The Assisted Decision-Making (Capacity) Act 2015: Implications for Healthcare Decision-Making

This is a pre-refereed version of an article published in (2016) 22(2) *Medico-Legal Journal of Ireland* 65-77

Mary Donnelly*

The Assisted Decision-Making (Capacity) Act 2015 (ADMA), which is expected to come into effect in 2017, is an ambitious piece of legislation which aims to alter radically law's response to adults with impaired capacity. Although the ADMA will have far-reaching implications in many contexts, because of the central role of consent in healthcare decision-making, its impact here will be significant and immediate. This article explores the implications of the ADMA for healthcare decision-making.[1] It begins by outlining the current legal framework and some of the practices which have developed in order to address gaps in this framework. This is important in identifying the changes and the continuities post ADMA. The article then examines the context for the ADMA, the extent to which it changes existing legal frameworks, and the structures for its delivery. This is followed by a detailed analysis of the most significant aspects of the ADMA relevant to healthcare decision-making. These are: the role of capacity; the replacement of a 'best interests' decision-making standard with a principles-based approach; the introduction of formal support roles; the introduction of new and extended forms of substitute decision-making; and, the introduction of mechanisms for advance healthcare decision-making. Drawing on experiences in other jurisdictions, in particular the Mental Capacity Act 2005 (MCA) in England and Wales, the article considers how these changes are likely to impact on how healthcare decisions are made in practice.

Healthcare Decisions: Current Law and Practice

As the law stands, most healthcare decisions are made without law's involvement where a patient's[2] capacity is impaired. However, in a small number of situations, the law determines how decisions are made.

The Scope of Law's Involvement

Law is involved in healthcare decision-making where the patient has been admitted to wardship under the Lunacy Regulation (Ireland) Act 1871. This vastly outdated process is

*Professor, School of Law, University College Cork. I am a member of the HSE Assisted Decision-Making Steering Group and this article has benefitted from discussions in this context. However, all opinions expressed here are personal and any errors are solely my own.

[1] Where possible, the article refers to healthcare decision-making rather than consent to treatment, so as to reflect more accurately the dynamic of a decision-making partnership between doctor and patient (which is endorsed by the Medical Council in a *Guide to Professional Conduct and Ethics* (8th ed, 2016), ch. 3) rather than the doctor offering an option to the patient to which s/he then consents or not.

[2] The article adopts the term 'patient' when speaking about healthcare decision-making, so as allow this context to be differentiated from other forms of decision-making.

Electronic copy available at: https://ssrn.com/abstract=3058627

engaged for approximately 200-300 people each year,[3] usually in situations where decisions have to be made about the person's property/business affairs.[4] The Lunacy Regulation (Ireland) Act 1871 long preceded contemporary concerns with healthcare decision-making and the matter is not addressed. The Law Reform Commission has suggested that admission to wardship results in a ward being automatically deemed to lack capacity to consent to medical treatment.[5] However, in the absence of a statement to this effect, it is difficult to see how this can be the case.[6] Therefore, under current law, a separate assessment of capacity in respect of healthcare decision-making should take place notwithstanding that the patient is a ward of court. It is highly unlikely that this occurs in practice and the fact of wardship tends to lead inexorably to healthcare decisions being made on behalf of the ward. In the absence of any legislative guidance, the practice has developed that, for less serious decisions, the consent of the committee of the ward is obtained and that the consent of the High Court is required for more serious procedures, such as surgery (unless the usual emergency exemption applies[7]). The applicable standard in such instances is the best interests of the ward.[8] It is probable that Court consent is generally forthcoming, although an accurate picture is not possible because written judgments are rarely issued and there are no publically available statistics regarding the outcome of applications nor indeed what steps (if any) are taken to seek the views of the ward on the proposed treatment.

