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### Trust or contract

**Citation for published version:**

Laurie, G & Mason, JK 2015, Trust or contract: How far does the contemporary doctor-patient relationship protect and promote autonomy? in P Ferguson & G Laurie (eds), *Inspiring a Medico-Legal Revolution: Essays in Honour of Sheila McLean*. Ashgate Publishing, pp. 73-94.  
<<http://www.ashgate.com/isbn/9781472434289>>

**Link:**

[Link to publication record in Edinburgh Research Explorer](#)

**Document Version:**

Peer reviewed version

**Published In:**

Inspiring a Medico-Legal Revolution

**Publisher Rights Statement:**

Details of the definitive version are available at <http://www.ashgate.com/isbn/9781472434289>

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## **Chapter 5:**

### **Trust or Contract:**

#### **How Far Does the Contemporary Doctor/Patient Relationship**

#### **Protect and Promote Autonomy?**

**G T Laurie and J K Mason**

##### **Introduction**

The law has intervened extensively in the last 30 years in the name of autonomy enhancement and the protection of those with reduced mental capacity. It is, however, far from clear how much this has resulted in a net increase in the substantial trust that patients feel towards health care professionals – indeed, the opposite might be true. This chapter considers these developments against the backdrop of Sheila McLean’s contributions on the topics of consent and autonomy. It argues that a failure by law and its institutions to grasp the nuances and contours of authentic autonomy has encouraged a pseudo-contractual doctor/patient dynamic in which patient abandonment is legally sanctioned and the spectre of paternalism remains. While recognising that law cannot prescribe trust, it nonetheless suggests ways in which law’s future direction of travel could be more conducive to the promotion of a genuine therapeutic partnership.

##### **The Changing Face of Medicine**

Sheila McLean published her doctoral thesis in 1989<sup>1</sup> and it is now trite to say that its influence on medical practice in general was profound. The title – *The Patient's Right to Know* – clearly signalled that her particular interests lay in an analysis of the doctor/patient relationship within the therapeutic ambience which, as we will see, has failed to mature into an alliance, despite the increasing political and judicial attention devoted to the concept of patient autonomy.<sup>2</sup> McLean's ground-breaking contribution came during what can be seen as the developmental stages of a United Kingdom medical jurisprudence. It is a matter of history that, around the 1980s, the medical profession was under intense and critical review. This was partly self-induced by way of a number of scandals related to indefensible examples of malpractice.<sup>3</sup> The major impetus was, however, derived from a growing, and increasingly accepted, belief in individualism in general and the parallel,

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<sup>1</sup> McLean, S.A.M., *A Patient's Right to Know*, Aldershot, Dartmouth Publishing, 1989.

<sup>2</sup> We do not mean to suggest that the patient experience today can simply be reduced to a straight-forward binary “doctor-patient” dynamic. In fact, the reality is that patients experience many encounters with a range of healthcare professionals in any journey through the healthcare system. Often, consent will be taken by a junior doctor, consultation by a different professional, perhaps diagnosis by another, and treatment by yet another. Notwithstanding, this simply compounds the concerns that we express in this paper. We use the term “doctor-patient relationship” merely as a shorthand that should be taken to encompass this reality.

<sup>3</sup> The gauntlet was thrown down by Kennedy, I., *The Unmasking of Medicine*, London, George Allen and Unwin, 1981.

specifically medical, demand for self-determination based loosely on the patient's right to protection from untoward interference with his or her persona – which is, effectively, a matter of assault.

However, the practice of medicine is by its very nature, based on personal interference. Thus, the distinction between a good and a bad doctor/patient relationship is defined – or refined – in the word 'untoward'. No-one would suggest that Dr Cameron of Tannochbrae<sup>4</sup> intended to *harm* his patients; his offence under the revisionist mantra was that of paternalism. Most doctors practising at a time when their pharmacopoeia was largely both homeopathic and herbal would have seen this as synonymous with the reputable principle of beneficence. Nevertheless, the medical profession fell foul of the public when it persisted in this stance in an era in which pharmacologically powerful drugs, and associated complex techniques, became freely available. Very rapidly then, 'untoward' treatment came to mean unconsidered treatment - that is to say, treatment which was given without, at the same time, giving the patient adequate opportunity to accept it or reject it. Thus was born the procedure-driven concept of informed consent which now constitutes the main pillar of medical jurisprudence in, at least, the greater part of the anglophone world – and this despite, in respect of the United Kingdom, the early, yet seemingly authoritative, words of Dunn LJ that: 'The concept of informed consent forms no part of English law.'<sup>5</sup> The unfortunate result of these terminological uncertainties

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<sup>4</sup> The archetypal general practitioner of the early to mid-twentieth century portrayed in the fictional BBC series *Dr Finlay's Casebook* (1960-70).

<sup>5</sup> *Sidaway v. Board of Governors of the Bethlem Royal Hospital* [1984] QB 493, CA, at 517.

has been that the right to informed choice of treatment and respect for autonomy have come to be regarded as synonymous. In our view, this is a misconception with worrying conceptual and practical consequences. McLean's understanding of consent could not have anticipated this collapse in the distinction between two related but distinguishable concepts which she attributes, broadly, to a differing jurisprudential interpretation of the meaning and purpose of 'informed consent' in the United States and the United Kingdom.<sup>6</sup> Another important distinction that McLean is keen for all to grasp is that between due and appropriate concern for a person and unwarranted paternalism: '...care must be taken to avoid opportunities for [the latter] to resurface where it interferes with autonomy'.<sup>7</sup> The line for McLean can be drawn thus: 'While there may be a role for beneficence ... this is not the same as a justification for paternalism.'<sup>8</sup>

This chapter walks the fine lines between autonomy and consent, and beneficence and paternalism, as these have been drawn in the last 30 years, and against McLean's own analysis. We suggest that a failure to maintain sufficiently clear and bright lines, principally on the part of the courts, has led to a distortion of the doctor/patient relationship. Crucially, we contend that, today, this is a relationship of three parties - clinician, patient and the courts - in that the last police the parameters of the relationship dynamic and have, increasingly, taken it upon themselves to interfere in the name of autonomy in ways that might at times serve to undermine the all-important value of trust.

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<sup>6</sup> McLean, S.A.M., *Autonomy, Consent and the Law*, London, Routledge Cavendish, 2010, at p. 40.

<sup>7</sup> McLean, (2010), at p. 12.

<sup>8</sup> McLean, (2010), at p. 15.

While the medical profession in the United Kingdom has made considerable efforts to redress any imbalances in power – as demonstrated by the General Medical Council’s guidance on *Tomorrow’s Doctors* with its emphasis on effective communication and joint decision-making<sup>9</sup> – it is far less clear that the same objective is being delivered by the law, especially by the way in which central notions of consent and autonomy are constructed and protected.<sup>10</sup>

Autonomy is a status whereby the human being is recognised as having the fundamental right, qua human, of control over his or her own body and the direction of his or her own life in both physical and intellectual senses. It is a quality, which – when present – indisputably merits respect. It is related to human dignity<sup>11</sup> which is an *inherent*

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<sup>9</sup> General Medical Council, *Tomorrow’s Doctors* (2009, updated 2012), especially para 15.

<sup>10</sup> More worryingly, the Francis report found that sustained and systemic communication failures that paid insufficient attention to patients and their needs contributed significantly to the unacceptable standards and outcomes in Mid-Staffordshire, see Francis, R., *Report of the Mid Staffordshire NHS Foundation Trust: Public Inquiry*, (2013), HC 947.

<sup>11</sup> This paper cannot do justice to the role of dignity in medical law. Its pre-eminence arose with the over-used phrase ‘death with dignity’ which implies death free from pointless invasive therapy. It has subsequently been subject to multiple variations in meaning – see most recently C-34/10 *Brüstle v. Greenpeace eV* [2012] 1 CMLR 41 on the patentability of inventions involving commercial and industrial uses of embryos - so much

quality, possessed of all persons and which exists irrespective of their ability to express it. Contrariwise, autonomy is contingent both on one's ability to recognise and to exercise it - and yet it is of no less fundamental importance for this fact. Consent, on the other hand, is a *means* to an end, that end being respect for the person and respect for their autonomy. It is an ethical and legal device or conduit by which we can achieve the desired end-point, but it is by no means the only way to do so. And yet, such is the sway which consent now holds over the discipline of medical law that this important distinction is often ignored. This error is compounded by the fact that it is consent rather than autonomy which emerges as the dominant paradigm of the two within the doctor/patient relationship – that is, that the means often comes to define the totality of the ends. Not only is this paradoxical and conceptually worrying, but it has profound practical consequences; once again, ones that we fancy were never intended or looked for by McLean when she wrote her seminal work.

