

Amber Boulton
Healthcare Ethics and Law LLM
University of Manchester
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Essay Question: Critically discuss the extent to which the law allows for the wishes, feelings, beliefs, and values of adult patients without decision-making capacity to be considered when decisions are made about their medical treatment, and how this compares to the way it accommodates the same considerations in relation to those with capacity.

The consideration of capacity: does the law regard the wishes, feelings, beliefs, and values of adult patients without decision-making capacity on equal grounds as those with?

Introduction

The right to bodily autonomy and self-determination are values that are vital to medical law and therefore the decisions made by adults with decision-making capacity are absolute.¹ However, the fundamental expectation of upholding these rights is a luxury often disregarded by those deemed by law to not have capacity. The wishes, feelings, beliefs, and values of patients in decision-making can arguably be considered of greater importance than the medical facts themselves; but these factors are inherently ambiguous and present unique challenges. Following the historically confusing common law, The Mental Capacity Act 2005 (MCA)² aimed to protect the interests of those who are unable to do so independently, yet this valiant aim has proven difficult to convey. In this essay, the MCA guidance will be determined with particular regard for s.4 and judicial interpretation of the best interest test. The current test's effectiveness will be analysed regarding both judicial and medical adherence, and the use of advance directives to uphold autonomy through incapacity will be explored. Lastly, the United Nations Convention on the Rights of Persons with Disabilities (CRPD)³ wills and preferences model will be explored in line with the MCA. It is argued that

¹ *Re MB (Medical Treatment)* [1997] 2 FLR 426.

² Mental Capacity Act 2005 (MCA 2005).

³ Convention on the Rights of Persons with Disabilities (adopted 13th December 2006, entered into force 3rd May 2008) UNTS 2515 (CRPD), art 1.

the lack of legal clarity and judicial uncertainty has resulted in an unattainable and unjust test, of which the rights of those who lack capacity can easily be disregarded in favour of medical opinion.

Best Interests: From the MCA to Judicial Interpretation.

The MCA was enacted to uphold the autonomy of adults who lack capacity to make their own healthcare decisions.⁴ The legislative framework expands the long-debated common law which contrasts the narrow medical best interest definition,⁵ and reinforces the need to ‘incorporate broader ethical, social, moral welfare considerations’.⁶ The adoption of s.4(6) requires consideration of factors which would likely influence the person’s decision if they had capacity such as the person past and present wishes and feelings;⁷ beliefs and values;⁸ and other relevant factors.⁹ The implementation of this autonomy-driven requirement removed the previously draconian elements in favour of a more patient-centred test.

The best interests test is a flexible test founded on a genuine and honest belief that the proposed treatment is in the best interests of the patient after having involved them in the decision-making process as far as practically possible.¹⁰ Initially, the MCA best interest test presents an amicable way of allowing patient autonomy to be respected in situations where capacity renders them incapable, but in practice, the Act lacks specificity and the guidance offered by the Code of Practise has been criticised as vague and inadequate.¹¹ This highlights the issue of uncertainty and the lack of primacy accorded to the subjective aspects, due to the obscurity of section 4’s requirements regarding relativeness of subjective matter, the judicial interpretations are bound for inconsistency.¹²

⁴ MCA 2005, s2.

⁵ *Re F (Mental Patient Sterilisation)* [1990] 2 AC 1.

⁶ *Re SL (Adult Patient: Sterilisation)* [2000] 3 WLR 1288.

⁷ MCA 2005, s.4(6a).

⁸ *ibid* s.4(6b).

⁹ *ibid* s.4(6c).

¹⁰ *ibid* s.4(4).

¹¹ Chong-Ming Lim, Michael Dunn, and Jacqueline Chin, ‘Clarifying the Best Interests Standard: The Elaborative and Enumerative Strategies in Public Policy-Making’ (2016) 42 J Med Ethics 542–549, 542.