The law is also formally engaged where the patient has been involuntarily admitted to an approved centre under the Mental Health Act 2001 (MHA).[9] For these patients, decisions about treatment to ameliorate the mental disorder must be made in accordance with the framework set out in Part IV of the MHA. Treatment in this respect includes 'the administration of physical, psychological and other remedies relating to the care and rehabilitation of a patient under medical supervision'[10] and has been held to include blood sampling in order to monitor anti-psychotic medication.[11] However, it remains unclear whether tube feeding in eg. cases of anorexia nervosa would come within the statutory definition.[12] Under the MHA, the consent of a patient is required for treatment except

[3] The Courts Service Reports do not distinguish between adults and children taken into wardship (although it is clear from statistics elsewhere in the Reports that the number of minors taken into wardship is very small: in 2013, 321 people were admitted; in 2014, 322 were admitted and in 2015, 237 were admitted: see Courts Services Annual Report 2014, p. 50 and Courts Services Annual Report 2015, p. 51.

[4] Although the wardship procedure may be used where only personal/health decisions have to be made (see *In re D* [1987] IR 449), the costs associated with admission to wardship tend to preclude its usage where property/affairs are not at issue.

[5] *Vulnerable Adults and the Law: Capacity* (LRC CP 37-2005), para. 4.24; *Law and the Elderly* (LRC CP 23-2003), para. 4.49.

[6] See M. Donnelly, 'Assessing Legal Capacity: Process and the Operation of the Functional Test' [2007] 2 *Judicial Studies Institute Journal* 141, 151.

[7] The 'emergency exemption' has tended to be narrowly interpreted as relating only to an immediate and significant threat if treatment without consent does not proceed: see *Murray v McMurchy* [1949] 221 DLR 224.

[8] See *In re a Ward of Court* [1996] 2 IR 79.

[9] In 2015, there were 2,363 such admissions: Mental Health Commission Annual Report 2015, p 47 and in 2014, the number was 2,162: Mental Health Commission Annual Report 2014, p 41.

[10] MHA, s. 2(1).

[11] *HSE v X* [2011] IEHC 326.

[12] There is a (dated) body of case law from England and Wales which suggests that such treatment fits within the somewhat different definition of treatment under the Mental Health Act 1983: see *Re KB (adult)(mental patient: medical treatment)* (1994) 19 BMLR 144; *B v Croydon Health Authority* [1995] Fam 133.

Electronic copy available at: https://ssrn.com/abstract=3058627

where, in the opinion of the consultant psychiatrist responsible for the patient's care and treatment, the treatment is necessary to safeguard the life of the patient, to restore his or her health, to alleviate his or her condition or to relieve his or her suffering *and* the patient is incapable of such consent.[13] Evidence cited by the Expert Group which reviewed the MHA indicates that the vast majority of involuntary patients are deemed to lack capacity to consent to treatment.[14] Thus, it would seem that the statutory requirement for consent is largely bypassed in practice. The MHA includes additional safeguards for a patient 'unable' (i.e. lacking capacity) to consent. These apply to electro-convulsive treatment (ECT) and where medicine to ameliorate the mental disorder has been administered for a continuous period of 3 months.[15] Treatment in these situations requires the authorisation of a second consultant psychiatrist, to whom the matter has been referred by the patient's own consultant psychiatrist. As originally enacted, the provisions relating to these additional safeguards were (probably inadvertently) phrased in a way which created an exception to the consent requirement for ECT and on-going medication and allowed treatment in these situations to be imposed on an 'unwilling' patient (i.e. a patient with capacity who refused). The Mental Health (Amendment) Act 2015 has now removed the word 'unwilling'. However, given the evidence that the vast majority of patients admitted under the MHA are found to lack capacity, the practical impact of the change may well be minimal.

Finally, the law may be formally engaged through the invocation of the High Court's inherent jurisdiction. This jurisdiction derives from the High Court's *parens patriae* jurisdiction[16] as well under Art. 34.3.1 of the Constitution of Ireland.[17] Under the inherent jurisdiction, the Court may make decisions, including healthcare decisions, on behalf of an adult lacking capacity.[18] There are relatively few written judgments on the application of the inherent jurisdiction, although a body of jurisprudence is slowly beginning to emerge. The most significant judicial analysis remains that of the Supreme Court in *Re a Ward of Court,* [19] although this case is far from typical. More recently, the inherent jurisdiction has been utilised in several cases to authorise the detention of adults who have personality disorders and therefore fall outside of the criteria for admission under the MHA. [20] In *HSE v O'B*, [21]

[13] MHA, s. 57(1). In this context, 'capable' is defined as 'capable of understanding the nature, purpose and likely effects of the proposed treatment': s.56(a).