From this prologue about conceptual confusion, the purpose of this chapter emerges as two-fold. First, we will explore what the collapse in the distinction between these central concepts has meant for medical law, arguing that it has impoverished both our understanding, and the very nature, of the doctor/patient relationship. This is true also with respect to the legitimate roles of those who play a part in the formation of the

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so as to render the phrase 'human dignity' one that, in our view, is best avoided. Nonetheless, it is a favourite device of the European courts and has been described as forming the base of 'a kind of ethical last stand': Brownsword, R., 'Regulating Human Genetics: New Dilemmas for a New Millennium', (2004) 12 *Modern Law Review*, 14-39, at p. 20.

relationship – being both medical and judicial personnel. Second, we will argue for the reinstatement of the distinction between the roles of autonomy and consent, and for further clarification of the legitimate basis for beneficent as opposed to paternalistic interference, in order to reorient the way in which the relationship should be seen. These contributions depend on two different sets of circumstances: (i) when autonomy is present and accepted in the therapeutic relationship, and (ii) when it is disputed or open to question.

As to the former, we will demonstrate that the focus on consent to date has reduced the doctor/patient relationship to one that is driven by claims, rights and entitlements, and by concerns about breaches of duty and the pursuit of remedies; it has overlooked the importance of, and necessity for, trust as the basis for that relationship. We posit that the drift towards a pseudo-contractual, legalistic model should be resisted for the benefit of a genuine therapeutic alliance and for the betterment of medical law itself. As to the latter context, we will examine recent developments concerning the emerging legal category of the ‘vulnerable adult’, as driven by the English High Court and Court of Appeal. While this has been done in the name of facilitating autonomy, we argue that far more procedural attention must be paid to the limits of court powers over this category of person, lest the developments bleed into the medical domain and return clinicians to the role of paternalist.

### **Autonomy: The Patient’s Protection**

We have already pointed to the semantic confusion that currently exists as to the distinction between autonomy and consent and we re-emphasise that autonomy is a multifaceted quality of humanness, the protection of which is now accepted as the prime



requirement of contemporary medical jurisprudence. Consent is not a complete reflection of that need. Fundamentally, the protection of a patient's autonomy as defined above lies in the criminal law of assault;<sup>12</sup> on this view, consent is no more than a device to protect the patient's autonomous right to accept or refuse the 'assaults' which are an integral aspect of modern medical practice. Thus, while it is undeniable that an intimate connection exists between consent and autonomy, the former represents no more than a secondary, or consequential, manifestation of the fundamental right. The two concepts are inseparable but they are not synonymous. In this section we explore some of the contours and the limits of consent as it is currently used in medical law, in both the therapeutic and research contexts. In particular, we posit that, whereas autonomy serves to *promote* the interests of the patient in general terms, the function of consent is limited to *protection* of his or her status against practices that drive the development of an unequal relationship.

#### *Consent as an Aspect of Self-defence*

Whether or not it is a derivative attribute only, the patient's practical *defence* of his or her autonomy lies in the primacy of *choice* as to medical interference – be it in the form of consent or refusal. Yet, it is one of the deep ironies about the groundswell of support for consent in the guise of patient empowerment that the reality is that the power that the patient derives is almost entirely negative: it is the right to say *no*. It is all too often forgotten that the doctor/patient relationship is one *between* supposedly autonomous individuals, and the courts have consistently ruled that the patient cannot *demand*

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<sup>12</sup> As interpreted in *Chatterton v. Gerson* [1981] QB 432.

treatment against the doctor's judgment.<sup>13</sup> From this, it follows that adoption of the mantra of consent is, in effect, an abrogation of autonomy. Moreover, refusal carries with it a rejection of opportunities proffered by the medical professionals, leading to a closing off of options and a restriction of possible life paths. This might indeed be what the patient chooses, but the scope of possible choice is limited to a binary yes/no and the so-called choice is reduced to the single option of rejection. We do not deny that such a choice can be liberating, but this is so only in the sense of a negative liberty: the right to respect for the integrity of the human persona. For us, then, one of the major and oft-heralded victories in the campaign for patient autonomy – reflected in the following case law dictum - has something of a hollow ring to it: '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.'<sup>14</sup>

In the medical ambience, where a patient is faced with a choice between two therapeutic management proposals, the ability – or entitlement – to choose between the two is scarcely empowering unless it is assisted by the doctor as therapeutic partner. Yet, too often the patient is left alone in the name of autonomy to choose between options, the doctor having fulfilled his or her duty of establishing that the patient is in possession of the relevant facts and has capacity. Consent, if it is given, thus becomes a protector of the doctor rather than of the patient.<sup>15</sup> It is acquiescence with the proposed medical

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<sup>13</sup> *R (Burke) v. General Medical Council* [2006] QB 273; (2006) 85 BMLR 1, CA.

<sup>14</sup> *Re T* [1993] Fam 95, at 102.

<sup>15</sup> Classically demonstrated in Lord Donaldson's famous dictum on the use of flak-jackets in *Re W (a minor) (medical treatment)* [1992] 4 All ER 627.

intervention, but it is scarcely patient-empowering beyond such limits. The enduring power remains one to say no – at any stage and for any reason<sup>16</sup> – but this may be of little assistance to the patient, or research participant, whose interests might be better served by a therapeutic or research alliance where the boundaries and contours of a relationship are negotiated on mutual terms. We suggest that patients and doctors alike are currently prevented from entering such an alliance by the constraints of consent as it has come to be constructed by these two key qualifying elements: capacity and informedness.

### *Capacity*

Capacity is a factor that is *internal* to the patient, albeit that it is mostly judged by medical professionals. In law, it is a threshold device that is used to determine whether further (caring) intervention can legitimately be taken towards individuals who purport to say ‘no’ or who cannot speak for themselves. The default, as we know well, is that capacity is present in all mature adult persons. As such, there is no incentive to promote autonomy. Indeed, quite the opposite is true. Only if there is incapacity can an individual be treated non-consensually in their own best interests.<sup>17</sup>

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<sup>16</sup> *Re T*, note 14, above.

<sup>17</sup> In Scotland, for adults, there must be ‘benefit’ after the Adults with Incapacity (Scotland) Act 2000. This formulation was preferred as less paternalistic than ‘best interests’.

McLean has revisited the subject as a whole in her recent monograph.<sup>18</sup> Very early in her presentation, she describes mental competence as the *sine qua non* of autonomy.<sup>19</sup> Certainly, many of the legal battles fought and won on the consent field over the last quarter century have been in and around questions of capacity. Case law<sup>20</sup> and legislation<sup>21</sup> now abound with attempts to define legal capacity and its role as a threshold mechanism for determining whether someone is *sufficiently* autonomous with respect to the *particular* decision they are facing to merit respect for any choices they purport to make.

We confess to being unimpressed with the majority of these templates which, of necessity, deal with the generality rather than the particular.<sup>22</sup> They do little more than recapitulate what most doctors would see as standard medical practice; as a result, the legal definition of capacity rests on the highly subjective opinions of individual practitioners. The answer to the broad question – has this adult person still got capacity? – is largely medically determined, but the legal consequence of a finding of capacity necessitates the unquestioning acceptance of any and all choices which are then made. As things stand, setting capacity as a legal threshold focuses all of our attention on the

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<sup>18</sup> Note 6, above.

<sup>19</sup> Note 6, above, at p. 17.

<sup>20</sup> See Mason, J.K. and Laurie, G.T., *Law and Medical Ethics* (9th edn), Oxford, Oxford University Press, 2013, chapter 4.

<sup>21</sup> Adults with Incapacity (Scotland) Act, Mental Capacity Act 2005, as amended, and Adults with Incapacity (Scotland) Act 2000, as amended.