¹² Select Committee Report, *Mental Capacity Act 2005* (HL 2013-14, 139) Ch 4; see also, Law Commission, *Mental Capacity and Deprivation of Liberty* (Law Com No 222, 2015) para. 12.42.

It is clear to see through progressive case law that the enactment of the MCA has done little to improve this uncertainty. Before the adoption of the MCA, through common law, the best interests test was adopted and presented through a balance sheet approach¹³ in which it was determined that ‘best interests encompasses medical, emotional and all other welfare issues’,¹⁴ but the patient’s views were not required to make the best interests assessment.¹⁵ In the case of non-capacity, the consideration of the patient’s views, often a complex and time-consuming task, is all in vain unless the objective is to achieve the outcome preferred by the patient provided this will not result in ‘sufficiently detrimental effect’.¹⁶ This autonomy driven interpretation was criticised for overstating the importance of the patient’s wishes, which are not the deciding factor of the best interest test.¹⁷ The judicial divide as for the importance of this principle is detrimental to ensuring the judicial system is fair and just.

After the enactment of the MCA, some effort was made towards a more autonomy-focused approach. In *Re JH and MH*, the clear and consistent views of the patient and wider evidence of the case resulted in favour of the individual’s wishes, feelings, beliefs, and values.¹⁸ This approach has been further implemented in subsequent case law¹⁹ and cemented through the Supreme Court case of *Aintree*.²⁰ In this case, Lady Hale rejects the objective test, instead directing the decision-maker to consider the test from the patient’s perspective with reference to ‘the patient’s wishes and feelings, his beliefs and values or the things which were important to him’²¹ and consider ‘welfare in the widest sense, not just medical but social and psychological’.²² This patient-centric approach was closely followed by both *Re M* where it was acknowledged that ‘the Court must surely have regarded the person’s assessment of her quality of life’ not just its prolonging from a paternalistic perspective,²³ and *Skye* where the centrality of the patient’s wishes and feelings in the test was demonstrated.²⁴ It is argued that the effect of these cases ‘provides the basis for a more expansive, arguably revolutionary,

¹³ *Re A (Children) (Conjoined Twins: Medical Treatment)* [2001] 2 WLR 480.

¹⁴ *Re A (Mental Patient: Sterilisation)* [1999] 12 WLUK 657, (Justice Butler-Sloss).

¹⁵ see *Re A (Medical Treatment: Male Sterilisation)* [2000] 1 FCR 193, 206 (Thorpe LJ).

¹⁶ *Re S (Protected Persons)* [2010] 1 WLR 1082, 1095 (Judge Marshall QC).

¹⁷ *Re P (Statutory Will)* [2009] 2 WLR 253, 265-266 (Justice Lewison).

¹⁸ *A London Local Authority v JH* [2011] EWHC 2420 (COP), (Justice Eldergill).

¹⁹ *United Lincolnshire NHS Trust v N* [2014] EWCOP 16; see also *An NHS Trust v Ms X* [2014] EWCOP 35.

²⁰ *Aintree University Hospital NHS Foundation Trust v James* [2014] AC 591.

²¹ *ibid* 592 (Lady Hale).

²² *ibid*.

²³ *Re M (Best Interests: Deprivation of Liberty)* [2013] EWHC 3456 (COP) (Justice Peter Jackson); see also *Newcastle-upon-Tyne Foundation Trust v LM* [2014] EWHC 454.

²⁴ *Westminster City Council v Sykes* [2014] EWCOP B9.

view of best interests under the MCA'.²⁵ The implication highlights strides towards a holistic approach to determining the best interests of patients without capacity, as not only does the rejection of these factors display a lack of respect, it also disregards their dignity and fails to show reverence.²⁶

