considerably more difficult. It is all too easy to conclude that a patient lacks reasoning ability simply because she makes an irrational decision. The temptation for this kind of backwards reasoning is increased if reasoning ability is made a part of the test for capacity.

Secondly, feminist critics argue that the inclusion of a requirement for rationality could have a disproportionate impact on women and lead more women to be found incapable. Stefan argues that "women have long been portrayed and perceived as irrational, as incapable of objectivity or of engaging in reasoned decisionmaking." She argues that, as a consequence, women's moral preferences

Supra note 119, p 137.

See text to note 109 supra.

[&]quot;Silencing the Different Voice: Competence, Feminist Theory and Law" (1993) 47 University of Miami Law Review 763, 773. This is supported by Gilligan's work on moral reasoning (In a Different Voice: Psychological Theory and Women's Development (Cambridge, Mass: Harvard University Press, 1982)) which showed that men (and boys) scored higher on moral reasoning tests because of their use of an objective, justice-based method of reasoning and that women (and girls from the age of 11 on) scored lower because of their adoption of a more contextual approach to reasoning.

are discounted by courts because they employ different kinds of decision-making.¹³⁰ While further empirical investigation would be required before this could definitively be stated to be the case,¹³¹ it is not appropriate to base a test for capacity on a requirement which may be applied differently on the basis of sexist presumptions.

Finally, a requirement for rationality, or reasoning ability, is not fundamental to the traditional liberal philosophy upon which healthcare law is based. Mill defended the individual's right to liberty, not on the basis of the individual's rationality, but on the basis that, through liberty, human individuality can develop. Thus, the essence of liberalism relates to the individual's right to make decisions regardless of rationality. It would seem inconsistent with liberal philosophy to require an individual to have the capacity to act rationally in order to be allowed to act irrationally. Therefore, a consistent approach to the capacity requirement does not require it to include an ability to act rationally.

Capacity as Authenticity

The authenticity view of capacity adopts an individualistic or subjective approach to the concept. Rather than using objective tests for understanding or reasoning ability, this conception of capacity focuses on the authenticity or consistency of an individual's decision using the individual herself as the measure. While issues arise regarding what constitutes an authentic or consistent decision, at a minimum this view of capacity requires the individual to have the ability to measure her decision against her view of what is important. As discussed above, 133 this view of capacity would allow a consideration of affective ability as part of the assessment of authenticity, depending on the individual's past behaviour.

Ibid. In making this assertion, Stefan relies (ibid, 770-771) on a study by Miles and August "Courts, Gender and the Right to Die" (1990) 18 Law, Medicine and Healthcare 85 which examined more than thirty cases where individuals sought to refuse life-saving treatment. They found that courts took very different approaches depending on the gender of the individual. Men's opinions were seen as thoughtful and rational while women were portrayed as "unreflective, emotional or immature."

A review of the case law from England and Wales shows that more findings of incapacity have related to women. The volume of caesarean section cases means that this is inevitable. However, the primary motivation behind the findings of incapacity in this context is likely to be at least as much the courts' desire to protect foetal interests as any discounting of women's methods of moral reasoning.

See *On Liberty* (London, 1859), p 70.

See text following note 127 supra.

There is a clear link between the authenticity view of capacity and the liberal understanding of the right of autonomy. For liberals, autonomy must be respected because it "allows each of us to be responsible for shaping our lives." It is therefore consistent to expect the autonomous individual to be capable of making the value choices necessary to do this. Thus, Dworkin regards autonomy as protecting "people's general capacity to lead their lives out of a distinctive sense of their own character, a sense of what is important to and for them". Whether patients have a right of autonomy turns on "the degree of their general capacity to live a life in that sense." Dworkin does not "assume that competent people have consistent values or always make consistent choices, or that they always lead structured, reflective lives." However, he does presume that the autonomous individual has "the ability to act out of genuine preference or character or conviction or a sense of self." Expanding on his view of capacity in the context of people with dementia, Dworkin argues that:

When a mildly demented person's choices are reasonably stable, reasonably continuous with the general character of his prior life, and inconsistent and self-defeating only to the rough degree that the choices of fully competent people are, he can be seen as still in charge of his life, and he has a right to autonomy for that reason. But if his choices and demands, no matter how firmly expressed, systematically or randomly contradict one another, reflecting no coherent sense of self and no discernable even short-term aims, then he has presumably lost that capacity that it is the point of autonomy to protect. 139

While, in general terms, there is a clear linkage between the authenticity view of capacity and the liberal principle of autonomy, this leaves open the question of what level of authenticity or consistency should be necessary in order to establish capacity. In describing the authenticity requirement, the President's Commission considered that a "framework for comparing options was necessary "if the person is to

Ronald Dworkin Life's Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom (New York: Alfred A Knopf, 1993), p 224.

¹³⁵ Ibid, p 224. See also Gerald Dworkin The Theory and Practice of Autonomy (New York: Cambridge University Press, 1988), p 20 who defines autonomy as: "a second-order capacity of persons to reflect critically upon their first-order preferences, desires, wishes and so forth and the capacity to accept or attempt to change these in light of higher-order preferences and values."

¹³⁶ *Ibid*, pp 224-225.

¹³⁷ *Ibid*, p 224.

¹³⁸ *Ibid*, p 225.

¹³⁹ *Ibid*.

evaluate possible outcomes as good or bad."¹⁴⁰ The individual must have reasonably stable values and be able to make "reasonably consistent choices."¹⁴¹ This requires a relatively high standard of consistency in order for capacity to be established. However, there may be difficulties with such a high standard because it requires the patient to have thought about what she is doing and why and to have a developed framework of values. As Faden and Beauchamp point out,¹⁴² most people do not engage reflectively with their motivations and imposing this standard would require more from patients whose capacity is at issue than is the norm. Faden and Beauchamp also point out that patients are not always consistent when confronted with the stresses of serious illness. Thus:

[N]ew and unfamiliar circumstances, problems and choices may generate apparently or actually anomalous actions that are out of character simply because the surrounding events are unprecedented in the actor's experience.¹⁴³

Once again, requiring a high degree of consistency may require patients whose capacity is at issue to meet a level of decision-making beyond the norm.

In light of this, perhaps the most suitable view of the authenticity requirement is to focus on the genuineness of the patient's decision. An individual need not be capable of making complex value judgements but those which she does make must be her own. This is broadly in line with Dworkin's conception of capacity as the "ability to act out of genuine preference or character or conviction or a sense of self" and with Faden and Beauchamp's view that capable decisions must be "intentional, understood, uncontrolled actions" which require "independence from control by neurotic compulsions, addictions, and related self-alienating psychiatric disorders." This is also similar to the view of capacity put forward by the Law Commission in its "true choice" test. On the basis of the foregoing discussion, it would seem that this

Ibid, p 58. See also Buchanan and Brock *supra* note 1, pp 23-25.

See text to note 44 *supra*.

Supra note 2, p 57.

A History and Theory of Informed Consent (New York, Oxford: Oxford University Press, 1986), pp 264-265. They argue that such a requirement would "result in morally unacceptable judgments regarding which actions are worthy of respect as autonomous and which are not" (original emphasis) and would lead "many familiar acts of consenting and refusing [failing] to qualify as autonomous".

¹⁴³ *Ibid*, p 266.

Life's Dominion supra note 134, p 225.

Supra note 142, p 268. See also the description of competence in Beauchamp "Competence" in Cutter and Shelp eds Competency: A Study of Informal Competency Determinations in Primary Care (Dordrecht: Kluwer, 1991), pp 63-64.

view of capacity is the most theoretically consistent with the principles underlying the autonomy paradigm.

Capacity as a Contingent State

The views of capacity discussed above all presume that the capable person (as a philosophical construct) can be distinguished from the incapable person. The only issue is deciding on what basis this distinction should be made. However, this view of capacity is becoming outmoded. Instead of simply regarding capacity or incapacity as naturally occurring states, many less traditional ethical approaches argue that people may become more or less capable depending on a range of factors, including some factors outside of their control. ¹⁴⁷ This view sees capacity as a variable and, in a sense, constructed state. At a theoretical level, this perspective may be found in feminist ethics, hermeneutic ethics and therapeutic jurisprudence.

Feminist theory draws attention to the political, social and personal impediments that prevent women from having access to power. In a healthcare context, this includes the power to make healthcare decisions free from external control. In the same way as a feminist critique of society identifies structural and other factors which create gender injustice, a feminist critique of capacity isolates factors that limit the individual's ability to comply with a capacity requirement and seeks to counter these factors as experienced in individual situations. These factors include the nature of the test for capacity and the abilities tested for, sexist presumptions which may be made by assessors and the gendered context within which capacity assessment takes place. 148 Therefore, a feminist approach to capacity does not simply accept that patients are capable or incapable but engages with this and requires that attempts be made to enhance each individual's capacity.

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See generally Berghmans "Ethicists and Practitioners in Collaboration on Capacity:
Development of New Approaches to Mental Capacity and its Assessment", Paper presented to
Final Conference EPICC Project (Ethicists and Practitioners in Collaboration on Capacity)
conducted through the Centre for Global Ethics, University of Birmingham, November 6-7
2003.

See Sherwin *No Longer Patient: Feminist Ethics and Health Care* (Philadelphia: Temple University Press, 1992), pp 93-94.

A hermeneutic approach to ethics is concerned with the way in which individuals interpret their lives and the world around them. As described by Lundin "[h]ermeneutics presupposes an interactive, relational, intersubjective self." The hermeneutic approach emphasises the importance of dialogue and the transformative effect of engagement with other people. Hermeneutic ethics does not presume an absolute truth but rather focuses on each individual creating her own meaning through a process of engagement. Thus, Clegg describes as key to a hermeneutic enquiry, "the commitment to generate questions that aim for engagement rather than alienation." Applied to the capacity context, this means that an individual is not simply viewed as capable or incapable but instead that the process of dialogue and engagement with the individual is essential in determining her capacity.

This view of capacity is also supported by the therapeutic jurisprudence approach to law. This approach is described by Winick as follows:

Therapeutic jurisprudence suggests the need for an assessment of the therapeutic impact of legal rules. [It argues that] a sensible policy analysis of law should take into account its consequences for the health and mental health of the individuals and institutions it affects. Therapeutic jurisprudence accordingly calls for theoretical speculation about and empirical investigation of the therapeutic or antitherapeutic effects of the law. 152

While the concept of therapeutic jurisprudence requires further development, ¹⁵³ the possible tension between therapeutic values and patient rights in the context of

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Hermeneutic ethics has its origins in the interpretation of texts. Traditional hermeneutics, as associated with the German philosopher, Freidrich Schleiermacher, is concerned with the interpretation of biblical and legal texts (see Bowie ed *Schleiermacher: Hermeneutics and Criticism* (Cambridge: Cambridge University Press, 1998)). The term philosophical hermeneutics was first used by the German philosopher, Hans-George Gadamer (*Wahreit und Methode* 1960) (Weinsheimer and Marshall ed *Truth and Method* (2nd rev Ed) (London: Sheen and Ward, 1989).

Lundin et al The Promise of Hermeneutics (Cambridge: Paternoster Press, 1999), p 134.

Clegg "Practice in Focus: A Hermeneutic Approach to Research Ethics" (2004) 32 British

Journal of Learning Disabilities 186, 186.

[&]quot;The Right to Refuse Mental Health Treatment: A Therapeutic Jurisprudence Analysis" (1994) 17 International Journal of Law and Psychiatry 99, 100. For further discussion of this approach to law, see Wexler and Winick Essays in Therapeutic Jurisprudence (Durham NC: Carolina Academic Press, 1991); Wexler and Winick eds Law in a Therapeutic Key:

Developments in Therapeutic Jurisprudence (Durham NC: Carolina Academic Press, 1996).

Slogobin "Therapeutic Jurisprudence: Five Dilemmas to Ponder" (1995) Psychology, Public Policy and Law 1933 argues that therapeutic jurisprudence leaves significant questions unexplored; for example, who determines what is 'therapeutic' and how are differences regarding what constitutes a 'therapeutic' approach to be resolved in a legal setting? See also the questions raised by Behnke and Saks "Therapeutic Jurisprudence: Informed Consent as a Clinical Indication for the Chronically Suicidal Patient with Borderline Personality Disorder" (1998) 31 Loy LA L Rev 945, 978-981. For the difficulties in applying therapeutic

treatment refusal means that there is a clear value in including a therapeutic enquiry in any discussion in this context.

In relation to capacity, Winick notes possible adverse psychological effects for the patient arising from a finding of incapacity.¹⁵⁴ As well as the social stigma, he points to effects such as learned helplessness¹⁵⁵ and lack of motivation and argues that, if an individual is diagnosed as incapable in one regard, this may contribute to a diminution of capacity in other regards. For this reason, Winick argues that capacity assessment should be viewed as "a teaching or helping process,"¹⁵⁶ an argument which clearly accepts the essential contingency of capacity.

These theoretical arguments are supported by empirical work in this area. Grisso and Appelbaum's comparative study of capacity in people with physical and mental illnesses found that the manner in which information is communicated is an important factor in whether or not a patient is found capable. This is confirmed by the results of the study conducted by Gunn *et al* into levels of understanding in patients with a range of mental conditions. The study showed a marked improvement in the levels of understanding achieved by patients with mental illness and learning disabilities when information was made more accessible by being broken down into smaller blocks. For patients with mental illness, the percentage of

jurisprudence in the practical context of the Mental Health Review Board for the Australian State of Victoria, see Freckelton "Decision-Making About Involuntary Psychiatric Treatment: An Analysis of the Principles Behind Victorian Practice" (1998) 5 Journal of Law, Psychiatry and Psychology 249.

"The Side Effects of Incompetency Labelling and the Implications for Mental Health Law" (1995) 1 Psychology, Public Policy and Law 6.

"The MacArthur Treatment Competence Study: Legal and Therapeutic Implications" (1996) 2

Psychology, Public Policy and Law 137, 151.

The study team (*ibid*, 276-277) investigated the capacity of patients to understand the purpose and nature of the procedure, the risk involved in the procedure, risks associated with not having the procedure and that they had a choice in consenting to the procedure or not.

Seligman's work on learned helplessness (Helplessness: On Depression, Development and Death (San Francisco: Freeman, 1975)) is best known in legal circles in the context of the criminal law defence of battered women's syndrome. The essential argument founded on learned helplessness is that, when an individual comes to believe that she cannot change her situation, she ceases to try to do so (see Winick note 154 supra, pp 8-9).

This study found (see "The MacArthur Treatment Competence Study III supra note 93, 173) that all patients groups (and the non-patient group) manifested considerably better understanding of the treatment information after it was disclosed to them part by part for the second time than when disclosed whole for the first time.

[&]quot;Decision-Making Capacity" (1999) 7 Medical Law Review 269. This study tested four groups of adult participants (see *ibid*, 270) in relation to a blood test which was required either for general health purposes or to monitor medication levels. The first group had chronic schizophrenia or schizophrenic disorder, the second group had a learning disability at the lower end of the mild disabilities range, the third group had (at least moderate) dementia, and the final control group was drawn from the general population.

participants found to be capable increased from approximately 50% to approximately 75%. ¹⁶⁰ For participants with learning disabilities, the increase was from approximately 45% to approximately 55%. ¹⁶¹ Interestingly, for patients with dementia, rendering information more accessible did not impact on findings of capacity at all. ¹⁶² While these findings do not suggest that patients can always be "taught" to have the necessary abilities, they do show that some patients, particularly patients with mental illness, can cross the line and be held capable because of the way in which they are treated in advance of the assessment and the way in which they are assessed. The findings therefore support the argument that capacity and incapacity cannot be seen as immutable states.

The preceding arguments, both theoretical and empirical, suggest a fundamental gap in traditional discourse relating to capacity. The recognition that capacity is a contingent state requires a shift in focus away from the individual alone and instead requires that account be taken of all the factors, both structural and personal, that prevent the individual from being capable. It also means that the capacity assessor may no longer be viewed as an objective outsider who tests the patient and decides her capable or not but as an essential part of the process of making the patient capable (or incapable). As will be seen in Chapter 5, this poses a significant challenge for the functional test for capacity which is, for the main part, premised on the traditional view that an individual is either capable or not and that the assessor's role is simply to decide which of these is the case. However, if the law is to take the principle of autonomy seriously, this aspect of the capacity requirement must be acknowledged.

Conclusion

This chapter has examined the test for capacity under the law and has argued that the law's approach is theoretically consistent with its endorsement of the autonomy principle. The law applies a presumption of capacity and adopts an individualised functional test. The decision made by the patient is routinely stated to be irrelevant in the assessment of capacity. Furthermore, the law does not make the error of allowing

See Figure 1, *ibid*, 280.

¹⁶¹ Ibid.

¹⁶² Ibid.

capable patients to refuse treatment and then setting the standard for capacity so high as to be unachievable by most patients. Therefore, the autonomy paradigm is, at a theoretical level, internally consistent.

However, the theoretical coherence evident in this chapter relates to the test as it is outlined in abstract terms. The reality of the test as applied in practical situations can be quite different. This is especially the case when the issue of capacity arises in the pressured context of treatment refusal when the effect of the refusal is to endanger the life or long-term health of the patient. A closer look at the reality of the test for capacity will show that the test comes under strain when applied in practice. In particular, difficult questions arise regarding definitions (for example, the level of understanding required and the meaning of the "use and weigh" test); the role of people other than the patient (for example assessors, family members and other healthcare professionals); the application of a capacity test in the context of fluctuating capacity; and the role played by the patient's decision in setting the standard for capacity. These questions will be addressed in Chapters 5, 6 and 7 of the thesis where it will be shown that the functional test for capacity cannot deliver the value-free, neutral assessment of capacity that is presumed within the autonomy paradigm. Therefore, the paradigm in an applied context will be shown to lack the internal consistency of the theoretical model.

Before engaging further with these questions, it is necessary to look at the first significant limitation of the autonomy paradigm identified in this thesis. This is the way in which the binary division of patients according to the capacity requirement has impacted on incapable patients. This will be the subject of the next chapter.

Chapter 3: The Autonomy Paradigm and the Incapable Patient

Introduction

Under the autonomy paradigm, described in the previous chapters, the right of autonomy is restricted to capable patients only. There is no mechanism to deal with patients who wish to refuse treatment but who do not reach the designated standard for capacity or to deal with the practicalities of administering treatment to incapable patients. This chapter will show that, nonetheless, the autonomy paradigm has had an indirect impact on the law relating to incapable patients. This is because the law's adherence to the autonomy paradigm has led it to neglect the need for a conceptual model within which to deal with patients without legal capacity. In particular, the law's obsession with autonomy has detracted attention from the other human rights relevant to treatment refusal which are especially important in relation to incapable patients.

In the absence of an independent theoretical model, the law traditionally dealt with healthcare decision-making for incapable patients using one of two unsatisfactory approaches. Each of these approaches derives from the autonomy paradigm. On the one hand, courts in England and Wales viewed a finding of incapacity as justifying a return to full scale paternalism (in this context, sometimes referred to as "soft" or "weak" paternalism) where treatment decisions may be made on the basis of the patient's best interests with few safeguards and little analysis. Once the patient's right of autonomy was deemed not to apply, the fact that he did not want treatment was regarded as irrelevant. The second approach, preferred by United States courts, has been to rely on the principle of autonomy, notwithstanding the patient's lack of capacity, and to seek to extend the right of autonomy to incapable

Buchanan and Brock *Deciding for Others: The Ethics of Surrogate Decision Making* (Cambridge: Cambridge University Press, 1989), p 3 describe a similar omission in ethical theory.

Feinberg "Legal Paternalism" (1977) 1 Canadian Journal of Philosophy 106 defines "soft" paternalism as paternalistic intervention on the basis of incapacity while "hard" paternalism is interference with capable decisions.

Pellegrino and Thomasma For the Patient's Good: The Restoration of Beneficence in Health Care (New York: Oxford University Press, 1988), p 7 define "weak" paternalism as "an action taken in the best interests of a patient who cannot give a fully informed consent for some reason, or who is not afforded the full possibility of free choice."

patients. In the latter instance, the law fails to concede the important role played by capacity in the autonomy paradigm. As will be seen in this Chapter, neither of these approaches provides an adequate basis for decision-making. The Mental Capacity Act 2005 recognises this and attempts to bridge the two unsuccessful models to provide a new framework for decision-making. This Chapter argues that the MCA 2005 is successful to a degree but that a more concerted move away from the limitations of the autonomy paradigm is required. In particular, a broader human rights based approach must be adopted which takes account of issues such as the role of restraint and of the patient's rights to bodily integrity and liberty and to be free from inhuman or degrading treatment. An essential part of this approach is the provision of mechanisms which enable treatment decisions to be monitored and allow patients an opportunity to object to proposed treatment notwithstanding their incapacity.

This chapter examines the law's response to healthcare decision-making for incapable patients under the shadow of the autonomy paradigm. Part I sets out the two traditional models for decision-making, the best interests test adopted in England and Wales and in Ireland and the substituted judgment standard adopted in the United States, and shows how these models are influenced in different ways by the pervasive influence of the autonomy paradigm. Part II examines the MCA 2005 and assesses the Act's attempts to synthesise the two traditional models and argues that the legislation on its own cannot provide an adequate legal framework. This Part then looks at the role of human rights, in particular jurisprudence arising under the European Convention on Human Rights, and argues that this broader approach to patient rights should provide the basis for healthcare decision-making in respect of incapable patients.

Part I: Decision-Making for Incapable Patients: The Traditional Legal Models

This Part sets out the two models for decision-making, each of which derives from the autonomy paradigm. The first section looks at the development of the paternalistic best interests model. This section focuses primarily on the case law arising under the declaratory jurisdiction in England and Wales. The second section will look at the

substituted judgment standard, using case law and legislation from the United States as the basis for its analysis.

The Paternalistic Model: Decision-Making Based on Best Interests

Traditionally, decisions relating to the person and property of mentally incapable adults were made under prerogative authority arising under the *parens patriae* jurisdiction, exercised by the Lord Chancellor and, subsequently, by the Courts of Chancery.⁴ The application of this jurisdiction required all decisions to be made for the benefit of the incapable person.⁵ The prerogative authority was given a statutory basis in the nineteenth century and the Court of Protection was given authority to protect the affairs of any adult who was "of unsound mind, and incapable of managing himself or his affairs, at the time of the inquiry." This required the adult to be formally admitted to wardship and the appointment of a committee of the ward to handle the day-to-day administration of the ward's estate.

In England and Wales, the *parens patriae* jurisdiction was abolished in 1959⁷ by the Revocation of the Royal Warrant under the Sign Manual. ⁸ Instead, the Court of Protection was given jurisdiction over "the property and affairs" of incapable adults⁹ and personal decisions, including healthcare decisions, were removed from the

The first formal statement of the jurisdiction may be found in the 13th century "statute" de Prærogativa Regis 17 Edward II, c.9 and c.10. However, the jurisdiction predates this. According to Shelford Practical Treatise on the Law Concerning Lunatics, Idiots, and Persons of Unsound Mind (Philadephia: JS Littell, 1833), p 6 the jurisdiction originates from the time of Edward I (1275-1306), when it would appear that an act was made which gave to the King the "custody of the persons and inheritances idiotarum et stultorum" (ibid, 6). See further Hoggett "The Royal Prerogative in Relation to the Mentally Disordered: Resurrection, Resuscitation, or Rejection?" in Freeman ed Medicine, Ethics and the Law: Current Legal Problems (London: Stevens, 1988); Seymour "Parens Patriae and Wardship Powers: Their Nature and Origins" (1994) 14 OJLS 159.

The term "best interests", now associated with decision-making for incapable people, was not in evidence in early cases in this area. Instead, the focus was on the "benefit" to the ward. Shelford *supra* note 4, pp 129-130 cites a number of such cases: see *In re Bird*, March 9 1827; *In re Baker*, June 20 1827; and *In re Harris*, August 9 1827.

Section 47 of the Regulation of Commissions in Lunacy Act 1853. See further Bartlett *The Poor Law of Lunacy: The Administration of Pauper Lunatics in Mid-Nineteenth-Century England* (London: Leicester University Press, 1999).

Bartlett and Sandland *Mental Health Law: Policy and Practice* (2nd Ed) (Oxford: OUP, 2003), pp 616-617 argue that the abolition was in line with the accepted wisdom of the time which viewed adult guardianship as a restriction on civil rights.

The effect of the revocation (combined with the introduction of section 1 of the Mental Health Act 1959) was to remove the jurisdiction of the Crown over the person and property of mentally incapable people. See Re F [1990] 2 AC 1, 57–59 per Lord Brandon. See further Hoggett supra note 4.

legislative ambit. The role of the Court of Protection is now set out in Part VII of the Mental Health Act 1983. However, the MHA 1983 does not provide any procedural means through which personal decisions, including consent to medical treatment, may be made. This difficulty was addressed by the House of Lords in *Re F:* (An Adult: Sterilisation).¹⁰ The House of Lords held that the common law doctrine of necessity allowed the medical treatment of adults who were unable to give personal consent. ¹¹ For the doctrine to apply, the intervention had to be in the best interests of the incapable adult and a formal application could be made to the Family Division of the High Court for a declaration that a procedure was in a patient's best interests. ¹² While the House of Lords did not consider a court declaration to be necessary in order for treatment to proceed, ¹³ the declaratory jurisdiction came to be widely used. ¹⁴ Because the decisions are made in open court (although patients' names are anonymised), an extensive body of relevant case law has developed. ¹⁵

In contrast to the position in England and Wales, the *parens patriae* jurisdiction continues to operate in Ireland.¹⁶ The jurisdiction resides in the High Court, ¹⁷ where it is currently exercised by the President of the High Court, Finnegan

See the Mental Health Act 1959. See further Bartlett and Sandland *supra* note 7, pp 654-662.

^{[1990] 2} AC 1, 74-77.

See *ibid*, 55-56 *per* Lord Brandon; *ibid*, 74 *per* Lord Goff.

Some cases require judicial review of a public authority in the exercise of its functions. In these situations, the case comes within the jurisdiction of the Administrative Division of the High Court. The relationship between the two jurisdictions is considered in A v A Health Authority and Others; Re J and Linked Applications [2002] 1 FCR 481.

See Lord Brandon [1990] 2 AC 1, 56-57. However, his Lordship (*ibid*, 57) regarded court involvement in a case such as *Re F*, which involved non-consensual sterilisation, as "highly desirable".

Subsequently, Practice Directions required that the declaratory jurisdiction be utilised in all cases involving non-consensual sterilisation (Official Solicitor: Sterilisation [1996] 2 FLR 111) and withdrawal of treatment from patients in a persistent vegetative state (Official Solicitor: Vegetative State [1996] 2 FLR 375). These Practice Notes were superseded by Practice Note: (Official Solicitor: Declaratory Proceedings: Medical and Welfare Decisions for Adults Who Lack Capacity) [2002] 1 WLR 325, which sets out in detail the manner in which the jurisdiction applies.

The declaratory jurisdiction has also been held to cover a wide range of personal decisions outside the medical context: see Re S (Hospital Patient: Court's Jurisdiction) [1996] Fam 1 and Re F (Adult: Court's Jurisdiction) [2001] 3 Fam 38.

In In re a Ward of Court [1996] 2 IR 79, 103-107, the Supreme Court held that the parens patriae jurisdiction had survived Irish independence. Note the doubts raised by Hogan and Whyte JM Kelly: The Irish Constitution (4th Ed) (Dublin: Lexis Nexis Butterworths, 2003), p 1399 regarding the correctness of the Court's conclusion in this regard. On this point, see also Tomkin and McAuley "Re a Ward of Court: Legal Analysis" (1995) 1 Medico-Legal Journal of Ireland 45.

The High Court's jurisdiction in this regard is contained in section 9 (1) of the Courts (Supplemental Provisions) Act 1961. In addition, there is a statutory wardship jurisdiction, also exercised by the President, set out in the Lunacy Regulation (Ireland) Act 1871 and Order 67 of the Rules of the Superior Courts. This jurisdiction arises in relation to a person found to

P.¹⁸ However, this jurisdiction is mainly exercised *in camera* and it is difficult to monitor the way in which decisions are made.¹⁹ Therefore, perhaps ironically given the ongoing application of the *parens patriae* jurisdiction, jurisprudence from Ireland can make only a limited contribution to this discussion.

The Development of the Best Interests Standard

The traditional response of the courts in England and Wales to treatment refusal has been to regard cases where the right of autonomy did not apply as if they did not need a conceptual basis. The lack of a detailed conceptual model for decision-making is evident in the foundational decision of the House of Lords in *Re F (Mental Patient: Sterilisation)*.²⁰ Although careful to develop the formal legal basis for decision-making, the House of Lords dedicated very little attention to the values underlying the law. The House of Lords confirmed the applicability of the best interests test but, other than identifying the relevance of medical best interests,²¹ it did not specify the test to be applied in any detail.²² There was also no mention of the rights of the mentally incapable person.²³ The House of Lords also stated that the *Bolam* test for medical

be "of unsound mind, and incapable of managing himself or his affairs" (see *In the Matter of Catherine Keogh* unreported High Court, Finnegan P, October 15 2002). For a summary of the wardship jurisdiction in Ireland, see Law Reform Commission Consultation Paper on *Law and the Elderly* (Dublin: LRC CP 23-2003), Chapter 4. For detailed coverage, see O' Neill *Wards of Court in Ireland* (Dublin: First Law, 2004).

The Irish approach raises questions in terms of its compatibility with Article 6 of the ECHR (which requires "a fair and public hearing" in the determination of the individual's civil rights and obligations). See further discussion in text following note 229 *infra*.

In practice, the President of the High Court had delegated the authority to consent to routine procedures to the Registrar of Wards of Court. For serious procedures, including those involving the administration of a general anaesthetic, the consent of the President must be obtained. See Consultation Paper on *Vulnerable Adults and the Law: Capacity LRC CP 37 2005* (Dublin: Law Reform Commission, 2005), pp 190-191.

^{[1990] 2} AC 1. In addition, see the decision of the House of Lords regarding the best interests of a minor in the context of healthcare treatment in Re B (A Minor) (Wardship: Sterilisation) [1988] 1 AC 199. See also Re B (A Minor) (Wardship: Medical Treatment) [1981] 1 WLR 1421. See generally Donnelly "Decision Making for Mentally Incompetent People: The Empty Formula of Best Interests" (2001) 20 Medicine and Law 405.

Ibid, p 55 per Lord Brandon.

To be fair, the assessment of best interests was not central to the decision to be made by the House of Lords. It had been accepted by Scott Baker J at first instance and by the Court of Appeal that the sterilisation was in F's best interests and this matter was not appealed to the House of Lords. The Court of Appeal considered briefly how to assess best interests. Neill LJ [1990] 2 AC 1, 32 noted the need to consider "the alternatives to an operation and the dangers or disadvantages to which the patient may be exposed if no action is taken".

This accords with the approach taken by the House of Lords in the earlier case of Re B (A Minor) (Wardship: Sterilisation) [1988] 1 AC 199 where, in a well-known display of irritation with rights-based arguments, Lord Hailsham (ibid, 204) commented "To talk of the 'basic

negligence²⁴ applied to determinations of best interests.²⁵ This meant that the task of determining best interests was effectively delegated to the medical professional.²⁶ In *Airedale NHS Trust* v *Bland*,²⁷ the House of Lords held that the best interests standard adopted in *Re F* was appropriate for end-of-life decision-making and that the appropriate question in relation to treatment withdrawal was whether it was in the patient's best interests to continue to receive medical treatment.²⁸

Notwithstanding this unpromising beginning, the expanding declaratory jurisdiction has facilitated the subsequent development of a more sophisticated conception of best interests.²⁹ The decision of the Court of Appeal in *Re A (Medical Treatment: Male Sterilisation)* ³⁰ shows this more sophisticated standard in operation, this time in the context of a proposed sterilisation of a young man with Down's Syndrome. Here, Dame Butler-Sloss LJ confirmed that a best interests test

right' to reproduce of an individual who is not capable of knowing the causal connection between intercourse and childbirth, the nature of pregnancy, what is involved in delivery, unable to form maternal instincts or to care for a child appears to me wholly to part company with reality". Lord Hailsham's criticism may have been directed at the High Court decision *In re D (A Minor) (Wardship: Sterilisation)* [1976] Fam 185 where, in determining the legality of a proposed sterilisation, Heilbron J referred to the young woman's right to reproduce.

In Bolam v Friern Hospital Management Committee [1957] 1 WLR 582, 587, McNair J stated that "[a] doctor is not guilty of negligence if he has acted in accordance with a practice accepted as proper by a responsible body of medical men skilled in that particular art." Since Bolitho v Hackney Health Authority [1998] AC 232, the Bolam test now incorporates some judicial scrutiny of the conduct of medical professionals. See generally Brazier and Minios "Bye-Bye Bolam: A Medical Litigation Revolution?" (2000) 8 Medical Law Review 85; Teff "The Standard of Care in Medical Negligence – Moving on from Bolam" (1998) 18 OJLS 477; Keown "Reining in the Bolam test" [1998] Cambridge Law Journal 248.

Re F (Mental Patient: Sterilisation) [1990] 2 AC 1, 52 per Lord Bridge; ibid, 68 per Lord Brandon; ibid, 69 per Lord Griffiths; ibid, 78 per Lord Goff. This interpretation of Re F is disputed by Dame Butler-Sloss LJ in Re A (Medical Treatment: Male Sterilisation) [2000] 1 FCR 193 (see further text to note 32 infra).

See Kennedy "Patients, Doctors and Human Rights" in Blackburn and Taylor eds *Human Rights for the 1990s* (London: Mansell, 1991), pp 89-90.

^[1993] AC 789.

Ibid, 808 per Lord Goff (note the similar view of the Irish Supreme Court in In re a Ward of Court [1996] 2 IR 79). In permitting the withdrawal of life-sustaining treatment, the House of Lords relied on the distinction between acts and omissions, holding that, although the withdrawal of treatment was intended to cause the patient's death, the cause of his death would not be the removal of treatment but his underlying condition. For a critique of this reasoning, see Keown "Restoring Moral and Intellectual Shape to the Law After Bland" (1997) 113 LQR 481; see also McGee "Finding a Way Through the Ethical and Legal Maze: Withdrawal of Medical Treatment and Euthanasia" (2005) 13 Med L Rev 357 and Keown's riposte "A Futile Defence of Bland: A Reply to Andrew McGee" (2005) 13 Med L Rev 393.

The issue of non-consensual sterilisation of young women has been the most frequently litigated issue in this regard: in addition to the cases discussed below, see Re W (Mental Patient) (Sterilisation) [1993] 1 FLR 381; Re Z (medical treatment: hysterectomy) [2000] 1 FCR 274; A National Health Trust v C unreported High Court (Family Division) February 8 2000.

³⁰ [2000] 1 FCR 193.

"encompasses medical, emotional and all other welfare issues." She also separated the assessment of best interests from the *Bolam* test and held that:

The doctor, acting to [the *Bolam* standard] has, in my view, a second duty, that is to say, he must act in the best interests of the mentally incapacitated patient. I do not consider that the two duties have been conflated into one requirement.³²

The Court of Appeal also moved towards a more systematic approach to the task of assessing best interests. ³³ Thorpe LJ advocated the use of a balance sheet setting out the actual benefits to be gained from the procedure and any "counterbalancing disbenefits". ³⁴ In making entries on either side, the judge should also include a realistic assessment of the possibility that the loss or gain would occur. ³⁵ It is only if the account is in "relatively significant" credit that the procedure will be considered to be in the best interests of the individual. ³⁶ In the most recent practice note, the Official

Ibid, 200. The move from a purely medical definition of best interests began in Re Y (Mental Patient: Bone Marrow Donation) [1997] Fam 110 where the High Court approved a bone marrow donation from a mentally incapable woman to her sister, although the donation had no medical benefit for the woman, because of the possible impact of her sister's death on the woman's relationship with her mother. Note also the broader definition of best interests adopted in In re S (Adult Patient: Sterilisation) [2001] 2 Fam 15, 30; Simms v Simms and Anor; A v A and Anor [2002] EWHC 2734 (Fam), [60]; R (Burke) v the General Medical Council and Others [2005] QB 424, 455-456. See generally Lewis "Procedures that are Against the Medical Interests of Incompetent Adults" (2002) 22 OJLS 575.

^{[2000] 1} FCR 193, 200-201. Dame Butler-Sloss LJ reiterated her position in Re SL (Adult Patient: Medical Treatment) [2000] 2 FCR 452 where her argument found the support of Thorpe LJ who emphasised the importance of the judicial role in the task of determining best interests. The importance of the judicial role was again affirmed by the Court of Appeal in NHS Trust v A and Anor [2005] EWCA Civ 1145. The extent to which this separation of best interests from the Bolam test is consistent with the approach of the House of Lords in Re F (as discussed in note 25 supra) is open to debate. To an extent, however, the way in which the law has developed since Re F (including the increased role of patient rights following the incorporation of the ECHR and the enactment of the MCA 2005) has made the question largely moot and removes any doubts regarding the correctness of Dame Butler Sloss LJ's approach.

This approach is evident in the Law Commission's Report on Incapacity supra note 32, para 3.28 which set out a checklist of factors to be taken into account in determining an individual's best interests. These are: (1) the past and present wishes of the individual, (2) the need to permit and encourage the individual to participate in the decision-making process, (3) the views of other relevant parties regarding the individual's best interests, and, (4) whether there is a less restrictive option than the proposed procedure.

Supra note 30, 206. This kind of approach is advocated by ethicists Buchanan and Brock supra note 1, pp 122-123.

In this respect, Thorpe J developed the principle established in his earlier decision in Re S (Medical Treatment: Adult Sterilisation) [1998] 1 FLR 944 that the actual level of risk of pregnancy occurring in the specific circumstances of the case must be taken into account. See Grubb "Incompetent Adult (Sterilisation): Best Interests and the Risk of Pregnancy" (1998) 6 Medical Law Review 354.

Supra note 30, 206. See application of the balancing test in A National Health Trust v C unreported High Court (Family Division), 8 February 2000 (in the context of non-consensual sterilisation); and A Hospital NHS Trust v S [2003] EWHC 365 (Fam), [47] (in the context of

Solicitor further formalises the process, noting that the court will wish to assess in percentage terms the likelihood of the advantages and disadvantages of the procedure occurring.³⁷

Assessing the Best Interests Standard

While preferable to the early efforts of the House of Lords, the current approach to best interests still falls short in a number of regards. Three in particular will be identified below. These are first, the limited role for patient participation in determining best interests, secondly, the lack of discussion of underlying values and in particular the status of the sanctity of life principle, and, thirdly, the failure of the test to address the issue of restraint which may be necessary in order to provide treatment to unwilling incapable patients.

A notable omission from the balance sheet in *Re A* was the fact that A had indicated that he did not want the proposed sterilisation.³⁸ The patient's views played no role in the assessment of his best interests.³⁹ There is also no mention of the views of the patient in the list of relevant considerations set out in the *Practice Direction*.⁴⁰ Judges have referred to the patient's views in the course of assessing best interests in a number of other cases. However, there is no indication that the patient's views actually impacted on the decision reached in the cases in question.⁴¹

receipt of a kidney transplant).

Supra note 37.

See Re X (Adult Sterilisation) [1998] 2 FLR 1124 where Holman J was caused to "hesitate" before granting a declaration to permit the non-consensual sterilisation of a woman who had significant disabilities due to Down's Syndrome because the woman had said that she would like a baby. See also Re SS (an adult: medical treatment) [2002] 1 FCR 73 where Wall J included the patient's "repeated and powerful insistence on termination [of her pregnancy]" in his best interests "balance sheet." However, Wall J ultimately concluded that the termination was not in the woman's best interests in spite of (ibid, [32]) "very finely balanced" expert evidence. See also NHS Trust v T [2004] EWHC 1279 (Fam), [66] where Charles J dismissed the incapable patient's reasons for wishing to refuse a blood transfusion (in this case contained in an advance directive which was held to be unenforceable because the patient had been incapable when had she made it).



Practice Direction (Declaratory Proceedings: Incapacitated Adults) [2002] 1 WLR 325, para 7.

This fact is mentioned by Dame Butler-Sloss *supra* note 30, 196, although it is clear that she does not regard the fact as relevant: "[The consultant psychiatrist] was clear that A had indicated no when asked about an operation, but it was not an informed no since he could not understand the reason for the operation."

Contrast the reference to such views in the list of relevant factors identified by the Law Commission and set out in note 33 supra.

While the patient's current views have played very little role in the determination of best interests, courts have recognised the right of capable patients to make advance refusals of treatment⁴² which can displace the best interests standard in some situations. 43. However, the decision in HE v A Hospital NHS Trust44 shows some of the difficulties in giving effect to patient autonomy in these situations especially if there appears to be a conflict between the patient's prior instructions and his current best interests. In this case, Munby J noted that there was a presumption in favour of life and held that this meant that the burden of proof should lie with the person seeking to uphold an advance refusal of treatment in a life-threatening situation.⁴⁵ Furthermore, he held that proof of both the validity of the advance refusal and of its continuing applicability must be clear and convincing and "[w]here, as here, life is at stake, the evidence must be scrutinised with especial care."46 Munby J also found that an advance refusal of treatment will not survive a "material change of circumstance."⁴⁷ He found that, in the case of an argument to this effect, ⁴⁸ the evidential burden falls on any person who seeks to argue that an advance directive is no longer applicable.⁴⁹ However, once it is established that there is some reason for doubt, the burden shifts back to the person seeking to uphold the advance directive to prove that the directive is still operative.50

A patient cannot demand the provision of treatment even if the treatment in question is artificial nutrition and hydration. See *R (Burke)* v the General Medical Council and Others [2006] QB 273, 302 where the Court of Appeal held that a patient could not demand that a doctor administer a treatment which the doctor considers to be contrary to the patient's clinical needs.

See Re T (adult: refusal of medical treatment) [1992] 3 WLR 782, 787; Re C (adult: refusal of medical treatment) [1994] 1 WLR 290; Airedale NHS v Bland [1993] AC 789, 864; St George's Healthcare NHS Trust v S [1998] 3 WLR 936, 969; Re AK (Medical Treatment: Consent) [2001] 1 FLR 129, 134.

⁴⁴ [2003] 2 FLR 408.

⁴⁵ *Ibid*, 415.

⁴⁶ Ibid. While holding that advance directives do not need to be in writing, Munby J noted that it may be difficult to establish the existence of a binding oral advance directive given the need for clear and convincing evidence and the need to demonstrate that the expressed views represent (ibid, 417) "a firm and settled commitment and not merely an offhand remark."

Ibid, 416. See also Lord Goff's statement in Bland v Airedale NHS Trust [1993] AC 789, 864 that "especial care" may be necessary to ensure that a prior refusal still applies in the circumstances that have subsequently arisen and Hughes J's list of issues to be addressed in determining the applicability of an advance refusal in Re AK (Medical Treatment: Consent) [2001] 1 FLR 129,134.

Munby J also held (*ibid*, 419) that any statement in an advance directive which purported to make the directive irrevocable or which required revocation to be in writing was contrary to public policy and would not be upheld.

⁴⁹ *Ibid*, 419.

⁵⁰ Ibid.

The decision in *HE* highlights the importance of all aspects of the surrounding legal framework in determining whether or not an advance decision is respected. Michalowski argues that the courts "approach advance directives with a bias against their validity and applicability, unless they are clear and unambiguous, which by their nature in most cases they cannot be." This is certainly true of the decision in *HE* which laid down very clear guidelines for future cases and which may therefore have an impact on the law beyond that which would normally be expected from a High Court decision.

The decision in *HE* is also important because it highlights the impact of values other than autonomy. The lack of discussion of underlying values is an ongoing difficulty with the best interests standard. Determining the appropriate values is especially challenging in the context of treatment refusal where, in many cases, the effect of the refusal will be the patient's death and therefore the refusal may come into conflict with the principle of the sanctity of life. The sanctity of life principle has been recognised by the House of Lords,⁵² the Court of Appeal⁵³ and in a number of decisions of the High Court.⁵⁴ The principle clearly provided the basis for the decision in *HE* discussed above.

The sanctity of life principle was also at the heart of another recent decision by Munby J. *R* (*Burke*) v the General Medical Council and Others⁵⁵ concerned the circumstances in which artificial nutrition and hydration (ANH) could be withdrawn from an incapable patient. Munby J stated that the sanctity of life principle required a presumption in favour of life to operate as follows:

There is a very strong presumption in favour of taking all steps which will prolong life, and save in exceptional circumstances, or where the patient is dying, the best interests of the patient will normally require such steps to be taken. In case of doubt that doubt falls to be resolved in favour of the preservation of life. But the obligation is not absolute. Important as the sanctity of life is, it may have to take second place to human dignity. In the context of life-prolonging treatment the touchstone of best interests is intolerability. So if life-prolonging treatment is providing *some* benefit it

⁵⁵ [2005] QB 424.

[&]quot;Advance Refusals of Life-Sustaining Medical Treatment: The Relativity of the Absolute Right" (2005) 68 MLR 958, 981.

⁵² Airedale NHS Trust v Bland [1993] AC 789, 863-864 per Lord Goff.

Re B (A Minor) (Wardship: Medical Treatment) [1981] 1 WLR 1421.
In addition to the decisions discussed in the text, see An Hospital NHS Trust v S and Others [2003] EWHC 365 (Fam).

should be provided unless the patient's life, if thus prolonged, would from the patient's point of view be intolerable.⁵⁶

On appeal, the Court of Appeal rejected the "intolerability" standard and stated instead that "the test of whether it is in the best interests of the patient to provide or continue ANH must depend on the particular circumstances." However, the Court did not distance itself from Munby J's identification of the very strong presumption in favour of life or from his view that best interests will normally require all steps which prolong life to be taken. The presumption in favour of life did not, however, feature as part of the Court of Appeal's decision to approve the withdrawal of medical treatment from an elderly patient in *An NHS Trust* v *A and Anor*. Although the Court noted the trial judge's description of the treatment as "painful, uncomfortable and undignified", tidd not address the question of whether the degree of discomfort was such as to outweigh a presumption in favour of life and appears simply to have applied a standard best interests test. Therefore, the current status of the presumption in favour of life and its implications for treatment refusal by incapable patients remains uncertain.

A final omission from the current common law approach to best interests is its failure to address the position of the unwilling, incapable patient and to engage with the practical reality of the restraint required in the imposition of treatment. Clearly, the degree and nature of the restraint will depend on the patient's level of unwillingness, the patient's physical and mental strength, and the nature of the treatment including whether the treatment is ongoing or is provided on a once-off basis. In *Re MB (An Adult: Medical Treatment)*, 62 the Court of Appeal held that treatment could be imposed on the patient, by force if necessary, provided that the treatment was in her best interests. The Court considered that the extent of the force

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^{164, 465.} Original emphasis.

^[2006] QB 273, 303. For commentary on the contrasting approaches of Munby J and the Court of Appeal, see Gurnham "Losing the Wood for the Trees: Burke and the Court of Appeal" (2006) 14 *Med L Rev* 253.

The Court, *ibid*, stated that no objection could have been taken to Munby J's summary (set out in text to note 56 *supra*), had it not contained the final two sentences.

⁵⁹ [2005] EWCA Civ 1145.

⁶⁰ *Ibid*, [89].

The presumption as described by Munby J was endorsed by Sir Mark Potter P in Trust A and Trust B v H (An Adult Patient) [2006] EWHC 1230 (Fam), [24].

⁶² [1997] 2 FCR 541.

to be used was to be judged in each individual case by the healthcare professionals.⁶³ Although the Court did note that the question of force might have to be considered in depth on another occasion, this issue has since received little attention. 64 In Re JT (adult: refusal of mental treatment). 65 Wall J described the use of restraint to administer kidney dialysis (required on an ongoing basis) to the woman without her consent as "inappropriate and, indeed, wholly unethical."66 However, he did not explore why this would be the case and instead, he found the woman to be capable and decided the matter simply on the basis of her right of autonomy. In a recent High Court decision, Sir Mark Potter P acknowledged the issue of restraint in the context of treatment provision. The President described it as lawful to provide treatment and "even to overcome non-co-operation of a resisting patient by sedation and a moderate and reasonable use of restraint." However, he noted that the extent to which restraint may be needed "has to be carefully considered when assessing the balance of benefit and disadvantage in the giving of the proposed medical treatment and where the best interests of the patient truly lies."68 This more overt recognition of the role of restraint is significant, however, the relationship between best interests and restraint still needs further development.

Some of the limitations of the best interests model identified above are addressed in the MCA 2005 (discussed in Part II). Before considering this, however, it is useful to consider an alternative approach to decision-making, specifically, substituted judgment as used in the United States. Like the best interests standard, the substituted judgment standard also operates under the shadow of the autonomy paradigm and, accordingly, provides an inadequate conceptual basis for decision-making for incapable patients. In the case of substituted judgment, this involves attempting to extend the right of autonomy to patients notwithstanding the fact of incapacity.

⁶³ *Ibid*, 556 per Dame Butler Sloss LJ.

⁶⁴ Cf the comments of Ward J in Re E (a minor) [1993] 1 FLR 386 where his Lordship rejected the argument that the young man in question would strenuously resist the imposition of a blood transfusion contrary to his religious beliefs. Ward J found that, unlike the situation in the Canadian case of Re LDK (1985) 48 Rep Fam L 2d (Ont) 164 to which he was referred, there was no evidence that the young man in question would suffer emotional trauma from the imposition of the transfusion.

^{65 [1998] 2} FCR 662.

⁶⁶ *Ibid*, 665.

Trust A and Trust B v H (An Adult Patient) [2006] EWHC 1230 (Fam), [27].

The Autonomy Model: The Substituted Judgment Standard

The term "substituted judgment" is used to describe a decision-making standard based on what, in the decision-maker's view, the patient would have decided had he been capable. ⁶⁹ Although the substituted judgment standard has been rejected in England and Wales⁷⁰ (and in Ireland⁷¹), some English courts have incorporated aspects of the standard by asking what the patient would have wanted as part of their assessment of best interests. ⁷² The standard is, however, primarily associated with United States jurisprudence.

The Substituted Judgment Standard Under US Law

The first significant application of the substituted judgment standard⁷³ is found in the decision of the Supreme Court of New Jersey in *Re Quinlan*⁷⁴ in response to an application to remove life-sustaining treatment from a young woman in a persistent vegetative state (PVS). The Court held that the woman's constitutional right of privacy could only be protected by permitting her guardian and family "to render their best judgment ... as to whether she would exercise it in these circumstances".⁷⁵ Following *Quinlan*, the substituted judgment standard was quickly adopted in most

The test originates from decisions relating to the use of funds in the estates of previously capable individuals. See *Ex Parte Whitbread* (1816) 35 Eng Rep 878, 879. For the history of the standard, see generally Harmon "Falling Off the Vine: Legal Fictions and the Doctrine of Substituted Judgment" (1990) 100 Yale Law Journal 1.

See Airedale NHS Trust v Bland [1993] AC 789, 872 per Lord Goff; 895 per Lord Mustill.

See In re a Ward of Court [1996] 2 IR 79, 133 per O'Flaherty J. The Supreme Court held that the right of autonomy extended to incapable patients, although it did not address the matter of how incapable patients could give effect to this right.

In Bland supra note 70, all three members of the Court of Appeal asked what the patient would have wanted as part of the process of assessing his best interests. Hoffman LJ expressly noted (ibid, 833) that, to the extent to which the patient's views are taken into account, "what the American courts have called 'substituted judgment' may be subsumed within the English concept of best interests". See also Re J (a Minor)(Wardship: Medical Treatment) [1991] Fam 33, 55; Portsmouth NHS Trust v Wyatt and Anor [2004] EWHC 2247 (Fam), [30]. See also the approach of Denham J in In re a Ward of Court [1996] 2 IR 79, 167.