<sup>22</sup> Mason, J.K., ‘Particularity in Medical Law’, in Bankowski, Z. and MacLean, J. (eds), *The Universal and the Particular in Legal Reasoning*, Aldershot, Ashgate, 2007.

establishment of capacity and none on what happens thereafter. Indeed, there is a positive disincentive in law to explore with a patient how he or she might maximise their autonomy, through choices or otherwise. Once the Rubicon has been crossed, the doctor is not permitted to accompany the patient on his or her journey. Put bluntly, the law supports the potential abandonment of autonomous patients to the vagaries of their own choices. This is at considerable odds with what many patients would reasonably expect of their healthcare professionals. Moreover, it fails to reflect the possibility that we are all, in some sense, vulnerable and “inevitably dependent” throughout our lives, and most especially when we are unwell.<sup>23</sup>

### *Informedness*

Achieving autonomy does not only depend on the intrinsic quality of capacity. It can depend as much on the externally-driven provision of information about the nature and quality of choices that are to be made. Once again, this apparently leaves considerable control in the hands of the medical profession, and yet - despite the triumph of the clarion call for the patient’s right to know – we would suggest that the legal result does little to promote either autonomy or a healthy therapeutic relationship.

Capacity and informedness must co-exist to create the autonomous patient. But this raises the question: how and how far does a patient have to be informed about a proposed medical intervention before his or her consent is valid? McLean published *The Right to*

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<sup>23</sup> See Fineman, M., *The Autonomy Myth: A Theory Of Dependency*, New York, The New Press, 2005.

*Know* in the immediate aftermath of the House of Lords' decision in *Sidaway*.<sup>24</sup> This decision is remarkable in two important respects: first, it confirmed the application of the *Bolam*<sup>25</sup> principle to information disclosure cases in the UK and stated explicitly that the American doctrine of 'informed consent' had no place in our law. Second, there was no mention in the entirety of the judgement of the term *autonomy*. Such features were the strongest possible evidence to activists like McLean that medical paternalism was alive and well and that the battle for the patient's right to know remained to be fought. And fight they did. And win they did. Indeed, so far has the pendulum swung from *Sidaway* that the decision must now be considered as little other than anathema. In its place sit a wide range of purportedly patient-centred judgements,<sup>26</sup> best typified by the Supreme Court ruling in *Chester v. Afshar*<sup>27</sup> which, again with deep irony, had astonishingly similar facts to those of Mrs Sidaway and yet which produced an equally remarkable – and diametrically opposite – result. What is particularly remarkable about *Chester* is not only

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<sup>24</sup> *Sidaway v. Board of Governors of the Bethlem Royal Hospital* [1985] AC 871.

<sup>25</sup> *Bolam v. Friern Hospital Management Committee* [1957] 1 WLR 582 (negligence and relevance of recognised medical practice to standard of care).

<sup>26</sup> See *Pearce v. United Bristol Healthcare NHS Trust* (1999) 48 BMLR 118; *Birch v. University College London Hospital NHS Foundation Trust* (2008) 104 BMLR 168; *Jones v. North West Special Health Authority* [2010] EWHC 178; and *Nicholas v. Imperial College Healthcare NHS Trust* [2012] EWHC 591.

<sup>27</sup> *Chester v. Afshar* [2005] 1 AC 134. For discussion, see Meyers, D., 'Chester v. Afshar: Sayanaro, Sub Silentio, Sidaway', in McLean, S.A.M. (ed.), *First Do No Harm*, Aldershot, Ashgate Publishing, 2006, Ch. 16.

its blatant distortion of the rules of causation so as enable the Court to find in favour of the claimant's argument that she was insufficiently informed, but also that the court appears to have brought us to the brink of a stand alone tort of affront to autonomy.<sup>28</sup>

We are not concerned here to revisit the legal particularities of informedness in order to demonstrate the ways in which this feature of consent has developed. Rather, we are driven to point out the consequences for autonomy of this fixation on *informed* consent, albeit not in the US doctrinal sense. First, and most obviously, this conceptualisation implies that a consent that is insufficiently informed is not valid and, a fortiori, is not a genuine expression of autonomy. Yet, as the following examples show, this conclusion cannot be universalised across the whole spectrum of health care relationships. Secondly, a requirement of informedness can serve to undermine or even entirely thwart autonomy interests; this is, again, ironic since it is generally considered that consent processes are made procedurally robust precisely because they involve information giving. In particular, what this drive towards informedness to promote consent achieves, indirectly, is a potential undervaluing of circumstances where an otherwise autonomous individual might trust another party to 'do the right thing', be it with their being, their tissue or their data. We can choose to trust in circumstances where information is less than complete or, even, where the very provision of information is considered to be an affront in itself.

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<sup>28</sup> See Laurie, G., 'Personality, Privacy and Autonomy in Medical Law', in Whitty, N. and Zimmermann, R. (eds.), *Rights of Personality in Scots Law: A Comparative Perspective*, Dundee, Dundee University Press, 2009, 453-84. This seems to be largely in line with the ratio in *Rees v. Darlington Memorial Hospital NHS Trust* [2004] AC 309.

*How Information Can Undermine Autonomy: (A) The Right Not to Know*

One of us was inspired by McLean's work on the Right to Know to ask whether the converse claim was also sustainable, that is: is there a Right Not to Know?<sup>29</sup> The notion is perfectly understandable because we can all imagine circumstances in which we might prefer not to be told of a particular diagnosis or family trait if, say, nothing can be done about it. Is it not an equal entitlement under our claim to autonomy to reject information as it is to require it? We wager most of us would intuitively agree that this is, at least, not an unreasonable exercise of our autonomy. Moreover, in doing so we would have to recognise that this is about a lack of information and relies on us being able to trust those in possession of information *not* to disclose it. We have argued for the subtleties of this elsewhere.<sup>30</sup> Our contention that consent (or refusal) cannot do all of the work to protect our autonomy and other personal interests<sup>31</sup> is illustrated by the limited protection afforded by instruments such as the UNESCO Universal Declaration on the Human Genome and Human Rights (1997), Article 5c of which provides: 'The right of every individual to

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<sup>29</sup> Laurie, G., *Genetic Privacy: A Legal Perspective*, doctoral thesis under supervision of McLean, S.A.M., University of Glasgow, 1997; Laurie, G., *Genetic Privacy: A Challenge to Medico-legal Norms*, Cambridge, Cambridge University Press, 2002.

<sup>30</sup> Laurie, G., 'Recognizing the Right Not to Know: Conceptual, Professional and Legal Implications', (2014) 42(1) *Journal of Law, Medicine and Ethics*, 53-63.

<sup>31</sup> We posit, in fact, that this is a matter of protection of privacy interests, related to but also distinct from autonomy interests.



decide whether or not to be informed of the results of genetic examination and the resulting consequences should be respected.’ Similarly, the Council of Europe Oviedo Convention on Human Rights and Biomedicine (1997), Article 10(2) states: ‘Everyone is entitled to know any information collected about his health. However, the wishes of an individual not to be so informed shall be observed.’ These provisions are based on two challengeable assumptions: first, that a timely and effectively-informed opportunity to say ‘No’ is available; and, second, that a person can be informed that there is something to know about themselves without revealing the essence of the information itself! If we take seriously the idea that a genuine state of ignorance is valuable to our autonomous selves, then these formulations as matters of choice and control of information are deficient.

#### *How Information Can Undermine Autonomy: (B) Broad Consent and Biobanks*

It is clear, however, that the requirement of respect for autonomy goes deeper than that from many aspects. The extreme antithesis to individualistic autonomy can, perhaps, be epitomised in some such phrase as ‘forgone autonomy’ whereby the originator empowers the receptor to proceed on the assumption that specific consent has not been given but is encompassed within a general acquiescence with the circumstances. Such a situation arises when the originator does not – or cannot – know the full use to which the receptor is likely to put the material over which he or she has assumed control; the consent model then becomes difficult to apply as a means of justifying surrender of one’s autonomy insofar as it seems to ignore the significance attached to ‘informedness’ in the concept of ‘informed consent’. The exemplary situation is to be found in contribution to data and tissue research - or biobanks - in which, given that not even the controller of the bank can be

certain of the future use of the material in his or her charge, application of the informed consent model is a virtual impossibility.<sup>32</sup> This has resulted in the literature and in practice in a flurry of attempts to reconceive and distinguish forms of consent variously as implied,<sup>33</sup> explicit,<sup>34</sup> informed,<sup>35</sup> specific,<sup>36</sup> broad,<sup>37</sup> and generic.<sup>38</sup> But, if as we suggest,

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<sup>32</sup> For in-depth discussion of this particular difficulty, see Harmon, S.H.E., ‘Semantic, Pedantic or Paradigm Shift? Recruitment, Retention and Property in Modern Population Biobanking’, (2008) 16 *European Journal of Health Law*, 27-43. For a proposed solution which emphasises robust governance mechanisms over consent-based approaches, see Laurie, G., ‘Reflexive Governance in Biobanking: On the Value of Policy Led Approaches and the Need to Recognise the Limits of Law’, (2011) 130(3) *Human Genetics*, 347-56.