However, some cases still display limited appreciation for patient-participation in determining best interest. Following the MCAs vague wording, Munby J highlighted the lack of hierarchical structure and stated that although acknowledgement of the subjective factors are important, the weight attached to these are 'case-specific and fact-specific'.²⁷ In the case of *RB v Brighton and Hove City Council*,²⁸ judicial indifference was shown towards the patient, the 'chaotic' past of the patient, his desire to live in the community and his non-compliance with rehabilitation highlighted the absence of consideration of a workable-solution and emphasised the need for greater judicial importance to be placed on the patient's wishes and feelings.²⁹ Furthermore, the problematic cases of *Re A and A*³⁰ and *Re E*³¹ emphasize judicial disregard towards the patient's perspectives, highlighting the need for consideration in the judgment even if it is unlikely to affect the outcome. It was even reported that only a minority of cases actually contained express evidence in relation to the patient's subjective preferences, with some justices even proposing that despite the radical reform, full weight should be denied to the s.4(6) requirements regarding incapacitated patients.³² Once again proving how the limited guidance from the MCA creates judicial inconsistencies.

Throughout these inconsistencies, it is clear to see that individualistic factors, such as wishes and feelings, are determinative to those with capacity and thus should play a role of equal importance for those without.³³ The importance of acknowledgement of the patient's wishes

²⁵ Mary Donnelly, 'Best Interests in the Mental Capacity Act: Time to Say Goodbye?' (2016) 24(3) Medical Law Review 318–332, 330.

²⁶ Jonathan Herring, 'Losing it? Losing What? The Law and Dementia' (2009) 21(1) Child and Family Law Quarterly 3-29, 14.

²⁷ *Re M (Statutory Will)* [2011] 1 WLR 344 (Justice Munby), 352.

²⁸ *RB v Brighton and Hove City Council* [2014] EWCA Civ 561, it is also important to note that this case is now in Strasburg Court awaiting review.

²⁹ Donnelly (n 25), 330.

³⁰ *A Local Authority v A* [2010] EWHC 1549 (Fam).

³¹ *A Local Authority v E and Others* [2012] EWHC 1639 (COP).

³² *Re P* (n 17), para 36 (Justice Lewison); see also, *Re M (Adult Patient) (Minimally Conscious State: Withdrawal of Treatment)* [2011] EWHC 2443 (Fam), para 85 (Justice Baker).

³³ *Ms B v An NHS Hospital Trust* [2002] EWHC 429 (Fam), MS B was found to have the capacity and thus her autonomy prevailed over the view of her carers regarding her best interest, mental competence allows for right to refuse life-saving treatment.

are not only ethically superior but make decisions patient-centred and serves as an important reminder of the vitality of the human aspect of these decisions as opposed to the purely medical and legal counterparts.

Section 4(6) in Application

The MCA establishes that decisions outside the social norm do not equate to non-capacity as autonomy and self-determination allow individuals to make decisions even if they are unwise.³⁴ But the foundations of this right conflict with paternalistic intervention which is triggered through non-capacity.³⁵ Williams describes this as the ‘concertina effect’ through which: ‘Rather than allowing the ‘unwise’ principle to prevail, practitioners regularly framed a person’s decision as proof of lack of capacity,’³⁶ which ‘strips the individual of the safeguards built into the Act’.³⁷ This inherent paternalism is tempting for the Court to uphold ‘but this would be unprincipled and wrong.’³⁸ Instead the Court must assess capacity in line with the MCA regardless of potential controversy. It is not the decision that should be in question but the ability of the patients to make the decision in line with capacity.

Instead, it is argued that capacity assessment runs on a sliding scale as opposed to the determinative test.³⁹ The amount of capacity needed to consent to treatment depends upon the risk associated and therefore some patients may have capacity to consent to a particular treatment but not to refuse it.⁴⁰ This presents a unique challenge as it conflicts directly with the requirement of s.1 and 4 of the MCA on the presumption of capacity and the recognition of individualistic factors, it suggests that the test is still interpreted through a paternalistic lens.⁴¹ The basis of this system essentially creates a ‘self-fulfilling doctrine: those who exercise approved choices have capacity, whereas those who exercise undesirable choices

³⁴ MCA 2005, s1(4).