This standard was first referred to in a medical context by the Kentucky Court of Appeals in Strunk v Strunk (1969) 445 SW 2d 145. The case concerned a non-consensual kidney transplant from a mentally incapable man in order to save the life of his brother. Although the Court stated that it applied a substituted judgment standard, in fact the standard applied was based more on the mentally disabled man's best interests.

⁷⁴ (1976) 70 NJ 10.

⁷⁵ *Ibid*, 41-42.

jurisdictions across the United States ⁷⁶ where it was used primarily in the context of treatment refusal in end-of-life situations. ⁷⁷

In their enthusiasm for the standard, some courts began to use substituted judgment in circumstances in which it was impossible to discern what the incapable person would have wanted. Substituted judgment began to look like a legal fiction where decision-makers made the decisions which they considered appropriate rather than those which the incapable person would have made. The zenith of this tendency was reached in the decision of the Supreme Judicial Court of Massachusetts in *Superintendent of Belchertown* v *Saikewicz*. Here, the Court used substituted judgment as the basis for its decision to refuse life-prolonging chemotherapy for a man who had had a profound mental disability since birth and clearly had never had an opinion regarding how he would wish such a decision to be made. The Court described the way in which the substituted judgment standard would apply in such circumstances as follows:

In short, the decision in cases such as this should be that which would be made by the incompetent person, if that person were competent, but taking into account the present and future incompetency of the individual as one of the factors which would necessarily enter into the decision-making process of the competent person.⁸⁰

The farcical nature of this reasoning was subsequently caricatured by the New York Court of Appeals as being equivalent to asking "if it snowed all summer would it then be winter?"⁸¹

In order to minimise the fictional aspect of the standard, courts in a number of jurisdictions⁸² opted to impose heavy evidential standards⁸³ (usually requiring "clear

For cross-jurisdictional surveys of case law, see Delaney "Specific Intent: Substituted Judgment and Best Interests: A Nationwide Analysis of an Individual's Right to Die" (1991) 11 Pace Law Review 565; Harmon supra note 69, 40-55.

Although see *In Re Grady* (1979) 170 NJ Super 98 and *In re Moe* (1982) 385 Mass 555 where substituted judgment was used in the context of non-consensual sterilisation of women who had lifelong intellectual disabilities.

Harmon supra note 69, 23 argues that the test as originally conceived was, in fact, a legal fiction, based on a general presumption regarding what the individual in question would have wanted rather than on any actual evidence of this fact. In time, however, the test began to move from a general presumption to an actual inquiry.

⁷⁹ (1977) 373 Mass 723.

⁸⁰ *Ibid*, 752-753.

In re Storar (1981) 51 NY 2d 353, 380.

See the decisions of the New York Court of Appeals in *In re Storar ibid* and *In re Eicher* (1981) 52 NY 2d 363 and of the Supreme Court of Missouri in *Cruzan* v *Harmon* (1988) 760 SW 2d 408.

The freedom of each State to set its own standard of proof in these cases was upheld by the

and convincing" evidence84 of intention) in order to establish the prior wishes of the incapable person.85 This high standard was most frequently (although not exclusively)86 met where patients, while capable, had executed an advance directive or created a power of attorney giving healthcare decision-making power to a specified person. All US states now have legislation providing formal mechanisms for prior decision-making⁸⁷ and, at a federal level, the Patient Self-Determination Act 1990 requires hospitals and other facilities for persons covered by Medicare and Medicaid to draw their patients' attention to their right to make an advance directive. Most states have also introduced legislation that gives decision-making power to surrogate decision-makers (usually, family members⁸⁸) notwithstanding the absence of any advance planning in this regard. 89 In general, surrogate decision-makers are required to reach decisions that the patient would have reached and should resort to using a best interests standard only if they cannot decide what the incapable individual would have wished.⁹⁰ Thus, the effect of surrogate decision-making provisions is to shift the decision-making function away from the courts and to the incapable patient's family members.

United States Supreme Court in Cruzan v Director, Missouri Department of Health (1990) 497 US 261.

This is the most demanding standard used in civil cases in the United States (see *Cruzan ibid*, 282)

In the absence of the required evidence, courts either refused to permit a withdrawal of treatment from patients (see *In re Storar* (1981) 51 NY 2d 353 where the treatment in question consisted of blood transfusions which were expected to prolong the patient's life for between three and six months and which caused him considerable discomfort) or resorted to a best interests test (see the decision of the New Jersey Supreme Court in *Re Conroy* (1985) 98 NJ 321).

See for example *In re Eicher* (1981) 52 NY 2d 363 where the required standard was reached on the basis of evidence that during serious community discussion of Catholic moral principles, the patient (an 83 year old priest) had indicated that he would not wish to have his life sustained in the circumstances which subsequently arose.

The Uniform Health-Care Decisions Act 1994 was drawn up following the decision of the Supreme Court in *Cruzan* which had placed the responsibility for deciding the appropriate standard of proof for the application of substituted judgment with the courts of each individual state (see note 83 *supra*). The Act provides a model for legislation relating to advance decisions and contains provisions relating to advance directives, the conferring of a special, durable power of attorney and for surrogate decision-making.

State law will generally set out the order in which family members will be asked to act as surrogates.

According to Francis "Decision Making at the End of Life: Patients with Alzheimer's or Other Dementias" (2001) Georgia Law Review 539, 561, the majority of people do not avail of the facility to make an advance directive and, accordingly, the surrogate facility must frequently be relied upon.

See section 5 (f) of the Uniform Health-Care Decisions Act 1994. For a critique of this approach, see further Cantor "Discarding Substituted Judgment and Best Interests: Toward a Constructive Preference Standard for Dying Previously Competent Patients Without Advance Instructions" (1996) 48 Rutgers Law Review 1193.

At first sight, the use of the substituted judgment standard appears to address the limitations of the autonomy paradigm. The standard allow the right of autonomy to subsist notwithstanding an individual's incapacity thus reducing the impact of the binary division between capable and incapable patients and the pressures on the capacity assessment process. The standard also provides a conceptual basis for decision-making for incapable patients which is consistent with the liberal underpinnings of healthcare law. It is therefore unsurprising that Dworkin argues that an advance directive should be respected even if this appears contrary to the patient's current best interests, contrary to his current desires and even if there has been a significant change in the patient's circumstance. 91 In developing these arguments. Dworkin contrasts two kinds of interests that people have in their lives. Experiential interests are concerned with quality of life issues such as lack of pain, pleasure, or contentment. Critical interests are concerned with making value judgements and making decisions on this basis. The purpose of the right of autonomy is to protect the individual's critical interests. Therefore the capable person's critical evaluation of his own life and how he wishes to live it must be prioritised ahead of his subsequent experiential interests if he becomes incapable.

Dworkin's arguments relate primarily to clearly indicated preferences from the time when the patient was capable, such as an advance directive. 92 He does not address in any detail the question of how preferences that are not clearly indicated should be dealt with.⁹³ However, the logic underlying Dworkin's defence of advance directives could also be applied to the broader substituted judgment standard, albeit with less force. The aim of the substituted judgment standard is also to respect the critical interests of the previously capable person, notwithstanding his current incapacity, although this is achieved through another person's estimation of his critical interests rather than his own evaluation.

In addition to its liberal credentials, the substituted judgment standard has a number of pragmatic advantages. For judges, the standard removes the need to make

⁹¹ Life's Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom (New York: Alfred A Knopf, 1993), pp 201-202.

⁹² See ibid, p 226.

See *ibid*, pp 232-233 for Dworkin's inconclusive description of a situation involving an

decisions regarding the relationship between best interests and the sanctity of life principle in treatment withdrawal cases. A court can approve the refusal of lifesaving treatment, not because it is in the patient's best interests to die in these circumstances, but because this is what he would have wanted. The standard also allows healthcare providers to avoid difficult issues relating to resource provision and healthcare provision in the context of patients in end-of-life situations. Costly treatment may be withdrawn from patients, not in order to save money, but in order to respect the patient's wishes. It is noteworthy that the Patient Self-Determination Act 1990, requiring patients in receipt of Medicare to be informed of their right to make an advance directive, was passed as part of the Omnibus Budget Reconciliation Act 1990. In such a context, treatment refusal saves resources yet, because it is ostensibly what the patient would have wanted, the question of resource allocation does not have to be addressed.

In spite of its attractions (principled and pragmatic), the substituted judgment standard has important drawbacks. First, any principled justification for the application of the standard will only be possible where the decision-maker makes the decision on the basis of what the patient would have wanted. If the decision-maker does not know this, the substituted judgment standard has no grounding in a right of autonomy and is simply a "judicial artifice [that] can render the exercise of state power invisible". Where a patient has not left precise instructions regarding his treatment choices, it is not clear that a surrogate decision-maker can in fact ascertain what the patient would have wanted. Feen if it could be presumed that surrogate

individual without a clear advance directive.

For discussion of the contentious nature of this matter, see Destro "Quality-of-Life Ethics and Constitutional Jurisprudence: The Demise of Natural Rights and Equal Protection for the Disabled and Incompetent" (1986) 2 Journal of Contemporary Health Law and Policy 71; Quinn "The Best Interests of Incompetent Patients: The Capacity For Interpersonal Relationships as a Standard for Decisionmaking" (1988) 76 California Law Review 897.

On the complex ethical issues raised by resource allocation, see generally Mooney and McGuire eds Medical Ethics and Economics in Healthcare (Oxford: OUP, 1988); Newdick Who Should we Treat? Rights, Rationing and Resources in the NHS (2nd Ed) (Oxford: OUP, 2005).

Harmon supra note 69, 71.

See In re Martin (1995) 538 NW 2d 399. The patient was legally incapable and significantly disabled following a car accident. He was fed by a feeding tube but otherwise did not require medical treatment. His wife brought a petition to have feeding stopped on the basis that, while capable, the patient had expressed a desire not to have his life sustained in these circumstances. Other members of the patient's family contended that, even if he had had these views prior to his accident, he had now had a change of heart and was contented and cooperative with his carers. The case was ultimately decided in favour of the continuance of feeding because of a lack of the necessary clear and convincing evidence of Martin's prior

decision-makers always act in good faith, there are indications that many surrogates cannot actually predict what patients would have chosen. Difficulties in this regard are accentuated by the fact that many patients do not discuss their treatment preferences with surrogates. Furthermore, family members may disagree regarding preferences and conflicts of interest between family members may influence interpretations of the incapable patient's former views. In such circumstances, the protection of the individual's right of autonomy afforded by substituted judgment is "at best indirect" and, at worst, meaningless.

Secondly, even where a patient has given a clear indication of preference, for example through an advance directive, some commentators question whether the right of autonomy of the previously capable person should take priority over his current best interests. Dresser provides the leading critique in this regard. ¹⁰² She advances two arguments. The first is that the now incapable person cannot be regarded as the same person as the one who made the original decision and therefore that he is not

desires (Mrs Martin's evidence was the sole basis for her claim). See further Marzen and Avila "Will the Real Michael Martin Please Speak Up! Medical Decisionmaking for Questionably Competent People" (1995) 72 U Det Mercy L Rev 833.

This is the finding of a number of surveys which compared patient preferences (of capable patients) with the views of the person who would be the surrogate decision-maker in the event of that patient becoming incapable. See Sulmasy et al "The Accuracy of Substituted Judgments in Patients with Terminal Diagnosis" (1998) 128 Annals of Internal Medicine 621 which found that in approximately 66% of cases surrogate decision-makers made accurate predictions regarding treatment choices for patients who had a predicted two-year survival rate of less than 50%. Interestingly, the study found that surrogates who had a strong religious belief and high church attendance tended to reach the most inaccurate conclusions. Inaccurate predictions by surrogates seemed to be equally likely to refuse treatment that the patient wished for as to consent to treatment that the patient did not wish for. Wicclair Ethics and the Elderly (New York: Oxford University Press, 1993), p 56 cites a number of studies that indicate that even in marriages of long duration, spouses may not accurately predict their spouses' resuscitation preferences. See also Francis, supra note 89, 569-570.

Wicclair Ethics and the Elderly supra note 98, p 55 notes that many elderly people (a category likely to be highly represented within the category of incapable patients making end-of-life decisions) do not discuss their preferences with family members and that, when elderly people do talk to their families about future care, comments may be vague, off-hand, and ambiguous. Statements such as "I would rather die than be dependent" may reflect a desire for reassurance, or may be a result of temporary depression and not represent considered views on future medical care.

See Wicclair *ibid*, p 56.

Francis supra note 89, 563.

See Dresser "Life, Death, and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law" (1986) 28 Arizona Law Review 373; Dresser "Relitigating Life and Death" (1990) 50 Ohio State Law Journal 425; Dresser "Missing Persons: Legal Perceptions of Incompetent Patients" (1994) 46 Rutgers Law Review 609; Dresser and Whitehouse "The Incompetent Patient on the Slippery Slope" (1994) 4 Hastings Center Report 6; Dresser "Dworkin on Dementia: Elegant Theory, Questionable Policy" [1995] Hastings Center Report 32.

bound by the prior decision.¹⁰³ Dresser's second argument is that fundamental information¹⁰⁴ (for example, information as to the kind of treatments available for the condition in question or what it would be like to have a condition, such as dementia, which renders one incapable) is absent at the time that the patient makes the advance directive.¹⁰⁵ This difficulty is accentuated where there is a significant time-lag (and consequent medical and technological developments) between the time at which the advance directive was made and the time at which it comes to be applied.¹⁰⁶

While the validity of Dresser's arguments are open to debate,¹⁰⁷ it does seem clear that, in individual cases, the upholding of an advance directive which runs contrary to the patient's current best interests and/or preferences will inevitably give rise to difficult ethical and legal questions.¹⁰⁸ It is presumably for this reason that legislation governing advance directives in a significant number of states in the United States includes a provision whereby an advance treatment refusal may be withdrawn by a patient, even if he is incapable, if he shows a desire for the treatment.¹⁰⁹ Thus, in these states the protection afforded to the right of autonomy is limited even where there is a clear advance indication of preference.

The ultimate difficulty with the substituted judgement standard is that it remains fixated on the right of autonomy and fails to provide any conceptual basis for decision-making where, because the decision-maker does not know what the patient

Dresser derives support for this view from Parfit's argument (*Reasons and Persons* (Oxford: Clarendon, 1984)) that there is no essential human identity but that identity is based on the fact of psychological continuity which in turn is dependent on various factors, including the retention of memories. If psychological continuity is broken through a loss of memory, the person becomes a different person to the person he was before this loss took place.

See also Bopp and Avila "The Sirens' Lure of Invented Consent: A Critique of Autonomy-Based Surrogate Decision Making for Legally-Incapacitated Older Persons" (1991) 42 *The Hastings Law Journal* 779, 808 who argue that "[t]here may be no identifiable act of consent, no opportunity to be informed, and ultimately no patient participation in the process".

See Dresser "Missing Persons" *supra* note 102, 624-630; Buchanan and Brock *supra* note 1, pp 101-108.

Studies suggest that patient preferences may change with time and with changing health states. Emanuel et al "Advance Directives: Stability of Patients' Treatment Choices" (1994) 154 Archives of Internal Medicine 209 found that patient preferences remained relatively stable for 1 to 2 years. Patrick et al "Validation of Preferences for Life-Sustaining Treatment: Implications for Advance Care Planning (1997) 127 Annals of Internal Medicine 509 found that, while patients remained relatively stable in their preferences, changing health states resulted in different approaches to treatment refusal.

For a critique of Dresser, see Rhoden "Litigating Life and Death" (1988) 102 Harv Law Rev 375. For a (partial) counter argument to the Parfit identity argument (set out in note 103 supra), see Buchanan and Brock supra note 1, pp 152-189.

See Morgan "Odysseus and the Binding Directive: Only a Cautionary Tale?" (1994) 14 Legal Studies 411.

According to Marzen and Avila *supra* note 97, 852, this is the case in almost thirty states.

would have wanted, the right of autonomy cannot apply in a meaningful way. Thus, issues relating to resistance, dignity, pain and suffering and the sanctity of life are all subsumed within the easy option of substituted judgment and no mechanisms are provided to deal with the real situations of incapable patients.

From the discussion in this Part, it is evident that, under both of the traditional methods of decision-making for incapable patients, the autonomy paradigm continues to determine what happens to patients notwithstanding that they are incapable. However, the law is changing and the next Part will assess the nature of these changes, focusing on the MCA 2005 and on the contribution made by the ECHR in this area.

Part II: Future Directions: The MCA 2005 and the Role of Human Rights

This Part begins by examining the MCA 2005 as it will impact on healthcare decision-making for incapable patients. It sets out the principles upon which the legislation is based, its core provisions and its treatment of advance decisions. This will be followed by a critical appraisal of the legislation in light of the limitations of the models identified in Part I. This Part will then examine the role of human rights and assess the contribution of ECHR jurisprudence to the developing legal framework.

The MCA 2005 and Healthcare Decision-Making for Incapable Patients

The Principles

Section 1 of the MCA 2005 sets out five basic principles, of which two relate to the decision-making process.¹¹⁰ The relevant principles are that any act done for an incapable person must be on the basis of his best interests; and that, in decision-making or action, the option which is least restrictive of the person's "rights and freedom of action" must be adopted.¹¹¹

The remaining principles in section 1 are relevant to the capacity assessment process. Section 1(6).

The relevant factors in determining "best interests" are set out in section 4. First, the decision-maker¹¹² must not make the decision merely on the basis of the person's age or appearance or on the basis of a condition of his which might lead others to make unjustified assumptions about his best interests.¹¹³ Secondly, the decision-maker must consider all relevant circumstances and, in particular, consider whether, and when, the person is likely to regain capacity¹¹⁴ and must "so far as reasonably practicable" encourage patient participation and improve the patient's ability to participate.¹¹⁵ Thirdly, where the determination relates to life-sustaining treatment, the decision regarding best interests must not be motivated by a desire to bring about the death of the incapable person.¹¹⁶ Fourthly, the decision-maker must consider "so far as is reasonably ascertainable,"

- (a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),
- (b) the beliefs and values that would be likely to influence his decision if he had capacity, and
- (c) the other factors that he would be likely to consider if he were able to do so.¹¹⁷

Finally, the decision-maker must take account "if it is practicable and appropriate to consult them" of the views of "anyone named by the person as someone to be consulted on the matter in question or on matters of that kind," anyone engaged in caring for the person or interested in the person's welfare, any donee of a lasting power of attorney, and, any deputy appointed by the court as to what is in the person's best interests and what his wishes would have been. 119

As will be seen in the next section, the identify of the decision-maker may vary and may include the court, a medical professional, a donee of a lasting power of attorney or a court appointed deputy.

Section 4(1).

¹¹⁴ Section 4(3).

Section 4(4). The Draft Code of Practice (Department of Constitutional Affairs, 2004), paras 3.18-3.20 sets out a set of steps to be taken in order to enhance communication and facilitate decision-making by the incapable person. These include such practical steps as choosing a suitable time and location, speaking at the right volume and speed and using appropriate vocabulary, visual aids, videos or tapes.

Section 4(5).

Section 4(6).

The MCA does not specify whether a patient must be capable in order to name a person in this context. However, it is in line with the approach of the MCA that an incapable person should be able to nominate a person to consult notwithstanding his incapacity.

The MCA 2005 gives statutory force to the common law position regarding the declaratory jurisdiction and the doctrine of necessity. The Act establishes a new Court of Protection¹²⁰ which has the same powers, rights, privileges and authority as the High Court¹²¹ and which may make declarations regarding capacity and the lawfulness of an act already done or to be done in relation to an incapable person. 122 The Court may also appoint a deputy who may make decisions on behalf of the incapable person, 123 including decisions relating to personal welfare, which includes "giving or refusing consent to the carrying out or continuation of a treatment." 124 However, a deputy may not refuse consent to "the carrying out or continuation of lifesustaining treatment."125

Section 5 places the common law doctrine of necessity on a statutory basis and states that a person will not incur liability because of a lack of consent for an act done in connection with the care and treatment of a person, provided he takes reasonable steps to establish the capacity of the person for whom he proposes to act and reasonably believes that the person lacks capacity in the matter and that it will be in the person's best interests that the act be done. 126 Such a person is not freed from liability if the act is performed negligently or in a way which gives rise to criminal liability¹²⁷ or if a valid advance refusal of treatment is in place. ¹²⁸

The defence afforded by section 5 is restricted in a number of regards by section 6. Section 5 does not apply to actions intended to restrain the person¹²⁹ unless the person taking the action "reasonably believes" that it is necessary to do the restraining act in order to "prevent harm" to the incapable person¹³⁰ and the restraining act is a proportionate response to the likelihood of harm and the seriousness of the

119 Section 4(7).

127

¹²⁰ Section 45. The new Court of Protection will take over the functions of the current Court of Protection (described in text to note 9 supra).

¹²¹ Section 47(1).

¹²² Section 15.

¹²³ Section 16.

¹²⁴ Section 17(1)(d).

¹²⁵ Section 20(5).

¹²⁶ Section 5(1).

Section 5(3). 128 Section 5(4).

¹²⁹ Section 6(1).

¹³⁰ Section 6(2)

harm.¹³¹ A person restrains, within the meaning of the Act, if he uses or threatens to use force to do an act which the incapable person resists or if he restricts the liberty of movement of the person whether or not the person resists.¹³² However, a person does more than merely restrain if he deprives another person of liberty "within the meaning of Article 5 (1)" of the ECHR.¹³³ The section 5 defence also does not apply if the act conflicts with a decision made by the donee of a lasting power of attorney or a deputy appointed by the court.¹³⁴

Advance Healthcare Decision-Making

The MCA 2005 allows a person, while capable, to make an advance healthcare decision either by conferring a lasting power of attorney on a donee¹³⁵ or by making an advance refusal of treatment. A donee of a lasting power of attorney may give or refuse consent to healthcare treatment,¹³⁶ including life-sustaining treatment, although in the latter case, the creating instrument must contain a specific provision to this effect.¹³⁷

Section 24 of the MCA allows a capable person over the age of 18 to make an advance decision to refuse specified treatment(s) in specified circumstances to apply if he subsequently loses capacity. The decision may be expressed in "layman's terms" and, unless the refusal relates to life-sustaining treatment, there is no requirement that the advance decision must be in writing. Before the advance decision will be given effect, it must be "valid" and "applicable to the treatment". A decision is not valid

¹³¹ Section 6(3).

Section 6(4). In the Draft Code of Practice, it is noted (para 5.28) that restraint may take many forms – it can be verbal and physical and can vary from shouting threats to holding someone down, locking them in a room or administering a large number of sleeping pills.

Section 6(5). This follows the decision of the ECtHR in *HL* v *United Kingdom* [2004] ECHR 45508/99. The Government proposes amending the MCA 2005 to deal with the deprivation of liberty of incapable compliant patients (see *Bournewood Briefing Sheet* (Gateway Reference 6794) available at Department of Health website www.dh.gov.uk. (last visited July 26 2006) and discussed further in text to note 219 *infra*).

¹³⁴ Section 6 (6).

Section 9. The formalities for appointment are contained in section 10.

¹³⁶ Section 11(7)(c).

Section 11(8). Contrast the approach in the Adults with Incapacity (Scotland) Act 2000 where no mention is made of a donee's power in this regard.

¹³⁸ Section 24(2)

An advance refusal does not apply to "life-sustaining treatment" unless verified by a written statement to the effect that it is to apply even if life is at risk (section 25(5)).

¹⁴⁰ Section 25(1).

if the person has withdrawn it when he had capacity to do so,¹⁴¹ if a later lasting power of attorney conferred authority on a donee to consent to or refuse the designated treatment,¹⁴² or if the person "has done anything else clearly inconsistent with the advance decision remaining his fixed decision."¹⁴³ In the last situation, there is no requirement that the person have been capable when he did the inconsistent action in question.

An advance decision is not applicable if the person has capacity at the time the question of treatment refusal arises, ¹⁴⁴ if the treatment in question is not specified in the advance decision, ¹⁴⁵ if any circumstances specified in the advance decision are absent, ¹⁴⁶ or if there are "reasonable grounds" for believing that circumstances exist which the person did not anticipate at the time of making the advance decision and which would have affected the decision had he anticipated them. ¹⁴⁷ Issues relating to the existence of an advance refusal and its validity or applicability may be the subject of a court declaration ¹⁴⁸ and nothing in an advance decision stops a person from providing life-sustaining treatment to a patient or preventing a serious deterioration in a patient's condition while a decision is sought from the court. ¹⁴⁹

Assessing the MCA's Approach to Healthcare Decision-Making

While the MCA 2005 adopts the best interests standard, it attempts to incorporate aspects of the patient's right of autonomy into the decision-making process by giving a statutory basis to the patient's right to make advance refusals and making patient participation an aspect of the best interests standard. Given that the common law already recognises advance treatment refusals, the statutory recognition of patients' rights in this regard does not constitute a significant departure. However, the establishment of the surrounding framework does provide a degree of clarity and gives statutory endorsement to the practice. As is evident from the discussion in Part

Section 25(2)(a). Section 24 (3) states that a person may withdraw or alter an advance decision while he has the capacity to do so. This need not be done in writing (section 24 (4)).

Section 25(2)(b).

Section 25(2)(c).

Section 25(3).

Section 25(4)(

Section 25(4)(a).

Section 25(4)(b).

Section 25(4)(c).

Section 26(4).

Section 26(5).

I, it is the detail of the surrounding framework that determines how meaningful the right to make advance decisions will be in practice. Ultimately, the way in which the patient's right of autonomy is protected through his right to make advance decisions will depend on judicial approaches in individual situations and, if Munby J's approach in *HE* is indicative of future judicial approaches, then, notwithstanding the statutory basis for advance refusals, patient autonomy is unlikely frequently to be accorded precedence over current best interests and over the principle of sanctity of life.

The statutory mechanism for participation by incapable patients is an innovation in the Act. By allowing the past and present views of the patient to be considered, the intention is that the patient remains part of the decision-making process notwithstanding his incapacity. As a model, this has clear attractions because it incorporates the pro-autonomy aspects of the substituted judgment standard without the descent into legal fiction that a simple substituted judgment test requires. However, there are reasons to be cautious regarding the feasibility of the participative best interests model adopted in the MCA 2005. Dresser identifies some of the practical difficulties with involving incapable patients in healthcare decisions. She notes that incapable patients frequently cannot use language to describe their experiences. 151 This means that observers have to rely on "behavioural and neurological data, which often can be difficult to interpret in patients whose cognitive processes are impaired."152 Dresser also notes the inherent difficulties in understanding the perspective of an incapable patient who will "often respond to the world in ways that mystify and perplex the 'normal' persons observing them." The involvement of other people who know the patient may provide some assistance but, as the discussion of substituted judgment in Part I shows, 154 this does not provide a guaranteed solution.

Given that, to date, the courts have not endorsed the participative model to any great extent, 155 the participative element of the MCA 2005 might end up as requiring little more than an acknowledgement of the patient's views before making the decision regarding best interests that would have been made in any case. This is

See text following note 44 supra.

See Dresser "Missing Persons" supra note 102, 638.

¹⁵² Ibid.

¹⁵³ *Ibid*, 666-667.

See text following note 97 *supra*.

See text following note 38 supra.

especially likely to be true in the context of life-sustaining treatment. It is difficult to imagine a court according much weight to the views of an incapable patient who wishes to refuse life-sustaining treatment in circumstances where this is considered to be contrary to his best interests. While there are important reasons to support the participative model contained in the Act, 156 ultimately it would be unwise to expect too much from this aspect of the Act, at least in difficult treatment refusal situations.

A further aspect of the MCA 2005 is not so immediately linked to autonomy and goes some way to addressing the limitations of the autonomy paradigm. The limits in section 6 on restraining measures are relevant to the practical question of how treatment may be given and may provide a means whereby incapable but unwilling patients may avoid unwanted treatment. As will be seen in the next section, the issue of restraint raises important issues relating to patient rights, including the rights to bodily integrity, privacy and liberty as well as the right to freedom from inhuman or degrading treatment. Section 6 of the MCA 2005 states that, in order to be permissible, a restraining act must be necessary to prevent harm to the incapable person and must be a proportionate response to the likelihood of harm and to the seriousness of the harm.¹⁵⁷ The extent to which section 6 will provide protection for the right to refuse of unwilling patients will depend on the interpretation of "harm" in the section.¹⁵⁸ However, the requirement for proportionality means that unwilling, resistant patients are unlikely to have treatment imposed unless a strong case for the treatment may be made. Ultimately, it is unlikely that section 6 will significantly limit freedom to impose treatment in any high-risk situations. However, the inclusion of the section in the MCA 2005 is an important first move towards the development of an independent model for decision-making for incapable patients.

This above discussion shows that the MCA 2005 provides a better model for decision-making than either of the traditional models. However, it is still influenced

The participative model accords with the requirements of Council of Europe Convention on Human Rights and Biomedicine (discussed in text to note 165 infra) and with Council of Europe Recommendation No R (99) 4 (discussed in text to note 168 infra). It also accords with the rights-based approach necessitated by the ECHR (see discussion in text following note 170 infra). The participative model also fits well with a therapeutic approach to the law in this area because, by involving the patient in the process, it makes the ultimate decision reached more acceptable to the patient. See further discussion in Chapter 6 at text to note 22.

Section 6 (3).

The Draft Code of Practice notes simply that "harm" is not defined as it is likely to vary (para 5.42) and that restraint must be the minimum necessary to achieve the desired result (para 5.43).

by the autonomy paradigm and, because of the limitations identified above, fails to provide sufficient protection for the rights of patients outside of the right of autonomy. The final section of this chapter looks at the impact of human rights protections on the law's response to incapable patients and argues that ECHR jurisprudence can make an important contribution in addressing the limitations of the autonomy paradigm.

Human Rights Protections and Incapable Patients

The human rights of mentally incapacitated people are recognised at international and European levels. ¹⁵⁹ The 1971 United Nations *Declaration on the Rights of Mentally Retarded Persons* ¹⁶⁰ states, using the language of the time, that the "mentally retarded" person shall, to the maximum degree of feasibility, have the same rights as other human beings. ¹⁶¹ These include the right to proper medical care, suitable education, training and rehabilitation, ¹⁶² the right to a guardian ¹⁶³ and to be protected from exploitation, abuse and degrading treatment. ¹⁶⁴ At a European level, the Council of Europe *Convention on Human Rights and Biomedicine* ¹⁶⁵ requires that, where an adult does not have the capacity to consent to an intervention, the intervention may only be carried out with the authorisation of the incapable adult's representative or of an authority or a person or body provided for by law. The Convention also requires that "the individual concerned shall as far as possible take part in the authorisation

See also the *Hague Convention on the International Protection of Adults* agreed in January 2000 which sets out private international law rules regarding the protection of incapable adults. The Convention covers questions of jurisdiction and enforceability of decisions where the incapable adult has connections with more than one country. The Convention does not impact on the substantive law of the contracting parties. The Convention has not yet received sufficient ratifications to enter into force. It has not been ratified by England and Wales or in Ireland but it has been ratified by Scotland.

General Assembly Resolution 2856 of December 20 1971. See also the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities (Resolution 48/96) adopted by the UN General Assembly on December 20 1993 and the Draft UN Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities (January 2004) drawn up by the UN Convention Working Group appointed by the UN Convention ad hoc Committee.

¹⁶¹ Article 1.

Article 2.

¹⁶³ Article 5.

¹⁶⁴ Article 6.

Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine Agreed at Oviedo, April 4 1997. The Convention was opened for signature in April 1997. At present, neither the UK nor Ireland is a signatory.

procedure"¹⁶⁶ and that an incapable patient's previously expressed wishes should be taken into account.¹⁶⁷ This approach is also reflected in the Council of Europe's *Recommendation on the Legal Protection of Incapable Adults*, ¹⁶⁸ which requires that the past and present views of the individual must be included in any assessment of best interests. ¹⁶⁹

While indicating approved international and European standards, these human rights provisions do not have binding legal force. In contrast, the ECHR, discussed below, has been incorporated into the domestic law and has immediate practical relevance for the law's treatment of incapable people.

The Impact of the ECHR

A number of ECHR articles are relevant to healthcare decision-making for incapable people. As discussed in Chapter 1, the right to refuse treatment is protected by Articles 3 and 8 of the ECHR. Unlike the right of autonomy, which is also protected by Article 8, the right to refuse treatment is not restricted to capable patients only. Article 5 and 6 also impact on the legal treatment of incapable people. Before considering these Articles in detail, it should be noted that the Article 2 protection of the right to life 171 has been interpreted in a way that does not view the withdrawal of life-sustaining treatment as a deprivation of life in the sense prohibited by the Article,

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Article 6 (3). Note the Additional Protocol to the Convention on Human Rights and Biomedicine, on Transplantation of Organs and Tissues of Human Origin agreed at Strasbourg on January 24 2002. Article 14 of the Protocol limits the circumstances in which organs or tissue may be removed from an incapable person. Only regenerative tissue may be removed and this may occur in very limited circumstances.

¹⁶⁷ Article 9.

Recommendation No R (99) 4 of the Committee of Members to Member States on Principles Concerning the Legal Protection of Incapable Adults (adopted February 23 1999).

Principle 9. This Principle also requires that the individual be given adequate information so as to enable him to express a view.

The right of autonomy as recognised in *Pretty* v *United Kingdom* [2002] ECHR 2346/02 is clearly restricted to capable people only. An attempt could be made to extend the right to incapable people on the basis of the Article 14 prohibition on discrimination. However, this is unlikely to be successful. Article 14 permits differential treatment if there is an objective and reasonable justification for the treatment and in *Pretty ibid*, para 88 (in the context of possible discrimination between disabled and able-bodied people arising from the prohibition on assisted suicide), the ECtHR set out rather generous parameters in establishing an "objective or reasonable justification" for differential treatment.

Article 2 states that "Everyone's life shall be protected by the law. No one shall be deprived of his life intentionally".

provided that the decision to withdraw treatment is made in the best interests of the patient.172

Article 3: Prohibition on Torture and Inhuman or Degrading Treatment

In Pretty v United Kingdom, 173 the ECtHR described treatment as inhuman or degrading where it "humiliates or debases an individual showing a lack of respect for, or diminishing, his or her human dignity or arouses feelings of fear, anguish or inferiority capable of breaking a person's moral and physical resistance". ¹⁷⁴ The treatment must involve "actual bodily injury or intense physical or mental suffering."175 It is not necessary that the aim of the treatment be to humiliate or degrade the person if the effect is humiliating or degrading for the person involved. 176 Further, an individual does not have to be legally capable in order to feel degraded.¹⁷⁷ It is less clear whether a person can be degraded if he cannot feel degraded. 178 However, Hale LJ's comments in R (Wilkinson) v Broadmoor Special Hospital Authority 179 suggest that the test for degradation has an objective, as well as a subjective, element. 180 Hale LJ noted that

[T]he degradation of an incapacitated person shames us all even if that person is unable to appreciate it, but in fact most people are able to appreciate that they are being forced to do something against their will even if they are not able to make the decision that it should or should not be done. 181

¹⁷² In Widmer v Switzerland Application 20527/92, unreported Commission decision, February 10 1992, the Commission held that Article 2 did not require a state to criminalise the removal of life-sustaining treatment. This view of Article 2 was shared by Dame Butler-Sloss in NHS Trust A v M; NHS B v H [2001] 2 WLR 942, 953.

¹⁷³ [2002] ECHR 2346/02.

¹⁷⁴ Ibid, para 52.

¹⁷⁵ Ibid.

¹⁷⁶ The intention behind the treatment is, however, a factor in the Court's assessment: see Price v United Kingdom (2002) 34 EHRR 1285, para 24; D v United Kingdom (1997) 24 EHRR 423. 177

See Herczegfalvy v Austria (1992) 15 EHRR 437.

¹⁷⁸ In NHS Trust A v Mrs M; NHS Trust B v Mrs H [2001] 2 WLR 942, 956 Dame Butler-Sloss P held that Article 3 could not apply to patients in a PVS because the Article "requires the victim to be aware of the inhuman and degrading treatment or at least to be in a state of physical or mental suffering". For a critique of Dame Butler-Sloss P's reasoning in this regard, see Maclean "Crossing the Rubicon on the Human Rights Ferry" (2001) 64 MLR 775, 790-791.

¹⁷⁹ [2002] 1 WLR 419.

This was also the view of Munby J in R (Burke) v the General Medical Council and Others [2005] QB 424, 474.

¹⁸¹ Ibid, 446.

In *Herczegfalvy* v *Austria*, ¹⁸² the ECtHR confirmed that Article 3 could apply to medical treatment, in this case treatment for a mental disorder which had been forcibly imposed contrary to the wishes of an incapable, involuntarily detained ¹⁸³ patient. ¹⁸⁴ Two factors are relevant in establishing Article 3 protection in relation to medical treatment. First, the treatment must reach a minimum level of severity. ¹⁸⁵ In individual cases, the question of whether treatment will reach this threshold will depend on the circumstances, including the nature of the treatment, ¹⁸⁶ the physical effects of the treatment, ¹⁸⁷ the way in which the treatment is administered, ¹⁸⁸ whether physical restraint is used ¹⁸⁹ and the level of resistance to the treatment on the patient's part. ¹⁹⁰

¹⁸² (1992) 15 EHRR 437.

The application of Article 3 is not restricted to people who are in state custody. See D v United Kingdom (1997) 24 EHRR 423, para 49. See also A v United Kingdom (1998) 27 EHRR 611, where the ECtHR accepted (ibid, para 22) that Article 3 requires States to take steps "to ensure that individuals within their jurisdiction are not subjected to torture or inhuman or degrading treatment or punishment, including such ill-treatment administered by private individuals".

See also the early ages of Kyr Daywark (1983) 33 DR 282, 283 where the Commission found.

See also the early case of X v Denmark (1983) 32 DR 282, 283 where the Commission found that Article 3 could cover "medical treatment of an experimental character and without the consent of the person involved". Cf Simms v Simms and Another [2002] EWHC 2734 (Fam), where Dame Butler-Sloss P permitted an experimental treatment to be carried out on two patients at an advanced stage of variant CJD on the basis that this treatment was in the patients' best interests. Dame Butler-Sloss did not refer to Article 3 in reaching this conclusion although she did refer (ibid, [61]) to Articles 2 and 8 of the ECHR.

This is a general requirement for the application of Article 3: see *Ireland* v *United Kingdom* [1978] ECHR 5310/71; *Keenan* v *United Kingdom* (2001) 33 EHRR 913.

In R (on the application of PS) v Responsible Medical Officer and Anor [2003] EWHC 2335 (Admin), [107], Silber J described the relevant factors to be taken into account as follows: "all the circumstances, including the positive and adverse mental and physical consequences of the treatment, the nature and context of the treatment, the manner and method of its execution, its duration, and if relevant, the sex, age and health of the patient".

In Grare v France (1991) 15 EHRR CD 100, the European Commission of Human Rights accepted that imposed anti-psychotic medication had distressing side-effects for the patient; however, these were not sufficiently distressing for the treatment to reach the level of minimum severity required under Article 3. Cf Jalloh v Germany Application No 54810/00 July 11 2006, where the administration of an emetic through the nose in order to force the regurgitation of a small plastic bag of cocaine was held to be a violation of Article 3. The Court held that the plastic bag could have been retrived by less intrusive means.

In R (on the application of PS) v Responsible Medical Officer and Anor [2003] EWHC 2335 (Admin), Silber J held that the, probably oral, administration of anti-psychotic medication would not reach the minimum severity level.

In *Herczegfalvy supra* note 182, the ECtHR did not question the proposition that the treatment imposed reached the minimum severity standard. The treatment in question included forced feeding, isolation and the forcible injection of sedatives, which involved the applicant being handcuffed and tied to a security bed.

In R (Wilkinson) v Broadmoor Special Hospital Authority supra note 179, the Court of Appeal appeared to accept that Article 3 was implicated by the forcible administration, under restraint, of anti-psychotic medication to a vigorously resisting patient.

The second factor to be taken into account in deciding if Article 3 applies is whether the treatment is therapeutically necessary. In *Herczegfalvy*, the ECtHR held that the imposed treatment was permissible because it was a medical or therapeutic necessity. The Court held that "as a general rule, a measure which is a therapeutic necessity cannot be regarded as inhuman or degrading". While the extent of the therapeutic necessity exception is unclear, is it seems clear that a therapeutic necessity requirement differs from the broader best interests standard adopted by the courts. In other words, treatment could be found to be in a patient's best interests yet not be therapeutically necessary. In *R* (on the application of *N*) v Doctor *M* and Others, Dyson LJ accepted that, provided the minimum severity threshold was reached, in order for treatment without the patient's consent to be permissible, it must be both in the patient's best interests and therapeutically necessary and that the best interests test "goes wider" than therapeutic necessity. In this way, Article 3 adds a new element to the decision-making process (where the minimum severity threshold is reached).

A further aspect of the therapeutic necessity exception relates to the steps that have to be taken to establish therapeutic necessity. In *Herczegfalvy*, the ECtHR held that the court must "satisfy itself that the medical necessity has been convincingly shown to exist." The ECtHR did not elaborate on what was necessary in order to do this. In the circumstances of the case itself, the Court accepted the argument of the Austrian government that the treatment was necessary according to the psychiatric principles generally accepted at the time of the treatment. This suggests that a fairly minimal level of proof would establish the therapeutic necessity of treatment. However, the Court of Appeal in *R (Wilkinson)* v *Broadmoor Special Hospital*

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The Court used the terms "medical" and "therapeutic" interchangeably in its judgment.

^{(1992) 15} EHRR 437, para 82.

Harris, O'Boyle and Warbrick Law of the European Convention on Human Rights (London: Butterworths, 1995), pp 72-73 argue that "[a]t the very least", Article 3 permits "compulsory treatment by the state in accordance with the 'standards accepted by medical science' of all persons in its custody where this is necessary to save them from death or serious injury." See the early decision of the Commission in X v Germany (1984) 7 EHRR 152 that the forced feeding of a capable prisoner on hunger strike did not constitute a violation of Article 3 because the State was justified in its intervention in order to fulfil its obligations under the Article 2 protection of the right to life. This position was recently reiterated by the ECtHR in Nevmerzhitsky v Ukraine [2005] ECHR 210.

¹⁹⁴ [2002] EWCA Civ 1789.

¹⁹⁵ *Ibid*, [16].

^{196 (1992) 15} EHRR 437, para 82.

¹⁹⁷ *Ibid*, para 83.

Authority ¹⁹⁸ required considerably more demanding steps to be taken in order to establish the therapeutic necessity of the treatment. The treatment in the case in question was for a mental disorder and, therefore it fell under section 58 of the MHA 1983, which sets out its own procedural steps, based on an independent second opinion, to be taken before treatment may be given. Nonetheless, the Court held that the claimant should have a full hearing, with expert evidence, including that of his own medical witness, to establish the matter of therapeutic necessity. ¹⁹⁹ The nature of the hearing required in the context of treatment covered by the MHA 1983 will be discussed further in Chapter 4. The significant point for the purposes of this chapter is that, if Article 3 is implicated by the provision of medical treatment, then the therapeutic necessity of the treatment will have to be convincingly shown and, in some cases at least, this will require a court hearing.

Article 8: The Right to Respect for Private and Family Life

As noted in chapter 1, the application of Article 8 is not restricted to capable patients. In Glass v UK, the right to physical integrity arising under Article 8 was held to extend to an incapable young man and the provision of treatment to the young man was held to constitute a breach of Article 8. The application of Article 8 to incapable patients was again confirmed in Storck v Germany where the ECtHR focussed on the patient's unwillingness rather than her capacity in deciding that Article 8 had been breached by the administration of treatment. Article 8 had been breached by the administration of treatment.

Unlike Article 3, Article 8 does not have a minimum severity threshold and therefore Article 8 may apply in circumstances in which Article 3 does not.²⁰⁴

¹⁹⁸ [2002] 1 WLR 419.

¹⁹⁹ Ibid, 432-433 per Simon Brown LJ; ibid, 439 per Brooke LJ; ibid, 447 per Hale LJ.

See Chapter 1 at text to note 214.

²⁰¹ [2004] ECHR 102.

²⁰² [2005] ECHR 406.

Ibid, para 144. However, because incapable patients do not have the right of autonomy, the nature of their rights as protected by Article 8 differs from those of capable patients (see R (B) v Dr SS, Second Opinion Appointed Doctor and Secretary of State for the Department of Health [2005] EWHC 1936 (Admin), [75] per Charles J). Note also that in Herczgafalvey supra note 182, para 86, the ECtHR noted the patient's lack of capacity in dismissing his claim under Article 8.

In Bensaid v United Kingdom (2001) 33 EHRR 205, para 46, the ECtHR noted that "the Court's case-law does not exclude that treatment which does not reach the severity of Article 3 treatment may nonetheless breach Article 8 in its private life aspect." See further Feldman Civil Liberties and Human Rights in England and Wales (2nd Ed) (Oxford: OUP, 2002), p 535.

However, also in contrast to Article 3, the protections afforded by Article 8 are not absolute. Article 8 (2) allows interference with rights protected by Article 8 provided that it is in accordance with law, for a legitimate aim and necessary in democratic society. The application of Article 8 (2) in a treatment context has received relatively little attention to date. 205 However, the issue was considered in B v Dr SS, Dr G and the Secretary of State for the Department of Health. 206 Charles J held that, where Article 8 is implicated by the administration of treatment, the test to determine whether the treatment comes within a permitted exception is that set out in Article 8 (2) and not, as had been argued in the case, the therapeutic necessity test from Herczegfalvy.²⁰⁷ In the case in question, which concerned treatment for a mental disorder covered by the MHA 1983, Charles J held that the treatment must be in accordance with law and that the statutory requirements concerning the provision of treatment must be shown to apply.²⁰⁸ The logical extension of this is that, for treatment not covered by the MHA 1983, Article 8 (2) would require that the treatment be in accordance with the patient's best interests (and the provisions of the MCA 2005 when it comes into effect). In this regard, Article 8 should not make any significant difference to the existing standards applied.

However, Article 8 may make a difference regarding the procedural protections available to incapable patients in ensuring that the best interests standard is met. While rejecting the applicability of the therapeutic necessity standard from *Herczgafalvey* to Article 8, Charles J did adopt the requirement from this case that the relevant legal standard be "convincingly shown" to apply.²⁰⁹ While there is room for discussion regarding what is required in order to convincingly show that, if Article 8

This proposition was accepted by Charles J in B v Dr SS, Dr G and the Secretary of State for the Department of Health [2005] EWHC 1936 (Admin), [47] and affirmed by the Court of Appeal in that case: R (B) v Dr SS, Second Opinion Appointed Doctor and Secretary of State for the Department of Health [2006] EWCA Civ 28, [49].

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Note however the relatively permissive attitude to the application of Article 8 (2) in the context of patient seclusion evident in the House of Lords decision in *R (Mumjaz)* v *Mersey Care NHS Trust* [2005] 3 WLR 793 (discussed in Chapter 1 at text to note 229).

²⁰⁶ [2005] EWHC 1936 (Admin).

²⁰⁷ *Ibid*, [82].

²⁰⁸ *Ibid*, [91].

Charles J did not seem to question the applicability of this aspect of the requirement and instead was concerned (*ibid*, [103]-[109]) with determining what the term "convincingly shown" meant. The Court of Appeal [2006] EWCA Civ 28 did not address the matter and appears to have accepted the relevance of the "convincingly shown" standard in the context of Article 8(2).

is implicated, the treatment is in accordance with law,²¹⁰ nonetheless the requirement suggests that an incapable patient is entitled to have an opportunity to ensure that the imposed treatment is, in fact, in accordance with his best interests.

Article 5: Right to Liberty

Article 5 states that "[n]o one shall be deprived of his liberty" save in certain stated circumstances²¹¹ and "in accordance with a procedure prescribed by law." Depending on the circumstances, the administration of treatment to an incapable patient may involve a deprivation of liberty and if it does so, Article 5 is implicated and the procedural requirement set out in this Article will arise. The question of what constitutes a deprivation of liberty in the context of medical treatment has been considered by the ECtHR in two leading cases. In *HL* v *United Kingdom*,²¹² the ECtHR held that the informal admission of an incapable but compliant person to a psychiatric facility could constitute a breach of Article 5 even if, as in the case in question, the patient was not physically restrained in the facility.²¹³ The Court held that a patient could be deprived of liberty if the healthcare professionals had exercised "complete and effective control" over the patient's "care and movements."²¹⁴ In this context, the absence of any procedural safeguards surrounding admission failed to protect the applicant against arbitrary deprivations of liberty and was held to be contrary to Article 5.²¹⁵ In the second case, *Storck* v *Germany*, ²¹⁶ the ECtHR held that

The details of what was required in the specific context of the MHA 1983 will be discussed in Chapter 4 in text following note 70.

The relevant circumstance in the context of medical treatment is found in Article 5(1)(e) which permits "the lawful detention of persons for the prevention of the spreading of infectious diseases, of persons of unsound mind, alcoholics or drug addicts, or vagrants."

^[2004] ECHR 45508/99. The applicant here was an autistic, profoundly intellectually disabled adult man who resided with paid carers. He became agitated at a day centre he attended and was taken to a psychiatric facility where, although clearly incapable, because he did not object he was informally admitted rather than formally admitted (or "sectioned" as it is colloquially termed) under the Mental Health Act 1983. This was the normal practice at this time. The House of Lords (R v Bournewood Trust, ex p L [1999] 1 AC 458) held that the applicant's admission was lawful as it came within the common law doctrine of necessity. See Fennell "Doctor Knows Best? Therapeutic Detention Under Common Law, the Mental Health Act, and the European Convention" (1998) 6 Med L Rev 322.

The patient did not resist admission and was held in an unlocked ward.

^[2004] ECHR 45508/99, para 91.

Ibid, para 124. The Court noted (*ibid*, para 120) the lack of any formalised admission procedures which indicated who could propose admission, and on what basis, and the absence of any obligation to fix limits in terms of time, treatment or care during the period of admission.

²¹⁶ [2005] ECHR 406.

the State has a positive obligation to protect the liberty of its citizens.²¹⁷ Although the patient was detained in a private psychiatric facility, in the words of the Court, the State is "obliged to take measures providing effective protection of vulnerable persons, including reasonable steps to prevent a deprivation of liberty of which the authorities have or ought to have knowledge."²¹⁸

Both HL and Storck concerned the admission of patients to psychiatric facilities. However, admission to any healthcare facility could come within the ambit of Article 5 if it involved a deprivation of liberty. An important aspect of the decision in HL is that Article 5 is implicated not just by the admission of a resistant or unwilling patient (as was the case in Storck) but also by the admission of a compliant but incapable patient. The Government has announced its intention to amend the MCA 2005 to provide a more formal admission procedure for these patients.²¹⁹ Under this proposal, patients who are deprived of liberty will be entitled to an independent assessment regarding whether the proposed measure is necessary in their best interests to protect them from harm and whether the measure is a proportionate response to the likelihood of them suffering harm and the seriousness of the harm.²²⁰ The briefing document also states that this amendment will apply only to compliant patients and that any patient who objects to detention for treatment for a mental disorder must be admitted under the MHA 1983. The briefing document does not state what the situation is where an incapable patient objects to treatment which is not covered by the MHA 1983 (i.e. treatment that is not for a mental disorder). Until the amendment is introduced, the Department has advised local authorities to have systems in place to identify if a proposed course of action is likely to amount to a deprivation of liberty²²¹ and, where possible, to avoid taking "complete and effective control" over a person's movements.²²² If it is necessary to take steps that would deprive an individual of liberty, then the formal detention powers under the MHA 1983 must be engaged.²²³

The question of what constitutes a deprivation of liberty is clearly critical in engaging Article 5. The Government briefing document does not define the term,

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²¹⁷ *Ibid*, para 102.