<sup>33</sup> Furness, P., ‘Consent to Using Human Tissue: Implied Consent Should Suffice’, (2003) 327 (7418) *British Medical Journal*, 759-60.

<sup>34</sup> Otlowski, M., ‘Tackling Legal Challenges Posed by Population Biobanks: Reconceptualising Consent Requirements’, (2012) 20 *Medical Law Review*, 191–226.

<sup>35</sup> MacLean, A., ‘From *Sidaway* to *Pearce* and Beyond: Is the Legal Regulation of Consent any Better Following a Quarter of a Century of Judicial Scrutiny?’, (2012) 20 *Medical Law Review*, 108-29.

<sup>36</sup> Note 34, above, at p.191.

<sup>37</sup> Caulfield, T. and Kaye, J., ‘Broad Consent in Biobanking: Reflections on Seemingly Insurmountable Dilemmas’, (2009) 10 *Medical Law International*, 85–100.

<sup>38</sup> Caulfield, T., ‘Biobanks and Blanket Consent: The Proper Place of the Public Good and Public Perception Rationales’, (2007) 1 *Kings Law Journal*, 209-26.

there should be a decoupling of consent from autonomy, where lies the alternative? In our view, there is no single answer but, in our search for that answer, we must first consider the precise circumstances in which one is pleading that autonomy rules.

### **Reconceptualising Autonomy in Practice – Alternative Models**

From our above analysis, we suggest that there are two ways in which a patient's autonomy arises as a contentious issue. The first, which broadly reflects the status quo and which we tentatively describe as *defensive autonomy*, relates to the autonomous right to choose what is to be done to or with one's body. It is exemplified, as we have seen, by the respect that is due to our choices as to our medical management and is intimately bound to the consent model on which hangs much of the contemporary definition of autonomy. It is heavily dependent on two key thresholds being overcome: having the capacity to make choices and having adequate levels of information by which to make choices. Attempts to exercise one's autonomy beyond these limits are treated as suspect, flawed and non-deserving of respect. This having been said, it is precisely in the realm beyond autonomy that there have been considerable statutory legal reforms in the guise of the Mental Capacity Act 2005 and the Adults with Incapacity (Scotland) Act 2000 to determine how incapacitated persons should be treated. There now exist extremely robust procedural mechanisms by which we can place trust that patients will be treated in their own 'best interests' (or 'to their benefit' in Scotland) when autonomy and consent do not come into play. When they do, however, we suggest that a defensive need to obtain consent drives a culture of potential patient abandonment whereby individuals are left to their own devices

to explore and exercise their autonomy. This casts consent as an aspect of control, albeit illusory in many cases. It follows that there is an expectation that control be facilitated.

Arguably, this has been compounded in recent years by the entry of the property model into the doctor/patient relationship.<sup>39</sup> Property is the paradigmatic legal device through which to exercise control. We pre-empted this more than a decade ago: ‘The concepts of property and consent need not be mutually exclusive; indeed they should operate in tandem to ensure full and proper respect for individual rights.’<sup>40</sup> We did not anticipate, however, that an unlooked-for consequence of these parallel developments would be the increasing approximation of the doctor/patient relationship to something akin to pseudo-contract. We suggest that the metaphor of contract is pertinent in that it evokes a relationship characterised by an essentially oppositional dynamic focussed on expectations of rights and entitlements, and with a growing cohort of remedies for non-performance and failure to satisfy, viz the apparent emergence of the stand-alone tort of affront to autonomy (above). The patient today, then, is entitled to information, is entitled to unquestioning respect for their refusals, is entitled to recognition of their property interests, and, ultimately, is entitled to be left alone entirely to determine his or her own

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<sup>39</sup> See Mason and Laurie, note 20, above, chapter 14 for discussion and literature.

<sup>40</sup> Mason, K. and Laurie, G., ‘Consent or Property? Dealing with the Body and its Parts in the Shadow of Bristol and Alder Hey’, (2001) 64 *Modern Law Review*, 710-29, at p. 727. See also, Harmon, S.H.E., ‘A Penny for Your Thoughts, A Pound for Your Flesh: Implications for Recognizing Property Rights in our Own Excised Body Parts’, (2006) 7 *Medical Law International*, 329-54.

*self* rule. This is, however, a view of autonomy in the most meagre of terms. It is a view that is likely to take the *care* out of the caring professions.

The alternative is to cast autonomy as *permissive* whereby the individual can legitimately and voluntarily surrender some aspect of his or her persona, as is typified by the originator entering the data- or bio-bank system or the organ transplant programme. On this interpretation, autonomy is no longer being used as a defensive shield but is, rather, being surrendered as an expression of community trust; and, again, consent fits uneasily into the resultant ethical pattern. The power to say no and withdraw usually remains (subject to the impracticalities of destroying data or samples) but, in this concept, there is no pretence of continuing control over said data or samples nor, indeed, of any necessary personal benefit. Indeed, the trusted surrender of autonomy might even bring risk, as in the example of recognising an interest in not knowing information about one's self: this can be a threat to privacy interests. Still, why should a pastiche of control – via consent – be the gold standard of our behaviour when our autonomy might be facilitated and exercised in ways which have no need for such control and are, instead, a reflection of our capacity and desire to trust? Developments in the law to date seem largely blind to these possibilities.

### **From Pseudo-contract to Trust**

The relationship between trust and law is under-examined. Unlike the connections or disconnections between autonomy and trust explored by O’Neill and others,<sup>41</sup> law’s role in the promotion of trusting dynamics – particularly those which encourage and facilitate autonomy to flourish – is relatively uncharted territory. An important and fundamental distinction, however, is that between what might be called *substantive* and *procedural* trust. Substantive trust refers simply to the situation when, as a matter of fact, a state of trust exists between parties. There is little that law can do directly to engender this. In contrast, there is much that law can do to promote procedural trust, that is, trust in systems and procedures of protection (and promotion) of interests, including those embodied in the mental capacity legislation, procedures for decision-making bodies such as the Court of Protection, and robust rules and approaches such as the presumption of capacity and the superlative of *best* interests when capacity is lacking. Procedural trust is founded on high degrees of certainty, transparency and a commitment to core values that ultimately guide decision-making.

While it can never guarantee substantive trust, procedural trust becomes particularly important when the law is still developing. Although we cannot know the end point that will eventually be reached, we ought to be able to trust that core values and precepts steer our course, and that auto-correction is possible when needed. This makes it all the more imperative that we are clear about what is at stake: particularly, what kind of autonomy we wish to support and promote, and which kinds of behaviour we accept or

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<sup>41</sup> O’Neill, O., *Autonomy and Trust in Bioethics*, Cambridge, Cambridge University Press, 2002; Manson, N.C. and O’Neill, O., *Rethinking Informed Consent in Bioethics*, Cambridge, Cambridge University Press, 2007.

reject, such as McLean's fine line between beneficence and paternalism. Arguably, it is precisely because we have been less than clear in the past about the respective roles of consent and autonomy that we find ourselves in the position outlined above. If we seek, in the future, to promote and facilitate richer conceptualisations of autonomy, we must be able to rely on procedural trust in the systems and personnel involved – from within law and medicine alike.

An example from an area of developing law illustrates the issues very well. This is the recent resurrection of the inherent jurisdiction of the High Court in England and Wales in respect of the protection of vulnerable adults. Previously, the jurisdiction had been thought to have been extinguished by the passing of the Mental Capacity Act 2005. However, its enduring role is now said to be determinedly about facilitating the autonomy of this class of persons. The following analysis outlines the developments and offers commentary on this legal attempt to promote autonomy in light of lessons we have outlined above.