[14] Report of the Expert Group on the Review of the Mental Health Act 2001 (Department of Health, 2014), p. 57.

[15] MHA, s. 59 (ECT) and s. 60 (medication) as am. by Mental Health (Amendment) Act 2015, ss. 2 and 3.

[16] This jurisdiction is vested in the High Court by virtue of the Courts (Supplemental Provisions) Act 1961, s. 9(1). Although the adult may be (and typically is) admitted to wardship as part of the exercise of the jurisdiction (see eg. *JM v St Vincent's Hospital and Ors* [2003] 1 IR 321), it is difficult to see that this is necessary for the exercise of the jurisdiction.

[17] See generally J. Donnelly, 'Inherent Jurisdiction and Inherent Powers of the Irish Courts' [2009] 2 *Judicial Studies Institute Journal* 122.

[18] A notable feature of the Irish case law to date has been that the inherent jurisdiction has only been used in circumstances where the adult has been found to lack capacity. In this, it has differed from the position in England and Wales, where in the wake of the MCA, the inherent jurisdiction is increasingly used where a person is 'vulnerable' notwithstanding that s/he meets the standard for capacity under the MCA: see J. Herring and J. Wall, 'Autonomy, Capacity and Vulnerable Adults: Filling the Gaps in the Mental Capacity Act' (2015) 35(4) *Legal Studies* 698.

[19] [1996] 2 IR 79.

[20] A personality disorder is excluded a basis for admission under MHA, s. 8(2).

[21] *HSE v O'B* [2011] IEHC 73.

Birmingham J used the jurisdiction to order the detention of Mr O'B in the Central Mental Hospital on the basis that this was in his best interests. Birmingham J found that 'where an adult lacks capacity and where there is a legislative lacuna so that the adult's best interests cannot be served without intervention of the Court … the Court has jurisdiction … to intervene'.[22] The jurisdiction was subsequently employed in similar circumstances in *HSE v VE*.[23] Feeney J stated that the court only exercises the inherent jurisdiction as a 'last resort'.[24] He was clear that it not simply a case of the Court deciding on balance that the order was required for Mr E's own good 'but rather that, absent an order, Mr E's physical and mental wellbeing will be seriously damaged, that he would be placed in a position where he would be at risk of injury or damage'.[25] The inherent jurisdiction was again used in two cases concerning minors who had been sent for treatment for personality disorder in the UK and who had now attained the age of majority and wished to return to Ireland. In *HSE v KW*, O'Hanlon J ordered the detention of a young woman in a psychiatric facility in order to enable her to transition back to living in Ireland.[26] KW was found to lack capacity 'in terms of making material decisions regarding her medical treatment and therapy'.[27] In these circumstances, her best interests and constitutional rights were found to be endangered, and O'Hanlon J found that in order to vindicate her personal rights under Art. 40, the Court had an obligation to intervene.[28] O'Hanlon J reached a similar conclusion in *HSE v JB*, again identifying the importance of the inherent jurisdiction in protecting JB's constitutional rights.[29]

Informal Decision-making

For most patients with impaired capacity, healthcare decisions are made without any of the formal mechanisms outlined above. The most detailed guidance on healthcare decision-making where the law is not involved is provided by the Health Service Executive *National Consent Policy* (2013).[30] This sets out a series of steps which healthcare professionals should take where a patient does not have capacity to consent to treatment. These include supporting and encouraging the patient to be involved in decisions; seeking evidence of any previously expressed preferences, wishes and beliefs of the patient; considering the views of anyone who has a close personal relationship with the patient and, in difficult situations, considering involving an advocate to support the patient.[31] The Policy is also clear that the patient's 'next-of-kin' has no legal status and that their involvement is relevant only in providing an indication of what the patient would wish to happen.[32] In spite of this, it appears frequently to be the case that the 'consent' of the patient's next-of-kin is relied upon in practice. Moreover, there are concerning indications, particularly in end-of-life