²¹⁸ Ibid.

See Bournewood Briefing Sheet supra note 133.

The nature of the assessor and more details of the assessment process are to be set out in Regulations.

See Advice on the Decision of the European Court of Human Rights in the Case of HL v UK (the "Bournewood" Case) (Gateway Ref 4269), issued December 10 2004, para 35.

Ibid, para 36. For a description of good practice in this context, see para 37.

other than noting the ECtHR comment from *HL* that whether or not someone is deprived of liberty will depend on the circumstances of the case.²²⁴ It is clear from the case law that physical detention in order to administer treatment would come within the ambit of the Article. However, Fennell makes the more extensive argument that, in some circumstances, Article 5 may be implicated by the provision of treatment *per se* (i.e. without the need to show detention).²²⁵ He argues that, where a decision-maker assumes complete control over a patient's treatment "to the extent that they are making decisions about the administration of strong psychotropic medication or even ECT to a patient,"²²⁶ this could be "a factor tipping the balance firmly towards there being a deprivation of liberty".²²⁷

Fennell's argument is most relevant in the context of compliant patients. For non-compliant patients, the imposition of strong psychotropic medication or ECT will almost inevitably require other deprivations of liberty beyond the actual imposition of the treatment and therefore Article 5 will clearly be implicated. However, Fennell seems to suggest that for compliant patients, even if they are not restrained in any way, the simple fact of the treatment is enough to constitute a deprivation of liberty. Fennell's argument relates specifically to certain treatments for a mental disorder. However, the principle could apply to other forms of treatment depending on the level of severity and the long-term implications of the treatment. This position would require a broader interpretation of Article 5 than has yet been in evidence in ECtHR case law. Nonetheless, the argument that certain kinds of treatment can constitute a deprivation of liberty (and therefore require procedural steps before this can take place) is an important one. If successful, it has the potential to extend the level of protection given to incapable, compliant patients. It is, of course, open to the Government to short-circuit the matter and to introduce a requirement for formal approval, or some other form of independent review, for certain treatments, extending the category of situations in which advance court approval was required beyond the current categories of sterilisation and the withdrawal of ANH. 228

²²³ *Ibid*, para 38.

Supra note 212, para 89.

[&]quot;The Mental Capacity Act 2005, the Mental Health Act 1983, and the Common Law" [2005] Journal of Mental Health Law 163.

²²⁶ *Ibid*, 167.

²²⁷ *Ibid*.

See the Practice Direction (Declaratory Proceedings: Incapacitated Adults) [2002] 1 WLR 325, 326.

Article 6: Right to a Fair and Public Hearing

Article 6 (1) states that "[i]n the determination of his civil rights and obligations ..., everyone is entitled to a fair and public hearing within a reasonable time by an independent and impartial tribunal established by law." A decision relating to best interests (or to the establishment of capacity) may be seen as a determination of civil rights and therefore to entitle a patient to a public hearing. In *R* (Wilkinson) v Broadmoor Special Hospital Authority, ²²⁹ the Court of Appeal rejected the argument that Article 6 entitled a patient in every case to challenge a treatment decision before being subjected to it. ²³⁰ However, Simon Brown LJ accepted that Article 6 required a "fair and public hearing" and that this would not be achieved simply by applying the procedural protections set out in the MHA 1983. ²³¹ In the case in question, Simon Brown LJ rejected the claim under Article 6 on the basis that the existence of the possibility of "a determination by an independent and impartial tribunal" in relation to future treatment ²³² and the possibility of bringing a tort action in relation to prior treatment met the requirements under the Article.

English courts have not taken Article 6 protection to mean that a claimant has an automatic right to judicial review in every case. In *R* (*B*) v *Dr SS*, *Second Opinion Appointed Doctor and Secretary of State for the Department of Health*,²³³ the Court of Appeal held that, while it was important that the requirements of Article 6 were satisfied, this did not mean that "permission must be given for judicial review proceedings where the papers do not disclose any arguable grounds for this".²³⁴ Thus, the possibility of an application for judicial review was sufficient to comply with the Article; it was not necessary for each application to be successful and for the case to go forward to a full hearing.

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^{[2002] 1} WLR 419.

Ibid, 434 per Simon Brown LJ.

²³¹ *Ibid*.

²³² *Ibid*.

²³³ [2006] EWCA Civ 28.

²³⁴ *Ibid*, [67].

Jurisprudence arising under the ECHR has made a significant contribution to the law's approach to healthcare decision-making for incapable patients. First, the ECtHR has recognised the category of resistant or unwilling patients and protects the rights of these patients regardless of their incapacity. This jurisprudence therefore moves beyond the limitations of the autonomy paradigm and recognises that the fact of incapacity is not the final determinant regarding what constitutes an appropriate response to the patient's views. Secondly, even compliant incapable patients are entitled to certain protections, including protection against unlawful deprivations of liberty. If Fennell's argument discussed above were to be accepted, this protection arises because of the nature of certain treatments.²³⁵ Once again, this moves beyond the limitations of the autonomy paradigm and recognises that certain kinds of treatment may be so invasive as to require more than simply a doctor's assessment of the patient's best interests.

To an extent, some of these ECHR requirements are already taken into account by the law in England and Wales. In the *Practice Direction*, the Official Solicitor suggests that applications should be made to court where there are "disputes or difficulties" regarding either a patient's capacity or best interests.²³⁶ On the basis of the arguments in this chapter, an application to court would be necessitated where a patient is resistant to treatment or, even if the patient is compliant, if the treatment is administered in circumstances amounting to a deprivation of liberty.

Most importantly, however, the ECHR provides a conceptual basis for decision-making for incapable people which escapes the confines of the autonomy paradigm. It shows that the right of autonomy is just one of a patient's rights and that other rights are also important. The developing jurisprudence of the ECtHR also provides some indication of the practical legal steps required in order to give effect to patients' rights. To date, in the context of treatment refusal, ECtHR case law has not consisted of simply stating the existence of a right but has set out specific obligations on the State arising from the existence of the right. The value of this approach may be seen by comparison with jurisprudence arising under the Irish Constitution. In *In Re a*

See discussion in text to note 225 *supra*.

Practice Direction (Declaratory Proceedings: Incapacitated Adults) [2002] 1 WLR 325, para 3.

Ward of Court, ²³⁷ the Supreme Court set out a long list of rights which had to be respected²³⁸ but provided no indication regarding how these rights interacted with each other or how, in a practical sense, respect was to be shown to these rights (outside of the immediate situation where the array of rights were held to support the withdrawal of life-sustaining treatment from a woman in a near-PVS).

However, the difficulty with ECHR rights is that the ongoing development of jurisprudence requires the active participation of patients. For many incapable patients, the obstacles to be confronted in order to establish their legal rights (consulting a solicitor, initiating a legal action) may be insurmountable. In some ways, the case of HL was extraordinary because of the unusual determination of the claimant's carers in pursuing the case through the UK courts and on to the ECtHR. Thus, it is a matter of happenstance that this opportunity for the recognition of the rights of incapable patients arose at all. For this reason, it is necessary to adopt a human rights mindset in dealing with incapable patients and not to wait until the relevant jurisprudence has become established.

Conclusion

This chapter has argued that the autonomy paradigm can continue to influence healthcare decision-making, even when the patients in question are incapable. The two traditional models for decision-making for incapable patients operated in the shadow of the autonomy paradigm and, as a result, are conceptually limited. This chapter showed why neither best interests nor substituted judgment provide an adequate model for decision-making. The MCA 2005 will address some of the limitations of these traditional models. However, this chapter has argued that, on its own, the legislation remains too tied up with the autonomy paradigm to provide a sufficient basis for decision-making. Instead, it is necessary to look beyond issues of autonomy and take on board broader human rights concerns. Issues of restraint, resistance, liberty, dignity and procedural adequacy are central in developing the law

²³⁷ [1996] 2 IR 79.

The Court stated that decision-making must respect the personal rights of the individual including the right to bodily integrity, the right to privacy, the right of autonomy and the right to dignity. See further Chapter 1 at text following 234.

in this area and these can only be adequately explored if the law does not fixate on the right of autonomy only.

These human rights issues are also central to the subject matter of the next chapter which considers the statutory exclusion of the autonomy paradigm in respect of treatment for a mental disorder. The alternative legal framework which has developed raises some of the most challenging questions regarding the status of autonomy and the application of the autonomy paradigm.

Chapter 4: Treatment for a Mental Disorder: An Exception to the Autonomy Paradigm?

Introduction

For many years, mental health legislation has been an anomaly within a legal system which privileges and protects the individual's right of autonomy. Once a patient has been involuntarily detained, her right to consent to treatment for a mental disorder is circumscribed. Thus, while the consent of a capable involuntary patient is required for treatment for a physical disorder, legislation, rather than patient consent, determines the circumstances in which treatment for a mental disorder may be provided. In recent years, this position has changed in some respects and the circumstances in which treatment may be imposed on an unwilling patient have been reduced. In this regard, the human rights protections afforded under the European Convention on Human Rights have played a significant role in England and Wales.

The recent demise of the Draft Mental Health Bill 2004² serves as a reminder of the difficult policy issues surrounding the development of an appropriate legal framework to cover the treatment of patients with a mental disorder. This chapter explores one aspect of the law in this area. This is the extent to which involuntary patients may refuse treatment for a mental disorder and the appropriate role for capacity in this regard. The argument that capable involuntary patients should have a right to refuse is not a new one. Since the work of the "Anti-Psychiatry movement"³

For a history of the law in England and Wales, see Fennell Treatment Without Consent: Law, Psychiatry and the Treatment of Mentally Disordered People Since 1845 (London and New York: Routledge, 1995); Unsworth The Politics of Mental Health Legislation (Oxford: Clarendon Press, 1987).

In March 2006, the Health Minister announced that the Draft Mental Health Bill 2004 would not proceed and instead outlined proposals for a shorter amending Bill (see *The Mental Health Bill: Plans to Amend the Mental Health Act 1983- Briefing Sheets on Key Policy Areas where Changes are Proposed* (Gateway Ref 6420) (available on the Department of Health website www.dh.gov.uk. (last visited July 26 2006)

This "movement" comprised a number of thinkers from different academic backgrounds and political perspectives. These included the English psychiatrist David Cooper (who coined the term in 1967); the Scottish psychiatrist RD Laing; and the American psychiatrist Thomas Szasz, who is the only member of the Anti-Psychiatry movement who continues to work and have an impact in this area. See also the work of the philosopher and historian, Michel Foucault, who explored the perceptions and functions of mental illness in society from a socio-historical perspective. See in particular *Madness and Civilisation: A History of Insanity in the Age of Reason* (Howard trans) (London: Routledge, 1967) and *Discipline and Punish: The Birth of the Prison* (Sheridan trans) (London: Allen Lane, 1977).

in the 1960s, the utilization of a different legal structure for treatment for a mental disorder has been questioned.⁴ The Anti-psychiatrists disputed the existence of mental illness⁵ and the utility of psychiatric methods employed at that time.⁶ While few would now share the view that mental illness does not exist,⁷ the potentially invasive nature of the treatments involved⁸ and the broader human rights issues raised by non-consensual treatment means that the matter of treatment refusal retains practical as well as theoretical importance.

This chapter asks whether the law relating to treatment for a mental disorder should move away from the current legislative model (or an equivalent) where treatment decisions are not determined by the patient's capacity to an autonomy-based model where a capable patient has the right to refuse treatment. The chapter argues that the refusal of treatment for a mental disorder cannot be dealt with by simply extending the autonomy paradigm to treatment for a mental disorder. It shows that the extension of an autonomy-based right to refuse treatment to capable patients would have a very limited impact in practice and that a human rights-based protective model is required for both capable and incapable patients. However, the chapter also argues that the right of autonomy should play a role within this human rights model, provided that the limitations of the autonomy paradigm are recognised. As with previous chapters, the primary focus in this chapter is on the law in England and

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Laing (see note 3 supra) attracted a considerable amount of popular attention and, ultimately, notoriety. In addition, autobiographical or semi-autobiographical works detailing experiences in mental hospitals brought the anti-psychiatry arguments to a wider audience (see, for example Kesey One Flew Over the Cuckoo's Nest (1962) and Plath The Bell Jar (1966) and the film One Flew Over the Cuckoo's Nest directed by Milos Forman.

See in particular Szasz The Myth of Mental Illness: Foundations of a Theory of Personal Conduct (New York: Paul B Hoeber, 1961).

Laing (The Divided Self (London: Penguin, 1960); Self and Others (London: Penguin, 1961); Sanity, Madness and the Family (with Esterson) (London: Tavistock, 1964)) argued that schizophrenia could be treated more effectively without the use of medication through a greater recognition of the individual's needs and personality. Laing rejected the view that he was "anti-psychiatry"; rather he argued that the methods used by conventional psychiatry at that time (lobotomies, ECT, compulsory detention) were not effective.

For rebuttal of this argument, see for example Roth and Kroll *The Reality of Mental Illness* (Cambridge: Cambridge University Press, 1986).

Modern treatment techniques have moved away from direct physical interventions (such as psychosurgery or ECT) and the primary focus is on medication, including anti-psychotic, anti-anxiety and anti-depressant medication. While medication can provide clear benefits for patients, some medication (in particular anti-psychotic medication) may have wide-ranging side-effects. Newer 'atypical' antipsychotic drugs have fewer side-effects but may have a higher risk of mortality in some patients. In order to alleviate this risk, a blood monitoring programme was introduced in the UK in 1993 for patients prescribed the 'atypical' drug, Clozapine. See further Cichon "The Right to 'Just Say No': A History and Analysis of the Right to Refuse Antipsychotic Drugs" (1992) 53 La L Rev 283, 299-310; Bartlett and Sandland Mental Health Law Policy and Practice (2nd Ed) (Oxford: OUP, 2003), p 327.

Wales although United States and Irish legislation will also be used to illustrate some of the arguments.

Part I of the chapter outlines the current law in England and Wales as contained in Part IV of the Mental Health Act 1983. This Part explores the impact of the ECHR on the interpretation of the MHA 1983 and shows that, while the ECHR has not required that capable patients be permitted the right to refuse treatment, it has enhanced the protections available to both capable and incapable patients before treatment may be imposed. Part I also discusses the possible direction of law reform and identifies the significance to the current discussion of the move towards compulsory care in the community. Part II examines the theoretical and practical questions involved in developing an appropriate legal position regarding treatment refusal. This Part outlines the reasons why the autonomy paradigm on its own cannot provide a sufficient level of protection to patients and shows why it is necessary to take account of a broader range of human rights.

Part I: The MHA 1983 and Treatment Refusal

The MHA 1983 provides a complex legal framework to regulate the detention and treatment of patients with a mental disorder. The legislation applies only to patients who have been formally detained (hereafter involuntary patients), which, in England and Wales, covers approximately 10% of patients admitted to psychiatric facilities. However, the ambit of the MHA extends beyond this immediate category of patients. In particular, the involuntary detention aspect of the legislation may be invoked where a voluntary patient in a psychiatric hospital refuses to comply with treatment, leading

See Bartlett and Sandland *ibid*, p 129. Since the decision in *HL* v *United Kingdom* [2004] ECHR 45508/99, an incapable patient must be formally admitted even if compliant if the admission constitutes a deprivation of liberty thus disapproving the practice at that time of informally admitting incapable, compliant patients. The "Bournewood" Consultation: The Approach to be Taken in Response to the Judgment of the European Court of Human Rights in the "Bournewood" Case (Gateway Ref 4706), March 2005, para 3.2 notes the lack of reliable information regarding the numbers of patients affected. It cites (para 3.3) estimates by the Mental Health Act Commission in 1998, that at any one time there were approximately 22,000 compliant, incapable in-patients in psychiatric facilities in England and Wales and that each year there would have to be approximately 48,000 more formal admissions under the MHA 1983. The Government has proposed to amend the MCA 2005 to introduce a new procedural framework to cover deprivations of liberty involving compliant, incapable patients (see Bournewood Briefing Sheet (Gateway Reference 6794) (available at Department of Health website www.dh.gov.uk. (last visited July 26 2006)).

to the patient's status being changed from voluntary to involuntary. Furthermore, the threat that treatment will be legislatively imposed, if not voluntarily acceded to, can lead patients to consent to treatment in order to avoid the stigma of detention.¹⁰ Thus, the possibility of compulsion has implications for all patients with mental disorders.

This Part begins by outlining the approach to treatment provision as set out in Part IV of the MHA 1983. It then establishes the impact of the ECHR on judicial interpretations of Part IV and looks at the ongoing efforts to reform mental health law.

Treatment Provision under Part IV of the MHA 1983

Most of Part IV¹¹ applies only to a patient "liable to be detained".¹² A patient in this sense must have been formally admitted for assessment (under section 2 of the MHA) or for treatment (under section 3 of the MHA) or have had her status changed from voluntary to involuntary (under section 5 of the MHA).¹³ The patient's capacity is not a relevant factor in admission for either assessment or treatment or in relation to a change of status.¹⁴

Bartlett and Sandland describe Part IV of the MHA 1983 as "double-edged". On the one hand, it gives extensive powers to impose treatment on patients; on the other, it restricts the imposition of treatment in some situations. Section 63 sets out the basic power to impose treatment. This section states that, other than for treatment covered in sections 57 and 58, the consent of a patient is not required for any medical treatment given for the mental disorder from which the patient is suffering provided that the treatment is "given by or under the direction of the responsible medical officer" (the RMO). There is no statutory indication of how the RMO should determine whether to provide treatment and the matter of the patient's best interests is not mentioned. The section also makes no distinction between capable and incapable

See Zigmond and Holland "Unethical Mental Health Law: History Repeats Itself" [2000] Journal of Mental Health Law 49, 53.

Only section 57 (which concerns psychosurgery) applies to all patients.

Section 56. Other patients may be admitted for treatment under section 131 of the MHA 1983. However, they do not come within the ambit of Part IV of the Act and come under the common law systems described in the previous chapters.

For a detailed description of the admission process, see Bartlett and Sandland *supra* note 9, Chapters 4 and 5.

A recent study by Bellhouse et al "Capacity-Based Mental Health Legislation and its Impact on Clinical Practice: 2) Treatment in Hospital" [2003] Journal of Mental Health Law 24 found that approximately 20% of patients admitted involuntarily (in this study 2 out of 10 patients) were legally capable.

patients. However, the Code of Practice to the Mental Health Act 1983¹⁶ notes that a detained patient is not necessarily incapable and states that consent should always be sought (although it does not specify what should happen if consent is not forthcoming).

"Medical treatment" for a mental disorder in the context of section 63 is broadly defined¹⁷ and has been very loosely interpreted by the courts.¹⁸ Court have seen themselves as adopting a holistic approach to treatment provision, allowing "a range of acts ancillary to the core treatment" to be provided. 19 Thus, treatments which have been approved under section 63 have included some treatments which might more naturally be described as treatments for a physical disorder, such as feeding anorexic patients by naso-gastric tube²⁰ and the performance of a caesarean section.²¹ However, there may be a move towards a narrower interpretation of section 63. In R v Ashworth Hospital, ex p B, 22 the House of Lords overturned the Court of Appeal's finding that a patient could only be treated under section 63 for the disorder which had provided the basis for his detention. However, Baroness Hale stated that "[i]t is obviously much more serious if a patient is given the wrong kind of medication, or the wrong kind of surgery, than it is if [as in the case in question] the patient is kept on a ward in the wrong kind of milieu."²³ This could suggest a more careful approach to the use of section 63 which may extend to prevent the use of the section as a basis for the provision of medical or surgical treatments which do not fall squarely within the

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Supra note 9, p 323. See generally ibid Chapter 7.

¹⁶ Revised in 1999 (London: Stationary Office, 1999) (Health Service Circular HSC 1999/050; Local Authority Circular LAC (99) 11), para 16.4.

¹⁷ Section 145 (1) defines medical treatment as including nursing as well as care, habilitation, and rehabilitation under medical supervision.

¹⁸ Fegan and Fennell "Feminist Perspectives on Mental Health Law" in Sheldon and Thompson eds Feminist Perspectives on Health Care Law (London: Cavendish Publishing, 1998), p 93 describe the courts as stretching "logic and the language of s 63 almost to breaking point".

B v Croydon Health Authority [1995] 2 WLR 294, 298 per Hoffman LJ. See also the approach of the House of Lords in R v Ashworth Hospital, ex p B [2005] UKHL 20, [31] where Baroness Hale described the purpose of psychiatric treatment as being "to treat the whole patient".

²⁰ See South West Herfordshire Health Authority v KB [1994] 2 FCR 1051; F v Riverside Health Trust (1993) 20 BMLR 1 (overturned on other grounds in Riverside NHS Mental Health Trust v Fox [1994] 1 FLR 614); B v Croydon Health Authority [1995] 2 WLR 294.

²¹ Tameside and Glossop Acute Services Trust v CH [1996] 1 FLR 762.

²² [2005] UKHL 20.

Ibid, [30]. The patient in this case objected to being treated in the hospital's Personality Disorder Unit, having been diagnosed after admission with a personality disorder in addition to the mental illness for which he had been admitted.

category of treatment for a mental disorder.²⁴ However, it remains to be seen whether there will be any significant change in the interpretation of section 63 at lower court level.

The power to treat set out in section 63 is restricted by sections 57 and 58 unless the treatment in question comes within the emergency treatment provision contained in section 62.²⁵ Section 57 is the only provision which imposes a requirement for consent to treatment. However, the section applies only to the rare instances of psychosurgery²⁶ and the surgical implantation of sexual suppressants.²⁷ The section requires that the patient must be capable of understanding the "nature, purpose, and likely effects" of the treatment and give consent to it. ²⁸ For other serious treatments, the limitations on treatment provision are procedural rather than substantive. Section 58 applies to the administration of medication for more than three months²⁹ and to any administration of electro-convulsive therapy (ECT).³⁰ These

See also the comment of Simon Brown LJ in the Court of Appeal in R v Ashworth Hospital, ex p B [2003] EWCA Civ 547, [78] that, "on no view does [section 63] extend to treatment of any physical condition, however serious."

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Section 62 prevents the application of sections 57 and 58 where treatment is "immediately necessary" to save the patient's life, to prevent a serious deterioration in the patient's condition, to alleviate serious suffering, or to prevent the patient behaving violently or being a danger to herself or others. Unless the treatment in question is immediately necessary to save the patient's life, there are limitations on the nature of the treatment that may be given. Treatment that is immediately necessary to prevent a serious deterioration in the patient's condition must not be irreversible and treatment that is intended to prevent the patient behaving violently or being a danger to herself or others must be neither irreversible nor hazardous and must represent the minimum interference necessary. Fennell (supra note 1, p 223) argues that, notwithstanding these limitations, doctors have tended to see section 62 as permitting them to provide treatment rather than restricting them in the treatment that can be provided.

Although older forms of psychosurgery involved the performance of a lobotomy, modern techniques involve the insertion of radioactive rods or electrodes in the brain in a way that separates the frontal lobe cortex from the limbic lobe and has the effect of reducing 'unwanted' emotions. See Bartlett and Sandland *supra* note 9, pp 333-334 for a description of the procedure involved. According to Bartlett and Sandland, *ibid*, this form of surgery is used as a last resort in a small number of (usually female) patients (two or three dozen in England and Wales) suffering from depression or obsessional disorders.

The section 57 protection was extended to the surgical implantation of sexual suppressants by section 16 of the Mental Health (Hospital, Guardianship and Consent to Treatment)
Regulations 1983. However, sexual suppressants are usually administered by depo-injections rather than surgically implanted (see Fennell supra note 1, pp 187-188) and therefore do not come within the section. Cf R v Mental Health Act Commission ex parte W (1988) 9 BMLR 77 where the High Court held that injections through a wide bore syringe of the Goserelin hormone for the purpose of suppression of sexual desires did not constitute surgical implantation and therefore did not come within the ambit of section 57.

The question of whether the patient is capable of understanding in this instance is determined by a three-person team including one psychiatrist.

The three month period runs from the first time in a specific period of detention that the patient was given medicine for her mental disorder (section 58 (b)).

ECT was included within the ambit of section 58 by regulation 16 of the Mental Health (Hospital, Guardianship and Consent to Treatment) Regulations 1983. ECT involves passing

treatments may only be administered if the patient consents to the treatment and is capable of understanding the nature, purpose and likely effects of the treatment or, if the patient is not capable or does not consent, if a registered medical officer other than the patient's own RMO, certifies that "having regard to the likelihood of its alleviating or preventing a deterioration of his condition, the treatment should be given." In this instance, the second medical officer (commonly referred to as a second opinion appointed doctor (SOAD)) is independently appointed by the Mental Health Act Commission (MHAC).

In setting up the second opinion system, the MHA 1983 makes no distinction between the capable refusing patient and the incapable patient. However, the *Code of Practice to the Mental Health Act 1983*³³ requires the SOAD to consider "where a capable patient is withholding consent, the reasons for such withholding, which should be given their due weight."³⁴ The matter of what constitutes "due" weight is not expanded on in the Code. Fennell's study³⁵ of the circumstances in which SOADs declined to approve treatment plans suggests that in some cases, the "lucidly expressed opposition of the patients" did impact on SOADs' decisions in this regard.³⁶ However, both Fennell's study and the Biennial Reports of the MHAC found that approval was forthcoming in approximately 96% of cases.³⁷

an electric shock through the patient's brain for approximately four seconds which induces a brief epileptic fit. The patient must be under anaesthetic and muscle relaxants must be used in order to prevent physical injuries. In a recent report, the *Systematic Review of the Efficacy and Safety of Electroconvulsive Therapy* (London: Department of Health, 2003), p 57 found that ECT appears to be an effective short-term treatment for patients with depression although there is no evidence regarding its effectiveness for other conditions.

Section 58 (3) (b).

The MHAC has the statutory function *inter alia* of administering the review procedures under the MHA 1983 (see section 121 of the MHA 1983).

³³ Supra note 16, para 16.21.

See also the MHAC Practice Note 1: Guidance on the Administration of Clozapine and Other Treatments Requiring Blood Tests Under the Provisions of Part IV of the Mental Health Act (June 1993) (updated March 1999) which states that blood sampling could be included within the section 58 certification (as a necessary part of the administration of the medication) but that the RMO and the SOAD should take account of the degree of resistance of the patient and its origins (including religious objections) in deciding whether to authorise the treatment.

See *supra* note 1, Chapter 12. This aspect of Fennell's study covers a period from December 1991 to August 1993. The relevant survey related to 1,009 MHAC2 forms, which must be completed by SOADs and returned to the MHAC.

Fennell *ibid*, pp 208-209 found 36 cases out of the 1,009 surveyed (approx 3.6%) in which the SOAD did not certify treatment. In these cases, patients' objections appeared to be relevant in six of the ECT cases and in two of the cases involving ongoing medication. In addition, Fennell cites seven cases in which "significant" changes were made to the treatment plan. Of these, one (*ibid*, 210-211) appears to have been due to the "aggressive refusal" by the patient to accept necessary blood monitoring.

See Fennell *ibid*, p 208.

Although capacity plays a limited role under sections 57 and 58, a determination of capacity is required by both sections. A notable aspect of the MHA in this regard is that the legislative standard for capacity is lower than the standard at common law. Sections 57 and 58 both adopt a definition which requires the patient to be capable of understanding the "nature, purpose, and likely effects" of the treatment. The ability to "use and weigh" the information, which is required at common law, is not mentioned. It is difficult to find any justification for the adoption of a lower standard for capacity in relation to treatment for a mental disorder. However, this is precisely what the statute appears to do. In R (Wilkinson) v Broadmoor Special Hospital Authority, Hale LJ suggested that the common law test "would be equally suitable for assessing capacity for the purpose of section 58 (3) (b) of the Mental Health Act 1983."38 It was not clear whether Hale LJ meant "would be" in a general policy sense (for example, that future statutes should include the common law test) or that the test should be applied notwithstanding the contrary wording of the statute. In B v Dr SS, Dr G and Secretary of State for the Department of Health, 39 Charles J seems to have taken the latter view, finding the patient to be incapable under section 58 of the MHA 1983 because of his inability to use and weigh information.⁴⁰ In considering the case on appeal, the Court of Appeal was conscious of the conflict between the wording of the statute and the common law test, stating that "[a]rguably these words [in the statutory test] do not go far enough to define capacity."41 The Court interpreted Hale LJ's comment to mean that she believed that the Re MB test would apply regardless of the statutory test⁴² but the Court did not give a clear approval to this position. Instead, the Court stated that "[w]hatever the precise test of the capacity to consent to treatment, we think that it is plain that a patient will lack that capacity if he is not able to appreciate the likely effects of having or not having the treatment."43

The legislative provisions set out above have been the subject of a considerable body of litigation, in particular since the incorporation of the ECHR into

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³⁸ [2002] 1 WLR 419, 443.

^[2005] EWHC (Admin) 1936. See also R (on the application of B) v Haddock and Others [2005] EWHC 921.

⁴⁰ *Ibid*, [190]

R (on the application of B) v Dr SS and Dr AC [2006] EWCA Civ 28, [33].

⁴² *Ibid*, [33].

⁴³ *Ibid*, [34].

UK law. The next section will look at the impact of ECHR jurisprudence on the interpretation of Part IV of the MHA 1983.

The Impact of the ECHR on Part IV of the MHA 1983

As a result of the surge in litigation following the incorporation of the ECHR, a number of principles have now been established regarding treatment refusal. It is clear that the ECHR does not require the consent of a capable involuntary patient to be obtained for treatment covered by the MHA 1983. However, patients' rights arising under the ECHR have limited the circumstances in which treatment may be imposed on both capable and incapable patients and have required procedural protections beyond those afforded on the face of the MHA 1983 itself.

The impact of the ECHR on the operation of the MHA 1983 first became apparent in R (Wilkinson) v Broadmoor Special Hospital Authority. 44 The claimant in this case had been formally detained at Broadmoor Special Hospital for 34 years following diagnosis with a psychopathic disorder. In July 1999, he came under the care of a new RMO who concluded that the claimant additionally suffered from a psychotic disorder, which could be treated with anti-psychotic medication which, if successful, could ultimately lead to the claimant's release. The claimant strenuously resisted any attempt at administration of this medication. As the medication was for a period of more than three months, the RMO obtained the necessary SOAD's certificate, which certified that the claimant was incapable. The claimant continued to resist and treatment was imposed by force. This led the claimant, who had a heart condition, to have an angina attack. The claimant sought judicial review of the decision to impose treatment on him and sought a full hearing, with the introduction of oral evidence from an independent psychiatrist hired by his legal team and the cross-examination of the prescribing doctor and of the SOAD who had authorised the treatment.45

Although the issue before the Court of Appeal was the procedural one of whether the patient was entitled to a formal hearing before treatment could be imposed, two members of the Court offered views regarding the extent to which an

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⁴⁴ [2002] 1 WLR 419.

involuntary patient could refuse treatment for a mental disorder in light of rights arising under the ECHR. Simon Brown and Hale LJJ found that Articles 3 and 8 of the ECHR⁴⁶ were implicated by the imposition of treatment on a patient in the claimant's situation.⁴⁷ However, in light of decision of the ECtHR in *Herczegfalvy* v *Austria*,⁴⁸ the imposition of treatment was permissible, provided it was convincingly shown to be therapeutically necessary.

Both judges discussed the relevance of the patient's capacity in determining whether treatment was therapeutically necessary. Hale LJ held that the law had not yet reached the pointed where it was an accepted norm that a capable patient "can only be treated against their will for the protection of others or for their own safety." This did not mean, however, that treatment could be imposed without having regard to the rights and the wishes of the patient. Rather, it had to be asked if the treatment was so likely to benefit the patient as to justify its forcible imposition. Hale LJ went on to note that "[g]iven that under the Convention forcible treatment which is not a 'medical necessity' may well be inhuman and degrading, substantial benefit from it would be required for it to be justified." Crucially, Hale LJ did not focus on the question of the patient's capacity but rather on the question of willingness, noting that "most people are able to appreciate that they are being forced to do something against their will even if they are not able to make the decision that it should or should not be done". 52

On first reading, Simon Brown LJ appears to have accorded greater significance to the matter of capacity than Hale LJ. He stated that "[t]he precise equivalence under section 58(3)(b) between incompetent patients and competent but non-consenting patients seems to me increasingly difficult to justify".⁵³ In the circumstances of the case, he considered that "[i]f in truth this claimant has the

A striking feature of *Wilkinson* is the extent to which the reports prepared by the RMO and the SOAD differed from the report of the psychiatrist employed by the patient's legal team. See the evidence outlined by Simon Brown LJ, *ibid*, 424-425.

See detailed discussion of these rights in Chapter 3 at text following note 173.

Supra note 44, 432-433 per Simon Brown LJ; 445-446 per Hale LJ. In addition, Simon Brown LJ considered that the right to life, protected under Article 2, was implicated given the real risk to the patient's life posed by a possible future angina attack brought on by the forcible administration of the medication.

⁴⁸ (1992) 15 EHRR 437.

⁴⁹ [2002] 1 WLR 419, 446.

⁵⁰ Ibid.

⁵¹ *Ibid*, 447.

⁵² *Ibid*, 446.

⁵³ *Ibid*, 433.

competence to refuse consent to the treatment proposed here, it is difficult to suppose that he should nevertheless be forcibly subjected to it."⁵⁴ This could be interpreted to support a capacity-based right to refuse treatment.⁵⁵ However, it is probable that his Lordship intended his comments to be restricted to the situation of the claimant before him.⁵⁶ This interpretation is supported by the fact that his Lordship referred to "this claimant" rather than "a claimant" and that later in his judgment, his Lordship reasserted the therapeutic approach in a more general context, noting "[c]ourts, after all, are likely to pay very particular regard to the views held by those specifically charged with the patient's care and well-being."⁵⁷

Subsequent cases have confirmed that a capable involuntary patient does not have an ECHR-based right to refuse treatment covered by the MHA 1983.⁵⁸

However, the patient's capacity does play a role in determining whether imposed treatment complies with the ECHR. There are different judicial approaches to the extent of this role. In *R* (on the application of *B*) v Dr SS and Dr AC, Silber J considered that the "present state of our law is that the views of the patient with capacity, who refuses treatment" are "a very important factor" and that "it would need an especially powerful case from the RMO to override [these views]".⁵⁹ In this regard, Silber J was overstating the position somewhat.⁶⁰ It is therefore not surprising that the Court of Appeal in this case took the view that the fact that treatment is imposed by compulsion is more important than the fact that the patient has capacity.⁶¹ This decision, which comes after the ECtHR in Storck v Germany⁶² had focussed on

54 Ibid.

This is the view of Hewitt "An End to Compulsory Treatment" (2002) 152 NLJ 194.

The level of resistance to the treatment in *Wilkinson* was extreme (and rare) (see evidence given by the RMO *supra* note 44, 424) and gave rise to additional health risks because of the claimant's heart condition. Simon Brown LJ described (*ibid*, 433) the impact of the forced treatment on the claimant's right to autonomy and bodily inviolability as "immense" and the prospective benefits as decidedly speculative.

⁵⁷ Supra note 44, 433-434.

See R (on the application of PS) v Responsible Medical Officer and Another [2003] EWHC 2335, [116], where Silber J described Simon Brown LJ's comments in Wilkinson as "case sensitive"); R (on the application of B) v Dr SS and Dr AC [2005] EWHC 86 (Admin); [2006] EWCA Civ 28.

R (on the application of B) v Dr SS and AC [2005] EWHC 86 (Admin), [31].

Indeed, the primary authority upon which Silber J relied in reaching his assessment of the state of the law was (*ibid*, [29]) his own judgment in *R* (on the application of *PS*) v

*Responsible Medical Officer and Another [2003] EWHC 2335.

⁶¹ [2006] EWCA Civ 28, [50].

⁶² [2005] ECHR 406.

patient unwillingness rather than capacity, would also seem to accord more closely with the approach of Hale LJ in Wilkinson.⁶³

While the ECHR does not require consent to be obtained for treatment in all circumstances, it does limit the circumstances in which treatment may be provided to a patient in two important ways. First, at a substantive level, treatment which implicates ECHR rights must be shown to comply with the ECHR. If Article 3 is engaged (i.e. if the minimum severity level is reached), the treatment must be therapeutically necessary. In R (on the application of N) v Doctor M and Others, 64 Dyson LJ set out the factors relevant for the establishment of therapeutic necessity in relation to an incapable involuntary patient.⁶⁵ These were:

(a) how certain is it that the patient does suffer from a treatable mental disorder; (b) how serious a disorder is it; (c) how serious a risk is presented to others; (d) how likely is it that, if the patient does suffer from such a disorder, the proposed treatment will alleviate the condition; (e) how much alleviation is there likely to be; (f) how likely is it that the treatment will have adverse consequences for the patient; and (g) how severe may they be.66

If only Article 8 is engaged (i.e. if the minimum severity standard is not reached), the treatment does not have to be therapeutically necessary but rather it must come within the permitted exceptions set out in Article 8(2).⁶⁷ This means that the treatment in question must meet the statutory standard i.e. it must have been authorised by a SOAD "having regard to the likelihood of its alleviating or preventing a deterioration of his condition, the treatment should be given". Although this statutory standard does not mention the patient's best interests as a relevant factor for the SOAD in reaching her decision, the Court of Appeal in R (on the application of B)

⁶³ See text following note 49 supra.

⁶⁴ [2002] EWCA Civ 1789.

⁶⁵ Dyson LJ did not specifically mention that his comments related to incapable patients only. However, given that the patient in question was clearly incapable and that Dyson LJ did not mention the issue of capacity at all at this point in his judgment, it might reasonably be assumed that he intended his comments to be restricted to incapable patients. This is also the view taken of Dyson LJ's remarks by Silber J in R (on the application of B) v Dr SS and Dr AC [2005] EWHC 86 (Admin), [28].

Supra note 64, [19]. Dyson LJ also addressed the question of whether it was necessary to convincingly establish both that the patient was suffering from a mental disorder and that the treatment in question was therapeutically necessary for the disorder in question. He considered (ibid, [20]) that this compartmentalised approach would not produce "a sensible outcome". This approach was confirmed by the Court of Appeal in R (on the application of JB) v Haddock and Others [2006] EWCA Civ 961, [43].

⁶⁷ B v Dr SS, Dr G and the Secretary of State for the Department of Health [2005] EWHC 1936 (Admin), [82].

v Dr SS and Dr AC⁶⁸ appears to have imported the best interests standard into the more permissive statutory standard. Thus, the Court noted that "English common law and medical ethics both require that medical treatment shall not be imposed without the consent of the patient unless the treatment is considered to be in the best interests of the patient." In the Court's view, a SOAD should only give the necessary approval if satisfied that the treatment is in the best interests of the patient.

Secondly, if either Article 3 or Article 8 is engaged, at a procedural level it must be convincingly shown that the treatment in question complies with the relevant standard. This requirement extends the procedural protections for a patient beyond those evident on the face of the MHA 1983 in two respects. The first of these procedural protections relates to the SOAD's function, which has been considerably increased. The SOAD must reach an independent judgement and not simply approve the RMO's decision. The SOAD must also give reasons for her decision "on the RMO's proposal to override [the patient's] will." Although "the law does not require a SOAD to dot every "i" and cross every "t" when giving reasons for his opinion", it is necessary that "he gives his reasons clearly on what he reasonably regards as the substantive points on which he formed his clinical judgment."

The second procedural protection arises in some circumstances and entitles a patient to judicial review to establish whether the standard for the imposition of treatment may be convincingly shown to have been reached. In *Wilkinson*, the Court of Appeal found that a case such as the one in question, which involved interference with an individual's human rights, required a higher level of judicial review than the "heightened scrutiny" provided for under the "super-Wednesbury test." On the facts

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⁶⁸ [2006] EWCA Civ 28.

Ibid, [62]. Noting the difference between the statutory standard and the best interests standard, the Court (ibid) stated that best interests "will depend on wider considerations than the simple question of the efficacy of the treatment, such as whether an alternative and less invasive treatment will achieve the same result. The distress that will be caused to the patient if the treatment has to be imposed by force will also be a relevant consideration."

⁷⁰ *Ibid*.

See Wilkinson supra note 44, 434.

See R (on the application of Wooder) v Feggetter and the Mental Health Act Commission [2002] EWCA Civ 554, [49] per Sedley LJ.

Ibid, [29] per Brooke LJ. This requirement is now reflected in the MHAC Guidance for professionals. See Guidance for SOADs: R (on the application of Wooder) v Feggetter (GN 1A/02) (June 2002); Guidance for RMOs: R (on the application of Wooder) v Feggetter (GN 1B/02) (June 2002) (available at http://www.mhac.trent.nhs.uk/).

Under the Wednesbury test (originating from the decision in Associated Provincial Picture Houses Ltd v Wednesbury Corporation [1948] 1 KB 223), an administrative decision is subject to judicial review on substantive grounds only when the decision is so unreasonable that no other decision-maker in a similar situation could have made it. A slightly more

of *Wilkinson*, the claimant was entitled to a full review hearing, with oral expert evidence, including that of his own medical witness and the possibility of cross-examination.⁷⁵ Hale LJ stated that:

The claimant is entitled to a proper hearing, on the merits, of whether the statutory grounds for imposing this treatment on him against his will are made out: i.e. whether it is treatment for the mental disorder from which he is suffering and whether it should be given to him without his consent 'having regard to the likelihood of its alleviating or preventing a deterioration of his condition'.⁷⁶

This did not mean that every patient was entitled to a hearing in advance of the imposition of treatment. A patient's doctor did not have to go to court to obtain authorisation to treat.⁷⁷ However, Hale LJ concluded by stating that, "once a situation exists in which the treatment can be scrutinised, whether before or after the event, then that scrutiny should take place."⁷⁸ Although not entirely clear, it would appear that Hale LJ intended that, if a patient challenges a treatment decision either before or after the treatment is provided, the decision to provide the treatment should be scrutinised.

The decision in *Wilkinson* left open a number of questions regarding the circumstances in which a hearing would be required before treatment could be imposed under the MHA 1983 and the nature of such a hearing. Some of these questions were answered in *R* (on the application of *N*) v Doctor *M* and Others⁷⁹ where the Court of Appeal sought to rein in the possible consequences of the decision in *Wilkinson*. Dyson LJ, speaking on behalf of the Court, rejected the argument that the criminal standard of proof beyond a reasonable doubt applied in a case which implicated ECHR rights.⁸⁰ He described the standard required as a high one but took

interventionist test was developed in the context of human rights in R v Ministry for Defence, ex p Smith [1996] 1 All ER 257, 263. Under the "super-Wednesbury" test, in cases involving human rights, the courts should conduct a "heightened scrutiny" of the decision or policy in question. In Smith and Grady v United Kingdom (1999) 29 EHRR 493, the ECtHR held that the super-Wednesbury test provided insufficient protection for individual rights arising under the ECHR.

⁷⁵ [2002] 1 WLR 419, 432-433 per Simon Brown LJ; ibid, 439 per Brooke LJ; ibid, 447 per Hale LJ.

⁷⁶ *Ibid*, 447.

⁷⁷ Ibid.

⁷⁸ Ibid.

⁷⁹ [2002] EWCA Civ 1789.

⁸⁰ *Ibid*, [18].

the view that the matter did not need "elaboration or further explanation." In determining how therapeutic necessity is to established, Dyson LJ stated that "[m]uch will depend on the nature of the right that has allegedly been breached, and the nature of the alleged breach." However, he offered the view that "it should not often be necessary to adduce oral evidence with cross-examination". In his view, the decision in *Wilkinson* should not be seen as "a charter for routine applications to the court for oral evidence in human rights cases generally." It should not "be overlooked that the court's role is essentially one of review".

This cautious approach to the form of review required was also evident in the Court of Appeal decision in *R* (on the application of *B*) v Dr SS and Dr AC.⁸⁶ Here the Court cast doubt on comments in the two High Court judgments in that case, which seemed to suggest that a patient would be automatically entitled to challenge a treatment decision at a full hearing with medical experts additional to those already involved.⁸⁷ Distancing itself from these views, the Court noted that permission for judicial review does not have to be given if the papers do not disclose an arguable case. The Court also noted that, if the SOAD system was properly utilised with the SOAD reaching an independent conclusion, then the need for cross-examination of medical witnesses "should not often arise."

The relationship between the Court of Appeal decision in *Wilkinson* and the more cautious later decisions was most recently considered by the Court of Appeal in *R* (on the application of JB) v Haddock and Others. All LJ (speaking for the Court) considered that the Court in *Wilkinson* "could not have intended or contemplated that every case would require the hearing and testing of oral medical evidence, especially where, as here, none of the parties requested it." Although the Court did not expressly say so, its reference to the lack of a request for an oral hearing could be taken to suggest that, if such a hearing had been requested, it would have had a high likelihood of being granted. This argument may be supported by the Court's

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Ibid.

⁸² *Ibid*, [39].

⁸³ Ibid.

⁸⁴ Ibid.

⁸⁵ Ibid.

⁸⁶ [2006] EWCA Civ 28, [67].

⁸⁷ Ibid.

⁸⁸ *Ibid*, [68].

⁸⁹ [2006] EWCA Civ 961.

⁹⁰ *Ibid*, [65].

statement that the view expressed in *R* (on the application of *B*) v *Dr SS* and *Dr AC* that the need for cross-examination of medical witnesses should not often arise "could prove to be somewhat optimistic." Thus, the approach of the Court in this case seems to suggest a movement towards a more liberal attitude to *Wilkinson*-type hearings.

In light of the above, it is clear that a patient under the MHA 1983 has a degree of procedural protection beyond that afforded on the face of the Act. The practical significance of this becomes clear in the discussion of the relationship between the MHA 1983 and the MCA 2005 which follows.

The Relationship Between the MCA 2005 and the MHA 1983

The MCA 2005, discussed in detail in the previous chapter, will place healthcare and personal decision-making for incapable patients on a statutory footing and will take over the regulation of the management of the property and affairs of mentally incapable people currently governed by Part VII of the MHA 1983. The MCA 2005 will apply to incapable patients, a category which, inevitably, will contain a large number of patients with mental disorders. However, section 28 of the MCA 2005 makes it clear that the MCA 2005 and the MHA 1983 will operate independently and that treatment of involuntary patients for a mental disorder will remain subject to the MHA 1983.⁹²

The existence of the two legislative schemes means that two incapable patients, one voluntary, one involuntary, resident in the same facility could have the same condition and, from a medical perspective, could require the same treatment yet be subject to different legal regimes. The patient covered by the MCA 2005 will be treated according to a best interests standard with little possibility of an independent review of treatment decisions while the patient covered by the MHA 1983 will be treated under the more procedurally protective mental health regime described above. Even if, as was argued in the previous chapter, the ECHR requires more attention to be paid to the procedures under which best interests are determined under the MCA

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⁹¹ Ibid.

Section 28 of the MCA 2005 states that "Nothing in this Act authorises anyone – (a) to give a patient medical treatment for mental disorder, or (b) to consent to a patient's being given treatment for mental disorder, if, at the time when it is proposed to treat the patient, his treatment is regulated by Part 4 of the Mental Health Act 1983".

2005, this still falls short of the automatic review under the MHA 1983. In a comparison of the common law position (largely reproduced in the MCA 2005) with the MHA 1983, Richardson ⁹³ notes the advantage of the MHA 1983 in terms of the accessibility of the protections it affords to patients. Under the common law and the MCA 2005, in order to give effect to her ECHR rights, a patient must take active steps to obtain relevant information, get legal advice and initiate a legal action. On the other hand, under the MHA 1983, procedural protections will slot into place either after medication has been prescribed for three months or when ECT is prescribed without any need for the patient to do anything to instigate the review process.

The impact of the gap between the two systems has been reduced since the ECtHR decision in *HL* v *United Kingdom*, ⁹⁴ which requires any incapable compliant patient whose admission amounts to a deprivation of liberty to be formally admitted (and therefore to be subject to the protections of the MHA 1983). As discussed in Chapter 3, it is stated Government intention to amend the MCA 2005 to set out a new procedural framework to regulate the care of incapable, compliant patients in circumstances where the care constitutes a deprivation of liberty. ⁹⁵ When, and if, the proposed amendment to the MCA 2005 becomes law, the difference between the two schemes will again become apparent. The protections afforded by the proposed amendment are less extensive than the protections arising under the MHA 1983. In particular, there appears to be no proposal regarding the introduction of protection to ensure the suitability of the treatment administered to patients admitted under the amended MCA 2005. Therefore, the spectre of two patients receiving the same treatment under different legal regimes remains.

A second consequence of the two legislative schemes relates to the right to make advance treatment decisions. Section 24 of the MCA allows a capable person over the age of 18 to make an advance decision to refuse specified treatment(s) in specified circumstances to apply if she subsequently loses capacity. The MCA does not exclude treatment for a mental disorder from the list of possible treatments. However, there is no mention of advance decisions in the MHA 1983 and, if a patient who has made an advance decision is subsequently involuntarily detained, Part IV of

⁹⁴ [2004] ECHR 45508/99.

 [&]quot;Autonomy, Guardianship and Mental Disorder: One Problem, Two Solutions" (2002) 65
 MLR 702, 710. For another perspective on the difference between the two systems, see
 Bartlett "Adults, Mental Illness and Incapacity: Convergence and Overlap in Legal
 Regulation" (2003) 25 Journal of Social Welfare and Family Law 341.

the MHA 1983 comes into play and the statute rather than the advance refusal determines when treatment should be provided. Thus, the right to make an advance decision is restricted in relation to certain kinds of treatments even where the patient was not actually involuntarily detained at the time the decision was made. However, the difference between the two systems may not be so extreme as first appears. The fact of the advance refusal should operate as a clear indication of unwillingness on the patient's part (regardless of her actual current response to the treatment in question). Furthermore, where the MHA 1983 has not been engaged (i.e. where the patient is incapable and compliant), it can be argued that the fact of the advance refusal may suggest that the patient is not in fact compliant with treatment (notwithstanding her current attitude) and therefore to require the procedures under MHA 1983 to be used before treatment could be imposed.

Ultimately, if the more protective approach to treatment of incapable patients advocated in the previous chapter becomes more developed, the incongruity of two systems dealing with the same kinds of patients will be reduced. However, the lack of "joined up thinking" identified by Bartlett and McHale% remains and, as will be seen in the discussion of reform possibilities in the next section of this Part, is unlikely to be addressed in the foreseeable future. The reluctance to adopt a single system to deal with treatment decisions for incapable patients, regardless of the nature of the treatment, arises in part from the ongoing influence of the autonomy paradigm in the MCA 2005. Where the paradigm is dominant, as is the case under the common law and under the MCA 2005, there is less space to develop other conceptual models for treatment of incapable patients. However, where, as under the MHA 1983, the paradigm has been displaced, a space is created, which must be filled by another legal and conceptual framework. Thus, the protective framework for incapable patients under the MHA 1983 is superior to that under the common law or the MCA 2005. The importance of this protective framework will be apparent in the discussion in Part II of this chapter.

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See Bournewood Briefing Sheet supra note 9.

[&]quot;Mental Incapacity and Mental Health: The Development of Legal Reform and the Need for Joined-up Thinking" (2003) 25 Journal of Social Welfare and Family Law 313.