### **Autonomy: The Promotion of a Core Human Value**

Common law and statute law have each been responsible for shaping two distinct aspects of autonomy in the last 30 years.<sup>42</sup> The common law has largely driven the consent-based developments outlined above, while statute has brought about extensive reforms to protect those persons who do not clear the threshold for competence, by introducing elaborate rules on determining capacity and best interests, and establishing the Court of Protection

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<sup>42</sup> The discussion now proceeds largely on the basis of English law. The position in Scotland is different and will be invoked only by way of comparative illustration.

to deliver the protections of the Mental Capacity Act 2005 (MCA). These changes have served to delineate the outer limits of autonomous action, albeit that the legislation requires attempts, so far as reasonably practicable, to encourage a person's participation;<sup>43</sup> and also efforts, so far as reasonably ascertainable, to take into account a person's wishes, feelings, beliefs and values.<sup>44</sup> The courts have made it very clear that the Act cannot be used to justify interventions based on professional concern about the outcome of an individual's decisions,<sup>45</sup> the jurisdiction of the Court of Protection only arises if capacity is lacking. As noted, however, capacity is largely an *internal* factor affecting a person, viz, s. 2(1) of the 2005 Act states:

For the purposes of this Act, a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter *because of* an impairment of, or a disturbance in the functioning of, the mind or brain.<sup>46</sup>

Thus, although the Act extends far beyond purely medical cases in the same way that our autonomy is implicated in all aspects of our lives - including social care, welfare and beyond - many assessments of capacity will depend on medical evidence. But what is the legal and procedural position if there are reasons to doubt a person's capacity because of *external* factors, i.e. not relating to the mind or brain?

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<sup>43</sup> 2005 Act, s. 4(4).

<sup>44</sup> 2005 Act, s. 4(6).

<sup>45</sup> *York City Council v. C* [2013] EWCA Civ 478; [2014] 2 WLR 1, para 53.

<sup>46</sup> Emphasis added.



Precisely this issue arose in *DL v. Local Authority and Others*, decided by the Court of Appeal in March 2012.<sup>47</sup> A local authority was concerned about the treatment of an elderly couple being cared for by their 50-year-old son. Allegations included threats, physical abuse, preventing his parents from leaving the house, and preventing carers and health professionals from visiting. The parents had capacity as defined under the 2005 Act, and so the Court of Protection had no jurisdiction to intervene. The local authority sought, instead, interim injunctive relief from the High Court, asking it to invoke its inherent jurisdiction that pre-dated the 2005 Act. The legal point at issue on appeal was summed up by McFarlane LJ in the opening paragraph of the judgment:

The question for consideration is whether, despite the extensive territory now occupied by the MCA 2005, a jurisdictional hinterland exists outside its borders to deal with cases of ‘vulnerable adults’ who fall outside that Act and which are determined under the inherent jurisdiction.

Answering in the affirmative, the Court of Appeal endorsed a body of case law that had been developing largely through the efforts of Munby J. on his way to assuming Presidency of the High Court (Family Division). The key points of that jurisprudence, and the confirmation of the Court of Appeal, can be summed up as follows:

1. The inherent jurisdiction of the High Court endures with respect to adults whose autonomy has been compromised by external factors and when this leaves them outside the protection of the MCA. In particular, this can include persons:
  - a) Under constraint; or
  - b) Subject to coercion or undue influence; or

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<sup>47</sup> [2012] EWCA Civ 253; [2012] 3 WLR 1439; [2013] Fam 1.

c) For some other reason deprived of the capacity to make the relevant decision or disabled from making a free choice, or incapacitated or disabled from giving or expressing a real and genuine consent.<sup>48</sup>

2. The category of persons potentially caught by the jurisdiction is determinedly open-ended. As Munby J. said in *Re SA*:

... I would treat as a vulnerable adult someone who, whether or not mentally incapacitated, and whether or not suffering from any mental illness, is or may be unable to take care of him or herself against significant harm or exploitation or who is deaf, blind, or dumb, or who is substantially handicapped by illness, injury or congenital deformation. This...is not and is not intended to be a definition. It is descriptive not definitive.<sup>49</sup>

3. The jurisdiction is aimed at ‘...enhancing or liberating the autonomy of a vulnerable adult whose autonomy has been compromised by a reason other than mental incapacity...’.<sup>50</sup> The Court of Appeal found there to be ‘...a sound and strong public policy justification for this,’<sup>51</sup> and it was emphatic that ‘either the

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<sup>48</sup> See *Re: SA (Vulnerable adult with capacity: marriage)* [2005] EWHC 2942 (Fam); [2006] 1 FLR 867, paras 76-79 per Munby J, entirely endorsed by the Court of Appeal in *DL*, note 47, above, at para 54.

<sup>49</sup> Note 48, above, at para 82. Also, *A Local Authority and Mrs A* [2010] EWHC 1549, para 79.

<sup>50</sup> Note 47, above, at para 54.

<sup>51</sup> Note 47, above, at para 63.

jurisdiction exists or it does not' (in response to arguments that it is not possible to extrapolate from medical best interest cases to the general class of the vulnerable).<sup>52</sup> Its application therefore is dependent on the facts of any given case, and covers a gamut of circumstances, including medical, welfare, social care and marital cases. But importantly, and unlike the Court of Protection, the High Court cannot take decisions on behalf of such persons and in their best interests. It therefore raises questions about the nature and scope of the court's powers to intervene, and we consider this below.

4. The common law jurisdiction must complement the MCA and not undermine the will of Parliament with respect to that statute or any other legislative provision. It can be exercised to fill gaps<sup>53</sup> where it is necessary, lawful and proportionate to do so.<sup>54</sup>

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<sup>52</sup> Note 47, above, at para 55.

<sup>53</sup> Munby J relied on the metaphor of the common law as a "the great safety net" to fill any gaps in protection of the vulnerable, as first stated by Lord Donaldson MR in *Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1; CA: (1989) 86(10) LSG 42, and later endorsed by Dame Butler-Sloss P in *Re A Local Authority (Inquiry: Restraint on Publication)* [2004] Fam 96.

<sup>54</sup> See *DL*, note 47, above, at paras 46-49, endorsing the earlier Court of Appeal ruling in *Westminster City Council v. C* [2008] EWCA Civ 198; [2009] 2 WLR 185 in which the judges confirmed strongly the jurisdiction as providing relief not otherwise

5. The nature and scope of court powers are both specific and wide-ranging. Commending the approach of Macur J in *LBL v RYJ and VJ*,<sup>55</sup> the Court of Appeal explained that exercise of the jurisdiction should reflect a ‘facilitative, rather than dictatorial, approach’ towards ‘the re-establishment of the individual's autonomy of decision making in a manner which enhances, rather than breaches, their ECHR Article 8 rights.’<sup>56</sup> However, this is not limited to granting interim relief to remove an undue influence and allow a vulnerable person the space to make their own decisions. For example, in *DL* injunctive relief was sought to prevent the son from seeking to persuade or coerce his parents, and to restrain him from interfering with the provision of care and support. But the totality of the High Court’s inherent powers extends much further, as seen in the case of *Westminster County Council v C*,<sup>57</sup> where an earlier CA bench endorsed the use of the inherent jurisdiction to prevent removal of a vulnerable person<sup>58</sup> from the jurisdiction because of a questionable marriage in Bangladesh.

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available, and which in turn cited with approval the analysis and ruling of Munby J in *Re PS (An Adult)* [2007] EWHC 623.

<sup>55</sup> [2010] EWHC 2665 (COP), para 62.

<sup>56</sup> Note 47, above, at para 67. The CA considered compatibility with human rights at para 66.

<sup>57</sup> Note 54, above.

<sup>58</sup> The 25 year-old man had autism and severe impairment of intellectual functioning.

Space does not permit us to take issue with the question of whether this is a legitimate resurrection of an archaic jurisdiction.<sup>59</sup> Views on this can be found elsewhere.<sup>60</sup> Rather, we are concerned with the possible implications of these rulings and their scope, which is now confirmed as jurisdiction over a new category of person: the vulnerable - which is a 'categorisation' potentially applicable to almost every class of patient in a health context.<sup>61</sup> Moreover, we are keen to explore what this might mean for autonomy, using McLean's benchmark of the fine line between paternalism and beneficence. The Law Commission, for its part, stressed in 2011 that: '...the inherent jurisdiction cannot be used to compel a capacitated but vulnerable person to do or not do something which they have after due consideration, decided to do or not do...'<sup>62</sup> While supportive of the trump value of autonomy, this still does not tell us whether we can currently trust the courts to remain on

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<sup>59</sup> Note, unlike the Children Act 1989 and the Family Law Act 1986, the Mental Capacity Act 2005 makes no explicit mention of, and places no express restriction on, any common law jurisdiction.