³⁵ Renu Barton-Henson, ‘Reforming Best Interests: The Road Towards Supported Decision-Making’ (2018) 40(3) *Journal of Social Welfare and Family Law* 277-298, 298.

³⁶ Val Williams, Geraldine Boyle, Marcus Jepson, Paul Swift, Toby Williamson, and Pauline Heslop, ‘Best Interests Decisions: Professional Practices in Health and Social Care’ (2014) 22(1) *Health & Social Care in the Community* 78–86, 82.

³⁷ Barton-Henson (n 34), 293.

³⁸ *Re Z & Others* [2016] EWCOP 4, para 67 (Justice Cobb).

³⁹ Helen Taylor, ‘What are ‘Best Interests’? A Critical Evaluation of ‘Best Interests’ Decision-Making in Clinical Practice’ (2016) 24(2) *Medical Law Review* 176-205, 197.

⁴⁰ Herring (n 26), 9.

⁴¹ Select Committee Report (n 12), [45].

lack capacity'.⁴² The vulnerability attached to these situations emphasises disregard for patient autonomy in favour of societal compliance which can result in adverse effects for the patients themselves.

Assessment of capacity is increasingly problematic in the case of anorexia as the condition presents 'a Catch 22 situation regarding capacity: namely, that by deciding not to eat, she proves that she cannot decide at all.'⁴³ The implications of such a diagnosis are vast, with case law often considered 'controversial and problematic' regarding the capacity threshold and decisions concerning force-feeding present a 'crude, biomedical explanation' of the condition.⁴⁴ This was particularly emphasised in the controversial case of *Re E*, where the patient in question had unsuccessfully received treatment in the past and both herself and her parents fought for her bodily integrity and right 'choose her own pathway.'⁴⁵ The Court was criticised as overstepping their authority and not engaging fully with the concerns raised by the patient,⁴⁶ but also applauded for its protection of life⁴⁷ in which it was determined that intervention although 'arduous, distressing and possibly futile, was still better than the alternative.'⁴⁸ This paternalistic judgment is difficult to dissect in both regards as the vitality of autonomy and bodily integrity compared to the protection of the sanctity of life present conflicting and important arguments. However, when this case is read in conjunction with *Re L*, in which the futility and detriment of force-feeding in the patient's frail condition meant that the withholding of treatment was lawful,⁴⁹ the judgment becomes harder to digest. The result of judgments such as these introduce elements of vulnerability and can eventually lead to patient disempowerment⁵⁰ and erosion of trust which is essential to the healthcare system.

In spite of the clear negative impacts of triggering capacity assessment in relation to unwise decisions, the tendency of defensive practice in fear of negligence claims could potentially

⁴² N Knauer, 'Defining Capacity: Balancing the Competing Interests of Autonomy and Need' (2003) 12 Temple Political and Civil Rights Law Review 321, 344.

⁴³ *A Local Authority v E* (N 31), 774 (Justice Jackson).

⁴⁴ Kirsty Keywood, 'Rethinking the Anorexic Body: How English Law and Psychiatry "think"' (2003) 26 Int J L Psychiatry 599–616, 601.

⁴⁵ *Re E* [2012] EWHC 1639 (COP), [80].

⁴⁶ Nell Munro, 'Taking wishes and feelings seriously: the view of people lacking capacity in Court of Protection decision-making' (2014) 36(1) Journal of Social Welfare and Family Law 59-75, 66.

⁴⁷ *ibid.*

⁴⁸ *ibid.*

⁴⁹ *Re L* (2012) EWHC 2741 (COP) [75] (Justice King).