Reforming Mental Health Law in England and Wales

The reform of mental health law in England and Wales has featured on government agendae since the publication of the *Review of the Mental Health Act 1983* (the Richardson Report).⁹⁷ In a wide-ranging consideration of policy issues in mental health law, this Report set out the case for and against the extension of the autonomy paradigm to mental health law (although it did not conclude on the matter⁹⁸) and made several important recommendations. These included according a role to capacity in deciding if a patient could be subject to a compulsory care order (which could operate without the requirement for detention),⁹⁹ recommending that ECT should never be imposed on any capable patient who did not consent,¹⁰⁰ and proposing the introduction of legislation to enable patients to make advance decisions about their care.¹⁰¹

In subsequent efforts at legislation, most of the Richardson Report's recommendations were ignored. The Draft Mental Health Bill 2002 proposed the introduction of compulsory care in the community with no role for capacity and relatively few other safeguards at admission stage (although the Bill did replace the SOAD system with a review by an independent tribunal). Unsurprisingly, the 2002 Bill received widespread criticism from a range of sources, including psychiatrists, lawyers and patients' groups and it became apparent that the Bill as drafted could not succeed. The Draft Mental Health Bill 2004 (DMHB 2004) also provided for compulsory care in the community and, although it extended the safeguards at admission stage, the Bill did not include a role for capacity at this stage. Once again, the Bill received trenchant criticism from legal and psychiatric sources. More damagingly, the Bill was criticised in the *Report of the Joint Committee on the Draft Mental Health Bill* 6 for its approach to patients' human rights. Once again, the

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Report of the Expert Committee Review of the Mental Health Act 1983 (Department of Health, HMSO, 1999). The Committee was chaired by Professor Genevra Richardson.

⁹⁸ *Ibid*, para 2.11.

⁹⁹ *Ibid*, para 5.95.

¹⁰⁰ *Ibid*, para 7.7.

¹⁰¹ *Ibid*, para 12.13.

See section 118 of the Draft Mental Health Bill 2002.

See Press Statement on Reform of the Mental Health Act 1983: Joint Statement by the Royal College of Psychiatrists and the Law Society (June 2002) (available at http://www.rcpsych.ac.uk/pressparliament/pressreleasearchive/pr336.aspx (last visited July 12 2006).

HL Paper 79-1; HC 95-1 (London: Stationary Office, 2005).

proposed legislation was dropped from the legislative agenda and instead it is currently proposed to introduce a new and shorter Bill to amend the MHA 1983.

The new Bill has not yet been published. However, the Government has indicated six key policy objectives for the new Bill in a series of briefing sheets. 105 These are the introduction of "supervised community treatment", expanding the skills base of professionals, allowing patients to appoint a nearest relative to represent them, introducing a new definition of mental disorder, removing the treatability requirement for admission, 106 and, improving the procedural protections afforded by the Mental Health Review Tribunals. From the point of view of this chapter, the most important of these policy objectives is the introduction of "supervised community treatment," which is discussed further below. Crucially, a number of other treatment-related reform proposals, which had been included in the DMBH 2004, are not in evidence in the new policy objectives. Although the DMHB 2004 had made one move in the direction of protecting patient autonomy by allowing capable patients to refuse ECT, 107 there is no mention of this as a current policy objective. There is also no mention of the introduction of legislation allowing patients to make advance treatment decisions, although the Government had indicated its willingness to introduce such provisions. 108 The development of proper treatment plans and the role of patient participation is also not an identified policy objective at this point.

The introduction of, what is now described as, "supervised community treatment" has been proposed since the beginning of the current reform process.¹⁰⁹

See The Mental Health Bill: Plans to Amend the Mental Health Act 1983- Briefing Sheets on Key Policy Areas where Changes are Proposed (Department of Health, May 2006) (Gateway Ref 6420) (available on the Department of Health website at www.dh.gov.uk (last viewed July 26 2006).

The "treatability" requirement contained in section 3 of the MHA 1983 applies to the admission of a patient with a psychopathic disorder or mental impairment and requires that treatment must be "likely to alleviate or prevent the deterioration of his condition". The Government has been eager to remove this requirement since the Report of the Committee of Inquiry into the Personality Disorder Unit, Ashworth Special Hospital (Cm 4194-ii) (London: Department of Health, 1999) recommended that psychopaths should be detained if they pose a risk to the public regardless of the treatability of their conditions. Section 9 of the DMHB 2004 removed the treatability requirement, requiring instead that any treatment administered be "appropriate in the patient's case."

Section 178. The DMHB 2004 also allowed for treatments to be designated as "Type B" treatments, the administration of which could be limited by regulation.

In response to a recommendation by the Joint Committee (supra note 104), the Government Response to the Report of the Joint Committee on the Draft Mental Health Bill 2004 Cm 6624 (London: Stationary Office, 2005), p 17 had accepted in principle the recommendation that advance decisions should be introduced in relation to treatment for a mental disorder.

See the White Paper Reforming the Mental Health Act: The New Legal Framework (Cm 5015-I, 2000).

Under this model, a patient may be given long-term treatment without being detained in a psychiatric facility. In addition to requiring the patient to accept designated treatment, the model may also impose other restrictions on the patient, including a requirement that the patient attend at a hospital or other specified place for monitoring and a restriction on other kinds of behaviour. Failure to comply with treatment or other requirements may result in the patient being involuntarily detained.

This kind of model is in operation in most jurisdictions in the United States (where it is generally referred to as Assisted Outpatient Treatment or AOT). 110

Section 9.60 of the New York Mental Hygiene Law is typical of legislative provisions in this regard. 111 Under the section, a patient aged more than 18 years with a mental illness may be ordered to obtain AOT if a court finds that the patient is unlikely to survive safely in the community without supervision and that the patient has a history of non-compliance with the treatment previously prescribed for her mental illness and is unlikely voluntarily to participate in the treatment programme. In addition, the patient must need an assisted treatment programme in order to prevent a relapse or deterioration that would be likely to result in serious harm to herself or others, it must be likely that the patient will benefit from assisted treatment and the treatment must be the least restrictive alternative for the patient. Crucially, the patient's capacity is not relevant to the decision. 112

The issue of capacity is especially important in relation to a "supervised community treatment" model. Because most patients who are well enough to live in the community if they take their medication are likely to be capable, a care in the community model based around capacity will have a much less extensive ambit than one which does not take account of capacity in deciding whether to subject the patient to compulsion. This is especially significant given the relative costs of detention and compulsory care programmes. From an economic perspective, the care in the

AOT legislation has been introduced in over 40 states. For a sample of the legislation, see section 9.60 of the New York Mental Hygiene Law (introduced in 1999) and the amendment to the Californian Welf & Inst Code (AB 1421) (introduced in 2002). Other recently enacted AOT legislation is the Florida Mental Health Act (the Baker Act) effective from January 1 2005; and the amendment to the Michigan Mental Health Code, effective from March 30 2005.

Much of the impetus for AOT legislation seems to come from the Treatment Advocacy Center which describes itself as a "nonprofit organization working to eliminate barriers to timely treatment of severe mental illnesses" (see www.psychlaws.org, last viewed July 26 2006) and which provides a "Model law" for AOT.

See Gutterman "Waging a War on Drugs: Administering a Lethal Dose to Kendra's Law" (2000) 68 Fordham L Rev 2401.

community scheme has the potential to apply to many more patients and therefore the legal limits on the application of the scheme assume particular significance.

Recognising this, the Richardson Report recommended that a higher level of risk must be established before a patient with capacity could be the subject of a treatment order against her will. The DMHB 2004 did not accord any role to capacity in determining whether a patient should be subject to compulsion. The Joint Committee on the Mental Health Bill took the opposite view and recommended that the patient must have "significantly impaired decision-making" before she could be subjected to compulsion. Significantly, however, the Government did not agree to this recommendation and it is not mentioned as part of Government policy in the briefing paper relating to supervised community treatment. However, the Government does include, as a limiting factor, the requirement that any individual being required to obtain supervised community treatment must be assessed and treated in a hospital first.

Part II: Mental Health Law and the Autonomy Paradigm

The MHA 1983 discussed in Part I of the chapter clearly excludes treatment for a mental disorder from the application of the autonomy paradigm. In doing this, the MHA 1983 challenges the liberal underpinnings of healthcare ethics and law. However, because it operates outside the autonomy paradigm, the MHA 1983 also avoids the limitations of the paradigm. As is evident in Part I, although the protections afforded to the patient's right to refuse on the face of the Act are limited, judicial interpretation of the MHA 1983 in the light of the ECHR has led to a reasonably protective regime. This is most apparent in the context of incapable patients. Crucially, the MHA 1983 contains mechanisms to allow unwilling patients to resist treatment at least to the point of requiring convincing evidence that the relevant statutory standard is satisfied. The importance of this kind of approach will

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Supra note 97, para 5.95. As noted above, the Report did not reach a conclusion as to whether a capable patient should have a right to refuse treatment.

Recommendation 26. For discussion of the Joint Committee's deliberations on this point, see *supra* note 104, paras 151-156.

However, the Government did agree (supra note 104, p 18) with the Joint Committee's recommendation (Recommendations 30 and 31) that "non-resident orders" (the term used in the DMHB 2004) should be restricted to a clearly defined and clinically identifiable group of patients who frequently relapse.

be apparent in this Part of the chapter, which will explore the limitations and possibilities of the autonomy paradigm in mental health law.

The question asked in this Part is whether the autonomy paradigm should provide the primary conceptual basis for the law relating to treatment for a mental disorder in the same way as it does for treatment for a physical disorder. This question is explored in the light of the view, sometimes associated with therapeutic jurisprudence, 116 that consensual care is the ideal. 117 As Winick argues, 118 patients are likely to respond better to treatment if they are internally motivated 119 to comply with the treatment. Further, relying on internal motivation will enhance patients' feelings of competence and self-esteem which will ultimately have therapeutic benefits. In addition, from a practical point of view, patients are generally in the best position to monitor the side-effects of treatment and therefore to ensure that the most effective treatment is provided.

This Part will begin by setting out why the MHA 1983 challenges the liberal underpinnings of healthcare law. It then looks at the more theoretically consistent model adopted under United States' law. In light of this and the lessons to be drawn from the Irish Mental Health Act 2001, this Part will then set out the limitations of the paradigm in the mental health context and explain why a broader framework based on respect for a range of human rights is needed. The final section of this Part will show why, provided that the limitations of the autonomy paradigm are recognised, the right to refuse of the capable patient should play a role within this broader framework.

Mental Health Law and Liberal Theory

On its face, any legal provision which limits the right of a capable patient to refuse treatment is directly in conflict with the liberal underpinnings of healthcare law. In

See further Chapter 2 at text to note 152. For a detailed discussion of the application of the principles of therapeutic jurisprudence to mental health law, see Winick Civil Commitment: A Therapeutic Jurisprudence Model (Durham NC: Carolina Academic Press, 2005); see also Perlin "A Law of Healing" (2000) 68 U Cinn L Rev 407.

This is acknowledged by psychiatrists as well as advocates of patients' rights. See for example Roth "The Right to Refuse Psychiatric Treatment: Law and Medicine at the Interface" (1986) 35 Emory Law Journal 139, 150.

[&]quot;The Right to Refuse Mental Health Treatment: A Therapeutic Jurisprudence Analysis" (1994) 17 International Journal of Law and Psychiatry 99, 104-105.

In this regard, Winick *ibid*, relies on the work of Edward Deci on motivation theory (*Intrinsic Motivation* (New York; Plenum Press, 1975)) which differentiates between intrinsic (or internal) and extrinsic (external) motivations.

addition, given that the limitation applies to patients with a mental disorder only, it would appear to discriminate against this category of patients by affording their right of autonomy less protection than is afforded to other patients. Campbell and Heginbotham argue that differential treatment of patients with a mental disorder is inherently discriminatory. It "enables society to utilize the terminology of mental illness as a way of legitimatizing the exercise of social control over conduct which we find difficult or disagreeable but are reluctant to regard as criminal." They argue that the same standards should be applied to people with mental disorders as are applied to those who are not mentally ill. In relation to treatment, this means that a patient's consent should be required for treatment unless the patient lacks capacity, regardless of whether the patient has a mental disorder. In the patient lacks capacity,

Two arguments may be made that, contrary to initial impressions, the differential treatment of patients with a mental disorder is not, in fact, in conflict with healthcare law's liberal underpinnings. First, as discussed in Chapter 1, Millian liberalism does not require absolute protection of the right of autonomy but recognises that the right may be limited in order to protect the rights of others. Secondly, it may be argued that the right of autonomy means something different in a mental health context. If either of these arguments were persuasive, it could justify the differential treatment. However, as will be seen below, neither argument is convincing.

While recognising the potential impact of the rights of others on the individual's right of autonomy, Mill and his modern successors set out clear limits on the circumstances in which the protection of others justifies interference with the right. Dworkin notes that the criminal law would be more efficient if it were possible to imprison people or to force them to accept treatment whenever this seemed likely to reduce future crime. However, he argues that such a move would

Mental Illness: Prejudice, Discrimination and the Law (Aldershot: Dartmouth, 1991), pp 24 - 26. See also Perlin "Half-Wracked Prejudice Leaped Forth': Sanism, Pretextuality, and Why and How Mental Disability Law Developed as it Did" (1999) 10 Journal of Contemporary Legal Issues 3 who argues that mental health law is inherently "sanist" (i.e. discriminatory on the basis of an individual's mental disorder). For the implications of "sanism" in practice, see Perlin "Where the Winds Hit Heavy on the Borderline': Mental Disability Law, Theory and Practice, 'Us' and 'Them'" (1998) 31 Loyola of Los Angeles Law Review 775.

Mental Illness: Prejudice, Discrimination and the Law, p 24.

Ibid, p 100. Although these commentators prefer the term, "lacking insight" to the term lacking capacity.

In On Liberty (London, 1859), p 90, Mill argued that a person can be stopped from doing something only if, in doing that thing, he would "violate a distinct and assignable obligation" to others

Taking Rights Seriously (London: Duckworth, 1977), p 11.

"cross the line that separates treating someone else as a fellow human being from treating him as a resource for the benefit of others." In this situation, he argues "[t]he insult is as great whether the process is called one of punishment or treatment." 126

In order to be consistent with healthcare law's liberal underpinnings, the imposition of treatment on a capable patient may be justified only where the threat posed to others reaches a certain level. Dworkin suggests that the danger presented to others must be "vivid", lathough he does not expand on what constitutes a "vivid" danger. Bottoms and Brownsword suggest that a "vivid" danger has three components. These are:

[S]eriousness (what type and degree of injury is in contemplation?; temporality, which breaks down into frequency (over a given period, how many injurious acts are expected?) and immediacy (how soon is the next injurious act?); and certainty (how sure are we that this person will act as predicted?)¹²⁹

Bottoms and Brownsword do not offer conclusions regarding what combination of these factors would amount to a justification for breaching an individual's rights. However, they argue that the certainty element is crucial; it is only if a risk is certain that the seriousness of the risk becomes relevant.

Even if one does not agree with Bottoms and Brownsword's fairly stringent requirement regarding certainty, the factors they identify are reasonable. The level of risk posed and the seriousness of the likely harm are of obvious relevance in determining the extent of a threat to others. Applying these factors to the question of treatment for a mental disorder, it must be asked, first, whether, as a category, involuntary patients pose a significant threat to others to justify a separate legal framework to govern their treatment and, secondly, whether specifically identifiable involuntary patients pose a sufficient threat to others to justify differential legal treatment in these individuals' cases. In considering the level of threat posed, a

126 Ibid.

Dworkin does make clear (*ibid*), that it would not be sufficient to calculate that it would "probably reduce crime" if a person were treated.

¹²⁵ Ibid.

¹²⁷ Ibid.

[&]quot;Dangerousness and Rights" in Hinton ed Dangerousness: Problems of Assessment and Prediction (London: Allen and Unwin, 1983), p 9.

See the critique of Bottoms and Brownsword's argument in Walker "Ethical and Other Problems" in Walker ed *Dangerous People* (London: Blackstone Press, 1996), p 10.

distinction must be made between a threat posed by allowing the patient to remain in the community (i.e. the threat addressed by detention) and the threat posed by the patient if left untreated once detained (i.e. the threat addressed by treatment).¹³¹ The threat to others, and therefore the argument that rights may be limited, is likely to be stronger at the detention stage than it is where a patient is already detained in a psychiatric facility. However, a patient could still pose a threat to fellow patients and staff once detained. 132

The level of threat posed to others by people with mental disorders, as a category, does not appear to be especially high. Epidemiological data from the UK suggest that there is a greater propensity to violence among people with mental disorders. However, in comparison with other factors such as age, gender, socioeconomic status, drug or alcohol usage and family breakdowns, the increased risk arising from mental disorder appears to be relatively low.¹³³ Even if the threat posed by involuntary patients is somewhat higher than that posed by other patients with a mental disorder, it is still difficult to argue, as a general proposition, that the level of risk or the seriousness of the harm posed by this category of patients provides sufficient justification for the law's differential approach to treatment for a mental disorder.

In the context of a particular individual with a mental disorder, there seems to be a better chance of identifying a threat to others. Sophisticated risk predication mechanisms are being developed¹³⁴ and these allow for more accurate assessment of risk. However, there is still no foolproof means of predicting the level of future

¹³¹ The legalisation of compulsory care in the community would make the distinction between detention and treatment less important because, under this model, the patient would remain resident in the community and therefore could be argued to constitute an ongoing threat to the community if she does not take prescribed medication.

See Crichton "Psychiatric Inpatient Violence" in Walker ed Dangerous People supra note

See Walsh and Fahy "Violence in Society" (2002) 325 BMJ 507. Using available epidemiological data, these authors conclude that less than 10% of serious violence, including homicide, is attributable to psychosis. See also the survey of studies in Bowden "Violence and Mental Disorder" in Dangerous People supra note 130, pp 19-22; Taylor and Gunn "Homicides by People with Mental Illness: Myth and Reality" (1999) 174 British Journal of Psychiatry 9. However, it should be noted that the risk of violence appears to increase considerably when people with a mental disorder are also drug users and it appears that violence in this context is both qualitatively and quantitatively different. See especially the study by Swanson et al "Violence and Psychiatric Disorder in the Community: Evidence from the Epidemiologic Catchment Area Surveys" (1990) 41 Hospital and Community Psychiatry 761.

threats.¹³⁵ According to Bartlett and Sandland, studies on predictive accuracy levels indicate that "between a half and three-quarters of those identified as dangerous by psychiatric professionals do not, in the end, turn out to be violent." ¹³⁶ Nonetheless, if one takes a fairly lax interpretation of the certainty requirement, the threat to others may justify overriding the patient's right of autonomy in some circumstances. This view is reflected in the Richardson Report which accepted that treatment could be imposed on a capable patient on the grounds of public safety ¹³⁷ and is also evident in the reasoning of the House of Lords in *R (Mumjaz)* v *Mersey Care NHS Trust.* ¹³⁸ However, given that the majority of involuntary patients are not likely to pose this kind of threat, this argument justifies the imposition of treatment in limited circumstances based on an individual risk assessment and cannot justify a wholesale exclusion of treatment for a mental disorder from the autonomy paradigm.

Given that there are difficulties in establishing the necessary level of threat to other people, it is necessary to consider an alternative argument based on the rights of others which was identified in the Richardson Report. This argument is that a failure to treat a patient with a mental disorder has a greater negative impact on her carers and relatives than a failure to treat a patient with a physical disorder. Given that the common law allows a capable patient to refuse life-saving treatment regardless of personal circumstances or responsibilities, this argument does not hold up. However, it is probable that, underlying the view identified by the Richardson Report is the belief that people who suffer from mental disorders are more likely to refuse treatment in "unreasonable" circumstances. Thus, while allowing patients to refuse

See for example the MacArthur Study of Mental Disorder and Violence: see Monahan et al Rethinking Risk: the MacArthur Study of Mental Disorder and Violence (New York: OUP, 2001).

See the discussion in the Joint Committee Report *supra* note 104, para 125 which shows different views among psychiatrists regarding risk prediction in individual contexts. Evidence from the Royal College of Psychiatrists indicated that risk assessment techniques were "highly inaccurate and unreliable" while other evidence suggested that risk assessment techniques were improving fast.

Supra note 9, p 179. As part of developing the MacArthur Risk Assessment test (supra note 134), the researchers compared their predictions with the actual levels of violence of the patients tested. Even under this sophisticated test, 37% of patients placed by the test in the two most violent categories (out of five categories in total) were not actually violent within one year of the prediction.

Supra note 97, para 2.7.

^{[2005] 3} WLR 793. In this case, the House of Lords held that the interference with the claimant's Article 8 rights arising from his being held in seclusion could be justified on the basis of the protection of the rights and freedoms of others (as set out in Article 8 (2) of the ECHR).

Supra note 97, para 2.9.

treatment for a physical disorder may occasionally lead to more serious consequences for relatives, in reality most patients will not exercise their right to refuse and these consequences will never actually materialise. In contrast, more patients with mental disorders will refuse treatment and therefore a larger number of relatives will be affected. It is difficult to ascertain whether this argument is based on fact or prejudice. However, assuming the argument to be true, it is still difficult to see how it can be consistent with liberal theory. The possibility of low-level interference with a lot of people cannot justify interference if the necessary level of threat cannot be reached in respect of any one of them. Therefore, within liberal theory, the interests of others in this broader sense does not justify limiting the right of autonomy.

A second effort to justify the different approach to treatment for a mental disorder is made by Appelbaum, a psychiatrist, who argues that the autonomy of a person with a mental disorder is already limited by her mental disorder. He argues that the role of medical intervention is to restore the patient's autonomy and therefore a limitation on the patient's right to refuse treatment may be justified in light of this greater goal. From a practical point of view, if the untreated patient is detained in a psychiatric facility, her freedom is already significantly limited. If treatment can lead to her being released from the facility, its imposition could be argued to be ultimately less invasive of the patient's rights. There are two difficulties with this assertion. First, the argument that treatment will lead to the patient's release is inevitably speculative where the patient has not in fact had the treatment in question. Secondly, some patients may prefer the limitations of detention to the forced imposition of treatment. While this may seem an unreasonable response to most people, the whole premise of autonomy is that capable people should be permitted to make unreasonable decisions.

A further difficulty with Appelbaum's argument is that it presumes that patients with a mental disorder are neatly distinguishable from other patients. This contention is persuasively rejected by Matthews, ¹⁴³ who attributes the law's separation

Almost a Revolution: Mental Health Law and the Limits of Change (New York: Oxford University Press, 1994), p 149.

The applicant in Wilkinson ibid is a case in point.

This was the reasoning of the RMO in R (Wilkinson) v Broadmoor Special Hospital Authority [2002] 1 WLR 419, 425.

[&]quot;Mental and Physical Illness – An Unsustainable Separation" in Eastman and Peay eds Law Without Enforcement: Integrating Mental Health and Justice (Oxford: Hart Publishing, 1999). See also Matthews "Autonomy and the Psychiatric Patient" (2000) 17 Journal of Applied Philosophy 59.

of physical and mental illness in part to the "baleful influence of Cartesian mind-body dualism"144 and in part to the lingering influence of the "ancient concept of madness". 145 Matthews does not reject the existence of mental illness but he challenges the view that mental disorder is a discrete category that can be neatly differentiated from physical disorder, arguing that, once we escape our preconceptions regarding the nature of mental disorder, it is clear that the conditions that we define as "mental disorders" are in fact "a collection of different sorts of human distress with only loose and varying relations between them". 146 Regardless of the nature of the disorder, an individual's ability to exercise a choice may be impeded for a range of reasons, including "intense pain, anxiety, temporary lapses in consciousness, or other forms of vulnerability". 147 Matthews' assertion that impediments to decision-making are not exclusive to the context of treatment for a mental disorder is well made and confirmed by any review of the case law on treatment refusal for physical disorders. This shows clearly that the real issue is not the nature of the condition for which the patient is being treated but the factors that impede a patient in making the treatment decision at issue.

In light of the above discussion, it is difficult to argue that treatment for a mental disorder constitutes a legitimate and justifiable exception to the autonomy paradigm. The point is acknowledged by the Richardson Report which recommended "wherever possible the principles governing mental health care should be the same as those which govern physical health." However, when one moves from the theoretical to the practical, the case for extending the autonomy paradigm to mental health law becomes more complicated. The next section will review United States law, where the autonomy paradigm has been dominant for several decades, in order to establish some of the possibilities and limitations of a system which is focussed on a respect for the patient's right of autonomy.

[&]quot;Mental and Physical Illness" *ibid*, p 50. Under the Cartesian model, the body and mind are seen as separate substances with the mind operating in rational ways and the body in mechanical ways. Therefore, a breakdown in the body is essentially a mechanical breakdown while a breakdown in the mind is (*ibid*) a "disorder in our very selves".

Ibid, p 47. Thus, he argues "[m]ad people are thought of as different from the rest of us, out of touch with reality as most of us conceive it".

¹⁴⁶ *Ibid*, p 55.

Ibid, p 57.

Supra note 97, para 2.15.

The Autonomy Principle in Action: Treatment Refusal Under US Law

A Right to Refuse Under US Law

The autonomy paradigm has been dominant in US law since the 1979 decision in *Rogers* v *Okin*, ¹⁴⁹ where Tauro J found that it was:

[A]n unreasonable invasion of privacy, and an affront to basic concepts of human dignity, to permit forced injection of a mind-altering drug into the buttocks of a competent patient unwilling to give informed consent.¹⁵⁰

Courts across the United States¹⁵¹ have recognised that the right of individual autonomy extends "equally to mentally ill persons who are not to be treated as persons of lesser status or dignity because of their illness." However, this approach has neither been confirmed nor rejected at Supreme Court level. 153

In addition to these judicial initiatives, many states introduced legislation enshrining the right of capable patients to refuse treatment for a mental disorder. At a practical level, there has been some variation among States at both judicial and legislative levels regarding the way in which the right to refuse treatment is to be given effect.¹⁵⁴ In some states, patients are entitled to a judicial determination of

^{(1979) 478} F Supp 1342. The case involved a class action taken by residents in the Boston State Hospital against the forcible administration of antipsychotic medication. For factual background to the case (including a description of the appalling living conditions for patients at the hospital at this time), see Appelbaum *Almost a Revolution supra* note 140, pp 114-116.

Ibid, 1371. The decision was appealed by the State, ultimately to the United States Supreme Court (sub nom Mills v Rogers (1982) 457 US 291). However, the Supreme Court declined to address the substantive issue and remitted this for consideration to the Massachusetts Supreme Judicial Court which upheld the District Court's decision sub nom Rogers v Commissioner, Department of Mental Health (1983) 458 NE 2d 308.

See Rennie v Klein (1978) 462 F Supp 1131, aff'd in part (1981) 653 F 2d 836, vacated and remanded (1982) 458 US 1119, on remand (1982) 700 F 2d 266; Bee v Greaves (1984) 744 F 2d 1387; Nelson v Heyne (1974) 491 F 2d 352; Scott v Plante (1976) 532 F 2d 939; Riese v St Mary's Hospital and Medical Centre (1987) 243 Cal Rptr 241, review granted (245 Cal Rptr 627), review dismissed and Court of Appeal decisions republished by order of the Supreme Court of California (1989) 259 Cal Rptr 669.

^{152 (1986) 67} NY 2d 485, 493.

The Supreme Court has recognised a limited right of prisoners to refuse treatment for a mental disorder (see *Washington* v *Harper* (1990) 494 US 210; *Riggins* v *Nevada* (1992) 504 US 127; *Sell* v *United States* (2003) 539 US 166). See commentary in Schultz "Sell-ing Your Soul to the Courts: Forced Medication to Achieve Trial Competency in the Wake of Sell v United States" (2005) 38 *Akron L Rev* 503.

See Winick *The Right to Refuse Mental Health Treatment* (Washington DC: American Psychological Association, 1997), Chapter 19.

capacity;¹⁵⁵ in others, the determination of capacity is an administrative or tribunal decision¹⁵⁶ or a decision made by the treatment team.¹⁵⁷ Where patients are found to be incapable, most states assign the power to make treatment decisions to a court using a best interests standard.¹⁵⁸

While it is not proposed to provide a comprehensive survey of the effects of the legal position set out above, some flavour may be obtained from Appelbaum's 1994 collation of a range of empirical studies relating to the impact of the right to refuse on the practice of mental healthcare at that time. Appelbaum (himself a psychiatrist, who does not agree with the legal position) describes psychiatrists' initial response to *Rogers* v *Okin* as "vitriolic." Psychiatrists feared that the recognition of the right would lead to wide-scale refusals by patients, that psychiatric hospitals would effectively become detention centres and that resources would have to be relocated into the legal process and away from providing patient care. In Appelbaum's words, "[t]he image of an untreated patient – huddling in the corner of a ward, ignored by everyone else, bearing in solitude the burden of a personal psychosis – pervaded the clinical imagination." In a frequently quoted comment, Appelbaum and Gutheil argued that "[t]he way is paved for patients to 'rot with their rights on". 162

The first notable point from Appelbaum's survey is that the wide-scale refusals initially feared by psychiatrists did not take place. Studies quoted suggest that refusal rates in civil psychiatric hospitals ranged from 0.4% to 15.6% with more than half the studies reporting rates at below 5% and very few recording refusal rates of

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See for example Massachusetts (Rogers v Commissioner, Department of Mental Health (1983) 458 NE 2d 308); New York (Rivers v Katz (1986) 67 NY2d 485).

For example, the Californian Welfare and Institutions Code (AB 1421) states that a patient is entitled to a hearing in front of a "law-trained decision maker" (an attorney appointed from a panel). See Morris "Judging Judgment: Assessing the Competence of Mental Patients to Refuse Treatment" (1995) 32 San Diego Law Review 343, 381 for a critique of the application of the legislation in this regard.

See for example New Jersey (Rennie v Klein (1981) 653 F 2d 836).

Cf Rogers v Commissioner, Department of Mental Health (1983) 458 NE 2d 308 where the State of Massachusetts adopted the substituted judgment standard (i.e a decision regarding treatment to be made on the basis of what the patient would have chosen if she had been capable).

Almost a Revolution supra note 140.

Ibid, p 124. For a full discussion, see ibid, pp 124-128.

¹⁶¹ *Ibid*, p 127.

Appelbaum and Gutheil "Rotting With Their Rights On: Constitutional Theory and Clinical Reality in Drug Refusal by Psychiatric Patients" (1979) 7 Bulletin of the American Academy of Psychiatry and the Law 306.

more than 10%. 163 Rates were higher for patients held at criminal psychiatric facilities, ranging from a low of 11% to a high of 45%. ¹⁶⁴ A second notable point is that, when patients did wish to refuse treatment, the review system, whether judicial or otherwise, did not generally permit them to do so. Appelbaum cites a number of studies which indicated a finding of patient incapacity in well over 90% of treatment refusal cases which went to a formal hearing.¹⁶⁵ He suggests that reviews at administrative level or by the treatment team led to fewer findings of incapacity than was the case with judicial reviews. However, here, too, a high proportion of patients were found to be incapable. 166 Thus, refusing patients were rarely left untreated, if their psychiatrists chose to pursue the matter, because the review mechanism in place generally led to an order for treatment.167

While patients may rarely win a capacity case, as Appelbaum concedes, only the strongest cases for imposed treatment actually reached the hearing stage. 168 Thus, for example, a study by Hoge et al found that the cases of only 18% of patients who refused treatment actually reached formal judicial review (although in each case that

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Supra note 140, p 133.

Ibid, p 134. Where patients were permitted to refuse, the studies cited suggest that rates of violence and the use of restraint increased considerably. However, assaults were still relatively rare. Appelbaum *ibid*, pp 134-135 quotes three studies in this regard. A study from Ohio found 63% of refusing patients required restraint as opposed to 25% of non-refusing patients (Rodenhauser et al "Treatment Refusal in a Forensic Hospital: Ill-use of the Lasting Right" (1984) 12 Bulletin of the American Academy of Psychiatry and the Law 59). A study from Massachusetts found 47% of refusers needed restraint and 19% of non-refusers needed sedation (Hoge et al "A Prospective, Multi-Centre Study of Patients' Refusal of Antipsychotic Medication" (1990) 47 Archives of General Psychiarty 949). A study from Minnesota found that 35% of refusers needed restraint and no non-refusers required restraint (Levin et al " A Controlled Comparison of Involuntarily Hospitalized Medication Refusers and Acceptors" (1991) 19 Bulletin of the American Academy of Psychiatry and the Law 161). Some care should be taken in assessing the import of these studies. It is arguable that the kind of patient who refuses treatment is more likely to be non-conformist and therefore may be the kind of patient who will be regarded as needing restraint regardless of medication. 165

Ibid, pp 143-144. These studies show that in Massachusetts treatment was approved in over 98% of cases (see Hoge et al supra note 164; Report of the Massachusetts Department of Health, draft issued July 7, 1988, final report not issued); in New York, treatment was approved in between 80%-100% of cases (see Cournos et al "A Comparison of Clinical and Judicial Procedures for Reviewing Requests for Involuntary Medication in New York" (1988) 39 Hospital and Community Psychiatry 851). See also the studies cited by Roth "The Right to Refuse Psychiatric Treatment: Law and Medicine at the Interface" (1986) 35 Emory Law Journal 139, 156.

¹⁶⁶ Ibid, p 144. According to the studies cited by Appelbaum, reviews by medical directors resulted in treatment being approved in the range of 70 -80% of cases.

¹⁶⁷ This view is confirmed by other commentators who favour the right to refuse. See Kirk and Bersoff "How Many Procedural Safeguards Does it Take to Get a Psychiatrist to Leave the Lightbulb Unchanged? A Due Process Analysis of the MacArthur Treatment Competence Study" (1996) 2 Psychology Public Policy and Law 45, 57; Morris supra note 156. 168

did reach judicial review, treatment was ordered). This study also found that 23% of the total number of patients who opposed treatment were successful in their refusal and that 54% of patients voluntarily acceded to the treatment which they had initially refused. This makes it clear that an assessment of the effectiveness of the right to refuse treatment should not be measured on the basis of the outcomes of judicial or administrative reviews of capacity alone.

The Move Towards Assisted Outpatient Treatment

While the right of the capable patient to refuse treatment continues to be accepted law in most states, the legislative approach to treatment for a mental disorder has undergone an important change. As noted in Part I, most US states have now introduced legislation allowing for Assisted Outpatient Treatment without reference to the patient's capacity.¹⁷¹ Under AOT legislation, a patient who refuses treatment as an outpatient may be subject to involuntary detention.¹⁷² To date, notwithstanding the clear acceptance of the capable involuntary patient's right to refuse treatment for a mental disorder under US law, AOT legislation has withstood legal challenge. In *In the Matter of KL*,¹⁷³ the New York Court of Appeals upheld section 9.60 of the New York Mental Hygiene Law¹⁷⁴ on the basis that AOT did not allow forced treatment. The Court held that a patient could exercise her right to refuse, albeit at the probable

Supra note 164, 956.

¹⁷⁰ Ibid.

These legislative changes seem to have been brought about by concerted public campaigns, which appear to be spearheaded by the Treatment Advocacy Center (see note 111 supra), focussing in part on the social consequences of mental illness if left untreated and playing in part on public fears about the dangerousness of people with untreated mental illness. For an example of these arguments, see Fuller Torrey The Invisible Plague: The Rise of Mental Illness from 1750 to the Present (New Jersey: Rutgers University Press, 2002); Kress "An Argument for Assisted Outpatient Treatment for Persons with Serious Mental Illness Illustrated with Reference to a Proposed Statute for Iowa" (2000) 85 Iowa Law Review 1269, 1276 – 1286. A number of high profile incidents involving people with mental illnesses have provided fuel for the campaigns and it is perhaps indicative of the kinds of campaign that the amending legislation in each State is often referred to by the name of a person who was killed allegedly as a result of overly lax laws on treatment of mental disorders (in New York, "Kendra's Law"; in California, "Laura's Law"; and in Michigan, "Kevin's Law").

Involuntary detention does not happen automatically if the patient fails to comply. For example, under section 9.60 of the Mental Hygiene Law, if the patient fails to comply with the treatment order and if the physician charged with her care believes involuntary detention to be necessary, the patient may be removed to a hospital for examination and held there for up to 72 hours while it is determined if the requirements for involuntary detention are met.

^{173 (2004) 1} NY 3d 362.

Described in text following note 111 supra. See the similar conclusion reached In The Matter of Leonel Urcuyo (2000) 714 NYS 2d 862.

cost of involuntary detention. Furthermore, the Court held that even if the right to refuse were interfered with, the patients' rights were outweighed by "the state's compelling interests in both its police and *parens patraie* powers". The state's interests in this regard were greater than in a case where the patient was already detained because a patient who was not in detention posed a greater risk to the community.

Because AOT is a relatively recent legislative phenomenon, there is little empirical evidence available regarding how AOT operates. A recent report of the New York State Office of Mental Health¹⁷⁶ concluded that the scheme led to reduced incidences of hospitalisation, homelessness, arrest and incarceration for individuals subject to AOT orders as well as a reduction in levels of harmful behaviour.¹⁷⁷ It is not clear from the report, however, how many, if any, patients chose to exercise their right to refuse AOT and what the consequences of this were for them.¹⁷⁸ The tenor of the report is to explain why AOT is desirable rather than to provide information on, what might be termed, civil liberties issues. Nonetheless, the enthusiasm evident in the report, together with the judicial endorsement of AOT, suggests that this kind of compulsion is likely to remain a feature of US law for the foreseeable future.¹⁷⁹

This survey of the US experience allows some of the limitations of the autonomy paradigm when applied to treatment for a mental disorder to be identified. Given that the majority of patients who seek to refuse treatment are found to be incapable if the matter goes to a formal hearing, the law's endorsement of a right to refuse has limited practical impact if the psychiatrist chooses to pursue the matter. Indeed, Perlin describes the right to refuse under US law as a "right without a remedy", creating "the illusion of a right without any legitimate expectation that the right will be honored." Further, the shift to AOT, which has been upheld as

¹⁷⁵ Supra note 173, 361.

177 *Ibid*, pp 17-18.

Kendra's Law: Final Report on the Status of Assisted Outpatient Treatment (New York State Office of Mental Health, 2005).

The report does include the views of recipients of AOT (*ibid*, pp 20-21) which generally favour the treatment programmes and acknowledge that they have been assisted.

In addition to legal compulsion through AOT orders, other incentives, such as the avoidance of prison or the receipt of social welfare and housing benefits, are increasingly being used to persuade patients to comply with treatment regimes. See Monaghan *et al* "Mandated Community Treatment: Beyond Outpatient Commitment" (2001) 52 *Psychiatric Services* 1198.

[&]quot;Is it More than 'Dodging Lions and Wastin' Time'? Adequacy of Counsel, Questions of Competence, and the Judicial Process in Individual Right to Refuse Treatment Cases (1996) 2 Psychology, Public Policy and Law 114, 119.

consistent with the right to refuse, shows the limited value of a right to refuse treatment where the price of the refusal is involuntary detention. Although the foregoing examination of the US experience is instructive, the way in which the autonomy paradigm is applied in the United States is just one version of what the paradigm might look like in practice. Therefore, it is necessary to identify the inherent limitations of the paradigm which are likely to transcend the specific application in the context of any single jurisdiction.

Limitations of the Autonomy Paradigm

Two important limitations of the autonomy paradigm in the case of treatment for a mental disorder will be identified in this section. The first is that the capacity requirement cannot be relied upon to provide the kind of definitive binary division of patients which the autonomy paradigm requires. The second limitation identified is that the autonomy paradigm fails to provide a framework to deal with the needs of incapable patients. Building on the arguments made in the previous chapter, it is argued that over-reliance on the autonomy paradigm would have negative therapeutic and other consequences for incapable involuntary patients.

The Reliability of the Capacity Requirement

One of the core arguments of this thesis is that capacity cannot be relied upon to provide the neat and accurate binary division of patients that the autonomy paradigm requires. This concern is expressed in various policy documents specific to mental health. In outlining the reasons against extending the autonomy paradigm to treatment for a mental disorder, the Richardson Report identified a mistrust of the capacity assessment process. The Report expressed the concern that "a failure to allow intervention to protect the patient from serious harm despite his or her capable refusal will lead in practice to a very broad interpretation of incapacity." This mistrust of the process is also evident in the MHAC response to the Richardson Report. The MHAC noted the concern that any refusal of "treatment that appears

¹⁸¹ Supra note 97, para 2.9.

See The Mental Health Act Commission's Response to the Green Paper Proposals on the Reform of the Mental Health Act 1983 (MHAC, 2000).

warranted" would be translated into a finding of incapacity on the basis of "lack of insight". It would seem that the MHAC did not trust the psychiatric profession to police incapacity. Indeed, in the context of ECT, the MHAC expressed a fear that clinicians would simply categorise as incapable all patients who refused ECT that their clinicians considered necessary. 184

The evidence of the Royal College of Psychiatrists, as presented in the Millan Report in Scotland, showed a similar mistrust of the capacity assessment process. 185 The Royal College suggested that a capacity test might be difficult to apply to certain categories of patient, specifically patients with mood disorders, obsessive compulsive disorders and eating disorders. They expressed the view that such patients might retain legal capacity but be at sufficient risk to justify intervention. ¹⁸⁶ Individual psychiatrists also indicated that they would have difficulty applying a capacity test, 187 especially in the context of patients with mental disorders. These patients were seen to raise particular difficulties; they may have ambiguous feelings about treatment, ostensibly resisting treatment but hoping that somebody will intervene, and their capacity may fluctuate above and below the capacity threshold on a daily or even more frequent basis. 188 Given that, for the main part, these concerns emanated from the professionals who would have the function of administering capacity assessments, they have something of a self-fulfilling quality. However, they are supported by the US experience outlined above. The next chapters of this thesis will show that these arguments are not fanciful and that there are particular difficulties in assessing the capacity of patients with certain kinds of mental disorders.

This limitation of the autonomy paradigm could result in a framework for treatment which is theoretically consistent with liberal theory but largely meaningless in terms of rights. This kind of framework is usefully exhibited in the Irish Mental Health Act 2001 (although because the Act has not yet commenced, 189 it is not

183 *Ibid*, Appendix A, p 34. In this regard, the MHAC was directing its criticism at the "true choice" test for capacity advocated by the Richardson Report (*supra* note 97, para 7.5).

¹⁸⁴ *Ibid*, p 25, para 103.

Review of the Mental Health (Scotland) Act 1984: New Directions (Edinburgh: Scottish Executive, 2001). The Committee was chaired by the Right Honourable Bruce Millan.

¹⁸⁶ *Ibid*, p 55.

¹⁸⁷ *Ibid*.

¹⁸⁸ *Ibid*, p 55-56.

The only commencement order issued under the MHA 2001 to date is the Mental Health Act 2001 (Sections 1 to 5, 7, 31 to 55) (Commencement) Order 2002 (SI 90 2002). The remainder of the Act is expected to commence on November 1 2006.

possible to assess its practical application). Section 57 of the Act gives a capable, involuntary patient the right to refuse treatment even if that treatment is considered necessary to safeguard the patient's life or restore her health. However, section 56 of the Act accords the consultant psychiatrist responsible for the patient's care the role of deciding if the patient is capable and provides no means of review of the psychiatrist's decision in this regard. The dual role envisaged for consultant psychiatrists requires them to prescribe a form of treatment, which, presumably in their professional judgement is appropriate, and then, if the patient objects to the treatment, to step outside their therapeutic role and assume the function of objective assessment of that patient's legal capacity. As a blatant invitation to determine capacity on the basis of the decision made by the patient, the Act can have few equals.

Recognition of the limitations of the capacity assessment process has led some policy documents in the area of mental health to prefer the alternative standard of "impaired judgment". The Millan Report¹⁹³ proposed such a standard, which it saw as "less legalistic" and easier to apply in practice. This suggestion was given effect in the Mental Health (Care and Treatment) (Scotland) Act 2003 which requires that, before a compulsory order may be made, the patient's ability to make decisions must be "significantly impaired".¹⁹⁴ The Report of the Joint Committee on the Draft Mental Health Bill also endorsed the "significantly impaired" standard.¹⁹⁵ However, these proposals seem to have little merit. As discussed more thoroughly in the Conclusion to this thesis, ¹⁹⁶ terms such as "significantly impaired" or "impaired" judgment lack the legal pedigree of the term capacity and therefore, their use as a standard places the protection of the patient's right of autonomy even more in the hands of individual psychiatrists.

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For a detailed discussion of the provisions of the MHA 2001, see Keys Annotation of Mental Health Act 2001 [2002] Irish Current Law Statutes Annotated 25-01. For a more general commentary on Irish mental health law, see O'Neill Irish Mental Health Law (Dublin: First Law, 2005).

Although, in fact, the right to refuse is significantly limited by exceptions contained in sections 59 and 60 (discussed further in note 199 *infra*).

This does not appear to have caused any unease during the parliamentary debates on the Mental Health Bill. Deputy Hanafin, Minister of State for Health and Children (Vol 536 Dáil Debates Col 1470) noted, with apparent equanimity, that it would be at the discretion of the consultant psychiatrist to decide on the patient's capacity or otherwise.

Report of the Review of the Mental Health (Scotland) Act 1984: New Directions (Edinburgh: Scottish Executive, 2001), p 57.

¹⁹⁴ Section 64 (5)(d).

See text to note 114 supra.

A point emerging from the preceding discussion is that many involuntary patients who seek to refuse treatment are likely to be found incapable, especially if the matter of capacity reaches the stage of formal review. Therefore, the way in which the law deals with incapable involuntary patients is often of more practical significance that whether a capable, involuntary patient may refuse treatment. From a therapeutic perspective, too, the fact that a patient has been found to be incapable does not make the imposition of treatment any less traumatic if the patient does not want the treatment. Indeed, a finding of incapacity necessitated by the autonomy paradigm may accentuate the patient's difficulties, making the involuntary patient feel even more stigmatised. This risk is recognised by the MHAC in its response to Richardson Report and led the MHAC to reject a capacity-based approach to treatment for a mental disorder.¹⁹⁷

The previous chapter showed that the pervasive influence of the autonomy paradigm at common law has led the law to neglect the need to develop a conceptual model for healthcare decision-making for incapable patients. In particular, because it focuses on capacity as the central determinant of the appropriate response to the situation, it fails to provide a framework within which to deal with unwilling or resistant incapable patients and issues of restraint, resistance, dignity, liberty and procedural adequacy are not addressed. The autonomy paradigm also fails to protect incapable, compliant patients. The best interests standard associated with the autonomy paradigm places primary decision-making power in the hands of the medical profession and provides no formal mechanism within which to monitor the appropriateness of prescribed medication.

The possible limitations of the autonomy paradigm from an incapable patient's perspective are usefully exhibited in the Irish Mental Health Act 2001 which ostensibly adopts an autonomy-based approach to treatment. Sections 59 and 60 of this Act are similar to section 58 of the MHA 1983 and allow certain treatments (ECT and medication for more than three months) to be provided where the patient is

See Conclusion at text following note 9.

Supra note 182, Appendix A, p 34. See also Winick "The Side Effects of Incompetency Labelling and the Implications for Mental Health Law" (1995) 1 Psychology, Public Policy and Law 6.

See discussion in text to note 191 *supra*.

"unable or unwilling to give ... consent" provided certain review procedures are employed. The review procedure in question requires a second opinion to be obtained from a consultant psychiatrist to whom the matter is referred by the patient's own consultant psychiatrist. There is nothing to stop a consultant psychiatrist choosing a colleague whom she knows will endorse the treatment decision and no possibility on the face of the Act for an independent review of treatment. In short, in enacting the legislation, the Irish legislature made the classic presumption under the autonomy paradigm that treatment issues relating to incapable patients simply do not need a legal or conceptual framework and it did so in the apparent belief that it was introducing a modern, liberal, rights-based measure. 200

The above discussion shows why the autonomy paradigm on its own cannot provide an adequate framework for treatment for a mental disorder. Having set out the limitations of the autonomy paradigm in relation to treatment for a mental disorder, the final section of this Part will now attempt to set out an appropriate model for treatment which takes on board the limitations identified above but also recognises the importance of the autonomy principle.

A Suggested Model: Autonomy Within a Human Rights Framework

In addition to the ECHR, which is discussed in Part I, recommended standards covering the treatment of patients with a mental disorder are set out in a number of international and European human rights instruments.²⁰¹ The *UN Principles for the*

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The inclusion of the word "unwilling" in these sections suggests that the sections apply to capable patients and seems to undercut the right of the capable patient to refuse treatment as set out in section 57. It is odd that patients have less protection for their right to refuse in relation to more serious treatments. Further, the relationship between section 57 (which allows capable patients to refuse treatment) and section 60 (which allows medication for more than three months to be given to unwilling patients provided that the necessary procedural steps are taken) seems contradictory. A review of the legislative history of the Act suggests that this odd relationship may have been the result of an error in drafting rather than any deliberate policy decision on behalf of the legislature. The Mental Health Bill 1999, as originally drafted, contained a clause similar to section 63 of the MHA 1983, permitting treatment to be imposed without consent. Following concerns raised at Committee stage, this provision was removed and replaced by section 57. In the subsequent parliamentary debates, Deputy Hanafin, then Minister of State for the Department of Health and Children, indicated (Vol 536 Dáil Debates Col 1470) that the change was on the basis of legal advice "based on safeguarding the legal rights of involuntary patients." It would seem that, in making the amendment, the parliamentary drafters did not look closely at the relationship between the new section 57 and the pre-existing sections 59 and 60 and, because of this, the current illogical situation arose.

Protection of Persons with Mental Illness and for the Improvement of Mental Health Care²⁰² state that the treatment and care of every patient shall be based on an individually prescribed plan which must be discussed with the patient, reviewed regularly and revised as necessary and that treatment must be provided by qualified professional staff.²⁰³ The Principles emphasize the importance of obtaining informed consent from involuntary patients.²⁰⁴ However, the Principles allow treatment to be given to an involuntary patient without consent if the patient is incapable of giving consent or, provided that domestic legislation so provides, if the patient has unreasonably withheld consent, having regard either to the patient's own safety or that of others.²⁰⁵ In such circumstances, the Principles state that an "independent authority" must approve the decision to provide the treatment on the basis that the proposed treatment is the best interests of the patient.²⁰⁶

The 1997 Annual Report of the European Committee for the Prevention of Torture (CPT²⁰⁷)²⁰⁸ (established under the European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment 1987) states that treatment should be based on an individualised approach, which requires a treatment plan to be drawn up for each patient.²⁰⁹ The Report also advocates regular reviews of a patient's state of health and of any medication being prescribed.²¹⁰ In the Committee's view, "[t]he admission of a person to a psychiatric establishment on an involuntary basis should not be construed as authorising treatment without his

Keys *supra* note 190, 25-03 notes the importance accorded to the ECHR in ministerial statements regarding the Bill.

See generally Gostin "Human Rights of Persons With Mental Disabilities" (2000) 23

International Journal of Law and Psychiatry 125.

General Assembly Resolution 119, adopted December 17 1991, UN Doc A/46/49 (1991). The Principles are not legally binding on member states. See also the Draft *UN Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities* (January 2004) drawn up by the UN Convention Working Group appointed by the UN Convention ad hoc Committee.

²⁰³ Principle 9 (2).

²⁰⁴ Principle 11 (1).

Principle 11 (6) (b).

²⁰⁶ Principle 11 (6).

The CPT has the function of visiting "any place within its jurisdiction where persons are deprived of their liberty by a public authority" (Article 2) "with a view to strengthening, if necessary, the protection of such persons from torture and from inhuman or degrading treatment or punishment" (Article 1).