<sup>60</sup> See Hewson, B., 'Neither Midwives Nor Rainmakers: Why DL is Wrong', (2013) *Public Law*, 451-459; Bridge, C., 'Inherent Jurisdiction' (2012) 42(Dec) *Family Law*, 1454-6; Hughes, R., 'The Inherent Jurisdiction over Vulnerable Adults', (2013) 3 *Private Client Business*, 132-9.

<sup>61</sup> It is to be noted that, despite their titles, neither the Safeguarding Vulnerable Groups Act 2006 nor the Protection of Vulnerable Groups (Scotland) Act 2007 has any relevance to the present discussion, both dealing with the criminal law.

<sup>62</sup> Law Commission, *Adult Social Care*, (2011), LC326, para 9.80.

the right side of the McLean line. We offer some considerations in this regard for courts and medical professionals alike.

*Who is Vulnerable?*

The deliberately diverse and non-exhaustive category of vulnerable persons has potential application to any one of us, healthy or ill. This is not the same as saying that we have descended a slippery slope whereby the courts can override genuinely autonomous decisions,<sup>63</sup> but, rather that actual *or perceived* coercion of circumstances in any of our lives can attract the attention of the court and lead them, and those around us, to ignore our apparent choices, temporarily at least. The difficulty here has already been pointed out by McLean:<sup>64</sup> the question underlying the very definition of an autonomous decision ‘... is not *whether* we are influenced by external considerations but, rather, what is the *extent* of that influence.’<sup>65</sup> In pointing out that ‘few decisions are totally free’, McLean identifies that we are perpetually confronted by ‘the underlying conundrum of how to translate autonomy from aspiration into decisional reality’.<sup>66</sup> Central to this is a robust sense of what counts as evidence of undue influence or coercion.

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<sup>63</sup> Note 47, above, at para 32.

<sup>64</sup> On coercion of circumstance, see J.K. Mason’s review of McLean’s book in (2011) 11 *Medical Law International*, at p. 307.

<sup>65</sup> Note 6, above, at p. 62.

<sup>66</sup> Note 6, above, at p. 65.

Munby J in *Re SA* elaborated on this in some of his examples.<sup>67</sup> For instance, ‘constraint’ is represented by ‘some significant curtailment of the freedom to do those things which in this country free men and women are entitled to do’, while coercion or undue influence are typified by the Jehovah’s Witness case *Re T*.<sup>68</sup> He noted that:

... where the influence is that of a parent or other close and dominating relative, and where the arguments and persuasion are based upon personal affection or duty, religious beliefs, powerful social or cultural conventions, or asserted social, familial or domestic obligations, the influence may, as Butler-Sloss LJ put it, be subtle, insidious, pervasive and powerful. In such cases, moreover, very little pressure may suffice to bring about the desired result.<sup>69</sup>

This suggests that autonomy is a fragile thing, potentially further undermined by a person’s status as ill, deaf, dumb or blind, according to the case law (see above). But how, then, can autonomy be protected and promoted as part of a beneficent, as opposed to a paternalistic, approach of the courts or our carers? We suggest three important features when dealing with the evidence base: (i) adducing relevant evidence in a balance sheet, (ii) determining whose evidence counts, and (iii) including the relevance of time.

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<sup>67</sup> Note 48, above, at para 78.

<sup>68</sup> *Re T (Adult: Refusal of Treatment)* [1993] Fam 95. See also, *In re Z (Local Authority: Duty)* [2004] EWHC 2817 (Fam), [2005] 1 WLR 959.

<sup>69</sup> Note 48, above, at para 78.

(i) In much the same way as we see the courts approaching a best interests test, the use of a balance sheet of considerations would be important in terms of helping to ensure that the full range of factors is taken into consideration. Vulnerability is likely to be brought about by the confluence of a range of factors, and it can depend as much on the behaviour of those around us and our own subjective state of being. A balance-sheet approach would promote clear articulation of, and justification for why, it is thought that the status of vulnerability had been reached – bearing in mind all the while that this category of person is, by law, mentally competent.

(ii) It matters very much *who* is giving evidence of vulnerability. For example, in *Re DL*, the Court of Appeal proceeded on the basis of the report of an independent social worker in whose opinion undue influence existed. This was so despite the fact that the son's version of events was not included. Unlike the position under the MCA in dealing with internal factors and likely to involve medical evidence, the external factors affecting vulnerability are subject to the vagaries of interpretation of a number of different persons – whose competence to do so is seldom defined. This makes it all the more incumbent on the courts to establish mechanisms to distinguish between opinion evidence, that simply disagrees with what are perceived to be 'bad' autonomous choices, and evidence that demonstrates that authentic autonomy is not being exercised.

(iii) The important point made by the Law Commission must be reiterated and recognised in court procedures to engender trust that they remain on the side of beneficence and not paternalism, viz, that there must be respect for a vulnerable person's decision to do or not to do something which, *after due consideration*, they



have decided to do or not to do. In other words, time-frames are of crucial importance in setting limits on the inherent jurisdiction. This should impact both on the quality of any evidence that is brought forward – e.g., is this a recent or long-standing situation? – and also on the scope of any interim relief, i.e. what amounts to a sufficient, and not excessive, time to allow for ‘due consideration’?

*What Does It Mean To Enhance or Liberate Autonomy?*

We have already seen that the common law long ago established the absolute right for autonomous persons to make ‘bad decisions’.<sup>70</sup> Whatever we might think of this as an ethical position, the legal question is whether this is the status that the inherent jurisdiction seeks to reinstate for vulnerable persons. We must assume that it is, given the formulation by Macur J in *LBL v. RYJ and VJ*, that was endorsed by the Court of Appeal in *Re DL*: ‘...the relevant case law establishes the ability of the court, via its inherent jurisdiction, to facilitate the process of unencumbered decision-making by those who they have determined have capacity free of external pressure or physical restraint in making those decisions.’<sup>71</sup> Furthermore, Munby J has said:

The inherent jurisdiction can be invoked wherever a vulnerable adult is, or is reasonably believed to be, for some reason deprived of the capacity to make the relevant decision, or disabled from making a free choice, or

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<sup>70</sup> Note 14, above, and text.

<sup>71</sup> [2010] EWHC 2665 (COP), at para 62.

incapacitated or disabled from giving or expressing a real and genuine consent.<sup>72</sup>

In the absence of any sense of what a ‘real and genuine consent’ for the person looks like, however, there is a real risk that there will be a blurring between cases that involve decisions with which others fundamentally disagree, and those which are examples of an actual absence of authentic autonomy. Moreover, authentic autonomy – question-begging though it is as a concept – is necessarily different for each of us. Some states of being, such as deafness or blindness, are permanent for most people who experience them. Many congenital deformations and illnesses will never go away. Some parents will genuinely prefer to live with their aggressive off-spring rather than never to see them again. All of this speaks to the importance of understanding what autonomy means for the people involved. This is not only a question for the courts. Indeed, a commitment to promoting autonomy requires early engagement with people about their values, preferences and options, most particularly in care and healthcare relationships. This can help to identify and promote the kind of autonomy that is meaningful for each person. For the courts’ part, it suggests that there might be a role for an autonomy plan as part of any relief granted, such that there is a benchmark against which to determine when and if autonomy has been ‘liberated’ (to use the Court’s own phraseology).

Moving into the realm of ethical conjecture, there is scope to consider how far beneficent promotion of autonomy implies on-going engagement with individuals about the range of options at their disposal. Rather than reverting to the legalistic position of *defensive autonomy* discussed above, this could support the flourishing of autonomous

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<sup>72</sup> Note 48, above, at para 79.

decision-making, even in cases where the ultimate outcome involves a decision with which many would disagree.<sup>73</sup>

*What Are the Limits of the Jurisdiction?*

An essential procedural safeguard, now standard as a result of the Human Rights Act 1998, is the importance of considerations of necessity and proportionality with respect to the protection and promotion of individual rights.<sup>74</sup> But what does autonomy demand of proportionality in this context? The courts have been at pains to point out that the inherent jurisdiction must not encroach on the will of Parliament, as manifested in the Mental Capacity Act and other legislation. Equally, it has been confirmed that the category of ‘vulnerable person’ extends to people suffering from mental incapacity and in respect of whom relief is not available under the MCA.<sup>75</sup> An example of this is found in the case of

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<sup>73</sup> See, for example, McCormack, B., Karlsson, B., Dewing, J. and Lerdal A., ‘Exploring Person-centredness: A Qualitative Meta-synthesis of Four Studies’, (2010) 24(3) *Scandinavian Journal of Caring Sciences*, 620-34.