[22] [2011] IEHC 73. Birmingham J recognized the impact of the order on Mr O'B's right to liberty and was clear that the detention would have to be reviewed on a regular basis; beginning with a two-month review.
[23] Unreported, Feeney J, 26 July 2012.
[24] *Ibid*., cited in *HSE v KW* [2015] IEHC 215, [35].
[25] Ibid.
[26] [2015] IEHC 215, [71].
[27] *Ibid*, [67].
[28] Ibid.
[29] [2015] IEHC 216, [116].
[30] Available at http://www.hse.ie/eng/about/Who/qualityandpatientsafety/National_Consent_Policy/.
[31] HSE *National Consent Policy* (2014) para 5.6.
[32] HSE *National Consent Policy* (2014) para 5.6.1.

situations, that sometimes family preferences are acceded to, notwithstanding that the decision is not considered by the healthcare professionals to be the most appropriate option for the patient, who at this point may well be unable to assert his or her own preferences.[33]

The widely-used informal decision-making mechanism just described has not been considered by the Irish courts and there is a degree of uncertainty regarding the nature and extent of the defence (to liability in trespass) available to a healthcare professional who, in a non-emergency situation, provides medical treatment without the consent of a patient who lacks capacity. In the United Kingdom, the House of Lords resolved a similar uncertainty on the basis of the principle of necessity, finding that this defence, long accepted in an emergency situation, applied more generally to the provision of healthcare.[34] The Irish courts might reasonably be expected to recognise a similar defence for professionals. It might also be presumed that a crucial determinant of whether the defence would apply in an individual situation would be whether the professional had acted with due care and diligence and had complied with all of his/her obligations under the HSE *National Consent Policy* and any relevant codes of practice/guidelines and, once the ADMA has commenced, with legal obligations arising under the ADMA. Thus, the ADMA is of considerable practical concern for healthcare professionals both in terms of their obligations to patients and their avoidance of liability.

An Overview of the ADMA

Notwithstanding the evident inadequacies of the current legal framework, the path to the ADMA has been tortuous, having taken well over a decade to progress to final enactment.[35] During this time, the impetus for legislative reform has changed. Although enhanced protection for human rights was an important justification for earlier reform proposals, in the wake of the State's commitment to ratify the United Nations Convention on the Rights of Persons with Disabilities (CRPD),[36] compliance with these obligations assumed a heightened political significance. A consideration of what compliance with CRPD might require is therefore a necessary first step in understanding the context for the ADMA.

CRPD Requirements

The purpose of the CRPD is to 'promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities.'[37] Its

[33] See C. Quinlan and C. O'Neill, *Practitioners' Narrative Submissions* (unpublished Irish Hospice Foundation, 2008).

[34] *In re F (Mental Patient: Sterilisation)* [1990] 2 AC 1. This was subsequently given statutory force in MCA, s. 5.

[35] The process began with the publication, in 2003, of the first of two consultation papers by the Law Reform Commission: see *Law and the Elderly* (LRC CP 23-2003). The ADMA was finally signed into law on 30 December 2015.

[36] Adopted by General Assembly Resolution (A/RES/56/168) of 13 December 2006, the CRPD entered into force on 3 May 2008. Ireland signed the CRPD on 30 March 2007 and committed to ratification.

[37] Persons with disabilities are defined in an expansive way as including 'those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others': CRPD, art. 1. For general overview of the CRPD, see R. Kayess and P. French "Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities" (2008) 8 *Human Rights Law Review* 1.

underpinning principles include 'respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons'.[38] The CRPD is also underpinned by ideals of non-discrimination[39] and frequently refers to protection of the rights of persons with disabilities 'on an equal basis with others'. The CRPD invokes a broad range of rights and, notably, acknowledges positive (eg. rights to education/live in the community etc) as well as negative rights. Rights of particular relevance to healthcare decision-making are the right of person with disabilities to respect for 'physical and mental integrity on an equal basis with others'[40] and the right to the highest attainable standard of health 'without discrimination on the basis of disability'.[41] One aspect of the latter right is the requirement that States Parties take steps to require health professionals to provide care of the same quality to persons with disabilities as to others, 'including on the basis of free and informed consent'.[42] The implications of these rights for people with impaired capacity must be understood in the context of the overarching framework created by Art. 12 of the CRPD.