^{208 8&}lt;sup>th</sup> General Report on the Committee for the Prevention of Torture's Activities Covering the Period 1 January to 31 December 1997 (CPT/Inf (98) 12) (1998)). The Recommendations of the CPT are not legally binding on member states; however, given the absolute prohibition on torture and inhuman or degrading treatment in Article 3 of the ECHR, CPT recommendations do have a significant persuasive effect on member states.

Supra note 207, para 37.

consent."²¹¹ Any derogation from the requirement for consent should be based upon law and only relate to clearly and strictly defined exceptional circumstances.²¹²

Council of Europe Recommendation 2004(10)²¹³ also recommends that treatment should be in accordance with an individually prescribed treatment plan and that, wherever possible, the treatment plan should be prepared in consultation with the person concerned and her opinion should be taken into account. A person should be subject to involuntary treatment only if her condition represents a significant risk of serious harm to her health or to other persons and there are no less intrusive means of providing appropriate care.²¹⁴ If involuntary treatment is provided, it must be proportionate to the person's state of health, it must be documented and in accordance with the patient's treatment plan, and the treatment plan must aim to enable the use of treatment which is acceptable to the patient as soon as possible.²¹⁵ The Recommendation also sets out a range of procedural protections for patients which should be available before a decision to impose involuntary treatment is made.²¹⁶

The most important aspect of the protections set out above is that they apply to patients regardless of capacity and therefore they avoid the limitations of the autonomy paradigm described above. For this reason, together with the ECHR rights discussed in Part I, they provide a more appropriate model for treatment than the autonomy paradigm. The central issue is not that a capable patient has an absolute right to refuse treatment but that treatment should be given in a strictly regulated

²¹⁰ *Ibid*, para 40.

²¹¹ *Ibid*, para 41.

²¹² Ibid.

Recommendation 2004(10) of the Committee of Ministers to Member States Concerning the Protection of the Human Rights and Dignity of Persons with Mental Disorders. See also Recommendation No R(83)2 of the Committee of Ministers to Member States Concerning the Legal Protection of Persons Suffering from Mental Disorders Placed as Involuntary Patients, which was adopted on February 22 1983 and which recommended that involuntary patients should have the right to refuse a limited range of experimental treatments.

Article 18.

²¹⁵ Article 19.

Article 20(2) recommends that the decision to impose treatment must be taken by a court or other competent authority. However, the Article continues by stating that the law may provide that, where a person has been subject to involuntary placement, the decision to subject the person to involuntary treatment may be taken by a doctor having the requisite competence and experience, after examining the person and taking her opinion into account. Article 20(3) requires that a decision to subject a patient to involuntary treatment should be documented and should state a maximum period beyond which it must be formally reviewed. Further, the patient must have a right to information (Article 22); to communication with her lawyers and personal representatives (Article 23); and the right to appeal and review the decision (Article 25).

manner, should be in the least intrusive form possible, and should aim to be consensual where possible.

However, there is a case to be made that these instruments do not go far enough in protecting the capable patient's right to refuse treatment and that there should be a greater role for autonomy within the wider human rights framework. In other words, in addition to providing a protective framework for both unwilling and compliant incapable patients, the law should recognise the capable patient's right to refuse treatment. In assessing the case for including the right of autonomy within the human rights framework, it is important to be aware of the limitations of the autonomy paradigm. In light of the arguments made above, and confirmed by the review of the capacity assessment process in later chapters of this thesis, it is clear that the majority of involuntary patients who refuse treatment are likely to be found incapable. Thus, Robinson is correct when he describes the principle of autonomy as "more a matter of form than substance for a person diagnosed as suffering from a serious mental illness who declines to accept medical treatment."217 This means that the extension of the autonomy paradigm may have little practical impact on the actuality of treatment refusal and, as the Richardson Report noted, any patient who is vulnerable to serious harm if left untreated will probably be found to be incapable.²¹⁸

However, there are other reasons of less immediate practical relevance why it is important to recognise the right of autonomy of patients with a mental disorder. First, as discussed in Chapter 1, while the right of autonomy is very often relied upon in the context of treatment refusal, the contribution of autonomy to healthcare law extends beyond this narrow context. The requirement of information disclosure derives from the law's endorsement of autonomy as well as the requirement that medical professionals take steps to ensure patients' consent to procedures. While it would be overly optimistic to argue that these requirements are always met, it is nonetheless the case that the recognition of the legal right of autonomy has facilitated the demise of unmonitored and unregulated paternalism outside the mental health sphere. Recognition of the right of autonomy could bring similar benefits in the context of treatment for a mental disorder.

[&]quot;Capacity as the Gateway: An Alternative View" [2000] Journal of Mental Health Law 44,

²¹⁸ Supra note 97, para 2.10.

Secondly, even if in reality few patients are actually permitted to refuse treatment, the existence of a baseline right to refuse may change the dynamic between medical professional and patient in a treatment refusal context. While the US experience shows that more difficult cases are likely to be resolved through a finding of incapacity, in less contentious situations the psychiatrist may accede to the patient's view, the patient may agree to the treatment or some kind of compromise may be reached. Clearly, the underlying existence of a right to refuse will contribute to the nature of the compromise reached. This argument is supported by Bartlett's discussion of the right to refuse in Ontario. 219 Bartlett notes that, although there do not appear to be any figures on levels of refusals, anecdotal evidence suggests that there are few outright refusals. He notes that some patients consent to medication which is not considered by their psychiatrists to be optimal but in practice both parties appear to negotiate a solution with which they can live. 220 The importance of the existence of an underlying right to the kind of compromise reached is evident in a study by Kasper et al²²¹ of treatment refusal in Virginia, where treating psychiatrists have the discretion to override patients' refusals. The study found that all patients who refused treatment were treated within an average of 2.8 days of the refusal.²²² Thirdly, a legal recognition of the right of autonomy removes one overt instance of discrimination from the law. Once again, this may have benefits beyond the immediate context of treatment refusal and may lead to a reduction in the stigmatising effect of a mental disorder within society.

The above arguments have a particular resonance in the context of compulsory care in the community. A shift to compulsory care involves a re-assessment of the fundamental premises of mental healthcare. Without appropriate limits at the point of admission, a scheme for compulsory care in the community could lead to widespread compulsion and to an increase in stereotyping of patients with mental disorders.²²³ As critics of the DMHB 2004 argued, it could also lead patients with mental disorders to fear presenting for treatment in case they find themselves brought within the

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[&]quot;The Test of Compulsion in Mental Health Law: Capacity, Therapeutic Benefit and Dangerousness as Possible Criteria" (2003) 11 Medical Law Review 326, 333-334.

²²⁰ *Ibid*, 334.

[&]quot;Prospective Study of Patients' Refusal of Antipsychotic Medication Under a Physician Discretion Review Procedure" (1997) 154 American Journal of Psychiatry 483.

²²² *Ibid*, 488. This may be contrasted with Hoge *et al*'s findings (discussed in text to note 169 *supra*) where a legal right to refuse was in place.

See further Zigmond and Holland *supra* note 10, 53.

compulsory scheme.²²⁴ In such circumstances, societal and patient perceptions of the law can be as important as the reality of the law. It is difficult for the law to operate effectively if patients with mental disorders do not trust the law or believe that the legal system is aimed at trapping them into treatment. The inclusion of protection for patient autonomy within a new legal framework provides a significant opportunity to enhance the degree to which patients with mental disorders can have trust in the law.

Ultimately, an appropriate model for treatment must take account of the limitations of the autonomy paradigm yet also recognise the broader value of the autonomy principle which goes beyond the practical application of the right to refuse treatment in individual cases.

Conclusion

Zigmond and Holland note that "[t]here is a danger that just like molecular genetics or brain scanning becoming the 'holy grail' for neuroscientists, 'capacity' becomes the same of 'enlightened' professionals and campaigning groups."²²⁵ This chapter has argued that the limitations of the autonomy paradigm mean that a system based on capacity does not, of itself, provide an appropriate model for the law relating to treatment for a mental disorder. However, the chapter also concluded that autonomy should play a role within a broader human rights based framework.

Part I of the chapter reviewed the MHA 1983 and the impact of the ECHR on the interpretation of the Act. It demonstrated that, while the MHA 1983 limits the right of the capable patient to refuse treatment, the effect of ECHR jurisprudence on the interpretation of the Act provides capable and incapable unwilling patients a degree of protection before treatment may be imposed. Part II looked at the appropriate role of the autonomy paradigm in the context of treatment for a mental disorder. This Part showed that the capacity requirement will almost inevitably come under strain where a patient has a mental disorder. It also demonstrated that the autonomy paradigm fails incapable patients and that the consequences of this failure are likely to be especially acute for patients with a mental disorder. However, this Part also recognised that the principle of autonomy is important in the context of

See The Mental Health Alliance Policy Agenda *Towards a Better Mental Health Act* (July 2005) (available at www.mentalhealthalliance.org.uk, last visited July 28 2006), pp 44-45. Supra note 223, 54.

treatment for a mental disorder and that autonomy should play a role alongside other rights in developing an appropriate model for treatment.

Having identified the difficulties with the practical application of the capacity requirement as an important limitation of the autonomy paradigm in the context of treatment for a mental disorder, this thesis now moves on to establish the nature of these difficulties and to show why these difficulties are especially acute in the case of patients with a mental disorder. The next chapter will review the functional test for capacity in detail and show that the theoretical consistency of the autonomy paradigm comes under sustained pressure once the paradigm has to be applied to real patients in difficult treatment situations.

Chapter 5: Limitations of the Functional Test for Capacity

Introduction

The model of the autonomy paradigm presented at the beginning of this thesis shows capacity acting as gate-keeper for the principle of autonomy. This allows the law to protect patients from the consequences of their decisions without having to depart from the liberal principles upon which healthcare law is premised. It was evident from the discussion in Chapter 2 that this consistency between the law and liberal theory is maintained in the law's choice of a standard for capacity. A patient's capacity is based on a functional test of his internal abilities, without reference to the nature of the patient's decision or the existence of any underlying condition. The abilities deemed necessary, the ability to understand and retain information and the ability to use and weigh that information, were also shown to be consistent with liberal principle.

However, when capacity is viewed as practical legal requirement which must be tested, rather than as a theoretical construct, the coherence of the autonomy paradigm comes into question. When the functional test must be applied to individual patients, it becomes much more difficult to remove from the test such considerations as the nature of the patient's decision or the existence of an underlying condition. This chapter shows why this is the case by breaking the functional test down into its component parts and reviewing the test in depth. In examining the functional test, the chapter will draw primarily on the law of England and Wales¹ as developed by the courts and as set out in the Mental Capacity Act 2005 (MCA 2005) and supplemented by the *Draft Code of Practice*² issued in advance of the Act. It will also rely on the

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In addition, the chapter will draw on aspects of the Adults with Incapacity (Scotland) Act 2000 as well as decisions from the courts in other jurisdictions, primarily the United States, and the policy discussions of the Irish Law Reform Commission in its Consultation Papers Law and the Elderly (Dublin: LRC CP 23-2003) and Vulnerable Adults and the Law: Capacity (LRC CP 37-2005) (Dublin: Law Reform Commission, 2005) and of the South African Law Commission Assisted Decision-making: Adults with Impaired Decision-making Capacity Discussion Paper 105 (Pretoria: Law Commission, 2004).

² Draft Code of Practice Mental Capacity Bill (Department of Constitutional Affairs, 2004).

discussions of capacity in the Law Commission's Report on Mental Incapacity³ and in the Review of the Mental Health Act 1983 (the Richardson Report).⁴

The chapter has three parts. Part I begins by setting out the kinds of capacity cases that have come before the courts and, arising from these cases, the aspects of the test which have been clearly established by the case law. Part II identifies the aspects of the test which remain open to interpretation or which give rise to particular tensions with the view of capacity required within liberal theory. These tensions are important for two reasons. First, their existence increases the malleability of the test according to the assessor's view of the patient's decision or of his underlying condition and, secondly, they establish why the pure version of the capacity requirement upon which the autonomy paradigm is premised is, in fact, impossible to maintain when applied to the reality of capacity assessment in individual patients' situations. Part III concludes the chapter by identifying particular difficulties when the test for capacity has to deal with patients with ongoing mental disorders, in particular patients with fluctuating capacity or with certain chronic conditions. The arguments in this Part show some basis in fact for the concerns discussed in the previous chapter regarding the way in which the capacity requirement would be applied in the context of treatment for a mental disorder.

Part I: The Functional Test in Practice: The Established Aspects

While there are some differences at a level of detail, the functional test for capacity under both the common law and the MCA 2005 focuses on a number of abilities: the ability to understand and retain and the ability to use and weigh information relating to the decision to be made. In addition, the MCA 2005 introduces a requirement based on the patient's ability to communicate his decision.⁵ Before looking in more detail at the tensions in the test, it is appropriate to look first at the kinds of capacity cases that have come before the courts and the issues upon which the law is clear.

Report of the Expert Committee Review of the Mental Health Act 1983 (Department of Health, HMSO, 1999).

Law Com No 231 (London: HMSO, 1995).

Section 3 (1) (d). The Act defines a person as incapable if he is unable "to communicate his decision (whether by talking, using sign language or any other means)." The *Draft Code of Practice*, para 3.14 requires that "strenuous efforts" must be made to assist and facilitate communication. The ability to communicate is also required in order to establish capacity under section 1 (6) of the Adults with Incapacity (Scotland) Act 2000.

The Causal Requirement

Both the common law test and the test for capacity in the MCA 2005 focus on the inability of the patient to make a specific healthcare decision. These tests further require that the patient's inability to make a decision must be caused by "an impairment of, or a disturbance in the functioning of, the mind or brain." Although not so clear a distinction as the "mental disability" diagnostic threshold recommended by the Law Commission or the "mental disorder" threshold adopted in the Adults with Incapacity (Scotland) Act 2000, this causal requirement aims to distinguish between categories of patients. Only those patients who show an impairment in the functioning of the mind or brain may have their capacity investigated.

The intention of the causal requirement is clear. It limits the category of people who may be made subject to an assessment of capacity and attempts to ensure that "unimpaired" patients will not have their capacity questioned because of the decisions they make. In this sense, the causal requirement reinforces the presumption of capacity and the separation of capacity assessment from the nature of the decision reached by the patient. The effect of the causal requirement is that, if a patient is generally behaving "normally" and showing no indication of an impairment of the mind or brain, the fact that he makes an unusual or high-risk decision will not be questioned. However, if there is a suggestion of such an impairment, his capacity will be investigated and his abilities under the various tests will be assessed.

The extent to which the causal requirement will actually protect patients from capacity assessment based on the nature of their decisions is unclear. On the one hand, the "impairment" requirement is defined in such a broad way that it is unlikely to provide much in the way of protection for patients who make unusual or high-risk decisions.¹⁰ The simple fact that a patient is proposing to make an unusual or

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Section 2 (1) of the MCA 2005. The requirement is phrased slightly differently in *Re MB* (an adult: medical treatment) [1997] 2 FCR 541, 553 where Butler-Sloss LJ refers to a disturbance of "mental functioning."

Report on Mental Incapacity supra note 3, pp 34-36. See discussion in Chapter 2 at text to note 37.

⁸ Section 1 (6).

See the Law Commission's justifications for its recommendation that a threshold be adopted *ibid*, p 34.

A similar argument was made in relation to the "mental disorder" requirement first recommended by the Law Commission (Law Commission Mentally Incapacitated Adults and Decision-Making: A New Jurisdiction Consultation Paper No 128 (London: HMSO, 1993), paras 3.10-3.14) (see Carson "Disabling Progress: The Law Commission's Proposals on

dangerous decision will most likely raise the implication of an impairment of the mind or brain and therefore lead to his capacity being investigated. In this sense, the causal requirement may have a limited useful function. Nonetheless, at a theoretical level, the causal requirement does allow the law to develop the test for capacity without having to concern itself with how this test will play out for "normal" or "unimpaired" patients. Thus, the fact that many patients do not necessarily understand relevant information or that they make decisions on the basis of instinct with little rational engagement will not result in large-scale findings of incapacity.

However, there is a price to be paid for this protection of "normal" patients. The association of incapacity with an impairment of the mind or brain associates mental incapacity with mental illness or disability and leads to the possibility that assessors will find patients to be incapable simply on the basis of an underlying condition and not following a rigorous application of the functional test. ¹¹ In other words, it invites assessors to reach conclusions about, rather than just commence the investigation into, a patient's capacity on the basis that the patient has an impairment of the mind or brain. The MCA 2005 attempts to protect patients from bias in the way in which the causal requirement is applied by stating that that a lack of capacity may not be established merely by reference to a person's age, appearance or behaviour. ¹² However, this is unlikely to rebut a presumption that a person with a mental disability or disorder who makes an unreasonable decision is lacking in capacity. Thus, patients with a mental disability begin the capacity assessment process in a disadvantaged position.

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Mentally Incapacitated Adults' Decision-Making" (1993) 15 Journal of Social Welfare and Fam Law 304, 313; Fennell "Statutory Authority to Treat, Relatives and Treatment Proxies" (1994) 2 Med L Rev 30, 36) and the "mental disability" standard contained in the Report on Mental Incapacity supra note 3, p 34 (see Jones and Keywood "Assessing the Patient's Competence to Consent to Medical Treatment" (1996) 2 Medical Law International 107, 130). Note the impact of the reverse argument on the recommendation by the Irish Law Reform Commission that a causal requirement should be rejected (Vulnerable Adults and the Law supra note 1, para 3.37). The LRC was concerned that a requirement that a patient must be mentally ill before her capacity would be questioned could lead incapable people inappropriately to be labelled as mentally ill. A similar argument was made by the South African Law Commission supra note 1, para 4.37. Section 2 (3).

Established Aspects of the Requirement to Understand, Retain and Communicate

Both the common law and statutory tests for capacity identify certain information that must be understood in order for a patient to be capable. In *Re MB* (an adult: medical treatment), ¹³ Butler-Sloss LJ stated that an individual will be incapable if "unable to comprehend and retain the information which is material to the decision, especially as to the likely consequences of having or not having the treatment in question." The MCA 2005 requires that a patient be able to understanding the "information relevant to the decision, defining "relevant information" as including information about the reasonably foreseeable consequences of "(a) deciding one way or another, or (b) failing to make the decision". ¹⁵

It would seem from the decision of the Court of Appeal in *R* (on the application of *B*) v Dr SS and Dr AC¹⁶ that the test for understanding goes beyond simple understanding and requires an additional ability to appreciate the information in a more personal context.¹⁷ It is not enough that the patient understands the information in some abstract sense ("if a person does not have this treatment, it is likely that he will die"); the requirement also means that the patient must be able to apply the information to his particular situation ("if I do not have this treatment, it is likely that I will die"). A review of the case law shows that there are very few findings of incapacity based on the patient's lack of understanding and, by and large, patients who have failed to meet the understanding requirement have also failed to meet the other requirements for capacity.¹⁸

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¹³ [1997] 2 FCR 541.

¹⁴ *Ibid*, 553.

Section 3 (4). In contrast, the Adults with Incapacity (Scotland) Act 2000 does not specify any information; section 1 (6) defines the term "incapable" as meaning incapable of "(a) acting; or (b) making decisions; or (c) communicating decisions; or (d) understanding decisions; or (e) retaining the memory of decisions."

^[2006] EWCA Civ 28. The Court stated (*ibid*, [34]) that "it is plain that a patient will lack ... capacity if he is not able to appreciate the likely effects of having or not having the treatment."

The view of "appreciation" in this case is similar to the view put forward by Fennell "Informal Compulsion: The Psychiatric Treatment of Juveniles under Common Law" (1992) 4 Journal of Social Welfare and Family Law 311, 324 who suggests that the individual must appreciate "the likelihood that serious harm will result to his or her own health or safety or to the safety of others if he or she does not have the treatment". For a slightly different view of what appreciation means, see Buchanan and Brock Deciding for Others: The Ethics of Surrogate Decision-Making (Cambridge: Cambridge University Press, 1989), p 24, who describe the ability to appreciate information as understanding "the nature and meaning of potential alternatives – what it would be like and 'feel' like to be in possible future states and to undergo various experiences"

See, for example, Tameside and Glossop Acute Services Trust v CH [1996] 1 FCR 753, 771

There is no reported case in the context of healthcare in which an inability to retain information has provided the basis for a finding of incapacity. The issue of an ability to communicate has also not come before the English courts, although the inability to communicate of a patient with an extreme form of Guillain Barré Syndrome (or Locked-in Syndrome) provided the basis for a finding of incapacity in *Auckland Area Health Board* v *Attorney General*. Given the rarity of such cases, findings of incapacity on this basis are likely to be infrequent.

Established Aspects of the "Use and Weigh" Requirement

In contrast to the ability to understand and retain, the ability to use and weigh information has provided the basis for most of the findings of incapacity encountered in the case law (although in many of these cases, treatment was actually imposed on a basis other than the patient's incapacity).²¹ The "use and weigh" test, as it has been applied by the courts, has focussed on the factors that prevent an individual from making a "true" decision or choice. Although the term "true choice" is not routinely used,²² the essence of the "use and weigh" test is to establish if there are factors beyond the patient's control which prevent him from being able to make a decision.²³ Case law indicates that a patient may be unable to reach a "true" decision for reasons

where the defendant (who refused her consent to a Caesarean section) was held to fail all aspects of the capacity test.

^{[1993] 1} NZLR 235; contrast the English case of Re AK (Medical Treatment: Consent)
[2001] 1 FLR 129 and the Canadian case of Nancy B v Hotel Dieu de Quebec (1992) 86 DLR
(4th) 385 where, notwithstanding their disabilities, the patients were able to communicate their wishes to have life-sustaining treatment removed.

Sometimes a means of communication can be established in even quite severe cases. See Re

AK (Medical Treatment: Consent) ibid where the patient communicated by very tiny

movements of his evelid.

In some cases, treatment was imposed because the patient was a minor (see for example Re R (a minor) (wardship: medical treatment) [1991] 4 All ER 177; Re W (a minor) (wardship: medical treatment) [1992] 3 WLR 758) and in others because the patient came within the ambit of the Mental Health Act 1983.

Although see *Re MB* (an adult: medical treatment) [1997] 2 FCR 541, 554 where Butler-Sloss LJ referred to a "true" decision.

The Law Commission originally proposed a "true choice" requirement for capacity (Mentally Incapacitated Adults and Decision-Making: Medical Treatment and Research Consultation Paper No 129 (London: HMSO, 1993), pp 20-21) but in the Report on Incapacity (supra note 3, p 37), the Law Commission rejected the terminology of a true choice because of the "elusiveness of the concept". However, it retained the principle behind the terminology. The Law Commission (ibid, p 39) described a decision as incapable if it is "a decision based on compulsion, the overpowering will of a third party or any other inability to act on relevant information as a result of mental disability".

arising from an underlying mental disorder or for more transitory reasons arising from a current medical condition.

In terms of underlying conditions, the courts have recognised that a patient may be incapable because he is delusional or because he suffers from a psychosis²⁴ or personality disorder²⁵ which leads to false beliefs. Among the false beliefs recognised by the courts have been the patient's belief that he is not ill;²⁶ that proposed treatment will do harm rather than good;²⁷ that proposed treatment was not intended to promote his welfare²⁸ and the patient's belief that she did not have children and that the proposed operation would interfere with her ability to have children.²⁹ Although the principle has not yet been established in the case law, it is probable that a patient with severe depression could also come within the ambit of the test if he rejects antidepressive medication because he cannot believe that any treatment could alleviate his symptoms.³⁰ Patients have also been found incapable because of a condition which creates, in the words of Lord Donaldson MR, "a compulsion to refuse treatment or only to accept treatment which is likely to be ineffective".³¹

An inability to use and weigh information may derive from more transitory factors arising from the nature of the situation in which the patient finds himself. In the view of Butler-Sloss LJ in *Re MB*, the pressures of the situation may be such that, "[o]ne object may be so forced upon the attention of the invalid as to shut out all others that might require consideration." Some of the relevant pressures are set out by Lord Donaldson in *Re T* as "confusion or other effects of shock, severe fatigue,

See Re D (Medical Treatment: Mentally Disabled Patient) [1998] 2 FLR 22.

See R v Collins and Anor, ex parte Brady (2000) 58 BMLR 173; NHS Trust v T [2004] EWHC 1279 (Fam).

See B v Dr SS, Dr G and Secretary of State for the Department of Health [2005] EWHC (Admin) 1936. The Richardson Report supra note 4, p 91 also gives the example of a patient with anorexia who refuses to believe that death is imminent.

See *NHS Trust* v *T* [2004] EWHC 1279 (Fam) where the patient refused blood transfusions on the basis that blood was evil.

See R (on the application of B) v Haddock and Others [2005] EWHC 921.

See Trust A and Trust B v H (An Adult Patient) [2006] EWHC 1230 (Fam).

See Grisso and Appelbaum "The MacArthur Treatment Competence Study III: Abilities of Patients to Consent to Psychiatric and Medical Treatments" (1995) 19 Law and Human Behaviour 149, 163-164. The study found that approximately 14% of patients with depression received low scores on tests to determine their ability to appreciate the potential value of treatment proposed.

Re W (a minor: medical treatment) [1992] 3 WLR 758, 769. See also Re C (Detention: Medical Treatment) [1997] 2 FLR 180.

^{[1997] 2} FCR 541, 554. This is a quote from the famous testamentary capacity case of *Banks* v *Goodfellow* (1870) LR 5 QB 549, 569 *per* Lord Cockburn CJ (who in turn was quoting from the earlier decision of *Harwood* v *Baker* (1840) 3 Moo PC 282). The reference to "object" in the original context was to the object of a testamentary disposition.

pain or drugs".³³ In *Re MB*, Butler-Sloss LJ recognised the possible relevance of these factors; however, she noted that they must operate "to such a degree that the ability to decide is absent."³⁴ Fear or panic may also be disabling factors if they "paralyse the will and thus destroy the capacity to make a decision."³⁵ In *Re MB* itself, the patient's phobic fear of needles was held to make her incapable of making the decision to refuse the proposed caesarean section.³⁶ Similarly, in *Bolton Hospitals NHS Trust* v O,³⁷ the patient, who suffered from post-traumatic stress disorder arising from her previous caesarean sections, panicked and withdrew her consent to a caesarean section on four separate occasions. Dame Butler-Sloss P held the woman to be incapable on the basis that her capacity "to see through the consequences of the act" was inhibited by the situation of panic in which she found herself.³⁸

Part II: Tensions in the Functional Test

While the case law provides an indication of how the functional test applies in certain kinds of situations, a number of unresolved questions remain. These questions show the potential malleability of the functional test according to the assessor's views of the appropriate conclusion. The questions also reveal some of the inherent tensions in the functional test. In particular, they show that, at times, the liberal underpinnings of healthcare law require that the functional test operate in ways which are, to a degree, contradictory.

An Analysis of the "Understand and Retain" Requirement

The most straightforward requirement of the functional test relates to the patient's abilities to understand and to retain information relevant to the decision. However, even this requirement gives rise to a number of questions which, when explored, reveal some of the inherent tensions in the functional test. The first of these questions

^{[1992] 3} WLR 782, 796. See also Norfolk and Norwich Healthcare (NHS) Trust v W [1997] 1 FCR 269; Rochdale Healthcare (NHS) Trust v C [1997] 1 FCR 274 where the stress and pain of labour were found to be incapacitating factors.

³⁴ [1997] 2 FCR 541, 554.

³⁵ Ibid.

³⁶ Ibid.

³⁷ [2002] EWHC 2871.

³⁸ *Ibid*, [15].

is whether the patient must actually understand the information provided in order to comply with the understanding requirement.

Actual Understanding or the Ability to Understand

The test for understanding requires a patient to "be able to understand" the information relevant to the decision. While there is some authority to the effect that the patient need not actually understand the information provided that he has the ability to understand it,³⁹ it is difficult to see how an ability to understand specific information can be measured in the abstract. Thus, Grisso and Appelbaum argue that, while the ability to understand is the "statement of a standard," the patient's actual understanding is the "specification of how achievement of that standard will be measured."

If the ability to understand is inevitably linked to actual understanding, this requirement gives rise to two interesting issues. First, it is probable that a sizeable number of patients whose capacity is not in any doubt and who have the ability to understand information relating to their treatment may not actually do so. They may place their trust in their doctors or may simply not wish to turn their minds to the task of understanding the procedure involved. It is in order to protect these patients' right to choose not to understand relevant information that the Court of Appeal in *Re MB* and the MCA 2005 introduced the causal requirement discussed above whereby only a patient with "an impairment" in the functioning of the mind or brain will have his capacity questioned.⁴¹ However, as noted above, this protection of the "normal" patients' right not to understand is bought at a cost to patients with such impairments who begin the investigation of capacity as a disadvantage.

If the causal requirement did not apply, an alternative method of dealing with the problem would be to base the test for understanding on the premise, suggested by Abernathy, that "good overall cognitive skill would be incompatible with a judgment

In R v Mental Health Act Commission ex parte X (1988) 9 BMLR 77, Stuart-Smith J stated obiter (in the context of the requirement for capacity under section 57 of the Mental Health Act 1983) that it was not necessary for the patient actually to understand information; the fact that he could have done so was sufficient.

Appelbaum and Grisso "The MacArthur Treatment Competence Study I: Mental Illness and Competence to Consent to Treatment" (1995) 19 Law and Human Behaviour 105, 109 note 2. A similar point is made by Gunn "The Meaning of Incapacity" (1994) 2 Med L Rev 8, 18 and Gunn et al "Decision-Making Capacity" (1999) 7 Medical Law Review 269, 304.

See discussion in text to note 9 supra.

of incapacity, no matter how ... or what the patient decided about medical interventions."⁴² In other words, if a patient generally understands information, it may be presumed that he understands the specific information. However, this would move away from the specificity of the functional test which aims to test a patient's ability in relation to the task to be performed and not on a general level. Further, Gunn *et al* correctly argue that such an approach would militate against findings of capacity for patients with learning difficulties who may have difficulty dealing with abstract concepts but may be quite capable of understanding information given in their own concrete situation.⁴³

The second issue arising from the requirement for actual understanding is that, as noted by Grubb, 44 this makes the patient reliant on the medical practitioner to provide information in such a way as to enable him to understand it and thereby makes the patient's capacity dependent on the behaviour of others. The importance of medical practitioners in enabling the patient to understand information is evident in the empirical work of Gunn *et al*⁴⁵ and of Grisso and Appelbaum. 46 These studies show that the way in which information is communicated to the patient can contribute significantly to his understanding and may lead to an ultimate finding of capacity. 47 Correspondingly, failure to communicate on the part of the professionals involved may result in a finding of incapacity. 48 Thus, it must be acknowledged that the functional test does not simply assess the inner workings of patients' minds, as is

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 [&]quot;Compassion, Control and Decisions about Competency" (1984) 141 American Journal of Psychiatry 53, 57. See also Roth, Meisel and Lidz "Tests of Competency to Consent to Treatment" (1977) 134 American Journal of Psychiatry 279, 281-282.

[&]quot;Decision-Making Capacity" supra note 40, 305.

Kennedy and Grubb Medical Law (3rd Ed) (London: Butterworths, 2000), p 616.

[&]quot;Decision-Making Capacity" supra note 40.

[&]quot;The MacArthur Treatment Competence Study III" supra note 30.

See the descriptions of the findings of these studies in Chapter 2 at text following note 157. Inadequate or inaccurate explanations may also impact on a patient's ability to consent in contexts other than the capacity requirement. See for example Re T (Adult: Refusal of Medical Treatment) [1992] 3 WLR 782 where the Court of Appeal held a young woman's advance refusal of a blood transfusion to be ineffective inter alia because she had been given falsely reassuring information by her medical advisors to the effect that she was very unlikely to require a blood transfusion. In Lord Donaldson MR's words (ibid, 799), "[a] refusal is only effective within its true scope and is vitiated if it is based upon false assumptions." In effect, the young woman could not refuse the treatment, not because of anything intrinsic to herself, but because of external behaviour over which she had no control.

The cases of Re E (a minor) [1993] 1 FLR 386 and Re L (medical treatment: Gillick competency) [1998] 2 FLR 810 show this in a striking way. In both cases, the minors were found to be incapable on the basis that they did not understand the implications of their decisions and the courts approved the doctors' decisions not to spell out in detail to the young people the manner of death they faced if they did not consent to the treatment. In doing this, the courts and doctors effectively made it impossible for the patients to be found capable.

assumed by the theoretical view of capacity within the autonomy paradigm, but has to operate within a context where the relevant medical practitioner can play as important a role as the patient.

The dependency of the patient on the medical practitioner is recognised in the MCA 2005. Section 3(2) of the Act states that a person is not to be regarded as unable to understand information "if he is able to understand an explanation of it given to him in a way that is appropriate to his circumstances (using simple language, visual aids or any other means)." This entitles the patient to the provision of accessible and appropriate information and facilitates the enhancement of patient understanding. However, the extent to which the MCA is effective in delivering this entitlement within the capacity assessment process will depend on how healthcare professionals are monitored regarding whether they make the necessary efforts to facilitate patient capacity. This is not addressed in the MCA 2005 and the Code of Practice is also silent on this question.⁴⁹

While the efforts made in the MCA 2005 to address the issue of dependency in a practical way are important, at a more theoretical level, the fact of the dependency identified in the discussion above reveals an important flaw in the view of the capacity requirement within the autonomy paradigm. It shows the fallacy of the view that the capacity requirement is simply a test of the patient's internal abilities which may be performed without reference to outside factors.

The Information to be Understood

If it is accepted that the patient must actually understand relevant information (although only if his capacity is at issue), the next question which arises relates to what constitutes "relevant information." While emphasising certain information, neither the Court of Appeal in *Re MB* nor the MCA 2005 place outer boundaries around the amount of additional information required. Thus, other than the generally

An interesting question in this regard is the extent of the common law duty of care owed by an assessor to the patient who is the subject of the assessment. Does this include a duty to take reasonable steps to facilitate capacity in addition to the duty to assess capacity with all due care? Because the issue of capacity assessment has not been considered in the context of negligence, there are no clear indications regarding the extent of an assessor's duties. However, if it is accepted that the requirement to take steps to facilitate capacity is an essential part of the capacity assessment process, then a failure to do should be regarded as constituting negligence.

accepted position that a patient does not have to have a technical understanding of the "precise physiological process involved" in a treatment,⁵⁰ the question of how much information must be understood remains unclear. This leaves room for manipulation of the understanding requirement depending on the outcome a court or assessor considers appropriate. This kind of manipulation may be seen in *Re E (a Minor)*⁵¹ where Ward J imposed a very demanding understanding requirement in relation to a 15 year-old Jehovah's Witness who had refused blood transfusions. Ward J held the boy to be incapable because:

[H]e has no realisation of the full implications which lie before him as to the process of dying. He may have some concept of the fact that he will die, but as to the manner of his death and to the extent of his and his family's suffering I find that he has not the ability to turn his mind to it nor the will to do so.⁵²

This decision was clearly motivated by the policy concern expressed by Ward J that the court "should be very slow to allow an infant to martyr himself." While *Re E* concerned the capacity of a minor, which requires a more demanding standard for understanding than in relation to adults ⁵⁴ (and arguably raises different policy imperatives), the case is notable because it shows the essential malleability of the understanding requirement.

Delimiting the amount of information to be understood in order to be deemed capable presents an interesting conundrum when viewed through the lens of the law's endorsement of the liberal principle of autonomy. On the one hand, it might be argued that the amount of information which the patient must actually understand should be relatively limited. This would increase the possibility of patients reaching

See the Law Commission Consultation Paper No 129 *supra* note 23, p 19. This principle was established in *R* v *Mental Health Act Commission*, *ex p X* (1988) 9 BMLR 77 *per* Stuart Smith J in relation to capacity to consent to treatment under section 57 of the MHA 1983.

^{51 (1990) [1993] 1} FLR 386.

⁵² *Ibid*, 391.

Ibid, 394. The decision in Re E was handed down on September 21 1990 and preceded the Court of Appeal decision in Re W (a minor) (wardship: medical treatment) [1992] 3 WLR 758 where the Court established that a capable minor's refusal of treatment could be overridden on the basis of the minor's best interests as determined by the court.

In Gillick v West Norfolk and Wisbech AHA [1986] AC 112, 189, Lord Scarman set out the test for capacity for minors under the age of 16 (the statutory age for consent under section 8 of the Family Law Reform Act 1969) in terms which required the minor to have "a sufficient understanding and intelligence to enable him or her to understand fully what is proposed". The Department of Health Guidelines Seeking Consent: Working with Children (London: Department of Health, 2001), p 5 use the Gillick formulation for minors under the age of 16 and (ibid, p 4) the test in Re MB for minors over the age of 16.

the necessary threshold and decrease the number of patients likely to be found incapable on this basis. For this reason, Grubb argues that for the test "to require an ability to understand a more limited set of information would be more empowering." Gunn also makes the argument that, if patients have to understand a greater amount of information, they will have to be given this information which in turn could lead to "information overload" where patients' capacity to understand any information is impeded by the amount of information provided. In a similar way, certain types of information, especially information relating to risks and side-effects, may lead patients to feelings of stress and panic which in turn could impede patient capacity.

On the other hand, however, outside of the capacity context, respect for the principle of autonomy, as given effect through the model of informed consent, requires that the patient should understand a significant amount of information in order to ensure that the medical decision is the patient's decision rather than that of his medical advisors.⁵⁷ The negligence-based duty to disclose "risks that [are] inherent in the proposed surgery" ⁵⁸ gives effect to this aspect of the principle, ⁵⁹ albeit to a limited degree. While the law relating to disclosure does not require patients, whose capacity is not at issue, actually to understand the information provided, the ideal upon which the duty to disclose is based is that patients should be provided with accessible information, understand it and then make their healthcare decisions based on this information.

At a practical level, the uncertainty regarding the limits of the information which a patient must understand may be fairly easily resolved. Professional guidelines provide a useful indication of an appropriate level of information.⁶⁰ In the

Supra note 44, p 614. This is also the approach of Jones and Keywood "Assessing the Patient's Competence to Consent to Medical Treatment" (1996) 2 Medical Law International 107, 134.

[&]quot;The Meaning of Incapacity" supra note 40, 24.

See the lengthy list of information required for "informed consent" in Faden and Beauchamp A History and Theory of Informed Consent (New York, Oxford: Oxford University Press, 1986), pp 307-308; see also Maclean "The Doctrine of Informed Consent: Does it Exist and Has it Crossed the Atlantic?" (2004) 24 Legal Studies 386.

⁵⁸ Chester v Afshar [2004] UKHL 41, [55].

The House of Lords in *Chester v Afshar ibid* clearly located the duty to disclose information within the protections afforded to the principle of autonomy. See in particular *ibid*, [18] and [24] *per* Lord Steyn; [92] *per* Lord Walker.

⁶⁰ Cf Grubb's exploration (supra note 44, p 614) of the possibility of using existing legal standards (the standard in battery or the standard in negligence) to determine the amount of information required.

mental health context, the *Code of Practice to the Mental Health Act 1983*⁶¹ states that "sufficient information must be given to ensure that the patient understands in broad terms the nature, likely effects and risks of [the] treatment including the likelihood of its success and any alternatives to it". 62 The Code also requires that the patient be invited to ask questions and that the doctor should answer "fully, frankly and truthfully". 63 The *Draft Code of Practice* under the MCA 2005 states that "the doctor will need to explain what is involved in the proposed course of treatment, why it is considered necessary, any alternatives and the consequences of consenting, or refusing consent to treatment." 64 It also states that it will not always be necessary to explain all the minutiae relating to the decision. 65 Both of these standards seem to represent a suitable compromise taking account of the issues raised above. 66

However, while a practical compromise may be reached, it is important to be aware, as Gunn *et al*⁶⁷ note, that it is one thing to adopt a standard but quite another to apply it in practice. Thus, the issue of malleability inevitably remains. Further, at a more theoretical level, the discussion above shows that adherence to the principle of autonomy does not point in any clear direction when the principle has to be applied to the reality of capacity assessment.

The Time Element in Relation to the Ability to Retain

The requirement that a patient must have the ability to retain information is in line with clinical work which suggests that "[i]f information has not been 'stored' in a manner that facilitates recall at the time one is making a decision, the relevant information is not available [to the patient]." Because the issue of retention has not been discussed by the courts, there is little clarity regarding how the requirement

Revised in 1999 (London: Stationary Office, 1999) (Health Service Circular HSC 1999/050; Local Authority Circular LAC (99) 11).

⁶² *Ibid*, para 15.15.

⁶³ *Ibid*, para 15.16.

Supra note 2, para 3.17.

⁶⁵ *Ibid*, para 3.10.

See also the level of information which Gunn et al "Decision-Making Capacity" supra note 40, 279 required a patient to understand in order to be capable in the context of their study of factors influencing patient capacity. See the authors' justification for their choices regarding the level of information they required (ibid, 294).

⁶⁷ *Ibid*, 301.

Grisso and Appelbaum Assessing Competence to Consent to Treatment: A Guide for Physicians and Other Health Professionals (Oxford University Press, 1998), p 41.

might apply. The MCA 2005 states that that a person is not to be regarded as unable to make a decision because he can retain information "for a short period only." ⁶⁹ It would seem that the Act is seeking to ensure that patients with long term memory difficulties (typically patients with early dementia) are not found incapable on this ground alone. However, the vague way in which the legislation is stated does not relate to the patient's ability regarding the function to be performed. The *Draft Code of Practice* offers some clarification, by stating that the necessary period of retention "will depend on what is necessary for the decision in question." This period will vary, depending on the circumstances of the case in question. While more in line with the purpose of the retention requirement, the variable nature of the requirement increases the malleability of the test.

As with the understanding requirement, the retention requirement reveals that the principle of autonomy does not point in any clear direction when applied to the reality of individual patients. While the adoption of a minimal retention requirement protects patient autonomy by allowing patients with early dementia to be found capable, it also limits the patient's opportunity to change his mind. If a patient cannot remember the basis upon which he made a decision, he may have difficulty in revisiting the decision or even in recalling that he made the decision. Thus, his right to change his mind, which is fundamental to the right of autonomy, is limited by a lack of retained information. In the context of treatment refusal, and especially if the treatment is for a serious or life-threatening condition, this also raises the question of whether patients with memory difficulties should be reminded of basic information. As with the understanding requirement, this shows again the essential dependence of patients on others to facilitate their capacity and reveals that the functional test is never simply about the patient's internal abilities.

⁶⁹ Section 3 (3).

Supra note 2, para 3.11. See also the recommendation of Grisso and Appelbaum supra note 68, pp 41-42 that the patient should be able to retain the information until the decision can be made.

The Code of Practice (*ibid*, para 3.11) suggests the use of aids, such as videos and voice recorders to assist longer term retention.

In theory, a patient could be reminded of the information and of the decision made and asked if he still agreed with this. However, this could be quite distressing for a patient with retention difficulties.

An Analysis of the "Use and Weigh" Requirement

The preceding discussion showed that even the straightforward requirements of understanding and retention reveal a dissonance between the theoretical conception of the capacity requirement and the reality of this requirement when applied in practice. This becomes even more apparent when the less accessible terminology of the ability to "use and weigh" information is examined. The discussion below will examine the roles of belief, undue influence and rationality in the functional test for capacity and establish the difficulties which these aspects of the test reveal when the capacity requirement is applied to the reality of individual capacity assessments.

The Functional Test and the Role of Belief

The ability to use and weigh information, as required by the functional test, would seem to be premised on the patient actually believing the information provided. 73 However, this apparently simple prerequisite gives rise to a difficult issue. A patient may disbelieve information for a range of reasons. He may refuse to accept that he is ill; he may think that the medical professionals do not have his interests at heart; he may not believe that his condition will be helped by the proposed treatment; or may believe that another cure will be found whether through divine intervention or the advances of medical science.

Some of these beliefs may seem reasonable to outside observers, even if the beliefs are not shared, while others may seem unreasonable or unacceptable. Thus, for example, while religious beliefs have little basis in provable fact, most people are prepared to accept the tenets of a believer's faith. On the other hand, the belief of the defendant in *State of Tennessee*, *Department of Human Services* v *Northern* ⁷⁴ that there was nothing wrong with her feet although they were "disfigured, coal black,"

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See B v Dr SS, Dr G and Secretary of State for the Department of Health [2005] EWHC (Admin) 1936 where Charles J accepted evidence that the patient did not believe he was mentally ill and that his decision to reject anti-psychotic medication, notwithstanding a very high chance (90%) of relapse in his condition, was taken against this background. Because the man did not "believe or accept a cornerstone of the factors to be taken into account," Charles J (ibid, [190]) held him unable to use or weigh the information to reach a conclusion to refuse the treatment.

⁷⁴ (1978) 563 SW 2d 197.

By focussing on the source of the disbelief, rather than on whether the disbelief is reasonable or not, the English courts may avoid some of the difficulties outlined above. It would seem that a patient's belief will lead to a finding of incapacity only if it can be associated with some form underlying mental impairment and therefore the reasonableness question can be avoided in many situations. However, because of the causal requirement discussed above, ⁸¹ the very fact that a patient's capacity is being questioned at all means that he has an underlying impairment. Therefore, in reality, if the patient's capacity is at issue, courts are unlikely to be able to avoid making a value judgment regarding the quality or reasonableness of the patient's belief. ⁸² For patients with mental disorders, this means that, if their beliefs are not reasonable in the eyes of the court or medical assessor, they are almost inevitably going to be regarded as evidence of their incapacity. Thus, although at a theoretical level, the functional test is required to assess capacity without making value judgements, when the test is applied to real patients, this kind of neutrality is in fact impossible.

The Test for Capacity and the Role of Undue Influence

A second way in which the reality of the test for capacity is inconsistent with the theoretical model of the capacity requirement under the autonomy paradigm relates to the role of undue influence in the test. While as discussed in Chapter 1, the issue of voluntariness is conceptually separate from the issue of capacity and is relevant outside of the capacity context,⁸³ the English courts have also linked the two concepts.⁸⁴ In *Re T*, Lord Donaldson MR identified two factors as relevant in

See text following note 6 supra.

See, for example, the decision of the Supreme Court of Ohio in *Re Milton* (1987) 505 NE 2d 255. Here, the appellant refused treatment for cancer, which her doctors argued would save or considerably prolong her life, on the basis of her firm belief in faith healing and in particular in the healing powers of a Reverend Jenkins to whom she had the delusional belief that she was married. Although the belief that she was married to Reverend Jenkins was rejected as clearly delusional, the majority of the Court held that her belief in faith healing stood "on its own, without regard to any delusion" and she was therefore permitted to refuse the treatment.

See for example Mrs U v Centre for Reproductive Medicine [2002] EWHC 36 (Fam) (sub nom Centre for Reproductive Medicine v U); [2002] EWCA Civ 565 (CA) where undue influence was argued in circumstances in which the patient's capacity was clearly not in doubt. See further Chapter 1 at text following note 169.

For a discussion of the linkage between these concepts (in the context of contractual and testamentary capacity), see Green "Fraud, Undue Influence and Mental Incompetency: A Study in Related Concepts" (1943) 43 Columbia Law Review 176.

determining if a patient's consent or refusal has been vitiated by undue influence. These were, first, the patient's strength of will and secondly, the relationship of the patient to the persuader. Lord Donaldson noted that the presence of these factors should "alert the doctors to the possibility – no more – that the patient's capacity or will to decide has been overborne. The concepts were again linked in *Re MB* where, in setting out factors which would render a patient incapable, Butler-Sloss LJ noted that "[o]ne object may be so forced upon the attention of the invalid as to shut out all others that might require consideration." This statement is in fact a quote from a case relating to undue influence and the statement could clearly be equally applicable to compulsion arising from external actors as well as that arising from internal sources.

The Law Commission also saw a role for undue influence in the test for capacity. In its *Report on Incapacity*, the Law Commission stated that "[t]here are also some people who, because of a mental disability, are unable to exert their will against some stronger person who wishes to influence their decisions or against some *force majeure* of circumstances." This led the Law Commission to define a decision as incapable where it is based on the "overpowering will of a third party". This is also the approach taken by Hedley J in *Re Z: A Local Authority* v *Mr Z and the Official Solicitor* who noted that the presumption of capacity may be rebutted by "being unduly influenced by the views of others or by undue concern for the burden ... imposed on others."

While the inclusion of undue influence within the test for capacity serves to address a genuine concern that some people whose capacity is in question may be less able to resist pressures,⁹³ treating undue influence as an aspect of capacity is

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⁸⁵ [1992] 3 WLR 782, 797.

⁸⁶ Ibid.

⁸⁷ [1997] 2 FCR 541, 554.

Harwood v Baker note 32 supra. The testator in the case in question had left all his property to his wife, excluding other relations who considered that they had an entitlement. Erskine J noted that "the protection of the law is in no cases more needed than it is in those where the mind has been too much enfeebled to comprehend more objects than one".

Supra note 3, p 38.

⁹⁰ *Ibid*, p 39.

⁹¹ [2004] EWHC 2871 (Fam).

Ibid, [14]. The case in question was concerned with whether the claimant had a right to travel to Switzerland in order to avail of euthanasia (where the procedure was lawful), hence Hedley J's focus on the issue of the concern for the burden the condition imposed on others.

See also the approach to consent taken in R (on the application of E) v Criminal Injuries Compensation Appeals Panel [2003] EWCA Civ 234. Here, the Court of Appeal concluded

problematic for a number of reasons. First, it has the effect that undue influence may push otherwise capable individuals into incapacity. A patient, who would be capable if he had not encountered a particular set of pressures, will be found incapable because of the behaviour of external actors. By focusing on the patient's incapacity rather than on the pressures brought to bear on the patient, attention is shifted away from the real cause of the problem, which in some instances could be alleviated if addressed.

Secondly, the inclusion of undue influence within the test for capacity requires consideration of what constitutes undue influence. In particular in the context of treatment refusal, the question arises of whether it counts as undue influence if the party exerting the influence is in fact persuading the patient to have the recommended medical treatment. In this context, it is relevant that many patients may feel ambivalent about their choices⁹⁴ and expect their doctors or family members to persuade them to accept treatment.⁹⁵ In light of the judicially accepted principle of sanctity of life, it might be argued that encouraging a patient to have recommended treatment will be less likely to constitute undue influence. However, if this were the case, the nature of the patient's decision is relevant in determining whether the patient is unduly influenced or not and, by extension, plays a role in the functional test for capacity. Thus, here too, the inconsistency between the application of the functional test in practice and the theoretical conception of the test within the autonomy paradigm is evident.

The Role of Rationality

A final issue raised by the ability to "use and weigh" relates to what the ability to weigh information actually involves and, in particular, whether there is a requirement

that an individual's vulnerability, his low IQ and his young age were all factors that should be taken into account in considering whether his consent to sexual relations with a fellow prisoner was valid.

Schneider *The Practice of Autonomy* (New York: Oxford University Press, 1998), p 89 notes that "[o]ne self may yearn to give up the struggle for health and even life. But another self wants to be encouraged to persist."