⁵⁰ Beverley Clough, 'Disability and Vulnerability: Challenging the Capacity/Incapacity Binary' (2017) Social Policy and Society 469-481, 475.

explain the need to ensure protection of life.⁵¹ It was concluded by a House of Lords Review that there was a ‘complete failure to embed the Act in everyday practice’,⁵² and an increased need to recognise medical decisions as a joint enterprise⁵³ of which is thwarted by the lack of social resources, time, and training.⁵⁴ Instead of the MCA presenting the foundations of promoting autonomy for those without capacity, it was found that professionals viewed the Act simply as means of enabling decision-making on the patients’ behalf, creating an atmosphere of paternalism and protection⁵⁵ as opposed to involvement and consideration. The lack of prioritisation of these factors can be said to have negated the aims of the Act altogether, leaving the decision subject to defensive medicine to avoid potential litigation, as well as being subject to medical bias. Where the patient’s wishes are at odds with the medical perception of best interest, there appears to be an additional requirement beyond that of the Act that there must be a ‘strong and persuasive argument’ for patient’s desires to be a ‘definitive factor.’⁵⁶

One reason why the s.4 requirements are challenging (for both healthcare professionals and the Courts) is due to the flexibility awarded to the decision-maker. Although this allows for a variety of factors to be taken into consideration, none of which will take automatic precedence, it has resulted in judicial uncertainty and perhaps even bias in cases where the facts presented are similar. This is particularly prevalent in the case of *Wye Valley*⁵⁷ regarding an elderly man with a long-standing mental illness. In this case, the patient had a severely infected leg that required amputation to prevent fatal implications, yet he strongly objected to the procedure. The opinion of the patient was held in high regard, with all factors surrounding his life and the basis of his opinion thoroughly explored by the judge who stated the importance of considering the beliefs of the patient, even if they are not real in a legitimate sense, as from an autonomy perspective they are real to the patient. Thus, the patient should be involved as an individual and not viewed through a stigmatised lens of mental illness

⁵¹ Taylor (n 38).

⁵² Select Committee Report, *Mental Capacity Act 2005* (HL 2013-14, 139), in Derick Wade and Celia Kitzinger, ‘Making Healthcare Decisions in a Persons Best Interests when they lack Capacity: Clinical Guidance Based on a Review of Evidence’ [2019] 33(10) *Clinical Rehabilitation* 1571-1585, 1572.

⁵³ John Coggon, ‘Mental Capacity Law, Autonomy and Best Interests: An Argument for Conceptual and Practical Clarity in the Court of Protection’ (2016) 24(3) *Medical Law Review* 396-414, 406; see also General Medical Council, *Consent: Patients and Doctors Making Decisions Together* (GMC 2008).

⁵⁴ Select Committee Report (n 12), [82].

⁵⁵ *ibid*, p6.

⁵⁶ Taylor (n 38), 202.

⁵⁷ *Wye Valley NHS Trust v B* [2015] EWCOP 60.

which resulted in the refusal of intervention.⁵⁸ However, this contradicts the judgment passed in *QZ* in which an elderly woman with schizophrenia was found to have a cancerous tumour. The symptoms of which, she had attempted to conceal for several months due to a long-standing fear of medical staff. She objected to treatment, and it was established that the nature of the treatment would further deteriorate her mental health, but it was still upheld as being in her best interest.⁵⁹ Therefore, it can be argued that the delusions she had towards the treatment were not seen as part of her personal independence and therefore separate from her mental illness unlike the autonomy awarded in *Wye Valley*⁶⁰ providing a stark contrast in the assessment of the subjective factors of best interests.

Even when the patient beliefs and wishes are clear, the law is conflicted as to how to balance the rights of the patient, this becomes even more complicated in cases where incapacity results in unknown or uncommunicated wishes, feelings, beliefs, and values. In situations where this ambiguity exists the decision-maker must consult with family and friends to try and understand the values of the patient.⁶¹ But the decision-maker is at risk of wrongful interpretation of the patient's wishes which can result in further expansion of paternalistic features.

Advance Directives

Advance decisions present a way of preserving autonomy even in the face of future incapacity, as long as the matter is related to the decision at hand, it will be binding provided that the patient was competent and the decision was voluntary,⁶² however, any doubt would result in favour of the preservation of life.⁶³ Following the common law these decisions are awarded greater safeguards by s24-26 of the MCA,⁶⁴ but legal validity does not always ensure application. Advance decisions can be invalidated if the patient has acted in a way that would prove inconsistent with the decision,⁶⁵ as demonstrated by *HE v A Hospital NHS Trust*, in which an advance directive for refusal of blood was made in line with the patients

⁵⁸ *ibid*, para [43-45].