Article 12 requires States Parties to recognise that 'people with disabilities enjoy legal capacity on an equal basis with others in all aspects of life'[43] and requires States Parties to take 'appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity'.[44] It also requires that all measures relating to the exercise of legal capacity must include safeguards to prevent abuse and that such safeguards must ensure respect for the rights, will and preferences of the person.[45] The language of Art. 12 is, at times, opaque[46] and its precise requirements are open to debate.[47] In its first General Comment (GC1),[48] the Committee on the Rights of Persons with Disabilities outlined its interpretation of Art. 12.[49] Two aspects are especially relevant in the context of the ADMA. First, GC1 states that Art. 12 does not permit 'discriminatory denial of legal capacity' on the basis of a functional test for capacity but requires instead

[38] CRPD, art. 3(a).
[39] CRPD, art. 3(b).
[40] CRPD, art. 17.
[41] CRPD, art. 25.
[42] CRPD, art. 25(d). Note also the absolute prohibition on medical or scientific experimentation without the 'free consent' of the person: CRPD, art. 15(1).
[43] Art. 12(2).
[44] Art. 12(3).
[45] Art. 12(4).
[46] This reflects political compromises reached during the sometimes contentious drafting of Art. 12: see A. Dhanda, 'Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future?' (2006-7) 34 *Syracuse Jl Int L & Com* 429, 438-456.
[47] For differing interpretations, see P. Bartlett, 'The United Nations Convention on the Rights of Persons with Disabilities and Mental Health Law' (2012) 75 *Modern Law Review* 752, 761-768 and E. Flynn and A. Arstein-Kerslake, 'Legislating Personhood: Realising the Right to Support in Exercising Legal Capacity' (2014) 10 *International Journal of Law in Context* 81, 89-91
[48] CRPD/C/GC/1, adopted 11 April 2014, available at http://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx.
[49] Interpretations of UN Conventions in General Comments are not legally binding, although they can be influential in developing policy positions, in particular where there is a consensus as to their normative legitimacy: see H Keller and L Grover, 'General Comments of the Human Rights Committee and their Legitimacy' in H Keller, G Ulfstein, L Grover (eds), *UN Human Rights Treaty Bodies: Law and Legitimacy* (CUP 2012) 128–29.

that 'support be provided in the exercise of legal capacity.'[50] Secondly, it states that the 'best interests principle' does not comply with Art. 12 and that 'the "will and preferences" paradigm must replace the "best interests" paradigm to ensure that persons with disabilities enjoy the right to legal capacity on an equal basis with others.'[51] GC 1 also states that Art. 12 requires that all substitute decision-making regimes (i.e. legal frameworks which allow decisions to be made by someone other than the person whose capacity is impaired) should be abolished.[52] However, the Department of Justice and Equality has indicated that, on ratification, Ireland will issue a declaration, along similar lines to the declarations issued by Australia, Canada and Norway that it is the State's understanding that the CRPD allows for substitute decision-making where such arrangements are necessary as a last resort and subject to safeguards.[53]

The ADMA in Outline

The ADMA is underpinned by the philosophy that a person with impaired capacity (referred to in the ADMA as a 'relevant person'[54]) should be supported as far as possible in making decisions for him/herself. The ADMA seeks to deliver this through several legislative strands (and a great deal of complex detail[55]). Before examining how the ADMA operates in the context of healthcare decision-making, some more general comments on the impact of the ADMA on current legal frameworks and on the mechanisms for delivery of the new framework are appropriate.