Schneider *ibid*, p 5 argues that some doctors are too ready to accept patients' refusals and do not attempt to understand what lies behind the patient's decision. He recounts (*ibid*, pp 88-89) patients' feelings of surprise and even abandonment when their doctors acceded too quickly to their decisions and did not try to persuade them to accept the doctors' recommendation.

for the patient to act rationally. Again, this question draws attention to the malleability of the test and the difficulty with divorcing the functional test from the nature of the patient's decision. As the case law discussed above indicates, 6 the primary focus of inquiry in the context of the "use and weigh" test has been whether the patient's ability to make a decision has been impeded. However, this does not address the question what specifically the patient is impeded from doing. The courts have given little indication regarding what the ability to use and weigh information requires in a positive sense. 1 In particular, the courts have not addressed the question of whether the patient must be able to reason logically in order to comply with a "use and weigh" requirement. 18

It is clear from the case law that, provided a patient is capable, he does not have to reason logically or to act rationally. This is evident in Lord Donaldson MR's famous statement that "the patient's right of choice exists whether the reasons for making that choice are rational, irrational, unknown or even non-existent." An equally robust view was expressed by Dame Butler-Sloss P in *Bolton Hospitals NHS Trust* v O^{100} who stated that:

Those who say no have, under our present law, the right to say no even if they do not give good reasons for it: even, as has been said, if they come to a decision which is outrageous in its defiance of logic or of the morally accepted standards...¹⁰¹

However, these statements are clearly directed at the right of a capable patient and do not assist in determining what is required when the patient's capacity has to be assessed.

There are a number of *obiter* comments which indicate judicial views regarding the role of rationality in capacity assessment. These suggest, at least a draw (although without any rational engagement regarding why) to the concept of

¹⁰¹ *Ibid*, 827.

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See text following note 22 *supra*.

The inability to weigh up information was central to many of the caesarean section cases (see Rochdale Healthcare (NHS) Trust v C [1997] 1 FCR 274, 275; Norfolk and Norwich Healthcare (NHS) Trust v W [1997] 1 FCR 269, 272; Re L (An Adult: Non-Consensual Treatment) [1997] 1 FCR 609, 612). However, these cases did not involve a detailed discussion of what the requirement actually entailed and therefore are of little assistance in relation to this question.

Cf the test for capacity suggested by the South African Law Commission supra note 1, para 4.37 which contains an express requirement for the ability to reason logically.

⁹⁹ In re T (Adult: Refusal of Treatment) [1992] 3 WLR 782, 796.

¹⁰⁰ [2003] 1 FLR 824.

rationality. In *Re MB (An Adult: Medical Treatment)*, Butler-Sloss LJ noted that "fear of an operation may be a rational reason for refusal to undergo it" and again, in *Re B (adult: refusal of medical treatment)*, Dame Butler-Sloss P approved the advice of an expert who had attested to the fact that Ms B has weighed up her life with a ventilator against inevitable death. In *Re AK (Medical Treatment: Consent)*, Hughes J noted that the patient was in no sense "impaired in his brain or in his rational processes." And, finally, in the strongest general statement regarding the role of rationality in the standard for capacity, in *(Burke)* v *The General Medical Council and others*, Munby J described capacity as being "dependent on having the ability, whether or not one chooses to use it, to function rationally." 106

On the basis of the above, there is a draw towards a standard for capacity which includes the ability to weigh information rationally. On the basis of the discussion in Chapter 2, there are a number of reasons why the courts should resist the draw of rationality. First, as discussed in Chapter 2, while the ability to weigh information rationally may, in theory, be distinguished from a requirement that a patient reach a rational decision, ¹⁰⁷ in practice, the separation of the two requirements may be much more difficult to achieve. An irrational decision may be regarded as evidence of an irrational or illogical reasoning process. ¹⁰⁸ Therefore the inclusion of any requirement regarding reasoning ability or the ability to function rationally is likely to increase the role played by the nature of the patient's decision in the capacity assessment process. Secondly, also as discussed in Chapter 2, the requirement for rationality does not, if fact, fit with the liberal theory which underpins the autonomy principle within healthcare law. Therefore, it does not have a theoretical pedigree as a part of the functional test to be applied to individual patients.

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^{[1997] 2} FCR 541, 554.

¹⁰³ [2002] 2 All ER 449, 468.

¹⁰⁴ [2001] 1 FLR 129, 131.

¹⁰⁵ [2004] EWHC 1879 (Admin).

Ibid, [42]. Munby J defined this as "having the ability to understand, retain, believe and evaluate (i.e. process) and weigh the information which is relevant to the subject-matter."

See Chapter 2 at text to note 109.

See, for example, South West Hertfordshire Health Authority v KB [1994] 2 FCR 1051, 1054, where Ewbank J held a woman with anorexia nervosa to be incapable notwithstanding the argument that the woman was (ibid, 1054) "quite rational, able to decide whether she wishes to live or die". The judge's conclusion was based on medical evidence that the woman in question (ibid, 1052) saw "the prospect of death as a long-term or theoretical prospect" and that she was aware that if she came close to death she was likely to be resuscitated by her doctors under the emergency provisions of the MHA 1983. Given that this was an entirely accurate assessment of the situation, it is difficult to see how this indicated a lack of capacity.

Part III: Tensions Specific to Patients with Mental Disorders

The discussion in Part II identified a number of tensions which arise in the practical application of the test for capacity. It argued that these tensions show that the functional test cannot provide the neutral assessment of capacity presumed by the autonomy paradigm. As the discussion to follow shows, the test's limitations in this regard are further increased where the patient suffers from certain kinds of mental disorders. Two particularly difficult situations may be identified: first, patients with fluctuating capacity and, secondly, patients with chronic or ongoing mental disorders. The discussion of these situations below will confirm why, as discussed in the previous chapter, there are genuine difficulties in applying the capacity requirement to treatment for a mental disorder within the autonomy paradigm.

The Functional Test and Fluctuating Capacity

The essence of the functional test is that capacity is determined at the time a decision is to be made. This is confirmed by the *Draft Code of Practice* which states that capacity can fluctuate and that the decision may sometimes be put off until the person has recovered capacity. ¹⁰⁹ This aspect of the test operates effectively where a patient has a single decision to make, for example where he wishes to refuse a specific medical intervention and where the patient's incapacity is caused by a transitory factor such as panic or fear. However, where a decision has an ongoing effect and where the patient's capacity fluctuates, this aspect of the functional test causes difficulties especially if the patient's decision while capable is likely to lead to his subsequent incapacity.

The nature of the difficulties caused is evident in Re G (an adult) (mental capacity: court's jurisdiction)¹¹⁰ which, although not concerning medical treatment, demonstrates the issues likely to arise in a treatment context. In this case, an interim order had been made limiting contact between a woman with a history of mental illness and her parents on the basis that her father had a negative impact on her mental

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Supra note 2, paras 3.23 -3.24. [2004] EWHC 2222 (Fam).

health. At the time of the interim order, the woman had been incapable of making a decision regarding whether or not to see her family. Following a period during which the order limited contact with her father, the woman's mental health improved, she regained capacity and then wished to see her father again. Medical evidence suggested that if the contact restrictions were lifted, she would lose capacity again. Bennett J rejected the view that the court's jurisdiction "would be entirely dependent on the shifting sands of whether or not G did, or did not, have the requisite capacity at the time of the final hearing." In determining capacity, he concluded that the "focal point" of the inquiry must be "the situation which resulted in the temporary measures being taken".

A difficulty, similar to that described in *Re G*, may be seen in *Re R (a minor)* (wardship: medical treatment)¹¹³ which concerned a young woman who fluctuated between psychotic and lucid periods. During these lucid periods, she refused to take antipsychotic medication thus leading to the onset of a psychotic period. The patient was a minor and had not been made subject to the Mental Health Act 1983. Although the matter was ultimately resolved with a finding that a minor patient did not have the right to refuse treatment if her parents or guardians gave consent on her behalf, Lord Donaldson MR addressed, in brief, the more general issue of fluctuating capacity.¹¹⁴ He suggested that the test for capacity needed to be "modified in the case of fluctuating mental disability to take account of that misfortune."¹¹⁵ He did not suggest how such a modification should take place although it is difficult to see any possible modification other than that the patient would be regarded as incapable of taking the particular decision at issue regardless of an actual finding of capacity at the particular time.

Beyond the decision in *Re R*, the situation of patients with fluctuating capacity has received little attention. This is presumably because patients with fluctuating capacity will often come within the ambit of the MHA 1983. However, should a capacity-based right to refuse be introduced in the context of treatment for a mental disorder, the issue of fluctuating capacity would take on a much greater practical

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115 *Ibid*, 187.

¹¹¹ *Ibid*, [91].

¹¹² *Ibid*, [112].

^{[1991] 4} All ER 177.

Although his Lordship later described Re R as having "no application to adult patients" (Re T (adult: refusal of medical treatment) [1992] 3 WLR 783, 786.

significance. Patients with fluctuating capacity pose a real problem for the autonomy paradigm if they wish to refuse the treatment that maintains their capacity. On a strict application of the capacity requirement, the patient may refuse treatment, become incapable, have treatment imposed on the basis of best interests, regain capacity and have the cycle begin again. In the absence of a facility for advance decisions covering treatment for a mental disorder, there is no way in which this cycle can be broken. The cycle also gives rise to the apeutic difficulties. It is presumably these difficulties which led the Richardson Report to reject the view that a person who had a fluctuating condition would have to develop "florid symptoms of psychosis" before treatment could be imposed.¹¹⁶ Instead, the Report stated that, "provided there was a clear history of relapse and positive response to treatment", a person in this situation would lack capacity because of their underlying mental disorder and their inability to foresee the reasonable consequences of their decision.¹¹⁷ This view of capacity requires that, in order to be found capable, a patient must decide in favour of the treatment which maintains his capacity. While having therapeutic advantages, this approach clearly determines the capacity of patients according to the decisions they reach. In doing this, it shows up, yet again, the impossibility of removing the nature of the patient's decision from the practical application of the capacity requirement.¹¹⁸

Chronic Disorders and the Concept of True Choice

The difficulties posed by the situation of patients with certain kinds of mental disorders may also be seen when the test has to deal with patients with certain kinds of chronic disorders. As noted above, the concept of a true choice pervades the application of the use and weigh aspect of the functional test for capacity.¹¹⁹ The Richardson Report described the premise behind the true choice test as follows:

A person may lack capacity, where, although intellectually able to understand and apply the information, that person nonetheless reaches a judgment which s/he would not have reached in the absence of the disorder. Such a judgment

Supra note 4, para 7.13.

¹¹⁷ *Ibid*, para 7.14.

Cf Gunn "The Meaning of Incapacity" supra note 40, 28 who acknowledges the therapeutic difficulties caused by patients with fluctuating capacity but suggests that their situation is better dealt with by compulsory care in the community.

See text following note 21 *supra*.

can be said to be primarily the product of the disorder and not to reflect the person's true preferences.¹²⁰

Although endorsing the true choice test, in light of the discretion to which the test gives rise, the Richardson Report emphasised the importance of establishing that the disputed decision is a "product" of an underlying condition, noting that "account should be taken of whether the decision conflicts with the individual's views, previously expressed or demonstrated at a time when s/he had capacity." This suggestion is one which can easily be put into operation in the once-off, panic-related situations which have provided the basis for much of the case law in this area. In panic-based cases such as *Re MB* or *Bolton Hospitals NHS Trust* v O, there is usually a fairly obvious course that the individual would have pursued had it not been for her panic. Indeed, in *Bolton Hospitals NHS Trust* v O, the patient supported the hospital in seeking a declaration that she was incapable and that the treatment should be imposed. 122

However, moving beyond the straightforward panic situations, it may be more difficult to separate a person from his compulsion, fear or other incapacitating factor. There may come a point, especially with some chronic conditions, where a person does not have "true" preferences, in the sense of preferences outside of his illness or current situation which can be referred to in order to challenge his current decision. In other words, the person's illness may become a part of who he is.¹²³ Tan *et al*¹²⁴ point out that this may be the case with chronic mental disorders such as anorexia.

Supra note 4, pp 88-89.

Ibid, p 90. The Report appears to assume that the individual is incapable at the point of the inquiry. This is premature given that the purpose of the inquiry is to establish capacity or otherwise.

¹²² [2002] EWHC 2871, [14].

A similar argument may be made in relation to any impeding factor even if it does not arise from the patient's mental disorder. See the decision of the Irish High Court in JM v Board of Management of St Vincent's Hospital [2003] 1 IR 321 where a woman's decision to refuse blood products was held not to be a "real" one because her cultural background had led her to assume her husband's religion on marriage. As discussed in Chapter 1, this case shows the difficulty with separating out a person's characteristics and deeming some to be "real" or "true" and others not to be. While the facts of JM shows the difficulty more acutely, the argument that a person's identity cannot necessarily be broken down into true and false aspects may be made even if the patient has an underlying mental disorder.

Tan, Hope and Stewart "Anorexia Nervosa and Personal Identity: The Accounts of Patients and their Parents" (2003) 26 International Journal of Law and Psychiatry 533. This article reports on a pilot qualitative study based on interviews with 10 young women aged between 13-22 years with a diagnosis of anorexia nervosa and with 7 of their mothers. For a full description of the study, see *ibid*, 538.

The illness can become an essential part of the sufferer's identity.¹²⁵ In such circumstances, a patient's decision to refuse treatment may be viewed as either a "true" choice arising from a part of the patient's identity¹²⁶ or as an "untrue" choice arising from the patient's underlying condition.¹²⁷ Neither view presents an accurate picture of the complexity of the patient's decision-making process.¹²⁸ In this situation, the functional test requires assessors to perform the impossible task of separating out "true" preferences from those which are the product of mental illness or disorders. Given the impossibility of this task, when called upon to perform it, assessors will almost inevitably conclude that the patient is incapable on the basis of the decision he proposes to make.

Conclusion

In Re B (adult: refusal of medical treatment),¹²⁹ Dame Butler Sloss described the test for capacity as "clear and easily to be understood by lawyers." However, she continued by stating that the application of the law to "individual cases in the context of a general practitioner's surgery, a hospital ward and especially in an intensive care unit is infinitely more difficult to achieve."¹³⁰ This chapter has argued that, when the functional test for capacity is broken down into component parts to be applied in practice, it is more complex and less consistent with underlying liberal theory than the theoretical conception of the capacity requirement within the autonomy paradigm.

This chapter has identified a range of tensions and unresolved questions relating to the functional test and argued that these unresolved questions are not

The phenomenon whereby patients experience their anorexia as part of their identity is called "egosyntonicity" (Tan *et al ibid*, 537). This factor makes the decision to accept treatment a difficult and painful one. Patients interviewed by Tan (*ibid*, 542) felt that recovery would lead to their losing a substantial part of who they were.

Draper's argument in favour of permitting some patients with anorexia to refuse life-saving treatment appears to be based on this view (although she does not specifically address the issue of identity as it relates to capacity). In her article, "Anorexia Nervosa and Respecting a Refusal of Life-Prolonging Therapy: A Limited Justification" (2000) 14 Bioethics 120, 123, Drapers argues that, in some cases involving anorexia, the decision to refuse life saving treatment may be on a par with other refusals of treatment made by a capable patient who decides that his life is no longer worth living.

See Tan *supra* note 124, 544-545.

A similar difficulty may arise with patients with long-standing depression. See Rudnick "Depression and Competence to Refuse Psychiatric Treatment" (2002) 28 Journal of Medical Ethics 155.

¹²⁹ [2002] 2 All ER 449, 455.

¹³⁰ *Ibid*.

simply caused by insufficient judicial engagement or bad decision-making (although this may be the case in some instances). Rather they show the inherent limitations of the functional test. This is evident from the fact that, in some situations, the principle of respect for patient autonomy leads the functional test simultaneously in opposing directions. This chapter also showed that the functional test for capacity is not, and cannot be, a test for something wholly internal. The extent to which patients can achieve capacity is dependent on the behaviour of external actors, and especially on the healthcare professionals involved in the process. The chapter also argued that the limits of the functional test are more acutely felt in the context of patients with ongoing mental disorders. In particular, patients with fluctuating capacity and with ongoing chronic mental disorders pose particular difficulties for the application of the functional test.

Having broken down the components of the functional test and established the malleability of the test, the next step towards providing a complete picture of the functional test in practice is to review the process whereby capacity assessments take place. This review provides the basis for the next chapter.

Chapter 6: Applying the Functional Test: The Process of Capacity Assessment

Introduction

The previous chapter argued that the legal test for capacity, which is premised on a value-free, individualised assessment of internal abilities, is very difficult to apply in this way in practice. Unresolved questions, inherent tensions and the role played by people other than the patient all contribute to a test which is malleable according to the assessor's desired outcome. This possibility is increased in the case of patients with ongoing mental disorders. However, the issues to which the functional test gives rise are not restricted to problems arising from the legal wording alone. Given that, in the words of Black J, a court "possesses no X-ray contrivance that can lay bare the workings of the human mind," the legal test must be applied in individual situations by a capacity assessor. This assessor and the process through which she assesses capacity are as much a part of the functional test for capacity as the wording used in the test itself.

It is widely accepted in other areas of law that the process followed in reaching a decision may have an important impact on the decision ultimately reached.² Factors such as the existence and quality of legal representation and the participation of the individual whose situation is being considered³ appear to have a significant impact on the way in which cases are resolved. This chapter argues that a proper understanding of the role of the capacity requirement within the autonomy

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Provincial Bank v McKeever [1941] IR 471, 485 (these remarks were made in the context of undue influence in relation to a banking transaction).

Most work in this regard concerns the criminal trial process. Lacey, Wells and Quick Reconstructing Criminal Law: Text and Materials (3rd Ed) (London: Lexis Nexis Butterworths, 2003), pp 93-94 examine the way in which parties to the trial process can have an impact on the outcome reached. They argue that prosecution and defence lawyers can materially affect the outcome of cases, including as relevant factors: "how hard they push particular points, their use of irony or ridicule and a whole range of rhetorical devices ... the quality and thoroughness of their preparation, the astuteness of the way they use their knowledge not only of the law, but of the tribunal". See also Ashworth The Criminal Process: An Evaluative Study (2nd Ed) (Oxford: Oxford University Press, 1998).

Galligan Due Process and Fair Procedures: A Study of Administrative Procedures (Oxford:

Galligan Due Process and Fair Procedures: A Study of Administrative Procedures (Oxford: Clarendon, 1996), pp 131-132 argues that participation by the individual provides the decision-maker with access to more and better information about the decision which, in turn, "helps the decision-maker to have a more complete and balanced view of the facts and the issues relating to the facts."

paradigm can only be achieved by exploring the motivations and limitations of capacity assessors and of the capacity assessment process at both formal (i.e. judicial determinations) and informal (i.e. determinations by members of the medical profession alone) levels.

By investigating the process of capacity assessment, it is possible to identify further difficulties with the practical application of the functional test. This chapter argues that, while the protections afforded by the formal assessment process have increased in England and Wales in recent years, the formal process is intended to be engaged in a relatively limited set of circumstances and may not operate in a manner which maximises patient capacity. Furthermore, the process at both formal and informal levels remains very dependent on the role played by medical professionals who are often ill-equipped, in both a practical and a philosophical sense, to carry out the functional test without being influenced by the nature of the patient's decision or the existence of any underlying condition. As will be seen, these difficulties may be increased in the context of treatment refusal, especially where the treatment which the patient seeks to refuse is life-sustaining treatment or treatment for a mental disorder. In addition to identifying these difficulties, the chapter makes a number of suggestions regarding how the capacity assessment process may be improved.

This chapter is divided into three Parts. Part I examines the formal procedural framework set out in the *Practice Direction (Declaratory Proceedings: Incapacitated Adults)* (hereafter the *Practice Direction*)⁴ and the Mental Capacity Act 2005 and identifies important policy imperatives in developing the most appropriate approach to the assessment process. Part II considers the contribution of medical professionals, who are often, although not invariably, psychiatrists, who provide expert evidence to inform the formal capacity assessment process and who perform informal capacity assessments based on the legal standard without formal judicial overview. The final Part of the chapter examines attempts by medical professionals to develop forensic testing mechanisms for capacity and in particular the contribution of Appelbaum and Grisso's MacArthur Competence Assessment Tool for Treatment (MacCAT-T). Testing mechanisms of this kind aim to increase experts' sophistication and to enhance the scientific credibility of their evidence. However, it will be argued that

^{[2002] 1} WLR 325.

forensic testing mechanisms are not the most suitable way to address the problems identified in this chapter.

Part I: The Formal Process for Determining Capacity

This Part begins with a consideration of the important preliminary question of whether a patient's consent is required before her capacity may be assessed. This is followed by a discussion of the circumstances in which the formal capacity assessment process is engaged and the way this process operates. This Part concludes with a discussion of broader policy concerns relating to process, exploring, in particular, the way in which the procedures employed impact on individual patients.

Is there a Requirement for Patient Consent to Assessment?

The question of whether patient consent is required for capacity assessment creates something of a dilemma in light of the presumption of capacity. Given that the patient is presumed capable, she should be entitled to refuse assessment. However, if a patient can refuse to be assessed, she could short-circuit the whole assessment process since if she cannot be assessed, there is no evidence to rebut the presumption of capacity. In this way, she could establish a right to refuse treatment notwithstanding her possible incapacity. This issue has not yet come before the courts and is not addressed in the Practice Direction. The Draft Code of Practice under the MCA 2005 states that it will normally be possible to proceed with a capacity assessment provided that the patient is compliant. It continues, however, that "in the face of outright refusal", a patient cannot be required to undergo a capacity assessment unless required to do so by a court.5 The requirement for court approval may be a sensible compromise. However, it does require the court either to override the (presumptively) capable patient's right to refuse assessment or, alternatively, to put aside the presumption of capacity in relation to a patient who is making an unreasonable decision who is refusing to permit her capacity to be assessed. The implication of this would be that the absolute presumption of capacity applies only where assessment of capacity is possible.

Draft Code of Practice Mental Capacity Bill 2004 (Department of Constitutional Affairs, 2004), para 3.39.

An essential part of consent to a process is that the patient knows that the process is taking place. It is not clear that, in practice, in informal assessment situations patients are given this information. The *Draft Code* does not mention an obligation to inform the patient that her capacity is being assessed. However, such an obligation would seem to be consistent with the general approach of the Code in that a patient can only give consent to (or acquiesce in) to a process if she knows it is taking place. A requirement that patients be informed that their capacity is being assessed also best achieves the MCA 2005's aims of facilitating patients in achieving capacity and involving them in the process.⁶

The Nature of the Assessment: Formal or Informal Assessments

While contentious cases, especially those involving treatment refusal, will generally be the subject of a formal decision regarding capacity, many capacity assessments will never move beyond informal assessments by the medical profession. In a set of guidelines issued by the Court of Appeal appended to its decision in *St Georges Healthcare NHS Trust* v S,⁷ the Court noted that, "[i]f the capacity of the patient is seriously in doubt it should be assessed as a matter of priority." The Court recognised three levels of capacity assessment. First, and least formally, assessment could take place by the patient's general practitioner or other qualified doctor. At a second level, for "serious or complex cases involving difficult issues about the future health and well being or even the life of the patient", capacity should assessed by an independent psychiatrist. The final level required a formal adjudication of capacity by the courts. This should take place "if there remains a serious doubt about the patient's competence, and the seriousness or complexity of the issues" requires it.⁹

The *Practice Direction*, issued after the guidelines in *St Georges Healthcare*, identifies two categories of case that always require court approval. These are cases involving non-consensual sterilisation and the discontinuation of artificial hydration and nutrition. In other situations, the *Practice Direction* states that court applications

These are evident in sections 1 (3) and 3 (2) of the MCA 2005.

⁷ [1998] 3 WLR 936.

⁸ *Ibid*, 969.

Ibid. The Court noted that, should this arise, (ibid) the psychiatrist must further consider whether the patient is also incapable of managing her own affairs, including the appointment of a legal representative. If she is, she may require the appointment of a guardian ad litem for the purposes of the hearing.

should be made where there are "disputes or difficulties" regarding either capacity or best interests. While phrased somewhat differently to the Court of Appeal's guidelines, both sets of guidance point in the same direction and require that serious or complex issues require reference to a court. There is nothing in the MCA 2005 or in the *Draft Code of Practice* to suggest any significant change in this regard. The *Draft Code* simply notes that other cases likely to be referred to court include those relating to ethical dilemmas in untested areas, or where there are otherwise irresolvable conflicts between professionals or between professionals and family members.

The Procedural Framework for Capacity Assessment

The current procedural framework for capacity assessment in England and Wales derives in large part from the decision in *St George's Healthcare NHS Trust* v *S*.¹²

The facts of this case provide a graphic example of procedural inadequacy¹³ and led the Court of Appeal to issue guidelines¹⁴ which subsequently were incorporated into the *Practice Direction*. The *Practice Direction* states that capacity (and best interests if the case requires) are to be determined through an adversarial hearing with the NHS Trust or other responsible body acting as claimant and the individual whose capacity is at issue acting as defendant. The defendant must be represented either by her own counsel or solicitor or by the Official Solicitor acting as a "litigation friend".¹⁵ Even if the Official Solicitor does not act as litigation friend, she may be joined by the court

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⁰ Supra note 4, 326.

Supra note 5, para 5.24.

Supra note 7.

In this case (see *ibid*, 967), a judicial declaration had been obtained to the effect that it was lawful to proceed with a caesarean section operation notwithstanding the patient's refusal. The patient had not been informed that an application for declaratory relief was being made and had no opportunity to be present or to be represented at the hearing. The application had not been properly instituted by the issue of a summons; no expert evidence was introduced; and no provision had been made for the patient to apply to vary or discharge the order. The judge was told some things which were not true (that the patient had been in labour for 24 hours at the time of the application) and was not informed about relevant factors (that the patient was believed by the doctors to be capable of refusing treatment; that she had consulted a solicitor; and that she had not been told of the application).

These Guidelines state (*ibid*, 970) that the hearing must be *inter partes* and the patient must be represented. The judge must be provided with accurate and relevant information, including the reasons for the proposed treatment, the risks involved, whether there are any alternatives and why the patient is refusing the treatment (if this can be ascertained).

as *ex officio* defendant or may be invited to act as a friend of the court. Unless the matter is urgent, the Official Solicitor is given a period of time (no less than eight weeks) during which to "conduct inquiries, obtain expert evidence and file his statement or report." This time scale is possible in the context of non-consensual sterilisation or the discontinuance of artificial hydration and nutrition. However, it is unlikely often to be feasible in the more dramatic treatment refusal situations which make up the bulk of the case law in this area. As part of the evaluative function, the Official Solicitor must meet with the patient, as well as with her carers, family members and other people close to her and must inquire regarding her wishes and feelings. The role of the Official Solicitor brings an inquisitorial aspect to the capacity determination process. It is only if the Official Solicitor opts to oppose the final application that the adversarial process in engaged. Otherwise, the final hearing may be disposed of without the presentation of oral evidence.¹⁷

The decision in *St George's Healthcare* and the *Practice Direction* mark a significant step forward in the procedural protections afforded to patients in England and Wales. This is especially evident if compared with the position in Ireland where the procedural framework for capacity assessment has received little attention. In the only relevant reported Irish case to date, *JM* v *St Vincent's Hospital and Ors*, ¹⁸ the President of the High Court considered an application to override an advance refusal of blood products by a woman who was unconscious at the time of the application. ¹⁹ The application, which was made in emergency circumstances, was brought by the patient's husband and proceeded on the basis of a draft plenary summons and oral evidence from the husband. The patient herself was a notice party to the proceedings, but, although she was unconscious, she was not separately represented. ²⁰ Instead, an oral response was entered on the patient's behalf by the second respondent, who was the surgeon responsible for her care and who (hardly surprisingly) agreed with the

See Practice Direction supra note 4, [9]. A litigation friend acts in legal proceedings on behalf of a "patient" (as defined under the Mental Health Act 1983) or a child. See further, Civil Procedure Rules 1998 Part 21 (SI 1998 No 3132 L 17).

See ibid [10]

See *ibid*, [10].
See *ibid*, [11] and [12].

^{[2003] 1} IR 321. While the Court in *JM* was not concerned with capacity assessment, the essential question of whether the patient's decision could be overturned on the basis of best interests was the same as in a capacity assessment situation.

The parens patriae jurisdiction continues in Ireland, where it operates alongside the wardship jurisdiction arising under the Lunacy Regulation (Ireland) Act 1871. Although it is not necessary for a person to be admitted to statutory wardship before the parens patriae jurisdiction may be used, this was the procedure adopted in JM.

patient's husband that the blood products should be administered to save her life. It is difficult to see how the procedural framework utilised in *JM* could have led anywhere other than to the eventual conclusion that the woman's advance refusal should be overridden and treatment provided.

While the English framework is now quite sophisticated, some issues require monitoring. The most important of these is the role of the Official Solicitor. Unless the patient has her own solicitor, it is clear from the *Practice Direction* that, if the Official Solicitor decides not to contest an application, her inquiry becomes the final determination of capacity.²¹ In this event, the Official Solicitor effectively makes the final decision, without the advantages offered by an oral hearing. Care must be taken to ensure that the device of the Official Solicitor's report does not allow decisions to be hidden from public scrutiny. From a patient's perspective, a further issue with the formal process relates to the effect of the process employed on the patients involved. This issue is discussed further below

Developing a Appropriate Process from a Patient Perspective

Empirical research shows that the nature of the process employed in reaching a decision may have important consequences beyond simply the decision reached.²² It may also impact on the way in which people respond to a decision reached about them,²³ and on the general well-being of the individual involved.²⁴ As yet, there has

Supra note 18, 322.

See for example the weight accorded to the Report of the Official Solicitor in Re X (Adult Sterilisation) [1998] 2 FLR 1124. See also the perfunctory treatment of the issue of capacity in NHS Trust and Another v C (adult patient: medical treatment) [2004] EWHC 1657 (Fam) where no opposition was raised by the Official Solicitor.

On the role of process on the decision reached, see Perlin "Is it More than 'Dodging Lions and Wastin' Time'? Adequacy of Counsel, Questions of Competence, and the Judicial Process in Individual Right to Refuse Treatment Cases" (1996) 2 Psychology, Public Policy and Law 114. Perlin ibid, 120 argues that empirical studies show that the quality of counsel is the single most important factor in the ultimate conclusion reached in civil commitment cases in the United States and that this is also of critical importance in cases relating to the right to refuse treatment.

See in particular the work of Tyler The Social Psychology of Procedural Justice (New York: Plenum, 1988) and Why People Obey the Law (New Haven: Yale University Press, 1990). In the area of mental health treatment, the MacArthur Coercion Study (Dennis and Monahan eds Coercion and Aggressive Community Treatment: A New Frontier in Mental Health Law (New York: Plenum Press, 1996) found that the process employed at the stage of admission to a psychiatric facility had an important impact on the patient's perception of her subsequent treatment. The study concluded that actual legal status (whether the patient was admitted voluntarily or not) was not the sole contributor to a patient's feelings about her treatment. Rather, the authors of the study found (ibid, p 24) that: "Patients who had a "good"

been no specific empirical investigation of the way in which process impacts on the patients involved in capacity cases. However, in the absence of a directly relevant investigation, some useful insights may be gained from investigations of the impact of the process used in admitting people to adult guardianship. Vittoria's investigation of the operation of judicial adult guardianship hearings in Kansas²⁵ and Carney and Tait's investigation of tribunal-based hearings in Australia²⁶ provide useful comparative perspectives in this regard.²⁷

Vittoria's study examines the impact of court hearings utilising the traditional adversarial method. She found that the hearings were "perfunctory, with little or no input from the potential ward even if he or she is present".28 Lawyers acting for the possible ward tended to keep her to the margins of the hearing and were afraid to allow her to speak. In the words of one lawyer, if she "allowed the proposed ward to speak, he would just end up proving his 'problem' to the judge when he opened his mouth".29 Vittoria found that alliances developed between judges and other professionals, which created a distance between these professionals and the potential ward. Professionals were referred to by their formal titles while the person whose

admissions process - who reported that others acted out of concern for them, treated them fairly, with respect, and without deception, gave them a chance to tell their side of the story, and considered what was said in making the admission decision - were much less likely to feel coerced, particularly when the decision ultimately made was not the one they preferred."

25 "The Elderly Guardianship Tribunal Hearing: A Socio-Legal Encounter" (1992) 6 Journal of Aging Studies 165.

Supra note 25, 167.

²⁴ See generally Wexler and Winick Essays in Therapeutic Jurisprudence (Durham NC: Carolina Academic Press, 1991); Perlin "A Law of Healing" (2000) 68 U Cinn L Rev 407.

²⁶ The Adult Guardianship Experiment (Annandale, NSW: Federation Press, 1997). Carney and Tait's study relates to tribunals in New South Wales and Victoria. At the time of this study, these tribunals were three-member bodies. Subsequently, the Victorian Guardianship Tribunal has become a one-member tribunal and has been incorporated into the Victorian Civil Appeals Tribunal (VCAT). The tribunal member moves between the guardianship tribunal and other tribunals within VCAT so, for example, a tribunal member may sit on a guardianship tribunal on one day and a residential tenancies tribunal on the next. This makes it more difficult for tribunal members to build up expertise in a particular area, such as guardianship. Carney and Tait's findings are therefore best understood in light of the circumstances of their time.

²⁷ Both studies draw on the work of sociologist Erving Goffman on the theory of encounters (see The Presentation of Self in Everyday Life (New York: Doubleday, Anchor, 1959); Asylums: Essays on the Social Situation of Mental Patients and Other Inmates (New York: Anchor Books, 1961)). Carney and Tait (supra note 26, p 116) describe an encounter in this sense as "a meeting which establishes a set of rules and boundaries, carries out some activities, and then dissolves itself". Vittoria (supra note 25, 165) notes that the hearing process, whether by court or tribunal has a number of characteristics which distinguish it from other kinds of encounters. First, it is structurally constrained by guardianship law; secondly, it has a substantial preparatory period (interviews, preparation of reports etc), which means that the boundaries established in the hearing process itself can be more stage-like (or apparent) than real; thirdly, the legal encounter is not a fully consensual gathering. 28

admission was being considered was often called by her first name or treated as if not present at all. In brief, although formal procedural protections were in place, the subjects of the hearings were generally marginalised by the hearing process. Vittoria does not measure the impact of these factors on the individuals involved or on the conclusion reached. However, it is likely the marginalisation described had an impact in both regards.

Carney and Tait found that the tribunals studied tended to adopt an inquisitorial rather than an adversarial approach to the hearing, either by gathering the evidence in advance or by direct questioning at the hearing.³⁰ During the hearing process, the tribunal members sought to incorporate the person whose guardianship was under consideration into the process, making efforts to welcome her and to explain the nature of the hearing³¹ and to involve her at various stages in the process.³² The tribunal members also sought to develop alliances between them and the individual whose guardianship was under consideration.³³ As a result, lawyers were sometimes made to feel marginalized, especially if they were hired by relatives rather than the individual herself³⁴ and medical evidence was carefully scrutinised, at times to the chagrin of doctors who were displeased to see their professional judgements treated as no more authoritative than the evidence of their patients.³⁵

Carney and Tait attempted to measure the success of the approach described above using a number of standards, including whether the individuals involved were satisfied with the process and its ultimate outcome.³⁶ In about half the cases, the individuals involved (including carers) were happy with the process and the outcomes and, in another third, they were partly satisfied.³⁷ It is difficult to know what conclusion to draw from these statistics because an individual's dissatisfaction with an outcome may not necessarily mean that the outcome was inappropriate and

²⁹ *Ibid*, 184.

31 *Ibid*, p 118.

³⁷ *Ibid*, p 156.

Supra note 26, p 192.

This included (*ibid*, pp 119-120) asking the person's views at different points and summarising medical evidence and giving the person the opportunity to comment on this.

Ibid, pp 120-121. Tribunal members also tried (*ibid*, pp 118-119) to minimise the impact of negative images emerging from professional evidence by stressing the similarities between the individual and the tribunal board members.

³⁴ *Ibid*, p 122.

³⁵ *Ibid*, p 123.

They also considered other indicia of success which were, first, whether the issue referred to the tribunal had been resolved, and, secondly, whether the individual's living conditions had improved. See generally *ibid*, Chapter 9.

because of the absence of comparable studies.³⁸ Nonetheless, the model described by Carney and Tait appears more likely to enhance patient capacity and to contribute to overall well-being than the more formal mechanism described by Vittoria.

The work outlined above suggests that developing an appropriate procedural framework for capacity assessment is not a straightforward matter. Different imperatives may suggest different requirements. For example, while legal representation may fulfil the fair procedures requirement in some ways, it may also have the effect of alienating the individual from the process. More work is needed and a specific study of the capacity assessment process would be important for the development of the law in this area. However, even in the absence of such a study, it appears clear that formal capacity assessment must be carried out in a way that is open and transparent and that treats the individual with respect and dignity and gives her a real opportunity to participate in the process.³⁹

Part II: Testing for Capacity: The Role of the Medical Profession

Regardless of the procedural framework employed, the medical profession is at the core of the capacity assessment process. Medical professionals are the primary capacity assessors in both formal and informal capacity assessments. Within the formal assessment process, the court's decision is almost inevitably based on expert evidence provided by medical witnesses. For the many patients for whom the formal capacity assessment process is not engaged, the determination of capacity is based solely on assessments made by doctors or psychiatrists regarding the patient's legal capacity. This Part begins by looking at the role of expert evidence regarding

In particular, it is not possible to determine whether the tribunal approach could operate equally well in a court setting if judges were prepared to take on the more inclusive attitude of the tribunal members. In another piece ("Sterilization: Tribunal Experiments in Popular Justice?" (1999) 22 International Journal of Law and Psychiatry 177), Carney and Tait compared decisions relating to non-consensual sterilisation made by the Australian Family Court and by tribunals and concluded that there were fundamental differences in approach. They found (ibid, 195) that, while some courts do use "narratives of consensus", the tribunals were "consistently more inquisitorial, and more skilled at scrutinizing, seeking out, and balancing evidence from a variety of sources than are the courts."

This may require judicial education as regards the best means of ensuring these values are upheld. See Shaddock et al "Communicating with People with an Intellectual Disability in Guardianship Board Hearings: An Exploratory Study" (1999) 24 Journal of Intellectual and Developmental Disability 279.

capacity within the formal process. It then looks at the informal process under which decisions are made without judicial overview. This Part concludes with a discussion of the limitations of medical professionals as assessors of legal capacity.

The Role of Expert Evidence

Expert evidence is an essential feature of capacity determination by courts. A survey of case law before the courts in England and Wales indicates that the vast majority of judicial decisions regarding capacity are based on psychiatric evidence regarding the patient's compliance with the legal test for capacity. This judicial approach is formalised in the *Practice Direction*, which states that "[e]vidence from a psychiatrist or psychologist who has assessed the patient applying the *Re MB* test to the particular decision in question is generally required. This goes somewhat further than the Court in *Re MB* (An Adult: Medical Treatment) itself, which described it as preferable but not essential to have psychiatric evidence of incapacity. However, perhaps the strongest endorsement of the importance of medical evidence is found in *Re B* (adult: refusal of medical treatment), where Dame Butler-Sloss P explained the legal position as follows:

[U]nless it is an exceptional case, the judicial approach to mental capacity must be largely dependent upon the assessments of the medical profession

A historical survey shows that courts have always placed a great deal of faith in medical evidence in capacity assessment. Shelford Practical Treatise on the Law Concerning Lunatics, Idiots, and Persons of Unsound Mind (Philadelphia: JS Littell,1833), p 40 describes the testimony of "medical men" as being "valuable" in the establishment of incompetence. As the medical profession became more systematic in its classification of mental disorders (this is often traced to the publication of Pinel's Treatise on Insanity (1801) trans Davis (reprinted New York: Hafner Publishing, 1962)), the evidence process became increasingly "medicalised" and the status of medical evidence increased accordingly. For a consideration of the changing role of medical evidence in the wardship process (primarily from a US perspective), see Krasik "The Lights of Science and Experience: Historical Perspective on Legal Attitudes Toward the Role of Medical Expertise in Guardianship of the Elderly" (1989) 33 The American Journal of Legal History 201.

Two exceptions to this rule are the original application under the declaratory jurisdiction in St George's Healthcare NHS Trust v S supra note 7 (which did not include medical evidence regarding capacity) and Ward J's finding of incapacity in Re E (A Minor) (Wardship: Medical Treatment) [1993] 1 FLR 386 (although medical evidence was adduced regarding the manner of death that awaited the young man in question).

⁴² Supra note 4, [7].

⁴³ [1997] 2 FCR 541, 562.

See also the guidance offered by the Court of Appeal in St Georges Healthcare NHS Trust v S supra note 7,970 which focuses on the judge's need for "sufficient information to reach an informed conclusion about the patient's capacity" rather than on the source of this information.

⁴⁵ [2002] 2 All ER 449.

whose task it is on a regular basis to assess the competence of the patient to consent or refuse the medical/surgical treatment recommended to the patient.⁴⁶

When uncontradicted expert evidence is presented to the court, the court's ultimate decision almost invariably accords with that of the medical expert.⁴⁷ However, as the law in this area has developed, it has become apparent that medical evidence regarding capacity may be in conflict, in some cases quite spectacularly.⁴⁸ In these cases, judges have had to decide between competing views. It is difficult to point to a pattern in terms of preferred evidence and, obviously, it is impossible to assess conclusions without having actually heard the evidence. However, one interesting aspect of some of the cases has been a judicial preference for the evidence of independent experts who do not have an immediate relationship with the person whose capacity is at issue. Thus, in Re C, Thorpe J preferred the evidence of psychiatrists appointed by the legal teams to that of the psychiatrist who had been the plaintiff's RMO for almost 18 months and who had gained the plaintiff's "trust and confidence."⁴⁹ Similarly, in Re JT, Wall J preferred the evidence of a psychiatrist who had met the patient twice⁵⁰ to that of a nurse sister employed by the hospital who did not have a specialisation in psychiatry but who appeared to have had an ongoing relationship with the patient.⁵¹ On the one hand, this preference, insofar as it exists, could be seen as favouring the objective perspective achieved by an outsider to the situation. However, it could also be argued that it fails to take account of the greater

Ibid, 471.

One notable (and widely criticised) exception is the decision in *Rochdale Healthcare (NHS)*Trust v C [1997] 1 FCR 274. Here, in circumstances of extreme urgency, Johnson J disregarded the views of the consultant obstetrician that a woman, who refused to consent to a caesarean section, was capable. Johnson J found the woman to be incapable without any supporting evidence. Cf the decision of the Irish Supreme Court in Re Glynn Deceased [1990] 2 IR 326 regarding testamentary capacity where the Court rejected the evidence that the testator was incapable given by the doctors who had cared for him after he had suffered a major stroke. The Court preferred evidence that the testator was capable given by the person who had drawn up and witnessed the testator's will and by the other witness to the will.

For a sample of some disagreements, see Re C (Adult: Refusal of Treatment) [1994] 1 WLR 290, 293; R (Wilkinson) v Broadmoor Special Hospital Authority [2002] 1 WLR 419, 425; Re JT (adult: refusal of medical treatment) [1998] 2 FCR 662, 665; B v Dr SS, Dr G and Secretary of State for the Department of Health [2005] EWHC (Admin) 1936, [190]. In Re T (Adult: Refusal of Treatment) [1992] 3 WLR 782, 791, the doctor in effect disagreed with himself, reversing completely his initial evidence (on the basis of which Ward J had made his first decision) that Ms T was incapable at the time she refused treatment.

⁴⁹ [1994] 1 WLR 290, 293.

⁵⁰ [1998] 2 FCR 662, 664.

⁵¹ *Ibid*, 665.

levels of knowledge that come from more intimate connections with the person whose capacity is being assessed.

Judicial reliance on the evidence of medical experts has often been the subject of critical comment and, in a public lecture delivered in 2001, Lord Woolf acknowledged that courts had, in the past, treated "the medical profession with excessive deference." Grisso, a psychologist writing from an American perspective, notes some of the problems with the quality of expert evidence in the context of capacity. First, the expert may be ignorant of the law and consequently fail to provide relevant testimony. Grisso uses the example of the expert who gives "diagnostic testimony" as conclusive evidence of incapacity; for example, where the expert gives evidence that the individual has a mental condition such as schizophrenia and then concludes on this basis that she is incapable. Secondly, the expert may be primarily concerned with persuading the court to accept her view and may therefore fail to present accurately the true complexity of a situation. Thirdly, experts may not take sufficient care in formulating the evidence they present. In Grisso's words:

Examiners sometimes may not obtain sufficient information about the examinee, in terms of quantity, type, or reliability of the observations, in order to reach certain conclusions credibly. In other instances, adequate data regarding the examinee may be available, but the interpretative meanings of the data in relation to the information needs of the court cannot be supported credibly by past research in psychiatry and psychology.⁵⁶

Some US legal commentators are more scathing in their critiques of the expert evidence given in capacity hearing in the context of refusal of treatment for a mental

⁵⁶ Supra note 53, p 17.

[&]quot;Are the Courts Excessively Deferential to the Medical Profession?" (2001) 9 Medical Law Review 1, 1. However, he argued that the position had begun to change for the better and that the balance is now "about right."

Evaluating Competencies: Forensic Assessments and Instruments (2nd Ed) (Dordrecht: Kluwer Academic, 2002).

Ibid, p 12. This would seem to be a longstanding difficulty with medical evidence. Writing in 1833, Shelford supra note 40, p 40 cautions against attempting to "try judicially the condition of any person by a comparison of his alleged symptoms with those which are stated by medical authorities to be usually the concomitants of insanity."

Ibid, p 15. This kind of approach is evident in Gutheil and Bursztajn "Clinicians' Guidelines for Assessing and Presenting Subtle Forms of Patient Incompetence in Legal Settings" (1986) 143 Am J Psychiatry 1020, 1020 where psychiatrists are advised on strategies for the presentation of evidence in relation to a patient whose capacity is not obviously impaired so as to avoid "the inexperienced assessor or judge" being "taken in".

disorder.⁵⁷ Morris⁵⁸ is very critical of the quality of psychiatric evidence presented at the capacity hearings he conducted in this context.⁵⁹ He found that:

Testimony was not merely conflicting; it was dissatisfying. Psychiatrists often assumed that patients' unwillingness to acknowledge their mental disorder was all that was needed to establish their incapacity. Many psychiatrists did not provide patients with needed information on medication side effects or respect patients' expressed concerns about side effects. To these psychiatrists, side effects were merely an annoyance but not a legitimate reason for rejecting the anticipated benefits of the proposed therapy.⁶⁰

Haroum and Morris⁶¹ argue that some psychiatrists provide evidence in a way that is essentially deceptive. They argue that this deceptive behaviour includes a failure to obtain informed consent for an assessment of capacity,⁶² a failure to acknowledge bias⁶³ and a failure to appraise courts of the true levels of their uncertainty in their opinions.⁶⁴ They argue that psychiatrists do not regard this kind of behaviour as inappropriate but instead:

[M]ost deceiving psychiatrists believe that they are behaving decently, properly, ethically, and in a saintly manner. They view their deceptions not as bad deeds, performed impulsively under the stress of the moment, but rather as planned heroic measures, designed to save Western Civilisation, or at least to promote Justice.⁶⁵

While it cannot be assumed that these critiques would apply in the different cultural and legal climate on this side of the Atlantic, they do show the need for a review of the quality of expert evidence relied upon. It is difficult to assess the

In addition to the commentators discussed in the text, see Stefan "Leaving Civil Rights to the 'Experts': From Deference to Abdication Under the Professional Judgment Standard" (1992) 102 Yale Law Journal 639; Bersoff "Judicial Deference to Nonlegal Decisionmakers: Imposing Simplistic Solutions on Problems of Cognitive Complexity in Mental Disability Law" (1992) 46 SMU Law Rev 329; Perlin "Pretexts and Mental Disability Law: The Case of Competency" (1993) 47 University of Miami Law Review 625.

[&]quot;Judging Judgment: Assessing the Competence of Mental Patients to Refuse Treatment" (1995) 32 San Diego Law Review 343.

Morris acted as a law-trained decision maker (as required for capacity-hearings under Californian law) and based his study on hearings conducted over a three-year period in San Diego county. During this time, under Californian law, capable patients had a right to refuse treatment and a right to a hearing with a "law-trained decision-maker" to establish capacity.

Supra note 58, 388.

[&]quot;Weaving a Tangled Web: The Deceptions of Psychiatrists" (1999) 10 Journal of Contemporary Legal Issues 227.

⁶² *Ibid*, 231.

⁶³ *Ibid*, 232.

⁶⁴ *Ibid*, 234.

⁶⁵ *Ibid*, 242.

quality of expert evidence relied upon by the courts without actually hearing the experts in question and empirical work in this regard would be useful. On the basis of the reported decisions alone, there is some variation in terms of the detail in which the expert evidence is recounted. Some decisions contain quite extensive summaries of the evidence presented⁶⁶ while others have tended to be terse and not to give much flavour of how the expert reached the conclusion.⁶⁷ There is not yet a systematic method of evaluating the quality of expert evidence and, with the exception of certain remarks of Dame Butler-Sloss in Re B,68 there has been little judicial attempt to provide guidance for experts in formulating appropriate evidence. The Practice Direction gives some assistance on the matter. The Direction rejects the relevance of expert evidence based on "global psychometric test results" as well as evidence based on references to the patient's "mental age". The Direction also emphasises the importance of expert evidence regarding whether the individual is likely to develop capacity in the future.⁷¹ While these are positive developments, they fall a long way short of the necessary systematic approach towards evaluating the role of expert evidence in capacity cases.

Notwithstanding the limitations of the actual overview process, it is clear from the preceding section that there is the possibility for judicial overview of medical evidence within the formal process. As will be seen in the next section, this is not the case with informal capacity assessments.

Informal Capacity Assessment

Medical professionals are the sole capacity assessors when the capacity assessment process is at an informal level. This is normally the case where there are no serious

See the detailed descriptions given by Butler-Sloss P in Re B (adult: refusal of medical treatment) [2002] 2 All ER 449, 462-470; by Thorpe J in Re C (adult: refusal of medical treatment) [1994] 1 WLR 290, 295; and by Charles J in B v Dr SS, Dr G and Secretary of State for the Department of Health [2005] EWHC (Admin) 1936, [190].

This was a feature of the early caesarean section cases where the basis for the expert's findings of incapacity was generally not set out in any detail.

Dame Butler-Sloss *supra* note 66, 470 drew particular attention to the evidence of one expert, a Dr Sensky, noting that the evidence "may be of assistance for clinicians in the future."

Although the *Practice Direction* does not expand on what this category of results includes, it may be assumed that the remarks were directed towards general tests such as the MMSE discussed further in text to note 113 *infra*.

⁷⁰ Supra note 4, 327.

⁷¹ *Ibid*.

doubts about capacity or the patient's decision is not high-risk.⁷² In these situations, the test applied is still the legal test for capacity. The doctor or psychiatrist is therefore required to make a legal decision without the benefit of legal assistance and with no likelihood of judicial oversight.

Professionals in this situation have some assistance regarding the capacity assessment process. In England and Wales, the Department of Health has published guidance on consent which incorporates the functional test for capacity. The General Medical Council includes capacity assessment within its ethical guidance relating to consent; the British Medical Association has developed a "Consent Tool Kit" which includes the functional test in outline and the Royal College of Psychiatrists covers the test for capacity in its guidance for professionals. However, this guidance is not especially detailed and can even be misleading. The Consent Tool Kit, for example, suggests that the test for capacity is solely concerned with understanding and retention and appears to run together the "use and weigh" aspect of the legal test with the ability to retain. A healthcare professional seeking advice from this source, which is presumably intended to be widely used, will immediately be led astray.

In light of the kind of guidance provided, it is hardly surprising that empirical studies suggest that healthcare professionals encounter relatively serious difficulties in applying the legal test for capacity. Jackson and Warner's survey of British healthcare professionals⁷⁸ reveals that only 20% of GPs, 34% of consultant geriatricians and 15%

See text to note 7 regarding when court approval is required.