⁵⁹ *NHS Foundation Trust v QZ* [2017] EW COP 11.

⁶⁰ *Wye Valley* (n 56).

⁶¹ MCA (2005) S.4(7).

⁶² *HE v An NHS Trust* [2003] EWHC 1017 (fam).

⁶³ *ibid*, (Munby J) [23].

⁶⁴ As per the MCA (2005) s.24-26, advance directive must also be signed and witnessed.

⁶⁵ *ibid*, s.25 (2)(c).

previous religious beliefs but in renouncing her faith and converting to Islam, her current actions were inconsistent with the directive, thus the directive was no longer effective.⁶⁶ Furthermore, if the consequences of the current circumstances were not anticipated at the time of creating the directive it can be invalidated,⁶⁷ this highlights that although autonomy is important, the sanctity of life will triumph in practice to override the patient's subjectiveness.⁶⁸ However, it can also be argued that upholding advance directives is to potentially reject the views of the incapacitated patient as they stand now. Their position before incapacity may be vastly different and their feelings and beliefs may have changed from the enactment of the directive in which case a new dilemma comes to light as to which autonomy should be protected their past autonomy or their present. The act provides a safeguard through section 25(2)(c) in which inconsistent actions with the directive will render it invalid altogether.⁶⁹ In the case of *Briggs v Briggs (No 2)*, it is made clear that this supposed safeguard does not specify whether capacity is required at the time of inconsistent action,⁷⁰ Charles J goes on to conclude that in the case of invalidation for contrary action, the court would have to take account of 'the impact of that removal of that person's right to self-determination that he or she has sought to exercise by making the advance directive.'⁷¹ Furthermore, in the case of *Re QQ*, Keehan J even went as far as to suggest that in light of the patient's recent and fleeting acceptance of treatment contrary to the directive would not in itself invalidate the otherwise valid advance directive.⁷²

In order to combat some of the confusion surrounding advance directives, the Code of Practice takes the requirement one step further by advising regular review of the decision in order to ensure it is valid and applicable,⁷³ this is because a decision made years ago may not reflect the individual's current views and therefore the Courts tend to err on the side of caution. But it is through this caution that the directives are made even less attainable as the infestation of doubt will make them invalid. In *A Local Authority v E* despite two formal

⁶⁶ *HE v A Hospital NHS Trust* (n 61).

⁶⁷ MCA (2005) s.25 (4)(c); see also *W Healthcare NHS Trust v H* [2004] EWCA Civ 1324, through which the specific facts of the case and the ramifications of the refusal were not discussed and thus invalidated the advance directive.

⁶⁸ Alasdair R Maclean, 'Advance Directives and the Rocky Waters of Anticipatory Decision-Making,' [2008] 16 *Medical Law Review* 1-22, 9.

⁶⁹ MCA (2005) s.25(2)(c).

⁷⁰ *Briggs v Briggs & Ors* [2016] EWCOP 53.

⁷¹ *ibid*, at para [22].

⁷² *Re QQ* [2016] EWCOP 22.

⁷³ Mental Capacity Act 2005 Code of Practice (Department of Constitutional Affairs, 2007), para 9.29.

advanced decisions being drafted in line with the MCA requirements, the evidence of doubt tipped the scale in favour of preservation of life.⁷⁴ This is further complicated again by the requirement to take into consideration past and present wishes especially when conflict is presented between these.⁷⁵ Advance directives pose a unique ethical question as for whether the past preferences of the individual when they had capacity should triumph over the conflicting current wishes of the patient without capacity.