<sup>74</sup> The human rights dimensions of these cases were discussed in *Local Authority X v. MM, KM* [2007] EWHC 2003 (Fam).

<sup>75</sup> See Munby J, in *Re SA*, note 48, above, para 83: “The inherent jurisdiction is not confined to those who are vulnerable adults, however that expression is understood, nor is a vulnerable adult amenable as such to the jurisdiction. The significance in this context of the concept of a vulnerable adult is pragmatic and evidential: it is simply that an adult who is vulnerable is more likely to fall into the category of the incapacitated in relation to whom the inherent jurisdiction is exercisable than an adult who is not vulnerable. So it is

*Westminster City Council v. C.*<sup>76</sup> The matter in dispute related to the validity in English law of a marriage conducted by phone to Bangladesh, involving a profoundly autistic young man who was also affected by severe intellectual impairment. The local authority was concerned both with recognition of the marriage and by the prospect that the family might remove the vulnerable adult to Bangladesh. The trial judge supported the concerns and the parents appealed on the grounds of error of law, both as to a declaration of non-validity of marriage and challenging the assumed jurisdiction to act in such a case. Wall LJ in the Court of Appeal addressed the jurisdictional point head-on:

I am also in no doubt that a combination of the inherent jurisdiction and the provisions of the 2005 Act is apt to confer jurisdiction on the High Court to make orders about where IC should live, including the decision as to whether or not it is in his interests to go and live in Bangladesh.<sup>77</sup>

As to the respective roles of the two areas of law, the Court of Appeal cited with complete approval the trial judge's finding that:

No part of the 2005 [sic] deals with the issue of preventing the mentally incapacitated person from leaving the country...[I]n my judgment, save where to do so would be demonstrably inconsistent with the will of Parliament, the inherent jurisdiction remains alive, in appropriate cases, to

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likely to be easier to persuade the court that there is a case calling for investigation where the adult is apparently vulnerable than where the adult is not on the face of it vulnerable. That is all.”

<sup>76</sup> [2008] EWCA Civ 198; [2009] Fam 11; [2009] 2 WLR 185.

<sup>77</sup> At para 54.

meet circumstances unmet by the scope of the legislation. That is not, to state the obvious, an invitation to a court so to do unless it is lawful, necessary and proportionate so to do.<sup>78</sup>

The prospect of the *co-existence* of the two jurisdictions, and what that might mean for vulnerable persons and patients, is now open to serious question. It was raised in the medical context in the case of *A Local Authority v. Mrs A*.<sup>79</sup> This involved a couple, both of whom had learning disabilities, and where the woman's desire, and ability to care, for another child was called into question because of her own inherent intellectual limits and the influence of her partner. The local authority was concerned by her refusal to use contraception and, initially, asked that force and restraint be authorised to require this. Acknowledging the practical difficulties in pursuing such a route, the court eschewed this prospect and ultimately made no order because it considered that the full range of options for the couple was yet to be explored.<sup>80</sup> Notwithstanding this, the ruling is important in at least two respects. First, Mrs A was judged to be incompetent within the terms of the Mental Capacity Act because of the co-existence of internal *and* external factors. As the judge said:

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<sup>78</sup> CA at para 56, citing [2007] EWHC 3096 (Fam) at 121.

<sup>79</sup> [2010] EWHC 1549 (Fam). Cf, *A Local Authority v. K* [2013] EWHC 242 (COP) involving a woman with Down's Syndrome and a more straight-forward application of best interests with respect to sterilisation and contraception and the importance of striking the right balance between 'protection and empowerment'.

<sup>80</sup> The male partner indicated his willingness to allow A to have access to health care professionals to explore her choices.

In view of what I find to be the completely unequal dynamic in the relationship between Mr and Mrs A, I am satisfied that her decision not to continue taking contraception is not the product of her own free will... For these reasons, I am in no doubt that Mrs A presently lacks capacity to take a decision for herself about contraception.<sup>81</sup>

Second, the inherent jurisdiction was also held to pertain, and thus afforded power, ... to prevent conduct by the dominant party which coerces or unduly influences the vulnerable party from making free decisions. The purpose, in respect of a capacitated but vulnerable adult, is to create a situation where he or she can receive outside help free of coercion, to enable him or her to weigh things up and decide freely what he or she wishes to do. In respect of an incapacitated adult, I consider the same should apply, except that the aim of providing him or her with relief from the coercion is first to gain capacity and, if achieved, then to enable him or her to reach a free decision.<sup>82</sup>

Most recently, in *XCC v. AA*,<sup>83</sup> Parker J seemed to confirm a cumulative rather than complementary relationship between the jurisdiction of the Court of Protection under the MCA and that of the High Court under the inherent jurisdiction. In circumstances similar to the *Westminster* case, the essential legal question concerned the recognition of a

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<sup>81</sup> At para 73.

<sup>82</sup> At para 79.

<sup>83</sup> [2012] EWHC 2183 (COP); [2013] 2 All ER 988; [2013] 2 FCR 401.

Bangladeshi marriage involving a vulnerable adult domiciled in the UK. Having established the incapacity of the adult – in terms of the 2005 Act – the court, nonetheless, felt able to provide relief in the form of a declaration of non-recognition of the marriage on the basis of the inherent jurisdiction; this particular outcome is not available under the legislation, but it was merited because ‘[i]t would be unjustifiable and discriminatory not to grant the same relief to incapacitated adults who cannot consent as to capacitous [sic] adults whose will has been overborne.’<sup>84</sup>

The court went further still in blurring the boundaries between the two jurisdictions. Because Part I of the 2005 Act concerning the relevant considerations to be taken into account about a person’s best interests – such as their wishes, desires and preferences – does *not* pertain to the inherent jurisdiction, these did not operate as a constraining benchmark against which to limit that jurisdiction. Wider public policy considerations could be considered, such as the prospect that the marriage was a vehicle to allow the Bangladeshi partner to enter the UK.<sup>85</sup> Finally, Parker J reiterated her earlier ruling that it is:

... the duty of a doctor or other health or social work professional who becomes aware that an incapacitated person may undergo a marriage abroad, to notify the learning disabilities team of Social Services and/or the Forced Marriage Unit if information comes to light that there are

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<sup>84</sup> At para 54.

<sup>85</sup> Paras 71-76.

plans for an overseas marriage of a patient who has or may lack capacity.<sup>86</sup>

If we examine this trend in case law relative to our concerns about facilitating autonomy and eliding the prospect of paternalism, there is much that raises concern as a matter of procedural trust, outlined above. The Court of Appeal in *DL* was adamant that it was not collapsing the distinction between incapable adults and those who are vulnerable.<sup>87</sup> And yet, these more recent rulings seem to do precisely this. It is possible to be mentally incapable for both internal *and* external factors (*Re A*), and it is possible to be, at the same time, caught by the provisions of the MCA as an incapable person and yet not have decisions bounded by the supreme safety consideration of one's own best interests (*XCC*).

It might make sense to argue that the category of 'vulnerable adult' necessarily encompasses everyone who is mentally incapable, except that the objectives of the law with respect to the two categories of patient have been explicitly stated to be quite different: those suffering from mental incapacity must be treated in their own best interests, while those who are capable and yet vulnerable must have their autonomy facilitated. But the impossibility of maintaining this supposedly clear bright line is revealed by persons whose vulnerable state is permanent. The persons affected by the declarations of non-recognition of marriage will never be in a position to marry. It is extremely concerning that best interests can be elided in terms of how they are treated under the law. We would argue that the important distinction as to the permanent or temporary nature of the source of vulnerability must be fully recognised if the common

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<sup>86</sup> Para 96, albeit delivered as a Postscript.

<sup>87</sup> Note 47, above, at para 15.



law is to continue to develop along these lines without further legislative intervention. We have argued above that an interim injunction must necessarily be time-limited if the objective of facilitating autonomy is to be realised. If this is an impossible objective, it cannot stand as the basis for an exercise of the jurisdiction. Contrariwise, if the essential nature of the inherent jurisdiction is, indeed, to be protective, then further elucidation of limiting parameters is required, such as a central role for best interests and full acceptance that beneficence is in play. Thus, we suggest that the law has now created three, and not two, categories of persons for whose autonomy might be in doubt:

1. the *mentally incapable* caught by the MCA (whether this is for a cause that is temporary or permanent)
2. the *vulnerable person* whose condition is *temporary* (and for whom interim measures can be instituted to promote genuine and authentic future exercises of autonomy), and
3. the *vulnerable person* whose condition is *permanent* (and for whom facilitation of autonomy is possibly a misnomer). This last category is in the greatest need of attention and protection at the current time.