See Department of Health Guidance Notes Seeking Consent: Working with Children (London: Department of Health, 2001); Seeking Consent: Working with Older People (London: Department of Health, 2001).

Seeking Patients' Consent: The Ethical Considerations (London: GMC, 1998). See also the Irish Medical Council's A Guide to Ethical Conduct and Behaviour (6th Ed) (Dublin: Medical Council, 2004), p 31 which simply states, in the context of acknowledging the patient's right to refuse treatment, "assessment of competence and the discussion on consent should be carried out in conjunction with a senior colleague."

Consent Tool Kit (2nd Ed) (London: BMA, 2003). See also the joint publication of the British Medical Association and the Law Society Assessment of Mental Capacity (London: BMA, 1995).

See *The Psychological Care of Medical Patients: A Practical Guide* (2nd Ed) (Royal College of Physicians and Royal College of Psychiatrists, 2003), pp 108-109.

Card 5 of the Kit states that "To demonstrate capacity individuals should be able to: understand in simple language what the medical treatment is, its purpose and nature and why it is being proposed; understand its principal benefits, risks and alternatives; understand in broad terms what will be the consequences of not receiving the proposed treatment; retain the information for long enough to use it and weigh it in the balance to arrive at a decision". See further Tan and McMillan "The Discrepancy Between the Legal Definition of Capacity and the British Medical Association's Guidelines" (2004) 30 Journal of Medical Ethics 427.

[&]quot;How Much Do Doctors Know About Consent and Capacity?" (2002) 95 Journal of the Royal Society of Medicine 601.

of medical students surveyed gave correct answers to basic legal questions⁷⁹ relating to consent and capacity.⁸⁰ Psychiatrists were found to have a better understanding of the law but, as a group, only 58% gave correct answers to the questions. Peay's study of professional decision-making under the Mental Health Act 1983 also found clinician discomfort with legal issues.⁸¹ While this study does not directly address decisions regarding capacity, Peay notes that "[t]he whole issue of capacity and consent was one with which practitioners understandably struggled."⁸² The introduction of legislation, such as the MCA 2005, is unlikely to change this underlying difficulty. In Scotland, a recent study indicated that healthcare professionals working in the field have limited knowledge of the Adults with Incapacity (Scotland) Act 2000.⁸³

A further study conducted by Warner and Wise attempted to look beyond simple awareness of legal information and to examine the way in which professionals carried out the actual assessment process. 84 The researchers studied approximately 90 mental health professionals at a North London Mental Health Trust to assess their abilities to investigate patient capacity in three different theoretical scenarios. The

The questions asked (*ibid*, 603) included: can a capable adult refuse treatment? and, should the Mental Health Act be used to treat a physical disorder when someone with a mental disorder is refusing treatment?

See also Knight "Judging Competence: When the Psychiatrist Need, or Need Not, be Involved" in Cutter and Shelp eds Competency: A Study of Informal Competency

Determinations in Primary Care (Dordrecht: Kluwer Academic Publishers, 1991) who describes a similar situation in the United States. Knight notes (ibid, p 4) that "[r]arely would [a general practitioner] be able to delineate a specific set of guidelines for establishing a diagnosis of psychological competence."

Decisions and Dilemmas: Working With Mental Health Law (Oxford: Hart Publishing, 2003). The study examined a total of 106 psychiatrists and approved social workers under the MHA 1983 in their methods of decision-making in three hypothetical scenarios involving the application of the Act. For a description of the study, see *ibid*, pp x-xi.

⁸² *Ibid*, p 105.

See Ramsey "The Adults with Incapacity (Scotland) Act – Who Knows? Who Cares?" (2005) 45 Scottish Medical Journal 20. The study investigated a total of 50 healthcare professionals (26 staff nurses, 6 charge nurses, 12 pre-registration house officers and 7 senior house officers and specialist registrars) working on acute and elective surgical and orthopaedic wards. Staff working on the acute wards showed greater awareness of the existence of the Act than those working on elective wards (85% rather than 54%). However, those staff that knew about the Act varied in their level of understanding of what the Act contained. None of the staff had received any formal training in relation to the Act.

The results of the study conducted by Dr ME Jan Wise, Specialist Registrar in Liaison Psychiatry, Hammersmith Hospital and Dr James W Warner were presented at the 2001 Annual Meeting of the Royal College of Psychiatrists. The paper does not appear to have been published and efforts to obtain further information from the authors have proved unsuccessful. The information in the text is based on a press-release of the Royal College of Psychiatrists relating to the 2001 Annual General Meeting and headed "Psychiatrists Fail to Assess Patients' Capacity to Consent". This is available at http://www.rcpsych.ac.uk/press/preleases/pr/pr 239.htm (last viewed July 26 2006).

assessments were based on fifteen minute interviews with the "patient". The professionals' responses were measured against those of an expert panel consisting of an expert in psychiatry, a professor of ethics and a medico-legal expert. All three scenarios involved the refusal of possibly life-saving but highly invasive treatment by an elderly woman with cancer. In the first scenario, the woman refused the treatment because she preferred to maintain her quality of life rather than to prolong her life. Here, the expert panel and 96.5% of professionals held her to be capable. In the second scenario, the woman did not wish to die but believed that the treatment would hasten her death and that she would die during surgery. The experts here regarded the woman as being incapable because she could not weigh the risks and benefits of the surgery. However, 25.6% of professionals regarded the woman as being capable. In the final scenario, the woman had Alzheimer's Disease and could not retain information. The experts regarded her as being incapable because of this inability but 18.2% of the professionals regarded her as capable.

The empirical studies outlined above support the contention that healthcare professionals have difficulty dealing with the concept of capacity. This is hardly surprising; after all, lawyers are just beginning to come to terms with the complexity of this legal concept. It does however indicate that deficiencies in this area need to be addressed by both the legal and medical professions and that more thorough guidance needs to be given to the medical profession.

Difficulties for Medical Professionals as Capacity Assessors

In addition to the difficulties with legal questions raised in the previous section, there are a number of broader issues which must also be taken into account in evaluating the role of medical professionals in assessing capacity. Two broad issues arise from the role of medical professionals as capacity assessors. First, medical professionals have a different philosophical focus to that of the law and this may impact on the way in which they perform their legal function. Secondly, medical professionals are no more immune to prejudice than any other sector of society and this may impact on their ability to perform their role as capacity assessors.

Some commentators draw attention to the potential conflict between the methodology, discourse and values of the law and that of experts from a non-legal background.⁸⁵ In the specific context of capacity assessment, doctors and lawyers have different methodological approaches which become apparent when they are confronted with the task of assessing a patient's capacity.⁸⁶ The fact that the assessment has legal consequences means that the law requires a certain and clear decision. From the doctor's perspective, however, definite answers are much less important or achievable. Knight, a psychiatrist, warns his fellow medical professionals:

When the psychiatrist interacts with the legal system, there is the constant danger that he will abandon the uncertainties of the clinical perspective for the alluring rationality of legal thought.⁸⁷

He notes the risk that the psychiatrist "may be led incorrectly to assess a person's functioning at a single time, in a single setting, with an uncertain factual base, and then draw a global conclusion about a person's functioning."88

The two professions may also have different motives. Operating from a legal perspective, Kirk and Bersoff characteristic the differences between the professions as arising from the fact that:

At a most extreme level, see the argument made by Teubner Law as an Autopoietic System (Florence: The European University Institute Press Series, 1993) that the law is autopoietic or self-referential. The effect of this is that, in the words of Eastman and Peay in Eastman and Peay eds Law Without Enforcement: Integrating Mental Health and Justice (Oxford: Hart Publications, 1999), p 21 (original emphasis), the law "cannot incorporate the concepts and 'thinking' of another discipline, including where it purports to utilise that other discipline as evidence within its own deliberations." Thus, "a discipline other than law cannot comment on legal provisions because any other discipline will necessarily use different constructs and ways of thinking from those of the law". Other commentators take a less absolutist position than Teubner but still argue that the law needs to be conscious of different motivations and philosophies in relying on evidence from experts outside the law. See Imwinkelreid Methods of Attacking Scientific Evidence (3rd Ed) (Virginia: Lexis Law Publishing, 1997).

Cf Moore Law and Psychiatry: Rethinking the Relationship (Cambridge: Cambridge University Press, 1984) who argues (*ibid*, p 432) that, in fact, law and psychiatry do not conflict in any major way in their underlying views of the individual and that if both disciplines were more philosophically aware of their underpinning views, the perceived differences between them would be removed.

⁸⁷ Supra note 80, p 26.

⁸⁸ Ibid. Note also the difficulties with the use of expert evidence of psychologists in capacity assessment identified by Roesch, Hart, and Zapf "Conceptualizing and Assessing Competency to Stand Trial: Implications and Applications of the MacArthur Treatment Competence Model" (1996) 2 Psychology, Public Policy and Law 96.

Psychiatrists are trained and ethically bound to heal. Presumably, they are highly motivated to provide treatment and eliminate symptoms of disease and illness. Lawyers and other law-trained persons are trained and ethically bound to defend individuals against foreseeable harm and governmental deprivation of constitutionally protected rights.⁸⁹

Abernethy⁹⁰ argues that psychiatrists are also put under pressure by other members of the medical profession to reach conclusions regarding capacity that facilitate the provision of treatment. She notes that "psychiatrists are gate-keepers who can frustrate other specialists in their drive to treat" and suggests that, "if psychiatric activities in support of patient's independence infringe too much on other specialists' turf, referral sources will dry up".⁹¹ Insofar as these arguments are true, it is likely that the pressures on psychiatrists would be accentuated when assessing capacity in the context of refusal of treatment for a mental disorder. Here, the conflict between therapeutic intentions and the capacity assessment process is enhanced because the patient's refusal directly challenges the assessor's own profession.

The view of the commentators outlined above is that healthcare professionals, including psychiatrists, are reluctant to reach conclusions themselves, or to facilitate courts in reaching conclusions, that will interfere with the medical profession's intrinsic desire for treatment. It is difficult to assess how realistic this view is. 92 However, this view was accepted by the Law Commission in its *Report on Incapacity* 93 and, in the context of treatment for a mental disorder, by the Richardson Report, 94 the Millan Report 95 and the Mental Health Act Commission. 96 Given that

[&]quot;How Many Procedural Safeguards Does it Take to Get a Psychiatrist to Leave the Lightbulb Unchanged? A Due Process Analysis of the MacArthur Treatment Competence Study" (1996) 2 Psychology, Public Policy and Law 45, 67.

[&]quot;Judgments About Patient Competence: Cultural and Economic Antecedents" in Cutter and Shelp eds *supra* note 80.

Ibid, p 218. Abernethy ibid quotes the following letter written by a psychiatrist: "In my experience as a psychiatric consultant, no cases have caused as much alienation of medical staff and the psychiatric service as finding a patient capable to refuse treatment. After such evaluations, requests for psychiatric consultation have dramatically decreased in number, with some medical staff viewing psychiatry as oppositional to good medical care."

See the study by Warner and Wise discussed in text to note 84 supra which, presuming that the experts were correct in the base-line capacity assessment, found that the most common professional error in dealing with capacity was an inappropriate finding of capacity rather than of incapacity. While interesting, the importance of this finding should not be over-estimated. Given that the experts had found the patient to be incapable in two of the three scenarios, the study was set up in such a way that most errors would have to happen in this way.

⁹³ Law Com No 231 (London: HMSO, 1995), p 40.

Report of the Expert Committee Review of the Mental Health Act 1983 (Department of Health, HMSO, 1999), para 2.9.

Review of the Mental Health (Scotland) Act 1984: New Directions (Edinburgh: Scottish Executive, 2001), p 55.

these Reports were based on contributions from psychiatrists in the field, it can be assumed that the views presented were based on experience in practice.⁹⁷

With current knowledge, it is not possible to assess the motives, whether proor anti-intervention, 98 which influence medical professionals in assessing capacity. This means that an important aspect of the functional test remains unobserved. This is also the case in relation to the second of the broader issues raised by the role of medical practitioners in capacity assessment, which is discussed in the next section.

Tensions in the Interaction between Assessor and Assessed

Capacity assessment requires a relatively complex interaction between two people – the assessor and the assessed – and brings with it a range of tensions and pressures. The quality of the interaction may be impeded by a number of factors. First, there is a power imbalance between the two parties. The process of inquiry places the patient in a disadvantaged position. As Stefan notes "[t]he very process that questions an individual's competence is disempowering and degrading to that person." This imbalance is increased by the fact that the process of inquiry is in large part controlled by the person who raises the question of capacity. As Abernethy points out in her anthropological study of capacity, a psychiatric evaluation is obtained in an "inherently coercive context". ¹⁰⁰ There is also an imbalance in the consequences of

The Mental Health Act Commission's Response to the Green Paper Proposals on the Reform of the Mental Health Act 1983 (MHAC, 2000) Appendix A, pp 33-34.

Supra note 80, p 219.

See also Richardson and Machin's findings ("Judicial Review and Tribunal Decision Making: A Study of the Mental Health Review Tribunal" [2000] Public Law 494, 507-508) on the way in which the medical members of Mental Health Review Tribunals operated. In particular, they found (*ibid*, 508) that "at the hearing itself and at the preliminary meeting... the medical member cannot resist being a doctor and addressing the well/unwell debate, despite official guidance to the contrary."

An, admittedly anecdotal, example from the author's experience shows how the assessor's anti-intervention views may also impact on capacity assessment. A geriatrician, who described himself as a "committed libertarian", when asked about his role in capacity determination within his specialist field (where a finding of incapacity would lead the patient to be admitted to a care home), expressed the view that his philosophy was to find as many patients as possible to be capable. When asked if his conclusions had any relationship with the actual legal standard for capacity, he responded that they had not.

[&]quot;Silencing the Different Voice: Competence, Feminist Theory and Law" (1993) 47 University of Miami Law Review 763, 782.

the assessment process. For the assessor, it is a professional decision;¹⁰¹ for the person assessed, the decision can quite literally be a matter of life and death.

Secondly, there may be communication difficulties between the parties. In some situations, these may be a result of the power imbalance described above.

Morreim¹⁰² sets out some of the other impediments to communication in the capacity assessment context:

A patient may deliberately avoid reporting his thoughts fully and faithfully. He may wish to test his physician's motives; to manipulate the health care team; to elicit sympathy from friends and family; to enjoy the gamesmanship of leading others on; or to secure any of a variety of other hidden agendas. A patient may not have the language or the cultural sophistication to express his beliefs and values explicitly and coherently. He may not feel like discussing certain things with the health care term, or may be embarrassed to reveal his real beliefs and goals. ¹⁰³

Communication difficulties may be accentuated by race,¹⁰⁴ gender,¹⁰⁵ class¹⁰⁶ and other differences between the assessor and the assessed.¹⁰⁷ MIND (the National Association for Mental Health) notes that psychiatric training in England is Eurocentric in its approach,¹⁰⁸ which may lead to difficulties in understanding and evaluating patients from different cultural or other backgrounds. The difficulty that this poses for effective evaluation may be seen in the following quote from a psychiatric evaluation of an African Caribbean woman: "She tends to talk past the point; it was difficult to tell whether this was a sign of psychosis or because of their

While the process may have professional consequences for the assessors, these consequences are almost inevitably less important. This point was recognised by the Court of Appeal in St George's Healthcare NHS Trust v S [1998] 3 WLR 936, 959 where the Court rejected the argument that it should take account of the impact of an adverse judgment on the career of the social worker who had made the initial decision to detain the claimant for assessment.

[&]quot;Competence: At the Intersection of Law, Medicine, and Philosophy" in Cutter and Shelp eds supra note 80.

¹⁰³ *Ibid*, pp 106-107.

On the impact of race on mental health law in England and Wales, see Fennell Treatment Without Consent: Law, Psychiatry and the Treatment of Mentally Disordered People Since 1845 (Routledge, 1995), pp 196-197 and Bartlett and Sandland Mental Health Law: Policy and Practice (2nd Ed) (Oxford: OUP, 2003), pp 383-384. On the position in the United States, see Stefan "Race, Competence Testing and Disability Law: A Review of the MacArthur Competence Research" (1996) 2 Psychology, Public Policy and Law 31, 33.

See Stefan *supra* note 99.

There has not yet been, to this author's knowledge, a class-based analysis of the way in which capacity assessments are made.

See generally Radden "Psychiatric Ethics" (2002) 16 *Bioethics* 397.

See the MIND Factsheet on *The Mental Health of the African and Caribbean Community in Britain* (August, 1998). This Factsheet notes research which suggests that African Caribbean people and especially those born in Britain were between ten and eighteen times more likely to be diagnosed as suffering from schizophrenia.

culture."¹⁰⁹ Similar cultural difficulties have been noted in relation to Irish-born people in Britain. In its Factsheet on *The Mental Health of Irish-Born People in Britain*, ¹¹⁰ MIND notes the difficulties which arise from different usage of the English language, misunderstanding of the role of religion and ritual in some Irish-born people's lives and a tendency to blame mental illness on "Catholic-guilt" or alcoholism while ignoring underlying causes. ¹¹¹ Thus, even when cultures are superficially similar, underlying differences between the assessor and the assessed may complicate the process of assessing capacity.

Tensions in the interaction between assessor and assessed are inevitable aspects of any functional test for capacity and would apply regardless of who assesses capacity. However, in order to evaluate properly the conclusions reached by the assessor, these tensions need to be made visible. This requires efforts by lawyers in the way in which they present expert evidence and by courts in the way in which they respond to this evidence and also by capacity assessors from the medical profession in the way in which they formulate their evidence and the way they assess capacity outside of the legal spotlight. As Gunn notes "any person assessing the competence of another individual must be aware of their own values so that assumptions and decisions are not made which are unjustifiable." In light of this, it is timely to assess efforts made by the medical profession to address issues of quality in the preparation of expert evidence.

Part III: The Contribution of Forensic Testing Instruments

Increased awareness of the deficiencies in the quality of expert evidence in capacity cases led medical professionals to develop a number of forensic testing mechanisms for capacity. The Mini-Mental State Examination (MMSE), developed in 1975, 113

Browne Black People and Sectioning – The Black Experience of Detention under the Civil Sections of the Mental Health Act (London: Little Rock Publishing, 1997), quoted in MIND Factsheet ibid.

⁽November, 2001).

According to the MIND Factsheet *ibid*, a disproportionately high number of Irish born people are likely to be compulsorily detained under MHA 1983 and ECT is more likely to be administered to Irish-born patients.

[&]quot;The Meaning of Incapacity" (1994) 2 Medical Law Review 8, 21.

The test (which is sometimes referred to as the Folstein Test) is described in Folstein, Folstein and McHugh "Mini Mental State – A Practical Method for Grading the Cognitive State of Patients for the Clinician" (1975) 12 J Psych Research 189. The test is based on a series of

was one of the earliest standardised capacity assessment methods. This test remains the first step for many general practitioners at an initial level of assessment. Among the test's attractions are that it is relatively quick to administer and requires little or no specific training on the part of the assessor. The test is not specific and does not relate in any way to legal standards for capacity. At most, it can point to possible cognitive difficulties that require further investigation. The *Practice Direction (Declaratory Proceedings: Incapacitated Adults)* appropriately rejects the relevance of these non-specific tests to the assessment of capacity in a legal context.

As capacity has become increasingly important in a legal context, forensic testing mechanisms for capacity have become more sophisticated. The aim of these tests is to improve the quality of expert evidence by increasing assessors' awareness of the range of issues involved in assessing capacity and of their role in the process. The best known of the tests is the MacArthur Competence Assessment Tool for Treatment (the MacCAT-T) which was developed in the United States by Grisso, a psychologist, and Appelbaum, a psychiatrist. While the MacCATT-T is based on a different standard for capacity to the law in England and Wales, the MacCATT-T merits discussion because it shows the possibilities and limitations of a rigorous forensic testing mechanism in addressing the difficulties with assessments of capacity by medical professionals outlined above.

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questions. These are intended to test orientation: the patient is asked the date, day of the week, as well as addresses and other basic information; memory: the patient is required to remember names of objects; concentration: the patient is asked to perform basic arithmetical functions and to spell words backwards; language: the patient is asked to write a sentence; visual-spatial ability: the patient is asked to copy a drawing. Scoring is out of a total of 30; it is recommended that patients who score below 23 should be referred for further assessment. Even in this regard, the MMSE has been surpassed by later, more sophisticated tests for understanding; see for example the Neurobehavioural Cognitive Status Examination (described further in Kiernan et al "The Neurobehavioural Cognitive Status Examination: A Brief but Quantitative Approach to Cognitive Assessment" (1987) 107 Annals Intern Med 481).

See text to note 70 *supra*.

See for example the Hopkins Competence Test (described in Janofsky, McCarthy and Folstein "The Hopkins Competency Assessment Test: A Brief Method for Evaluating Patients' Capacity to Give Informed Consent" (1992) 43 Hospital and Community Psychiatry 132); and the Capacity to Consent to Treatment Instrument (CCTI) (described by Marson, Ingram, Cody and Harrell "Assessing the Competency of Patients with Alzheimer's Disease Under Different Legal Standards: A Prototype Instrument" (1995) 52 Arch Neurol 949). For a useful summary of the most widely recognised tests, see Grisso Evaluating Competencies supra note 53, Chapter 9.

The test was developed from the authors' work on the MacArthur Treatment Competence Study. Details of the test may be found in Grisso and Appelbaum Assessing Competence to

The MacCAT-T in Outline

The MacCAT-T tests for four abilities, which were chosen by its authors based on their views of the standards applied by the courts in the United States and the appropriate standards based on ethical commentaries.¹¹⁸ These are the ability to express a choice, to understand relevant information, to appreciate the situation and its consequences, and to manipulate information rationally.

The MacCAT-T is administered through a semi-structured interview before which patients must be informed about the purpose of the interview. The tests do not need to be administered by a trained psychiatrist¹¹⁹ and should take approximately 20 minutes to administer together with a few minutes for preparation and evaluation.¹²⁰ The test itself involves three separate test measures. The first test measure is called "Understanding Treatment Disclosures" (UDT). Under this measure, the assessor provides the patient with information relating to the disorder, the treatment proposed and the risks and benefits. The assessor then tests the patient's understanding through questions that demand the patient's own words description of the information provided and through the patient's response to statements that must be identified as being 'the same as' or 'different to' the information. The second test measure relates to the patient's "Perceptions of Disorder" (POD) and is designed to test the patient's capacity to appreciate the relevance of the information provided in her own circumstances. This test has two parts; the first part tests whether the patient acknowledges the existence of the disorder and the second part tests whether the patient believes that the treatment proposed can improve her condition The final test measure is called "Thinking Rationally About Treatment" (TRAT). This assesses the patient's reasoning processes, by looking at the way in which the patient reaches the decision. The test requires the patient to state reasons for her decision. The patient is then marked on the basis of consequential reasoning, comparative reasoning, generating consequences and logical consistency. 121

Consent: A Guide for Physicians and Other Health Professionals (Oxford University Press, 1998).

Assessing Competence to Consent ibid, p 32.

¹¹⁹ *Ibid*, p 78.

¹²⁰ *Ibid*, p 105.

Ibid, pp 187-188.

Two features of the MacCAT-T merit special attention. First, each test measure is scored separately and there is no overall score. 122 Further, there is no set level at which capacity in any particular field is achieved. In fact, Grisso and Appelbaum are careful to point out that "[t]here are no test scores, ratings, or hardand-fast rules to which clinicians can turn for definitive conclusions about patients' competence."123 The aim of the test is not to provide definitive conclusions about capacity but to facilitate assessors in preparing and giving expert evidence while leaving the ultimate determination of capacity in the hands of the court (or other designated body). Grisso and Appelbaum note elsewhere that "[c]onclusions about legal competence are assisted by empirical observations, but they are ultimately moral in nature."124 A second feature of the MacCAT-T is that the test attempts to take account of the role of the assessor. The test places considerable emphasis on the assessor's ability to explain and the testing tools employed are administered in a way that depends on (and indeed tests) the assessor's ability to explain information and respond to patient difficulties. Thus, the test is aimed not just at assessing capacity but at enhancing capacity and, as part of their description of the test, Grisso and Appelbaum set out detailed techniques to maximise patients' performance. 125 In this regard, the MacCAT-T attempts to take on board more sophisticated views of capacity as a contingent rather than an immutable concept. 126

Given that that the standard for capacity utilised in the MacCAT-T differs from the legal standards adopted by the English courts, its potential application to actual capacity assessment is limited. However, even in the United States, where the test is more legally relevant, the MacCAT-T does not appear to have been widely adopted for use in the field. Grisso offers a number of reasons why this is the case. First, it is easier, faster and cheaper not to rely on testing mechanisms of this kind. Secondly, some clinicians may regard the test as too sophisticated for (what they regard as) more clear-cut cases. Finally, he notes that the adoption of more

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Details of the scoring procedure are found *ibid*, pp 183-190.

¹²³ *Ibid*, p 129.

Grisso and Appelbaum "Values and Limits of the MacArthur Treatment Competence Study" (1996) 2 Psychology, Public Policy and Law 167, 169. For a similar argument, see Grisso supra note 53, p 15.

Assessing Competence to Consent supra note 117, pp 92-98.

See discussion in Chapter 2 at text following note 147.

Supra note 53, pp 481-482.

sophisticated and detailed testing mechanisms leaves experts more open to scrutiny during the legal process.

The Value of Forensic Testing Mechanisms

Given its limited practical relevance, the most interesting question arising from the MacCAT-T experience is whether forensic testing mechanisms of this kind are a suitable way of dealing with the difficulties in expert evidence identified in this chapter. There are undoubtedly positive features to the development of mechanisms that are legally aware and, at the same time, accessible and usable by medical professionals. A legally appropriate equivalent to the MacCAT-T could improve the quality of expert evidence and allow courts to engage in closer scrutiny. However, such a development should be approached with care. As was evident in the last chapter, there are still significant gaps in the legal test for capacity. Without more clarity in the legal test, the testing mechanism could come to determine what is being tested for, rather than the other way round. The legal test for capacity represents the law's compromise between the competing values of patient autonomy and patient protection. While this may be influenced by the views of the medical profession, this should take place only in an overtly policy-conscious context where its impact can be openly discussed and not though the adoption of apparently neutral testing mechanisms which hide the ethical judgements made.

There is also a danger that any testing mechanism cannot avoid becoming an apparently objective measure or, as described by one set of commentators, a "capacimeter"¹²⁸ and that courts and expert assessors will not be able to resist regarding evidence arising under the test as conclusive in determining an individual's status. Given the need for certainty in the law, Grisso and Appelbaum's contention¹²⁹ that the MacCAT-T is not intended to provide hard and fast answers is unlikely to survive for long in a court setting. Instead, the results under the MacCAT-T would probably prove decisive. The existence of the test would create a false impression of objectivity which would serve to obscure still further the underlying biases that

Kapp and Mossman "Measuring Decisional Capacity: Cautions on the Construction of a 'Capacimeter'" (1996) 2 Psychology, Public Policy and Law 73.

See text to and following note 123 supra.

inevitably pervade the capacity assessment process and which should be more clearly acknowledged in evaluating expert evidence.

Ultimately, while the work of Grisso and Appelbaum and others should be welcomed for bringing a more thoughtful approach to the medical professional's role in capacity assessment, it does not present an obviously desirable way to improve the quality of expert evidence. Rather than adopting a more "scientific" approach to the inevitably messy process of assessing capacity, the process could be improved through the more simple steps of increasing medical professionals' awareness of the nature of the legal tests which they are actually applying and of their own limitations in applying such tests. As Gunn notes, values cannot be removed from the assessment process, but "assessors of capacity can be educated to be aware of their own values". 130

Conclusion

This chapter has argued that the legal test for capacity cannot be understood simply in terms of its technical requirements. A proper understanding of the test must also take account of the process of inquiry employed, the format and conduct of the hearing and the nature of the evidence relied upon. This chapter identified the problems in the capacity assessment process and established the ways in which this process deviates from the theoretical model of the capacity requirement within the autonomy paradigm. Even within the more protective procedural framework set out in the *Practice Direction*, there is no guarantee that capacity assessments are conducted in a way which reaches the most appropriate resolution and which takes sufficient account of the relevance of the process employed on the ultimate decision reached and on the patient's broader well-being. Further, a review of the role of the medical profession shows the difficulties encountered at the frontline of capacity assessment which are rarely acknowledged in legal discussions of capacity. As Stefan notes:

Although competence is a matter of a dynamic or dialogue between doctor and patient ..., legal doctrine sets up this dialogue so that the powerful half of the conversation remains entirely invisible."¹³¹

Supra note 112, 21.

Supra note 99, 783.

While identifying these limitations, this chapter also set out ways in which these limitations can be addressed and the assessment process can be improved. In particular, greater involvement of patients, greater scrutiny of medical evidence and better guidance for professionals could reduce the problems identified. However, even if these steps are taken, this chapter still shows that capacity assessment will never be the neat and unbiased process assumed under the autonomy paradigm. In light of this and of the arguments made in the previous chapter regarding the scope and nature of the functional test, it falls in the next, and final substantive chapter of the thesis to look again at the role played by the nature of the patient's decision in establishing the patient's capacity.

Chapter 7: Revisiting the Role Played by the Patient's Decision in Establishing Capacity

Introduction

Within the conceptually pure autonomy paradigm outlined in the first chapters of this thesis, it is clear that the nature of the patient's decision should be irrelevant to the test for capacity and to the capacity assessment process. It would be meaningless to allow a capable patient to do as he wished and then determine a patient's capacity on the basis of whether or not one agreed with his decision. In the words of the Law Commission, assessing a patient's capacity on the basis of the decision he makes "penalises individuality and demands conformity at the expense of personal autonomy." This theoretically consistent position is routinely affirmed by the courts² and defended in policy discussions³ regarding the nature of capacity. This position is also given legislative effect in the Mental Capacity Act 2005 (MCA 2005) which states that a person is "not to be treated as unable to make a decision merely because he makes an unwise decision."

Notwithstanding this theoretical consistency, it was argued in the preceding two chapters that, when capacity is examined as a practical rather than a conceptual requirement, it is much more difficult to remove the nature of the patient's decision from the process of assessing capacity. Put simply, a patient who makes a decision which appears to the capacity assessor to be unreasonable is highly likely to be found to be incapable, especially if the decision has serious implications for the patient's life or health. Chapter 5 argued that, when the functional test for capacity is broken down, it reveals tensions which make it difficult for an assessor to apply the test without

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Report on Mental Incapacity Law Com No 231 (London: HMSO, 1995), p 33.

See for example Re MB (An Adult: Medical Treatment) [1997] 2 FCR 541, 554 per Butler-Sloss LJ; St George's Healthcare NHS Trust v S [1998] 3 WLR 936, 957 per Judge LJ; Bolton Hospitals NHS Trust v O [2003] 1 FLR 824, 827 per Dame Butler-Sloss P.

See the Law Commission Report on Mental Incapacity supra note 1, p 33; President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research Making Health Care Decisions: A Report on the Ethical and Legal Implications of Informed Consent in the Patient-Practitioner Relationship (Washington DC: US Superintendent of Documents, 1982), p 61; Law Reform Commission Consultation Paper Vulnerable Adults and the Law: Capacity (LRC CP 37-2005) (Dublin: Law Reform Commission, 2005), para 3.45.

⁴ Section 1 (4).

reference to the nature of the decision. Chapter 6 argued that the process of capacity assessment provides little overview of how assessors' reach conclusions regarding capacity and consequently facilitates assessors in assessing capacity on the basis of their view of the patient's decision. In both chapters, it was argued that the pressures on assessors to look to the nature of the patient's decision were greater where the patient had an underlying mental disorder.

In light of these arguments, this final substantive chapter revisits the role played by the patient's decision within the assessment of capacity. The chapter has two parts. Part I explores the ways in which the nature of the patient's decision influences capacity assessment in practice, showing up the dissonance between the practical reality of the test and the theoretical model of the autonomy paradigm. In this regard, the chapter pays special attention to the English courts' apparent adoption of a variable standard for capacity dependent on the gravity of the decision. As will be seen, more serious decisions are regarded as requiring a higher standard of capacity. Part I argues that this variable standard allows the nature of the patient's decision to dictate the capacity assessment process and, therefore, that it is inconsistent with the view of the capacity requirement within the theoretical model of the autonomy paradigm. Having established the ongoing role played by the nature of the patient's decision, Part II of the chapter asks how best to deal with this. It argues that the courts will never be able entirely to avoid reference to the nature of the patient's decision, especially in difficult treatment refusal situations. There is therefore an argument that the variable standard based on gravity may provide a means of monitoring the inevitable impact of this factor on the capacity assessment process. However, this comes at a cost to the patient's right of autonomy. For this reason, regardless of the approach ultimately taken to the variable standard, the analysis in this chapter reinforces the argument that, in practice, the capacity requirement can never deliver the pure form of autonomy conceived within liberal theory.

Part I: The Impact of the Patient's Decision on Capacity Assessment

This Part identifies three ways in which the nature of the patient's decision impacts on capacity assessment. First, the nature of the decision is central to whether the issue of

capacity requires a court hearing. Secondly, there is some evidence in the case law that the patient's decision plays a covert role in the assessment of capacity and this is supported by evidence from medical professionals. Thirdly, the variable standard for capacity, whereby a higher level of capacity is required for more grave or serious decisions, accords a role to the nature of the patient's decision in setting the standard for capacity.

Challenging Capacity and the Nature of the Patient's Decision

It is widely accepted that, in practice, several factors influence whether or not a patient's capacity will be questioned by healthcare providers. First, capacity will be questioned primarily where the patient makes a decision that is unacceptable to the person charged with his care. In the healthcare context, this means that a compliant patient who agrees to treatment is less likely to be subjected to a capacity assessment. Secondly, capacity is more likely to be questioned in high-risk situations where the stakes are sufficiently high to merit the expense and trauma of a referral to a psychiatrist or a court application. This position is acknowledged in *St Georges Healthcare NHS Trust* v S, where formal assessment of capacity was considered necessary only in "serious or complex cases involving difficult issues about the future health and well being or even the life of the patient". The position is also acknowledged in the *Draft Code of Practice* under the MCA 2005 which states that the need for an investigation of capacity may arise "if an individual repeatedly makes unwise decisions which will place him/her at a significant risk of harm or serious exploitation."

According a role to the nature of the patient's decision at this preliminary stage of the process may be justified on a number of grounds. First, it makes practical sense not to require an assessment of capacity in every situation if the patient's

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See the Law Commission Report on Mental Incapacity supra note 1, p 33. Similar arguments are made by the President's Commission for the Study of Ethical Problems supra note 3, p 61 and Jones and Keywood "Assessing the Patient's Competence to Consent to Medical Treatment" (1996) 2 Medical Law International 107, 107-108.

⁶ [1998] 3 WLR 936.

⁷ *Ibid*, 969.

Braft Code of Practice Mental Capacity Bill 2004 (Department of Constitutional Affairs, 2004), para 3.22.

decision does not have serious implications for the patient. In the words of the President's Commission:

[N]either the self-determination nor the well-being of a patient would usually be advanced by insisting upon an inquiry into the patient's decisionmaking capacity (or lack thereof) when patient, physician, and family all agree on a course of treatment.⁹

While the President's Commission conceded that a formal assessment process "would undoubtedly results in 'better' decisions for some patients", ¹⁰ it rejected such a process on the basis that it would impose "substantial additional costs and burdens on the health care system." Secondly, it can be argued that challenging the capacity of a patient may have adverse implications for other aspects of the patient's wellbeing and that this trauma should be avoided unless it is necessary.

However, relating the questioning of capacity to the nature of the patient's decision has some disadvantages. Clearly, it means that the decisions of non-compliant patients are the only ones likely to be overridden on the basis of incapacity. Thus, these patients' right of autonomy comes under greater pressure because of what they choose to do. This adds to the stresses imposed on the non-compliant patient and arguably makes it more difficult for patients to raise legitimate questions about treatments. This approach also means that decisions of compliant patients are less subject to review. It raises the possibility that treatment may be provided on the basis of a nominal consent which is legally and ethically meaningless.¹³

Notwithstanding these practical concerns, the role played by the patient's decision in initiating the capacity assessment process is not inconsistent with liberal principle. There is an important difference between raising questions about a person's capacity to do something on the basis of the decision he makes and concluding on

11 *Ibid*, p 62 note 15.

⁹ Supra note 3, pp 61-62.

¹⁰ *Ibid*, p 62.

See the arguments made by the Mental Health Act Commission in *The Mental Health Act Commission's Response to the Green Paper Proposals on the Reform of the Mental Health Act 1983* (MHAC, 2000) Appendix A, p 34 and by Winick "The Side Effects of Incompetency Labelling and the Implications for Mental Health Law" (1995) 1 *Psychology, Public Policy and Law* 6.

Although cf the Practice Direction (Declaratory Proceedings: Incapacitated Adults) [2002] 1 WLR 325 which requires court approval to be obtained for certain procedures, for example, non-consensual sterilisation.

whether the person is capable on the basis of that decision.¹⁴ In the first situation, all that is required is that the existence of the right of autonomy be established as a matter of fact before it may be exercised, while in the second situation, the exercise of the right is directly prevented.

The Hidden Role Played by the Patient's Decision in Capacity Assessment

Any attempt to discuss the role of the patient's decision in capacity assessment runs into the obvious difficulty that courts and assessors will rarely acknowledge this role and therefore arguments in this regard are inevitably speculative. One of the few acknowledgments is found, perhaps ironically, in *Re T (Adult: Refusal of Medical Treatment)*¹⁵ where Lord Donaldson MR noted:

That his choice is contrary to what is to be expected of the vast majority of adults is only relevant if there are other reasons for doubting his capacity to decide. The nature of his choice or the terms in which it is expressed may then tip the balance.¹⁶

Beyond this, there is evidence that a hidden role is played by the patient's decision in capacity assessment. First, all the major policy documents relating to capacity recognise this hidden role. The Law Commission recognised that an "outcome based approach" to capacity "is almost certainly in daily use"¹⁷ and the Richardson Report, ¹⁸ the Millan Report, ¹⁹ and the Mental Health Act Commission²⁰ all identified the likely role played by the nature of the patient's decision in determining capacity in the context of treatment for a mental disorder. Because of the significant professional

Support for this distinction may be gained from Mill's famous wayfarer example (see On Liberty (London, 1859), p 107) which may be applied by analogy to the situation discussed in the text. In this example, Mill states that, if a wayfarer is approaching a dangerous bridge and an observer does not know if he is aware of the danger, it is permissible to stop him to warn him of the dangers ahead. However, if, following the warning and presuming he is a capable adult, the wayfarer still wishes to proceed, he should be permitted to do so. Requiring a capacity assessment to be carried out to ensure the patient's capacity to make a decision is the equivalent of stopping the wayfarer to check that he knows the risks involved.

^{15 [1992] 3} WLR 782. 16 *Ibid*, 796-797.

Supra note 1, pp 39-40.

Report of the Expert Committee *Review of the Mental Health Act 1983* (Department of Health, HMSO, 1999), para 2.9.

Review of the Mental Health (Scotland) Act 1984: New Directions (Edinburgh: Scottish Executive, 2001), p 55.

Supra note 12, Appendix A, pp 33-34.

input into these policy documents, it can be assumed that the views expressed in the documents accurately represent practice on the ground among capacity assessors.

Secondly, as is clear from the discussion in Chapter 1, courts generally reach convenient conclusions about capacity which enable them to affirm the importance of the general principle of patient autonomy while, at the same time, protecting the patient's other interests. In some instances, the capacity assessments involved seem to have been carried out with a very clear judicial eye on the outcome of the decision. The decision in Rochdale Healthcare (NHS) Trust v C²¹ is perhaps the most notable in this regard. Here Johnson J rejected the view of the consultant obstetrician that "the mental capacity of the patient was not in question and that she seemed to him to be fully competent" and held that the patient did not have the legal capacity to refuse a caesarean section, although he had no basis upon which to base this conclusion other than the information he had been given that the woman was in labour.²²

While the Court of Appeal decisions in Re MB (an adult: medical treatment)²³ and St George's Healthcare NHS Trust v S²⁴ have affirmed the right of a pregnant woman to refuse a caesarean section, it is unlikely that these decisions will remove outcome-based capacity assessment in this emotive area. Showing unusual openness in this regard, Thorpe J, writing extra-judicially noted:

Whatever emphasis legal principle may place upon adult autonomy with the consequent right to choose between treatments, at some level the judicial outcome will be influenced by the expert evidence as to which treatment affords the best chance of the happy announcement that both mother and baby are doing well.25

Fegan and Fennell²⁶ show why findings of incapacity are likely to continue to be a feature of the law in this area. They argue that "the exclusion of the foetus from legal status may actually strengthen the extent to which moral obligations to take account of its interests can be imposed on the mother, and women risk being thought 'unmaternally mad' if they do not succumb [to the recommended treatment]."27 In

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Ibid, p 91.

²¹ [1997] 1 FCR 274.

²² Ibid, 275.

^{(1997) 2} FCR 541. 24

^{[1998] 3} WLR 936.

²⁵ "The Caesarean Section Debate" [1997] Fam Law 663, 664.

²⁶ "Feminist Perspectives on Mental Health Law" in Sheldon and Thompson eds Feminist Perspectives on Mental Health Law (London: Cavendish Publishing, 1998), p 89. 27

other words, while the law allows a capable woman to place the foetus' life in danger through treatment refusal, the courts' vision of normality is so challenged by any woman who actually avails of her right in this regard that her decision will automatically lead to her capacity being called into question.

A further likely context in which the nature of the patient's decision will play a hidden role relates to the refusal of treatment for a mental disorder. While the body of case law relating to capacity assessment in this context is still developing,²⁸ it is notable that there has not yet been a reported case in which a refusing patient has been held to be capable.²⁹ This accords with the US experience, discussed in Chapter 4, where the vast majority of patients who sought to refuse treatment for a mental disorder were found to be incapable if the formal capacity process was engaged.³⁰

While the classic cases in which the patient's decision impacts on capacity assessment are likely to result in a finding of incapacity, this is not the only possible way in which the patient's decision may have a bearing on the assessment. Another more unusual possibility arises where a patient refuses life-sustaining treatment in, what the court believes to be, reasonable circumstances. As discussed in Chapter 2, there are complex legal and ethical questions regarding when the quality of a patient's life justifies the withdrawal of treatment on the basis of best interests.³¹ Furthermore, as noted in that chapter, the law has still not found an adequate framework within which to take account of patients' unwillingness or resistance to treatment. In this climate, the court's reference to the nature of the patient's decision is likely to lead courts to find patients to be capable and therefore to allow these questions to be

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Although, as discussed in Chapter 4, an involuntary capable patient does not have the right to refuse treatment under the MHA 1983, in some situations the patient does have a right to have his capacity assessed and taken into account in determining if the case for the statutory imposition of treatment has been made. As a result, capacity assessments are becoming more of a feature of the law in this area.

See B v Dr SS, Dr G and Secretary of State for the Department of Health[2005] EWHC (Admin) 1936, [190] where Charles J held the patient to lack capacity because of his inability to accept that he had a mental illness; R (B) v Dr Haddock and Ors [2005] EWHC 921 (Admin), [29] where Collins J concluded that the patient was incapable because of his "belief that any proposed treatment could not be in his best interests and his inability as a consequence to weigh properly and sensibly the advantages and disadvantages." Capacity was not contested in R (PS) v RMO and Ors [2003] EWHC 2335 (Admin); the patient was clearly incapable in R (N) v Dr M [2002] EWHC Civ 1789; and the issue of capacity was not determined in R (Wilkinson) v Broadmoor Special Hospital Authority [2002] 1 WLR 419.

See Chapter 4 at text to note 165.

See Chapter 2 at text to note 55.

avoided and treatment to be withdrawn on the basis of the patient's right of autonomy.³²

Ultimately, it is likely to prove impossible completely to remove either subconscious or tacit glances at the nature of the patient's decision from the capacity assessment process. Judges may believe that they are assessing capacity using a simple functional test but, as Thorpe J conceded, one part of the judicial mind will almost inevitably be drawn towards the consequences to which the assessment will give rise.³³ The difficulty of the task and the limitations of the functional test make it very difficult to assess capacity to make a decision without using the decision made as an indicator of capacity to some degree. Alongside this unstated recourse to the nature of the patient's decision, the courts have also endorsed a more overt role for the nature of the decision in adopting a variable standard for capacity based on the gravity of the decision involved. This role will be discussed in the next section.

A Gravity-Based, Variable Standard for Capacity

In Re T (Adult: Refusal of Medical Treatment),³⁴ Lord Donaldson MR expressed the view that the standard for capacity should vary according to the gravity of the decision, stating that:

See Re JT (adult: refusal of mental treatment) [1998] 2 FCR 662 where Wall J held that an intellectually disabled patient had the legal capacity to refuse dialysis following renal failure. The evidence upon which Wall J based his conclusion was, first, that of the medical team (ibid, 664) which appeared to address primarily the question of understanding and was less strong on the patient's ability to weigh information; secondly, that of the patient's family (ibid, 664-665) which indicated that the patient was consistent in her views, and, finally, that of a representative of the Official Solicitor (ibid, 665) which established that the patient sounded calm and rational on the telephone and that she said she did not want the treatment. He rejected the evidence of a nurse who had been caring for the patient (ibid, 665) that the patient believed that she would get a kidney transplant and did not fully understand the consequences of refusing the treatment. This evidence does not appear entirely convincing and it is notable that Wall J also noted (ibid, 665) that it would be very difficult to administer dialysis to the woman without her consent.

The attitude identified by Thorpe J (see text to note 25 supra) is borne out in his own approach in Re C (Adult: Refusal of Treatment) [1994] 1 WLR 290, 293 where he famously held the claimant to have the capacity to refuse a leg amputation. Thorpe J noted that amputation carried a 15% mortality risk and set out the alternatives to amputation before finding that the hospital authorities had failed to discharge the burden of finding the patient to be incapable. Whether he meant to or not, it would seem that Thorpe J could not resist investigating the reasonableness of the patient's decision as part of the capacity assessment process.

³⁴ [1992] 3 WLR 782.

[T]he doctors should consider whether at that time [the patient] had a capacity which was commensurate with the gravity of the decision which he purported to make. The more serious the decision, the greater the capacity required.³⁵

As will be seen below, this position has been endorsed in a number of later judgments. While Lord Donaldson MR did not expand further on the point, the view that the standard for capacity should vary according to the nature of the patient's decision has a theoretical pedigree albeit a hotly-debated one. In order to appreciate the import of Lord Donaldson's statement, it is necessary to review this broader debate. This will be followed by discussion of the status of the gravity-based standard in English law.

The Theoretical Basis for the Variable Standard for Capacity

The argument that the standard for capacity should vary according to the nature of the patient's decision was first put forward by Drane³⁶ in his "sliding scale model"³⁷ for capacity. Under this model, the level of capacity required in order for a patient to be capable varies according to the risks and benefits of the decision. The lowest level of capacity³⁸ is required for medical decisions "that are not dangerous and are objectively in the patient's best interest"³⁹ and the highest level of capacity is required where the patient's decision is contrary to his best medical interests, for example, where the patient refuses effective treatment for an acute illness. Thus, under this model, a patient may be capable of consenting to a treatment while, at the same time, being incapable of refusing the same treatment.

Drane's model is a simple one. He uses "reasonable" or objective outcomes in determining risk and benefit; a decision requires a high level of capacity if it does not accord with the patient's best medical interests. Buchanan and Brock present a rather

Ibid, 796. Later in his judgment, Lord Donaldson repeated this requirement in slightly different language. In summarising his conclusions, his Lordship noted (ibid, 799) that "What matters is whether at that time the patient's capacity is reduced below the level needed for a refusal of that importance, for refusals can vary in importance. Some may involve a risk to life or of irreparable damage to health. Others may not."

[&]quot;The Many Faces of Competency" (1985) 15 Hastings Center Report 17.

³⁷ *Ibid*, 18.

Drane proposes a very low standard in these situations. He argues (*ibid*, 18) that a patient is capable if he is aware of his situation and has assented to the proposed treatment.

Ibid, 18. Treatments of this kind would include life saving treatments as well as low-risk, high-benefit treatments.

more sophisticated model, also based on the sliding scale principle.⁴⁰ They accept Drane's argument that capacity should vary according to the levels of risk and benefit of the decision. However, rather than advocating an objective standard for the assessment of risk and benefit, they argue that the assessment of risk and benefit should "focus on the expected effects of a particular treatment option in forwarding the patient's underlying and enduring aims and values, to the extent that these are known."41 For example, in calculating the risk/benefit ratio for a practicing Jehovah's Witness who refuses a life-saving blood transfusion, account should be taken of factors beyond the patient's best medical interests, for example, the patient's concern to avoid eternal damnation. In these circumstances, this patient would not have to meet a higher standard for capacity. Buchanan and Brock argue that their model avoids the "objectionable" aspects of an outcome based standard of capacity. 42 However, their model still involves an objective element. If the patient's aims and values are not known, Buchanan and Brock envisage the use of objective values to determine the risk/benefit ratio. In this instance, the assessment should balance the expected outcome of the treatment and the risk of harm against "the general goals of health care in prolonging life, preventing injury and disability, and relieving suffering."43

The variable standard was accepted in the influential Report of the President's Commission, *Making Health Care Decisions*.⁴⁴ In the Commission's view, any determination of capacity "must relate to the individual abilities of the patient, the requirements of the task at hand, *and* the consequences likely to flow from the decision."⁴⁵ The standard was also adopted by Grisso and Appelbaum in developing

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Deciding for Others: The Ethics of Surrogate Decision-Making (Cambridge: Cambridge University Press, 1989), pp 51-57.

⁴¹ *Ibid*, p 52.

⁴² *Ibid*, pp 55-56.

⁴³ *Ibid*, p 52.

Supra note 3.

Ibid, p 57 (emphasis added). It should be noted, however, that the Commission also stated: "When the consequences for well-being are substantial, there is a greater need to be certain that the patient possesses the necessary level of capacity." This might be interpreted to mean simply that more care should be taken in assessment in high-risk situations rather than that the standards actually vary (see arguments explored in text to note 84 infra). However, this is unlikely to be what the Commission intended given that it continued "[w]hen little turns on the decision, the level of decisionmaking capacity required may be appropriately reduced (although the constituent elements remain the same and less scrutiny may be required about whether the patient possesses even the reduced level of capacity)." (Emphasis added).

the MacCAT-T.⁴⁶ However, there seems to be no evidence of judicial endorsement of the standard or of its application in individual cases by United States' courts.

An extensive theoretical debate has developed regarding whether the variable standard constitutes an unacceptable erosion of the individual's right of autonomy and/or an inappropriate interference with the logical coherence of the role of capacity within the autonomy paradigm. Wilks⁴⁷ characterises the two sides of the debate as "internalists" and "externalists" and these terms are adopted in the discussion below. Internalists argue that capacity is based on each individual's internal mental abilities only. The nature of the decision may be relevant insofar as it affects the individual's intrinsic capacity. For example, the enormity of the decision may cause a person to panic or to be unable to make a decision or may increase the information to be understood and applied. However, unless the nature of the decision to be made impacts on the actual internal process of decision-making, it is not a relevant factor for consideration. In contrast, externalists such as Drane and Buchanan and Brock look outside the individual and relate capacity assessment to external factors, specifically, to the nature of the decision reached.