Furthermore, it must also be proven that the patient had capacity at the time of creation. But to implement a capacity assessment into the requirements of the Act would undermine the presumption of capacity and make the process 'more costly, time-consuming, and bureaucratic'⁷⁶ but the absence of which has left the law 'opaque, imprecise, and open-ended.'⁷⁷ In the review of *Kerrie Woollorton*, having ingested anti-freeze in an attempt to end she life, Woollorton called an ambulance and presented hospital staff with a letter clearly stating that: she refuses treatment, is fully aware of the consequences, and that in phoning the ambulance she wished to be comfortable and not die alone. Following the doctors upholding of this decision and her subsequent death as a result, an inquest was made in the circumstances of the death and the weight of the advance directive. Ultimately, it was found that at the time of making the decision she had full capacity and thus the decision to refuse treatment was lawful. This inquest is perhaps one of the most controversial in terms of ethical acceptance, the determination of capacity is often deliberated based on attempted suicide and her decision to call an ambulance is perhaps contrary to the directive although she preempted this argument.⁷⁸ As she was held to have capacity her autonomy rendered her wishes, feelings, beliefs, and values essential and absolute. But if she did not have capacity, it is questionable how far these subjective factors would be taken into consideration over preservation of life.⁷⁹ It is clear to see how these absolute rights are protected in the case of capacity and yet how easily they can be disregarded through incapacity.

⁷⁴ *A Local Authority v E* (n 31), 65.

⁷⁵ MCA (2005), 4(6)(a).

⁷⁶ Robert Heywood, 'Revisiting Advance Decision-Making under the Mental Capacity Act 2005: A Tale of Mixed Messages' (2015) 23(1) *Medical Law Review* 81, 93.

⁷⁷ *ibid*, 96.

⁷⁸ Sahjid Muzaffar, 'To treat or not to treat'. Kerrie Woollorton, Lessons to Learn' (2011) 28 *Emergency Medicine Journal* 741, 743.

⁷⁹In Dworkin's approach he argues that past wishes should be protected as they present the values of which underpin the life of the patient. Dresser rejects this argument instead suggesting that the present wishes cannot be affiliated with the past due to the vast alteration of the person though non-capacity. See, Ronald Dworkin, *Life's Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom* (Alfred A. Knopf, 1993)

Advance decisions present an opportunity for those without capacity to make decisions about their lives. But judicial rejection is argued to essentially ‘rob the patient of his right to his own personality’⁸⁰ and even infringe upon their Human Rights by failing to allow partial control over incapacity.⁸¹ The ability to invalidate advance decisions based on an ‘ill-defined measure of doubt’⁸² suggest that the fragility of these directives renders them ineffective instruments of autonomy.⁸³ Therefore, through the MCA, patients without capacity are not presented with an effective means of granting autonomy equal to that of those with capacity.

Compliance with the CRPD.

The CRPD requires that persons with disabilities should enjoy legal capacity on an equal basis,⁸⁴ representing a ‘paradigm shift’ for equality and inclusion.⁸⁵ This inclusion regarding decision-making is implemented through a wills and preferences model.⁸⁶ This places MCA s.4 requirements at the forefront of decision-making, as incapacity should not dismiss patient preferences and hinder their ability to act autonomously.⁸⁷ In this respect, the CRPD has created an ‘educative, expressive and proactive role’,⁸⁸ as for how people without capacity are viewed and respected within society. Forcing treatment upon an individual not only has a detrimental physical and psychological effect on the person themselves it also is a violation of their dignity, liberty, and integrity.

The lack of incorporation into domestic law and the compliance of the MCA with this Article have been somewhat debated. The objective test of best interests is at odds with the

at 224. Rebecca Dresser, ‘Missing Persons: Legal Perceptions of Incompetent Patients’ (1994) 46 Rutgers Law Review 609-719, 666–667.

⁸⁰ Ian Kennedy, *Treat Me Right* (Clarendon, 1992), 56.

⁸¹ Penney Lewis, ‘Medical Treatment of Dementia Patients at the End of Life: Can the Law Accommodate the Personal Identity and Welfare Problems?’ (2006) 13 European Journal of Health Law 219-234, 220; see also Human Rights Act 1998, art 3 and art 8.