This is not to suggest that this last category of person cannot act autonomously in certain circumstances. Rather, it is a plea to recognise that *caring autonomy*<sup>88</sup> is required which will involve robust protection of their interests, as well as promotion of their overall well-being as part of a package of care.

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<sup>88</sup> We borrow this expression from our doctoral graduate, Katri Löhmus, who developed the concept as part of her research: Löhmus, K., *Caring Autonomy: Rethinking the Right to Autonomy under the European Court of Human Rights Jurisprudence* (2013).

### *What is the Future for the Jurisdiction?*

A final concern about these developments relates to the scope of relief that might be granted in the future. The Court of Appeal refused to limit this to interim measures. Furthermore, the marriage cases suggest that the jurisdiction does not only extend to orders against third parties, such as a non-interference injunction to create space for the vulnerable person. Instead, the jurisdiction might extend to actual control over the movements of the vulnerable persons themselves, including prohibition on leaving the country. It requires little imagination to contemplate where this might lead. For example, subject to a court being satisfied that a measure was necessary and proportionate (as might happen if all other options were exhausted), it could be used in the case of medical tourism and with respect to those seeking ‘inappropriate’ procedures abroad; or it might be extended to persons seeking assisted dying in foreign jurisdiction, and for whom the desperation of their situation is deemed to meet the criteria as operative external factors rendering them subject to the inherent jurisdiction. The liberty and human rights implications are considerable in such hypotheticals, and the practicalities might well mean that no court would attempt to go down such a route. None the less, the re-emergence of the inherent jurisdiction in the extensive grey circumstances that we outline above requires considerable vigilance for the possible impacts – actual and perceived – that the prospect of its exercise might have on both autonomy and trust.

The very existence of the jurisdiction will raise dilemmas for health care professionals and others in care situations. The Law Commission pointed out in its report, *Adult Social Care*, that High Court proceedings are costly and time-consuming and ‘an

inappropriate way of dealing with emergency safeguarding cases'.<sup>89</sup> This might well be true, but the fact that this avenue is now open will necessarily mean that professionals working at the coal-face will be called upon to explore it. The High Court declaration of legality can be sought and obtained with relative ease.<sup>90</sup> Accordingly, the messages and concerns that we raise above are not only directed at the courts. The words of Munby J. in *Local Authority X v. MM and KM* must be taken seriously by all:

... The court must be careful to ensure that, in rescuing a vulnerable adult from one type of abuse, it does not expose her to the risk of treatment at the hands of the state which, however well intentioned, can itself end up being abusive of her dignity, her happiness and indeed of her human rights. That said, the law must always be astute to protect the weak and helpless, not least in circumstances where, as often happens in such cases, the very people they need to be protected from are their own relatives partners or friends ... The emphasis must be on sensible risk appraisal, not striving to avoid all risk, whatever the price, but instead seeking a proper balance and being willing to tolerate manageable or acceptable risks as the price appropriately to be paid in order to achieve

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<sup>89</sup> Note 32, above, at para 9.80.

<sup>90</sup> See now, Practice Note, “The Official Solicitor to the Senior Courts: Appointment in Family Proceedings and Proceedings under the Inherent Jurisdiction in Relation to Adults” (March 2013). We envisage considerable practical difficulties for healthcare professionals in determining the *cause* of vulnerability and so the appropriate route to court, viz, Court of Protection or High Court.

some other good – in particular to achieve the vital good of the elderly or vulnerable person's *happiness*. What good is it making someone safer, if it merely makes them miserable?<sup>91</sup>

As to the future, The Department of Health has expressed scepticism about the role of the courts in exercising the inherent jurisdiction. For example, in a consultation for a new safeguarding power, it said:

...we do not believe leaving such cases to be resolved on a case-by-case basis using the Court's inherent jurisdiction is a satisfactory solution. Resorting to the courts in every instance could increase the caseload of courts, result in differing outcomes, be expensive for local authorities and is likely to be extremely disempowering for individuals. If we establish that a proportionate and effective legislative solution could help resolve this issue, it would not be necessary to rely on case law to settle the matter.<sup>92</sup>

The Government's reply to the Law Commission's report recognised the resurrected inherent jurisdiction and confirmed, that it had 'no further plans to legislate in this area at this time',<sup>93</sup> especially in light of the reforms that now appear in the Care Act 2014.<sup>94</sup>

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<sup>91</sup> [2007] EWHC 2003 (Fam), at para 120. Emphasis as in original.

<sup>92</sup> Department of Health, *Consultation on a New Safeguarding Power*, (2012), para 13.

<sup>93</sup> Department of Health, *Reforming the Law for Adult Care and Support: The Government's Response to Law Commission Report 326 on Adult Social Care*, July 2012, para 9.28.

Reforms in the Care Act will not impact directly on the inherent jurisdiction and, instead, lay down a single over-arching principle of ‘well-being’ upon which local authority action relating to adult social care is to be organised. The Government has indicated that it prefers a single organising principle linked to key outcomes, rather than a more granular or detailed approach. Given this, and the uncertainties that it entails until put into practice, we contend that our contribution herein gives further specification and direction to the implementation of such a principle, particularly as it involves the promotion of individual well-being,<sup>95</sup> which explicitly include, inter alia, ‘personal dignity’ (including treatment of the individual with respect), physical and mental health and emotional well-being and protection from abuse and neglect’ of persons.<sup>96</sup>

### **Conclusion: A Focus on Relationships Not Rights**

It may well be that the doctor/patient relationship suffers from the constraints imposed by its close association with a legal system and this may operate in diametrically opposed fashion. On the one hand, as McLean has put it:

In an ideal world, judges would use the law to reinforce the fundamental value of patient autonomy. To the contrary, however, courts have devised a system that has arguably been overly concerned not with prioritising

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<sup>94</sup> For comment on the lead up to this legislation, see Ruck Keene, A., ‘The Inherent Jurisdiction: Where Are We Now?’, (2013) 3(1) Elder Law Journal, 88-92.

<sup>95</sup> Section 1(1) of the Care Act 2014.

<sup>96</sup> See ss 1(1)(a), (b), and (c).

patient rights, but rather with balancing them with other, often policy based, considerations.<sup>97</sup>

The alternative view, which we support, starts with the premise that a consent-based relationship is based almost entirely on patients' rights. The language of rights, even when not unilateral, implies conflict and conflict inevitably attracts legal intervention and legalism. From very early times in the debate, we have been impressed by the view that the rights model is suspect in that: '[I]t can turn what may have been a caring and amicable [doctor/patient] relationship into an adversarial one, inimical both to constructive dialogue and [the patient's] own future health.'<sup>98</sup> Moreover, as we have argued throughout this chapter and as amply demonstrated by the second half of our discussion, consent cannot be the dominant framing device for the value that we place in autonomy. This sums up our main motive for seeking a more conciliatory or 'user friendly' model for a relationship which is, at least, under threat.

If doctors and carers are to take seriously McLean's passionate commitment to autonomy – and if they are to remain on the acceptable side of the beneficence/paternalism line in seeking to promote this – they would do well to consider the fundamental role of the value of trust in the carer relationship. There will always be reasons to refuse to respect refusals, and this is not in itself a problem because a trusting relationship is not one in which parties must always agree. It is, however, one in which we *care* about people's

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<sup>97</sup> Note 6, above, at p. 95.

<sup>98</sup> Teff, H., *Reasonable Care: Legal Perspectives on the Doctor-Patient Relationship*, Oxford, Clarendon Press, 1994, at p. 115. Although old, this remains the quintessential 'middle of the road' monograph on the subject.

reasons,<sup>99</sup> and also one in which agreeing to disagree is a mutually recognised and important option in its own right. This is true whether we are involved in the process of giving information to facilitate autonomous choice, or creating spaces to do the same. On the route to actual trust in the doctor/patient relationship, we must be able to trust that the rules of engagement have our entire range of interests at heart.

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<sup>99</sup> For discussion of the distinction between caring and caring *for*, see Herring, J., *Caring and the Law*, Oxford, Hart Publishing, 2012, pp. 15-6. Also, Herring, J., 'Forging a Relational Approach: Best Interests or Human Rights?', (2013) 13 *Medical Law International*, 32-54.