Externalists justify the standard primarily because it balances respect for a patient's autonomy with respect for other values such as patient welfare or the sanctity of life. Drane argues that his sliding scale model best achieves a balancing of values which he argues "is the cornerstone of a good competency assessment." He argues that maximum autonomy is guaranteed because patients are free to make choices while, at the same time, beneficence is respected because "patients are protected against harmful choices, when these are more the product of pathology than of self-determination." This justification is also used by Buchanan and Brock who argue that a variable standard allows "a better and more sensitive balance between the competing values of self-determination and well-being that are to be served by a

Grisso and Appelbaum Assessing Competence to Consent: A Guide for Physicians and Other Health Professionals (New York: Oxford University Press, 1998). Grisso and Appelbaum suggest (ibid, p 33) that different levels of decision-making ability will be required depending on "the nature of the decision to be made (e.g. its complexity and risks)". They advocate (ibid, p 24) "adjusting upward or downward the degree of disability that is required in order to categorize patients as incompetent, depending on the degree of harm associated with their probable choice."

[&]quot;The Debate Over Risk-Related Standards of Competence" (1997) 11 *Bioethics* 413.

⁴⁸ Supra note 36, 21.

⁴⁹ *Ibid*, 21.

determination of competence". ⁵⁰ This was also the justification of the President's Commission which described its reasons for endorsing a variable standard as follows:

Since the assessment must balance possibly competing considerations of well-being and self-determination, the prudent course is to take into account the potential consequences of the patient's decision.⁵¹

In addition, some externalists seek to justify the variable standard on a number of bases which are not linked to normative considerations. Buchanan and Brock argue that the variable standard is "more consonant with the way people actually make informal competence determinations"52 and that the standard therefore has an intuitive appeal. To support this argument, Buchanan and Brock use the example of a five year-old child and argue that most people would be happy to allow this child decide what to have for lunch but not how to invest a large sum of money. They argue that this response is because of an intuitive reaction to the relative risks involved and that people automatically take account of risks in deciding which choices should be permitted.⁵³ There are difficulties with this intuitive appeal argument. Wicclair⁵⁴ disputes the basis for the intuitive appeal identified. He argues that the intuitive response is not because of the risks involved but because of the relative complexity of the different tasks.55 However, this does not provide a full explanation of the intuitive response. Serious decisions, for example those about life and death, are very often more complex only because they involve greater risk. While decisions that are not risky can, of course, be complex, some life and death decisions can be stated in the simplest possible terms.⁵⁶ For example, the choice faced by a Jehovah's Witness between saving his life and facing damnation through the acceptance of a blood transfusion may be stark and difficult, but it cannot be

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⁵⁰ Supra note 40, p 64.

⁵¹ Supra note 3, p 60.

⁵² Supra note 40, p 60.

⁵³ Ibid.

[&]quot;Patient Decision-Making Capacity and Risk" (1991) 5 Bioethics 91. See the similar argument made by Gunn et al "Decision-Making Capacity" (1999) 7 Medical Law Review 269, 273 in the passage quoted in text to note 86 infra.

Ibid, 96-97. Wicclair develops Buchanan and Brock's child example to illustrate this point. He argues that the choice of lunch is neither complex nor risky unless, for example, the child is allergic to a certain food. In this instance, the choice becomes more risky but it also becomes more complex because a wider range of factors has to be understood and appreciated. He argues that it is the increased complexity of the task that justifies a finding of incapacity rather than the increased risk.

See also Gunn *et al supra* note 54, 272.

described as especially complex. In short, complexity and risk are two different concepts which sometimes intersect but sometimes do not.

While Wicclair's attempt to separate risk from complexity is unsuccessful, Buchanan and Brock's argument also lacks force. First, they make the mistake in their example of confusing the child's ability to make a choice about his lunch with the question of whether the child should be permitted to make that choice. Capacity assessment is, theoretically at least, not about what a person should be permitted to do but about whether he has the ability to do the thing in question. Secondly, the attempt to argue by analogy is unconvincing. Intuitive responses to one situation do not enhance understanding of an appropriate legal response to a completely different set of circumstances. Indeed, if one resorts to the level of intuition, it might well be argued that most people intuitively accept that a person's ability to make decisions does not change depending on the nature of the decision made.

Buchanan and Brock also draw support for the variable standard from the law on informed consent, arguing that the law requires the level of information to be provided to patients to vary depending on the risks involved.⁵⁷ However, the purpose of the law on informed consent is to give patients information about risks. It is therefore to be expected that the law will require patients to be given more information as the procedure becomes more risky. Therefore, there is no support to be drawn from the law on informed consent for a variable standard for capacity.⁵⁸ Buchanan and Brock also argue that the inclusion of risk in the standard for capacity will ensure that people will only be found incapable where absolutely necessary, thus minimising "the potentially devastating assault on self-esteem that a finding of incompetence represents to some individuals."59 However, as discussed above, because of the "weeding out" role played by risk at the initial stage at which capacity is questioned, 60 most patients whose capacity is formally questioned are likely to already be proposing to make a high-risk decision and therefore would be required to achieve the higher standard of capacity. The therapeutic benefit argument is therefore likely to have little practical application.

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⁵⁷ Supra note 40, pp 60-61.

Buchanan and Brock also draw on the law in another context to support the variable standard. They argue (*ibid*, pp 62-63) that the law's treatment of minors reflects a variable approach to capacity although they do not elaborate further on this point.

⁵⁹ Supra note 40, p 64.

See text following note 8 *supra*.

The discussion above shows that, ultimately, the only feasible externalist defence of the variable standard is the normative one that it allows a better balancing of the values of autonomy and beneficence. The internalist critique of the variable standard derives from its inconsistency with both components of the autonomy paradigm. Some internalists criticise the standard because it favours values other than autonomy at the expense of autonomy. As is evident from the discussion above, this is undoubtedly true. For these critics, autonomy is the pre-eminent value and anything which challenges this value must be rejected.⁶¹ For other critics, the principal difficulty lies in the inconsistency between the variable standard and the accepted view of capacity as a separate concept which is unrelated to the nature of the patient's decision. Critics from this perspective argue that the variable standard yields the illogical and asymmetrical result that a person may be legally capable of consenting to treatment but incapable of refusing the identical treatment. Wicclair summarises the criticism as follows:

[N]o matter what [the patient] finally decided, the decision she faced was: to accept or forgo life-extending measures. Insofar as a choice between these options requires an ability to comprehend and to weigh the consequences of *both*, it seems odd to maintain that accepting treatment calls for significantly less decision-making ability than refusing treatment.⁶²

More colourfully, Wilks describes this aspect of the standard as appearing reminiscent of show-elections in totalitarian regimes.⁶³ The voter has the right to vote but no choice.

Supporters of the variable standard make enthusiastic (although ultimately unsuccessful) efforts to defend the standard against this criticism. Brock argues that it is possible to separate the decision-making processes utilised depending on the kind of decision made. He argues that:

[T]he two choices to consent or refuse will be based on different processes of reasoning or decisionmaking; the overall processes of reasoning must be different if for no other reason than that they result in different choices.⁶⁴

See, for example, Silver "Reflections on Determining Competency" (2002) 16 *Bioethics* 454.

Supra note 54, 103-104.

⁶³ Supra note 47, 418.

[&]quot;Decisionmaking Competence and Risk" (1991) 5 Bioethics 107, 112.

This is not a very satisfactory defence. While, clearly, the patient who decides to consent has applied different values to the patient who decides to refuse, this is no reason to argue that different reasoning processes are employed. Thus, the different conclusions may mark a difference in values rather than in underlying capacity.⁶⁵

Wilks offers a more detailed, but no more persuasive, defence of the asymmetrical result yielded by the variable standard. Like Brock, he argues that the process of decision-making involves two separate tasks: "the task of making a yesdecision, and the task of making a no-decision"66 and that different capacities are necessary for each task, depending on the level of risk involved. As an example, he posits two tightrope walkers, one of whom never falls and the other of whom sometimes falls. He then specifies the task of walking the tightrope, in the first instance, with a safety net and, in the second, with the safety net removed without the walker's knowledge. He argues that the first walker remains capable regardless of the removal of the net but the second walker's capacity is changed, not because his ability has changed, but because of an external factor, namely the increase in risk levels caused by the removal of the net.⁶⁷ This argument is unconvincing. As with Buchanan and Brock's example of the five year-old's dietary choices discussed above, 68 Wilks confuses the individual's capacity to do something with whether he should be permitted to do the thing in question.⁶⁹ As Cale notes, Wilks only succeeds in showing that risk impacts on the tightrope walkers in his example because he adopts a normative position that favours safety and caution. Unless the walker notices the absence of the net and panics, 71 his intrinsic abilities are not changed by the absence of the net; it is simply that we feel a greater need to protect them.⁷²

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See also the arguments made in Buller "Competence and Risk-Relativity" (2001) 15 *Bioethics* 93, 105-106.

⁶⁶ Supra note 47, 422.

⁶⁷ *Ibid*, 419.

See text following note 56 supra.

Wilks also gives a second (and equally unconvincing) example (supra note 47, 422) relating to an offer to purchase shares in a high-risk endeavour. Wilks argues that he (not being an expert in this area) does not have the capacity to say yes to the offer while he has the capacity to say no even though he has no more knowledge or expertise in the latter case than in the former. Once again, Wilks confuses the issue of capacity in the sense of whether a person should be permitted to make a decision with the issue of whether the person would be good at making the decision in question.

[&]quot;Risk-Related Standards of Competence: Continuing the Debate Over Risk-Related Standards of Competence" (1999) 13 *Bioethics* 132, 140-141.

See discussion in text following note 47 supra.

Indeed, in a later article, ("Asymmetrical Competence" (1999) 13 *Bioethics* 154, 157) Wilks does not attempt to dispute that his examples favour values such as safety over autonomy but

Ultimately, attempts to argue that reasoning processes differ depending on the decision made are unpersuasive. Even a whole circus troupe of tightrope walkers cannot disguise the fact that a variable standard prefers one outcome or decision to another and that, in so doing, it deliberately raises the standard in some circumstances. As noted above, for some critics, the difficulty with this is not necessarily with the normative basis for the raising of the standard but with the location of this normative judgement within the realm of capacity. For example, Buller argues that the nature of the patient's decision may play a role in deciding what a capable patient should be permitted to do but that it should not be relevant to capacity assessment. In his words,

[T]here may be good paternalistic reasons for demanding a higher standard of competence for a patient to choose to reject life-sustaining treatment ... however these are reasons ... for overriding a patient's decision, rather than reasons for determining whether the patient is competent or not."⁷³

For Buller and those other commentators who share this view, the essential neutrality of the concept of capacity must be protected and value judgements must be seen to operate outside of this environment. This view will be discussed further in the next Part of this chapter. However, it is clear at this point that, regardless of whether this is viewed as appropriate or not, the variable standard serves to protect values other than autonomy at the expense of autonomy. For this reason, judicial support for the variable standard involves a direct challenge to the liberal underpinnings of healthcare law. In light of this, it falls to consider the status of the variable standard in English law.

The Variable Standard in English Law

When introducing the variable standard into English law in *Re T*, Lord Donaldson MR did not indicate why he thought such a standard was appropriate. Presumably, however, his endorsement of the standard derives from the same source as his statement that "[i]n cases of doubt, that doubt falls to be resolved in favour of the

rather argues that capacity as a concept is an "irreducibly normative notion."

Supra note 65, 109. Similar views are held by Robertson "The Geography of Competence" in Cutter and Shelp eds Competency: A Study of Informal Competency Determinations in Primary Care (Dordrecht: Kluwer, 1991), p 144. See also Culver and Gert "The Inadequacy of Incompetence" (1990) 68 The Milbank Quarterly 619.

preservation of life.⁷⁴ Thus, while famously affirming the patient's right of autonomy and the right to refuse treatment, his Lordship was keen to ensure that mechanisms were in place to protect patients from the consequences of the exercise of this right and the variable standard was one aspect of this protection.

The issue of capacity was not central to the Court of Appeal's decision in *Re T* and neither of the other members of the Court of Appeal commented on the variable standard. However, Lord Donaldson MR's position was subsequently endorsed by Butler-Sloss LJ in *Re MB (An Adult: Medical Treatment)*. Relying on *Re T* as authority, she stated that "[t]he graver the consequences of the decision, the commensurately greater the level of capacity is required to take the decision." Dame Butler-Sloss P again endorsed the variable standard in *Re B (adult: refusal of medical treatment)* where she held the applicant's capacity to be "commensurate with the gravity of the decision she may wish to make." Lord Donaldson MR's identification of the risk-related standard was again reiterated in *R (on the application of B)* v *Dr SS and Dr AC*, where the Court of Appeal described capacity as "an important, but by no means straightforward concept under English law" before noting Lord Donaldson's remark that "capacity must be commensurate with the gravity of the decision purported to be made."

The most obvious interpretation of Lord Donaldson's comments is that he (and the courts who endorsed these comments) intended a higher level of capacity to be required for more serious decisions. This interpretation is taken by a number of commentators⁸¹ and by the Richardson Report⁸² and the Irish Law Reform

⁷⁴ Supra note 34, 796.

^{[1997] 2} FCR 541, 553. In addition, Butler-Sloss LJ cited as authority Sidaway v Board of Governors of the Bethlem Royal Hospital [1985] AC 871 and Gillick v West Norfolk and Wisbech AHA [1986] 1 AC 112. However, these decisions do not provide direct support for the proposition in question. The most relevant statement in Gillick appears to be that of Lord Fraser ([1986] 1 AC 112, 169) that "[i]t seems to me verging on the absurd to suggest that a girl or boy aged 15 could not effectively consent, for example, to have a medical examination of some trivial injury to his body or even to have a broken arm set".

⁷⁶ [2002] 2 All ER 449.

Ibid, 472. See also St George's Healthcare NHS Trust v S [1998] 3 WLR 936, 958 per Judge LJ (where Lord Donaldson's dictum was cited but not discussed or specifically applied in the circumstances); Re AK (Medical Treatment: Consent) [2001] 1 FLR 129, 135 per Hughes J. [2006] EWCA Civ 28, [49].

⁷⁹ *Ibid*.

⁸⁰ Ibid.

See Richardson "Autonomy, Guardianship and Mental Disorder: One Problem, Two Solutions" (2002) 65 MLR 702, 705; Stern "Competence to Refuse Life-Sustaining Medical Treatment" (1994) 110 LQR 541, 545. Cf Stern's argument that Lord Donaldson's approach was "[i]mplicitly" rejected by Thorpe J's adoption of the functional test in Re C (adult: refusal

Commission.⁸³ Some commentators, however, take a different interpretation. Grubb argues that Lord Donaldson MR's statement "cannot mean that the courts require more reasoning powers the more serious the decision".84 He suggests instead that Lord Donaldson simply required that:

[T]he patient should be able to understand more information the more serious the decision and that the courts will give the most careful scrutiny to the process of reaching such decisions, in particular where the patient's life is at stake."85

Thus, he suggests that his Lordship did not intend the standard for capacity to vary but rather that the courts were to be more careful in applying the same standard in higher risk situations. Gunn et al also reject the view that Lord Donaldson intended to apply different standards of capacity depending on the level of risk. They argue that the "proper interpretation" of Lord Donaldson's statement is that "the nature of the decision may make the threshold of capacity more difficult to pass, but this does not involve a change in the definition of capacity; rather it is a reflection of the greater complexity of the decision to be made."86

Grubb and Gunn et al are correct in identifying the apparent contradiction between judicial rejection of any role for the nature of the patient's decision in capacity assessment on the one hand and judicial endorsement of the variable standard on the other. However, it is more difficult to find support for their arguments that Lord Donaldson MR did not intend to adopt a variable standard based on seriousness. Lord Donaldson's statement that "[t]he more serious the decision, the greater the capacity required" is not ambiguous. It is also clear from Lord Donaldson MR's

of medical treatment) [1994] 1 WLR 290.

⁸² In setting out "key points to bear in mind when identifying the boundary between a decision taken with capacity and one taken without", the Richardson Report supra note 18, p 90 stated "[c]apacity is a sliding scale - it may be easier to establish lack of capacity where the consequences of the decision to be taken are more onerous". See also the examples chosen in the Report (ibid, pp 90-91) which adopt different standards for capacity depending on the gravity of the decision.

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Vulnerable Adults and the Law supra note 4, para 7.18. Grubb Kennedy and Grubb Medical Law (3rd Ed) (London: Butterworths, 2000), p 627. 84

⁸⁵ Ibid.

Supra note 54, 273. However, the authors do acknowledge the difference between complexity and risk: see ibid, 272 note 19, where they note "[a]rguably, more sophistication is required to choose between two complex treatments with different and, possibly, complex outcomes, even though there is no risk of death, than the decision faced by Mr C who was, nevertheless, running a real and significant risk of death."

⁸⁷ For full quote, see text to note 35 supra.

own summary that his Lordship intended the term "serious" to mean risky and not complex. Lord Donaldson MR noted that:

[R]efusals can vary in importance. Some may involve a risk to life or of irreparable damage to health."88

Butler-Sloss LJ is equally clear in *Re MB (An Adult: Medical Treatment)*. Her statement that "[t]he graver the consequences of the decision, the commensurately greater the level of capacity is required to take the decision" does not leave room for alternative interpretations based on complexity or the levels of judicial care required.

There is no indication from the case law that the judges had reflected on the apparent contradiction in their approaches. Nor have the courts engaged with the matter of how the variable test would actually apply in practice. Among the questions which would arise are how the higher standard of capacity should be set; what constitutes a grave decision; and how the gravity of a decision should be proven. There has been surprisingly little discussion of the variable standard in policy considerations of capacity. In one of its early Consultation Papers, the Law Commission expressed "some difficulty with the idea that there should be a 'greater capacity' as opposed to an ability to understand more, or more significant, information" depending on the nature of the decision. 91 However, the matter was not discussed in any detail in the Consultation Paper and was not mentioned at all in the later Report on Incapacity.92 However, the variable approach to capacity appears to be endorsed by the Richardson Report⁹³ and the Millan Report⁹⁴ although without detailed engagement with the issues of policy involved. In brief, it might be concluded at this point that the weight of English authority favours the variable standard but that there is still room for a principled rejection of the standard if the matter were engaged with in detail. The MCA 2005 is unlikely to make a difference to this position. The Act silent on the matter of a variable standard and there is no

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For full quote, see note 35 supra.

⁸⁹ [1997] 2 FCR 541.

⁹⁰ *Ibid* 553.

Mentally Incapacitated Adults and Decision-Making: Medical Treatment and Research, Consultation Paper No 129 (London: HMSO, 1993), pp 18-19.

⁹² Supra note 3.

⁹³ See discussion in note 82.

Report of the Review of the Mental Health (Scotland) Act 1984: New Directions (Edinburgh: Scottish Executive, 2001), p 57. The Report considered that, in determining if intervention was permissible, the nature and degree of the patient's impaired judgement should be judged alongside the nature and degree of risk and the likely benefits of the treatment.

reference to such a standard in the Draft Code of Practice. Therefore it would still be open to a court to accept or reject a variable standard.

Describing the variation in responses to the Richardson Report's endorsement of the variable standard, Eastman and Dhar note that "[t]o some this [standard] represented throwing in the ethical towel, whilst to others it offered a sensible 'balance.'" The next Part of this chapter will ask which of these is the case before concluding on the lessons to be learnt from the ongoing role played by the nature of the patient's decision in the capacity assessment process.

Part II: Confronting the Role Played by the Patient's Decision

The preceding Part identified a number of ways in which the nature of the patient's decision impacts on capacity assessment. The fact that the patient's decision continues to play a role, notwithstanding judicial statements to the contrary, is hardly surprising. Given the pressures placed on capacity as gatekeeper for the right of autonomy, the difficulties posed by some treatment refusals, and the essential malleability of the functional test, it is inevitable that the nature of the patient's decision will play a role in the capacity assessment process. This Part asks how the ongoing role played by the patient's decision should be addressed. It begins by assessing attempts to eradicate any reference to the nature of the patient's decision from the capacity assessment process and argues that these attempts will ultimately prove unsuccessful. It then looks at the possibility of recognising the role played by the patient's decision in an overt way by using the variable standard as a means of monitoring this role.

Efforts to Eradicate the Patient's Decision from Capacity Assessment

In the Report on Mental Incapacity, the Law Commission recommended that capacity legislation should include a statement that a person should not be regarded as incapable merely because he makes a decision that would not be made by a person of ordinary prudence. This was in order to "emphasise the fact that the 'outcome' approach to capacity has been rejected, while recognising that it is almost certainly in

[&]quot;The Role and Assessment of Mental Incapacity: A Review" (2000) 13 Current Opinion in Psychiatry 557, 559.

daily use." The MCA 2005 includes as one of its underlying principles that a person is "not to be treated as unable to make a decision merely because he makes an unwise decision."97 Given that the numerous judicial rejections of a role for the nature of the patient's decision have not succeeded in preventing this from being taken into account, it is highly unlikely that a general legislative statement of this kind will have any significant impact. It is true that these judicial and legislative statements will lead judges and others not to acknowledge the role played by the patient's decision in their assessment thus making it harder to track down evidence of this role. However, this is a different matter to preventing the actual role itself.

Failure to recognise the law's inability to remove the patient's decision entirely from the capacity assessment process allows the conceptual consistency of the autonomy paradigm to be maintained at a cost of a failure to deliver actual protection of the right of autonomy to patients in the majority of difficult situations and in particular in the context of the right to refuse treatment. An alternative approach is to accept the inevitability of the role played by the patient's decision and to attempt to control this through the utilisation of a variable standard for capacity.

Controlling the Role Played by the Patient's Decision

If, as argued in this thesis, it is impossible to remove a consideration of the nature of the patient's decision entirely from the process of capacity assessment, a second option is to recognise this factor and take steps to monitor (and limit in a practical way) the way in which it is played out in practice. One means of doing this is to allow the inclusion of the seriousness of the decision in setting the standard for capacity. In order to assess the suitability of this approach, it is useful to consider how a variable standard of capacity might operate at an optimal level.

A proper application of the variable standard would have to be consistent with the presumption of capacity and the underlying pro-autonomy perspective of the law. This would require that the burden of proof would be placed on the person who alleges that a decision is grave and therefore that the decision requires a higher standard of capacity.98 This in turn would require the level of gravity to be openly

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Supra note 1, pp 39-40.

Section 1 (4).

⁹⁸ As noted by Richardson supra note 81, 721, a mere statement that a decision is high-risk does

discussed rather than simply assumed. Medical evidence would have to deal directly with questions of risks, benefits and alternatives before a court could determine which version of the functional test should apply. In this regard, it would be appropriate to measure gravity in the light of the alternatives to the proposed treatment and not as a simple proposition. For example, if a patient were prepared to consent to a treatment which was not optimal but which carried a lower level of risk than treatment refusal,99 this should be factored into the measurement of gravity. This could lead to the decision being categorised as less grave. This would move the matter of alternatives to the proposed treatment away from its current peripheral position and ensure that a consideration of alternatives would play a more central role in the process. Further, in light of the law's endorsement of individual autonomy, the question of gravity should be assessed in a way specific to each patient rather than on the basis of objective medical standards.¹⁰⁰ Thus, to apply the test properly, a court would first have to assess the gravity of the patient's decision, from the patient's own subjective perspective and then, having decided on the appropriate standard, the court would look at the actual capacity of the patient.

If this systematic approach to the assessment of gravity were taken, patients would be more aware of all the factors impacting on the assessment of their capacity and would be in a better position to counter the evidence regarding what constitutes the most suitable outcome in their particular case which, this thesis has argued, inevitably colours capacity assessment. This would also mean that the patient's values and beliefs would be accorded a more central role in the process of determining capacity.

The benefits of this systematic approach would be likely to be most apparent in those situations where the nature of the patient's decision has the most significant impact on capacity assessment. In particular, the adoption of a variable standard (if operated as set out above) could help facilitate the extension of autonomy-based healthcare into the realm of treatment for a mental disorder. If psychiatrists had to make a case for treatment based on the level of risk before assessing the patient's capacity, a system could be established whereby these professionals would have to

not demonstrate that this is in fact the case.

For example, in Re C (Adult: Refusal of Treatment) [1994] 1 WLR 290, the applicant was prepared to accept antibiotic treatment of his gangrenous foot but refused to countenance an amputation.

See the position advocated by Buchanan and Brock in text following note 40 supra.

address formally matters such as benefits, alternatives and least invasive options, and patients would have the opportunity to respond accordingly. Furthermore, the variable standard would address concerns regarding the inability of the test for capacity to distinguish appropriately between patients with mental disorders whose right to refuse treatment should be respected and those whose right should not. With the variable standard, a greater level of protection would be provided to those patients who proposed to make the most grave decisions.

While the variable standard may have the advantages outlined above, it also gives rise to a number of difficulties. First, the model suggested above has not been tested in practice. The sophisticated model for incorporating risk, based on an individual-specific standard and the introduction of complex evidence of risks and benefits, could prove difficult to apply in a court setting. There is a real possibility that a variable standard would be reduced to a simple equation whereby grave procedures would inevitably require higher levels of capacity regardless of the patient's subjective perspective. If this difficulty is likely to occur when capacity is considered at a judicial level, it is even more probable where capacity is informally assessed by psychiatrists or other medical professionals. In such circumstances, the advantages of a variable standard, such as they are, would be offset by the damage done to the underlying status of the right of autonomy. Secondly, even if an optimal application of the variable standard could be guaranteed, the variable standard still encounters difficulties at a level of principle because it allows capacity assessment to be used in a clearly normative manner to undermine the patient's right of autonomy.

Conclusion

This chapter has shown that the nature of the patient's decision continues to play a role in the functional test for capacity. It determines when capacity is questioned and how the test is applied in practice and it underpins the variable standard for capacity. While it has been argued that the weight of English authority tends to favour the variable standard, in the absence of judicial deliberation on the principles at stake, it is possible that this standard could be rejected by a court in the future.

The adoption of a variable standard throws up interesting theoretical questions regarding the role of capacity within the autonomy paradigm. This chapter has argued

that the variable standard constitutes a direct challenge to the liberal underpinnings of healthcare law. It argued that, nonetheless, there is an argument to be made that, by incorporating the role of risk expressly into the capacity assessment process, the courts could develop a more sophisticated understanding of the functional test for capacity and that, if done properly, the variable standard may address concerns regarding the extension of the autonomy paradigm to treatment for a mental disorder. However, the chapter expressed doubts regarding whether this could actually be achieved in practice.

Ultimately, the primary thrust of this chapter is to reinforce the arguments made in previous chapters that capacity is a malleable concept by showing that it cannot be separated from the nature of the patient's decision. The impact of this, as well as the other arguments made throughout this thesis, will be considered in the next chapter which presents the conclusions of this thesis.

Conclusion

Introduction

The refusal of medical treatment gives rise to important legal and philosophical questions. While the legal position appears to be well established and stable and to accord neatly with basic liberal principle, the reality is more complex. In particular, difficult treatment refusal cases show the compromises that the law has to make in order to maintain its theoretical adherence to the liberal principle of autonomy. This thesis has argued that the law's endorsement of a pure form of autonomy has been possible because of the limits or checks provided by the requirement for capacity within the autonomy paradigm. Therefore, instead of engaging with the appropriateness of autonomy as an underlying principle, the law has been able to deal with treatment situations in an individualised context through the mechanism of capacity assessment. For this reason, this thesis has evaluated the principle of autonomy and the requirement for capacity as a single model. The interaction between the principle and the requirement has been referred to in the thesis as the autonomy paradigm.

The thesis has argued that the autonomy paradigm has important limitations. Two core difficulties have been identified. First, the model is too simplistic. It assumes that patients can be divided according to their capacity or lack of it and fails to take account of the complexity of each individual's abilities. Secondly, the model is based on a false presumption that the capacity requirement can be operated in a value-free environment, without reference to the nature of the patient's decision. However, the thesis does not argue that the law should abandon the autonomy paradigm, nor does it deny the broader benefits arising from the law's endorsement of autonomy-based healthcare. Instead, the thesis argues that the limitations of the autonomy paradigm must be recognised in order to develop a more realistic framework for the law relating to healthcare decision-making. It argues that only a human rights model (which includes, but is not limited to, a right to autonomy) can deliver an appropriate framework for the law in this area.

In Part I of the Conclusion to the thesis, the main arguments made throughout the thesis will be reiterated and in Part II, final reflections will be offered and some recommendations will be made regarding appropriate future directions for the law.

Part I: A Review of the Thesis

The first two chapters of the thesis described and evaluated the component parts of the autonomy paradigm. Chapter 1 explored the nature of autonomy as a philosophical construct and as a legal right. The chapter showed that the principle of autonomy, as recognised in the context of the right to refuse treatment, has its primary philosophical basis in Millian liberalism and that Mill's injunction that "[o]ver himself, over his own body and mind, the individual is sovereign" provides the basis for modern healthcare law relating to treatment refusal. Chapter 1 identified important flaws in the liberal conception of autonomy and showed that the "isolated, independent, rational agent" of liberal theory cannot adequately represent the complexity of individuals as they make healthcare decisions. However, the chapter also acknowledged the importance of the principle of autonomy to the law, especially in difficult treatment situations and recognised the benefits of the law's tendency to deal with the flaws in the liberal conception of autonomy through individualised limits or checks on the application of the right to refuse rather than more wide-ranging departures from the principle of autonomy.

Chapter 2 completed the analysis of the autonomy paradigm, by examining the role of the capacity requirement within the paradigm. The chapter showed that traditional liberal philosophy regarded capacity as an essential pre-requisite for the individual right of autonomy. However, both traditional and modern-day liberals have generally neglected the question of what constitutes an appropriate standard for capacity. Chapter 2 showed that setting the standard for capacity is fundamentally a normative exercise. The task of setting the standard and of deciding what abilities should be tested involves important value judgements. This chapter put forward a view of capacity which it argued

On Liberty (London, 1859), p 14.

Sherwin No Longer Patient: Feminist Ethics and Health Care (Philadelphia: Temple University Press, 1992), p 53.

is most consistent with the liberal conception of autonomy. It demonstrated that a consistent view of the capacity requirement would require that a capacity assessor focus on the patient's abilities rather than on the patient's underlying condition or the nature of the patient's decision. It also showed that, in order to maintain consistency with liberal theory, the test for capacity should assess the patient's ability to understand relevant information and to make authentic or consistent decisions. This chapter also showed that capacity is, to a degree, a contingent state and that patients can be made more or less capable depending on a range of factors, including the efforts made by the assessor. Chapter 2 demonstrated that, when measured against this view, the law's standard for capacity is, by and large, consistent with liberal theory. Therefore, the autonomy paradigm is internally consistent; the law's endorsement of the principle of autonomy is, by and large, matched by the theoretical approach it takes to the capacity requirement.

Having established the philosophical coherence of the autonomy paradigm, the thesis then explored the limitations of this paradigm. Chapters 3 and 4 addressed the first difficulty with the paradigm identified, namely its over-simplicity. These chapters show how the assumption that patients can be divided according to their capacity or lack of it impacts on patients who do not meet the required standard for capacity. Chapter 3 showed how healthcare decision-making for incapable patients has taken place in a conceptual vacuum created by the autonomy paradigm. Because of the pervasive influence of the paradigm, the law has either relegated the matter of decision-making to the unregulated subjectivity of the best interests standard or attempted to extend the right of autonomy to patients notwithstanding their incapacity. Either way, an appropriate conceptual framework has not yet developed. This chapter argued that the autonomy paradigm remains the dominant conceptual model underlying the Mental Capacity Act 2005 and that the limitations of this paradigm must be recognised in developing this new legal order. In particular, this chapter argued that the appropriate legal model for decision-making must look beyond autonomy and must be based around a broader human rights agenda, which takes account of issues of restraint, resistance, liberty, dignity and procedural adequacy. In this context, this chapter identified the importance of the European Convention on Human Rights to future development of the law in this area.

The argument that a broader human rights framework is important is also central to Chapter 4. This chapter looked at the anomalous position of the Mental Health Act 1983 within a legal system which has a stated commitment to protecting individual autonomy and at the arguments that the autonomy paradigm should be extended to treatment for a mental disorder. This chapter argued that, while there are strong principled arguments for extended the autonomy paradigm to treatment for a mental disorder, the autonomy paradigm should not become dominant in this area. Using the example of legal models from the United States and Ireland, this chapter argued that, in practice, most patients with a mental disorder would be likely to be found incapable and therefore would not be entitled to have their right of autonomy respected. It was argued that the law must address the refusal of treatment for a mental disorder within a broader human rights framework. While arguing against allowing the autonomy paradigm to dominate, this chapter also argued that the right of autonomy should be recognised within the broader human rights framework.

The remaining three chapters of the thesis address the second difficulty identified with the autonomy paradigm and demonstrate why the capacity assessment process cannot be a neutral, value-free endeavour undertaken without reference to the nature of the patient's decision. Chapter 5 reviewed in detail each component of the functional test for capacity. It showed that the abilities required by the functional test may be interpreted in a number of different ways and that, accordingly, the test can be manipulated according to the assessors' views of the nature of the patient's decision. This malleability is increased in the case of patients with mental disorders and in particular for patients with fluctuating capacity or with ongoing, chronic mental disorders. However, the difficulty identified in Chapter 5 is not simply that paternalistic assessors can manipulate the test for capacity. Rather, the chapter shows that, when the functional test is reviewed in detail, it is intrinsically unable to deliver the kind of neutral, value-free assessments which is assumed by the theoretical conception of the capacity requirement within the autonomy paradigm.

Chapter 6 continued the review of the functional test by examining the role of the assessor and of the procedural framework within which assessors operate. This chapter showed that, in practice, the task of assessing capacity has been largely delegated to the

medical profession. The chapter argued that the medical profession has inadequate guidance or training for this legal role and that it may encounter a motivational conflict in cases where the assessment of capacity will determine whether or not a patient may refuse medically appropriate treatment. The review in this chapter showed that there are ways to improve the capacity assessment process and set out some of the ways in which this could take place. However, ultimately, the review of process reinforced the argument that the capacity requirement cannot be operated in the way presumed by the autonomy paradigm.

Chapter 7 revisited the role played by the patient's decision in the capacity assessment process in light of the arguments made in the preceding two chapters. This chapter argued that the limitations of the functional test and of the assessment process mean that the influence of the patient's decision cannot be eradicated from the way in which capacity is assessed. It showed that the variable standard for capacity, which appears to have judicial endorsement, allows an overt role to the nature of the patient's decision in setting the standard for capacity and is therefore inconsistent with the autonomy paradigm. Chapter 7 argued that, notwithstanding this inconsistency, a case could be made for the variable standard as a means of monitoring the inevitable role played by the patient's decision in capacity assessment. This could only be justified, however, if a rigorous approach were to be taken to the application of the standard and Chapter 7 expressed serious doubts regarding whether this would be achievable. Consistent with the argument make in the preceding chapters, the ultimate conclusion of Chapter 7 is that the test for capacity cannot be decisively separated from the nature of the patient's decision and that the conceptual purity of the autonomy paradigm cannot be delivered in practice.

Part II: Final Reflections and Recommendations for the Future

Drawing on the conclusions reached in the individual chapters, it is possible to present some final reflections as well as a number of recommendations regarding the way in which the law in this area should develop. Three key recommendations may be identified. First, the thesis recommends that the law must focus on the development of a

decision-making model for incapable patients which is free from the pervasive influence of the autonomy paradigm. Secondly, it recommends that, while the capacity assessment process will inevitably lack the precision and neutrality presumed by the autonomy paradigm, the process can, and should, be improved. Thirdly, the thesis recommends that, despite the limitations identified in the thesis, the right of autonomy should play a more significant part in the context of treatment for a mental disorder. This final section will develop each of these recommendations in the context of broader reflections derived from the arguments made in the thesis.

The Need for a Human Rights Framework for Incapable Patients

This thesis has argued that the autonomy paradigm dominates healthcare decision-making even where the patient is incapable and the principle of autonomy does not apply in the patient's particular situation. It was argued that this has led the law to neglect the need for an independent model for decision-making for incapable patients. This lack of engagement must be addressed. There is a clear need for a conceptual framework which is not premised solely on the presence or absence of capacity. The law must take account of the rights to privacy, liberty, bodily integrity, dignity and freedom from inhuman or degrading treatment. At a broader level, the law must also ensure that decision-making for incapable patients takes place in a procedurally appropriate way which accords patients an opportunity to participate insofar as this is possible.

The view advocated in this thesis is one which Beyleveld and Brownsword regard as increasingly prevalent in "the new European bioethics" which, they argue "takes dignity, integrity, and vulnerability to be the guiding (protective) values (alongside autonomy)." According to this view of the law, the question of whether the patient is capable is just one of a series of important questions to be asked and a designation of incapacity does not mean that treatment should be imposed simply on the basis of

Human Dignity in Bioethics and Biolaw (Oxford: Oxford University Press, 2002), p 42. See also Parizeau "The Tension Between Autonomy and Dignity" in Kemp et al Bioethics and Biolaw: Vol II: Four Ethical Principles (Copenhagen: Rhodos International Science and Art Publishers and Centre for Ethics and Law, 2000), pp 54-57 who characterises European bioethics as grounded

within the discourse of human rights, and most specifically, the right to dignity. Cf Dwyer "Beyond Autonomy: The Role of Dignity in 'Biolaw'" (2003) 23 Oxford Journal of Legal Studies 319.

medical opinion. An engagement based on these broader human rights principles requires the investigation of matters such as the levels of restraint required and the invasiveness of the treatment and also requires the provision of mechanisms whereby patients may object to treatment decisions made regardless of their incapacity. The rights-based approach does not mean that incapable patients may never have treatment imposed against their will nor does it provide simple answers to complex questions regarding the interaction between different rights. However, it does provide the foundations for a means of decision-making which escapes the limitations of the autonomy paradigm.

In developing an appropriate model for incapable patients, the European Convention on Human Rights is of key importance. Because existing legislation must be interpreted in a way which complies with the ECHR⁴ and new legislation must include a statement of compatibility,5 the ongoing relevance of the ECHR is clear in relation to the Mental Health Act 1983 and any possible amendments of this Act and to the Mental Capacity Act 2005. However, the development of jurisprudence in this regard will require patients to take the steps necessary to use their ECHR-protected rights. For some incapable patients, the task of finding the relevant information, accessing a solicitor and initiating a legal action may be very difficult. Especially if these patients are compliant with proposed treatment, the degree of review of proposed treatment from a human rights perspective is likely to be limited. Although the proposed amendment to the Mental Capacity Act 2005 to take account of the decision of the European Court of Human Rights in HL v United Kingdom⁶ will provide a better level of review in the case of compliant patients, this is intended to apply only in the context of a deprivation of liberty. Therefore, no new protections will be given to compliant patients whose situations fall short of a deprivation of liberty. The introduction of some form of review for these patients, at least in relation to more serious treatments, would take account of the need for accessible protections.8 The development of jurisprudence in this area

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Section 3(1) of the Human Rights Act 1998.

Section 19(1) of the Human Rights Act 1998. However, the Government may state that, although a statement of compatibility may not be provided, it wishes to proceed in its absence.

⁶ [2004] ECHR 45508/99.

See *Bournewood Briefing Sheet* (Gateway Reference 6794) (available at Department of Health website www.dh.gov.uk. (last visited July 26 2006)).

The Mental Health Alliance recommend that a second opinion should always be obtained before a person may be given serious treatment: see "Alliance's Response to Government Decision on

should not be left to the level of each individual's initiation. Instead, a more concerted effort should be made to give effect to the human rights of incapable patients.

Engaging with Capacity

This thesis has shown that the theoretical consistency of the autonomy paradigm begins to break down under the pressures of the actual task of capacity assessment. It showed that in real patients' situations, it is impossible to remove the nature of the patient's decision from the capacity assessment process. The thesis also demonstrated that medical professionals, who are the primary assessors of capacity, have real difficulties in carrying out this legal task. In light of these problems, one suggestion, which has gained some currency in recent debates in relation to treatment for a mental disorder, is that the terminology of incapacity should be replaced with a new term of "impaired decisionmaking". This standard was recommended by the Millan Report⁹ and given effect in the Mental Health (Care and Treatment) (Scotland) Act 2003 which requires a patient's ability to make decisions to be "significantly impaired" before a treatment order can be made. 10 The standard of "significantly impaired decision-making" was also favoured by the Joint Committee in its discussions regarding the Draft Mental Health Bill 2004.¹¹ While these arguments have been made in the specific context of treatment for a mental disorder, it is difficult to see why, if the impaired decision-making standard is suitable in the context of treatment for a mental disorder, it would not be equally suitable in the context of other forms of treatment. Therefore, the possibility of a more wide-ranging move to a standard based on "impaired decision-making" must be considered.

Bournewood Amendments to Capacity Act" Press Release June 29 2006 available at www.mentalhealthalliance.org.uk/resources/press/Bournewood.html (last viewed July 24 2006). Report of the Review of the Mental Health (Scotland) Act 1984: New Directions (Edinburgh: Scottish Executive, 2001), p 57. This test was seen (ibid) as "less legalistic" and easier to apply in practice.

Report of the Joint Committee on the Draft Mental Health Bill (HL Paper 79-1; HC 95-1) (London: Stationary Office, 2005), Recommendation 26.

Section 64 (5)(d). The Irish Mental Health Act 2001 also adopts this standard at admission stage: under section 3, a patient may only be admitted if she has impaired judgment or if she is at risk of causing immediate and serious harm to herself or others. However, the Act adopts a capacity-based test in relation to treatment and there is no indication in the Act regarding the meaning of "impaired judgment" or of the relationship between this concept and capacity.

Report of the Joint Committee on the Draft Mental Health Bill (HI, Paper 79-1: HC 95-1)

In endorsing a standard based on "significantly impaired decision-making," the Joint Committee quoted an argument made by Dr Zigmond from the Royal College of Psychiatrists which included his view of the distinction between this standard and the capacity-based standard. Dr Zigmond argued that:

The notion that there is a particular cut off point one side of which somebody lacks capacity, the other side they retain capacity, is of itself wrong. We are only adding to that variation. Why do we use the words we do? One of the acknowledged difficulties with the current definition of 'incapacity' is that it relies almost entirely on a person's ability to think, what we call cognitive ability, and we recognise that in the field of mental health, of course, emotions play a large part, and so at a very practical clinical level we think that the notion of impaired decision-making by reason of mental disorder would be much easier for people to understand and relate to patients with mental health problems¹²

The arguments in this thesis suggest that Dr Zigmond is correct in identifying the lack of an obvious cut-off point between capable and incapable patients. It has been argued throughout the thesis that the binary division of patients on the basis of capacity fails to take account of the complexity of human abilities. However, the difficulty here is not with whether the basis for the binary division is called "incapacity" or "impaired decision-making" but with the need for a division in the first place. A standard based on impaired decision-making does the same thing as a standard based on capacity; it divides people into those whose right to refuse treatment will automatically be respected and those whose right to refuse will not necessarily be. Simply calling the dividing point a different name does not solve any of the problems of the artificialness of the divide.

While a move to a standard based on impaired decision-making will not address the binary division problem, it is still possible to argue that the concept has other advantages. Dr Zigmond suggests that the move would allow account to be taken of emotional abilities in addition to cognitive abilities which he argues are inadequately addressed within the legal test for capacity. However, as the discussion in Chapter 2 of this thesis shows, the concept of legal capacity does not require a focus on cognitive abilities at the expense of emotional abilities. The "use and weigh" requirement, which focuses on the patient's ability to make authentic or consistent decisions, provides a

¹² *Ibid*, para 153.

perfectly adequate mechanism to take account of emotional abilities. Notwithstanding this misunderstanding of the possibilities of the legal test for capacity, it might still be argued that, because the psychiatrists who have to apply the legal test are unsure about its ambit, the test is effectively unsuitable regardless of the theoretical arguments which may be made.

However, psychiatrists' uncertainties suggest a need for better education and guidance in the legal test and not a need to change the nature of the test. The use of capacity as the standard has the advantage that it has been subject to a significant degree of theoretical and legal discussion, an advantage which the concept of impaired decision-making does not have. The difficulty with a standard based on impaired decision-making is that the sheer vagueness of the term could make it even more susceptible to the problems associated with the capacity assessment process identified in this thesis.¹³ Thus, the likelihood of patients being found to have impaired decision-making ability where they disagree with medical advice is even greater than it is under a standard based on capacity. Further, the possibility for legal review is diminished because the concept derives from medical rather than legal discourse. For these reasons, it is difficult to see any advantage in a shift to a standard based on impaired decision-making. The capacity-based model may not be perfect but it provides the best basis for future progress.

In working with the concept of capacity, it is necessary to engage critically with the realities of the capacity assessment process. First, courts need to set out more clearly the parameters of the test and to engage more explicitly with the value judgements that underpin the choice of a standard for assessing capacity and the way in which the capacity requirement plays out in the detail of individual cases. Secondly, given that a patient's capacity may vary according to the way in which capacity is tested and other surrounding circumstances, more emphasis must be placed on the duties owed to a patient whose capacity is being assessed. The Mental Capacity Act 2005, which includes a provision that a person is not to be regarded as incapable unless all practicable steps to

Neither the Mental Health (Care and Treatment) (Scotland) Act 2003 nor the Irish Mental Health Act 2001 contains a definition of the concept. The need for clear guidance regarding the definition was recognised by respondents to the Mental Health (Care and Treatment) (Scotland) Act 2003 Consultation Report on Draft Code of Practice and Regulations Policy Proposals (Edinburgh: Scottish Executive Social Research, 2005).

help her have been taken without success,¹⁴ is a step in the right direction. However, the extent to which this duty will be complied with will depend on a number of factors, including the enforceability of the provisions. The matter is not dealt with in the Act itself or in the draft Code of Practice. Therefore, ensuring the enforceability of this aspect of the Act should be an important focus for the future.

Thirdly, more attention needs to be paid to the role of the capacity assessor. It was argued in this thesis that capacity assessment takes place in the context of a dialogue between assessor and assessed and that the law has tended to neglect the assessor's part in this dialogue. Given the extent to which the task of capacity assessment has been delegated to the medical profession, action is required by both legal and medical professionals. Courts need to elucidate the way in which they use expert evidence to reach conclusions about capacity. Medical professionals must be given better guidance regarding the legal standards and assistance in identifying the conflicts in motive and other factors that may influence them in making capacity assessments. In this context, too, there is need for culture-specific, empirical studies regarding the way in which assessors actually operate.

Fourthly, the ongoing role played by the nature of the patient's decision must be acknowledged. In particular, the variable standard must be engaged with. Either the standard must be rejected because it conflicts with liberal principle, which underlies the law in this area, or if the variable standard is to be used, a rigorous framework within which to apply the variable standard must be developed. Finally, in the longer term, it may be that the necessary expertise in relation to capacity assessment will be better created through a specialist tribunal with both legal and medical members rather than through the current system of courts and expert evidence or, in informal cases, of medical assessors only.¹⁵ In this regard, there may be reasons to favour the extension of the mental health tribunal model to the context of capacity assessment so that a degree of expertise can be developed. However, detailed empirical work regarding the actual process currently employed in capacity assessment and further investigation of the

¹⁴ Section 1 (3).

Carney and Tait's study of the adult guardianship process in Australia (*The Adult Guardianship Experiment* (Annandale, NSW: Federation Press, 1997)), discussed in Chapter 6, suggests important advantages to the use of an expert tribunal in this area.

operation of mental health tribunals would be necessary before such a move could be firmly advocated.

The Principle of Autonomy and the Refusal of Treatment for a Mental Disorder

While this thesis has identified limitations of the autonomy paradigm, it has also acknowledged the lack of a feasible alternative to the autonomy paradigm in the context of treatment refusal. In light of this, the thesis examined the case for extending the right to refuse to treatment for a mental disorder to capable involuntary patients. This argument was explored against a background which accepted that the autonomy paradigm on its own cannot provide an appropriate conceptual model to cover treatment for a mental disorder and that the ECHR-based model provides a much more suitable basis for the law in this area than a simple iteration of the capable patient's right to refuse treatment.

Perhaps ironically, the limitations of the autonomy paradigm identified in this thesis can be used to support a shift to an autonomy-based approach to treatment for a mental disorder. All the evidence suggests that patients with mental disorders who refuse treatment in high-risk situations will be found incapable. This thesis showed that this is not simply because of paternalistic assessors (although it was noted that there are particular pressures on a psychiatrist in assessing the capacity of a patient to refuse treatment recommended by a fellow psychiatrist). Patients with mental disorders do pose real challenges for the functional test for capacity which is best suited to dramatic, onceoff situations rather than ongoing conditions. Regardless of why refusing patients are more likely to be found incapable, the indications are that a shift to the autonomy paradigm will not leave very ill patients, in Appelbaum and Gutheil's memorable phrase, to 'rot with their rights on'. ¹⁶

However, as this thesis has also shown, the importance of the autonomy principle is not restricted to the resolution of individual, difficult treatment decisions; the principle also creates the climate within which interactions between healthcare professionals and

Appelbaum and Gutheil "Rotting With Their Rights On: Constitutional Theory and Clinical Reality in Drug Refusal by Psychiatric Patients" (1979) 7 Bulletin of the American Academy of Psychiatry and the Law 306.

patients take place. At a fundamental level, the principle of autonomy requires the respect of the professional for the patient whose treatment is at issue. The more vulnerable the group of patients, the more important it becomes for this respect to be a fundamental aspect of the relationship. By extending the autonomy paradigm to patients with mental disorders, the law would give its confirmation to the importance of informed consent in relation to treatment for a mental disorder. It would also represent a first step towards a non-discriminatory approach to patients with mental disorders. These benefits are especially important in the context of a move towards compulsory care in the community.

Final Comments

To conclude, it is appropriate that the long-established principle of autonomy retains symbolic and practical significance within healthcare law. However, the limitations of this principle must be acknowledged. This thesis has attempted to provide a more realistic picture of the legal framework within which issues relating to treatment refusal are considered. It is hoped that in doing this, the thesis may contribute to the development of a legal model which better reflects the complexities of the individuals upon whose decisions the law is required to adjudicate.

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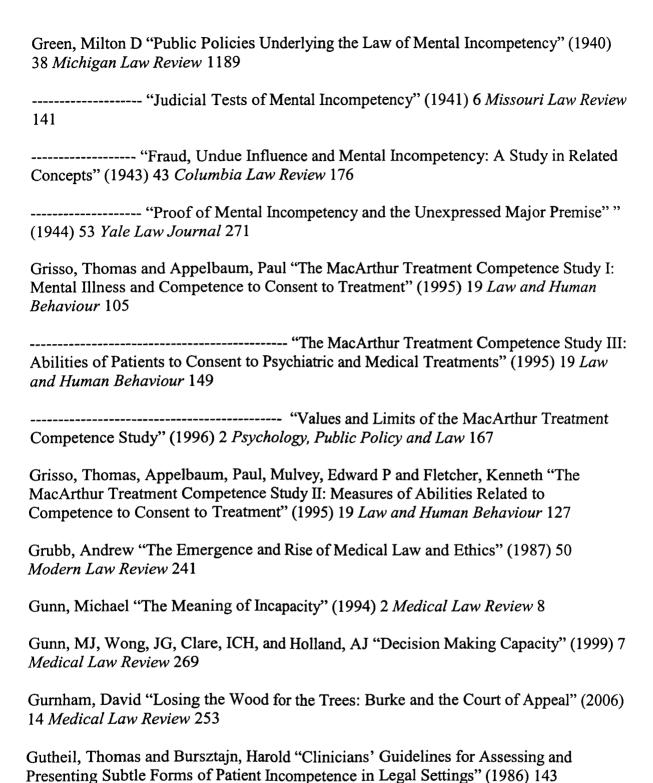
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