⁸² Heywood (n 71), 92.

⁸³ Maclean (n 67), 22.

⁸⁴ CRPD (n 3), art 12.

⁸⁵ Genevra Richardson, ‘Mental Disabilities and the Law: From Substitute to Supported Decision-Making?’ (2012) 65 Current Legal Problems 333–354, 351.

⁸⁶ CRPD (n 3), art 12(3).

⁸⁷ Donnelly (n 25), 322.

⁸⁸ Oliver Lewis, ‘The Expressive, Educational and Proactive Roles of Human Rights: An Analysis of the United Nations Convention on the Rights of Persons with Disabilities’ in B McSherry and P Weller (eds), *Rethinking Rights-Based Mental Health Law* (Hart Publishing 2010) 97-128 at 113-126.

subjective test of wills and preferences,⁸⁹ but this perhaps does not necessarily mean the MCA is acting out of accordance with the Convention. This is because s.4 requires an individual assessment to be made but flexibility ensures that an appropriate degree of protection is awarded where necessary.⁹⁰ But the same appreciation of placing the individual at ‘centre stage in their world’⁹¹ cannot and has not been achieved through the still highly paternalistic application of best interests. The UN Committee in their assessment suggests that the best interest test must be replaced in favour of the will and preferences model,⁹² however, the Law Commission stated that the removal of this test was ethically and politically challenging as a substantive change would have to be made for the abandonment of the best interest test, which would raise issues that could not be resolved. They further state that a ‘complete reconfiguration’ of the MCA is a radical reform that is not within the remit of their review.⁹³ In spite of this, it is clear to see that s.4(6) of the MCA does not go far enough to protect the individualistic rights of the patients.

However, although the CRPD model appears ethically superior, in reality, the same issues are posed where it is difficult to uncover patients’ wills and preferences, and when coercion, manipulation or undue influence impact preferences. A fallback position is thus adopted providing that in certain situations the ‘best interpretation of will and preferences’ should be relied on, but this does not safeguard against the bias held by the decision-maker which can easily overpower the true feelings of the patients themselves in favour of paternalistic or personal preferences. Furthermore, it is argued that the very statement itself “forgoes epistemic humility and assumes levels of knowledge”⁹⁴ of which cannot be possible. Therefore, in vulnerable situations, the same issues appear as those present in the MCA and it is clear that although significant strides have been made to promote societal, legal, and medical change it is still not sufficient to protect autonomy in the same regard as patients with capacity.

Conclusion

⁸⁹ Barton-Hanson, (n 34), 282.

⁹⁰ Mary Donnelly, ‘Capacity Assessment Under the Mental Capacity Act 2005; Delivering the Functional Approach?’ (2009) 29(3) Legal Studies 464, 465.

⁹¹ Richardson (n 80), 350.

⁹² UN Committee on the Rights of Persons with Disabilities in its first General Comment, ‘Article 12: Equal Recognition Before the Law’, (GC1April 2014), para 29.

⁹³ Law Commission, Mental Capacity and Deprivation of Liberty (Law Com No 222, 2015) para. 12.44.

⁹⁴ Donnelly (n 25), 327.

The confused application of the best interests test in practice and the judicial inconsistency means that the MCA is insufficient in protecting the rights of those without capacity. There is a clear divide between the fundamental rights attached to those with absolute decision-making capacity and those without. The flexibility awarded to the MCA can safeguard individuals in certain cases, but the removal of hierarchy has resulted in the rejection of patients' wishes, feelings, beliefs, and values in favour of paternalistic intervention at the cost of compliance with Human Rights and the CRPD. The systematic failure to acknowledge basic human factors essential to the decision-making process needs to be amended and accepted regardless of capacity unless necessary to prevent vulnerable circumstances: substantive legal reform is required to acknowledge the humanity of those without capacity.

Table of Cases

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