Impact on the Current Legal Frameworks

The ADMA repeals the Lunacy Regulation (Ireland) Act 1871[56] and, from commencement, abolishes the wardship jurisdiction for all new applicants. Wardship remains in place for people who are already wards of court prior to commencement.[57] However, a ward (or a relative or friend who has a relationship of trust with the ward) may make an application to the wardship court[58] for a declaration that the ward does not lack capacity (and should be discharged from wardship); or that s/he lacks capacity without a co-decision-maker (and should have a co-decision-maker appointed[59]) or that s/he lacks capacity even with the assistance of a co-decision-maker (and should have a decision-making representative appointed).[60] If an application of this kind is not made (and it is unclear whether many will be), every ward is entitled to an automatic assessment of this kind within 3 years of commencement of the ADMA.[61] Until this assessment has happened, some of the old

[50] GC1, para. 15.
[51] GC1, para. 21.
[52] GC1, para. 28.
[53] See Roadmap to Ratification of the United Nations Convention on Persons with Disabilities (Department of Justice and Equality: October 2015).
[54] A 'relevant person' is a person whose capacity is in question or may shortly be in question in respect of one or more matters or a person who lacks capacity in respect of one or more matters: ADMA, s. 2(1).
[55] In addition to the detail in the ADMA itself, provision is made for the introduction of several sets of regulations (all of which must be laid before each House of the Oireachtas and may be annulled by a resolution passed by either House): ADMA, s. 5.
[56] ADMA, s. 7(2).
[57] ADMA, s. 56(1).
[58] This is the High Court or Circuit Court: ADMA, s. 53.
[59] This mechanism for supported decision-making is discussed at text to n. 125 below.
[60] ADMA, s. 55(1).
[61] ADMA, s. 54(2).

provisions relating to wardship remain in place. This includes the requirement for the consent of the High Court for serious medical treatment.[62] However, the principles under the ADMA apply notwithstanding that the relevant person is a ward of court and any decision made on his/her behalf must take account of these.

The ADMA makes no attempt to integrate the overlapping MHA and ADMA frameworks in respect of healthcare decision-making. Instead, the ADMA disapplies elements of the ADMA where a person has been admitted under the MHA. It states that nothing in the ADMA authorises a person to give a patient treatment for a mental disorder or to consent to a patient being given such treatment where the directive-maker's treatment is regulated by the MHA.[63] The ADMA also excludes the obligation to comply with an advance healthcare directive made under the ADMA where the person's treatment is regulated by the MHA (or the Criminal Law (Insanity) Act 2006).[64] This way of dealing with the inter-relationship between the frameworks is wholly unsatisfactory. As has been recognised by the Expert Group which reviewed the MHA, there is a clear need for detailed reform of the MHA[65] to integrate the two frameworks.[66] In the meantime, however, it is important to be clear that only limited aspects of the ADMA are disappplied where the MHA is engaged. Thus, the ADMA principles continue to apply and these must be complied with where treatment decisions are being made for a 'relevant person', notwithstanding that s/he has also been involuntarily admitted under the MHA.[67] Similarly, nothing in the ADMA disapplies the support frameworks a person is admitted under the MHA. This means that where a 'relevant person' has appointed a decision-making assistant or co-decision maker, these people can assist the person in making a decision about treatment and in reaching the standard for capacity (and thus activate the right to refuse treatment) under the MHA .

A final issue relates to the High Court's inherent jurisdiction. The ADMA makes no reference to this and so the jurisdiction clearly continues. However, how and when the inherent jurisdiction will be used post- ADMA is less unclear. In *Re FD*, Laffoy J (on behalf of the Supreme Court) rejected the argument that the High Court had an inherent jurisdiction, in addition to that statutorily vested in it by wardship legislation, to make decisions in respect of the assets of a person found to lack capacity.[68] She considered that such a finding would be 'to trespass on the legislative role of the Oireachtas'.[69] This would seem to suggest that the Irish courts may be more reluctant to use the inherent jurisdiction post-ADMA unless the matter arising is not covered by the ADMA.

Delivering the ADMA

The ADMA establishes a complex structure for delivery of the new framework. Two strands are relevant to the oversight of healthcare decision-making. The first is the role of the

[62] Note however that, under AMDA s. 57, the wardship court, after consultation with the Director of Decision Support Services, may in respect of either a ward or a class of wards, direct the Director to exercise his or her functions in respect of the ward/class of wards.
[63] ADMA, s. 136(1).
[64] ADMA, s. 85(7)(a).
[65] The ADMA makes only very minor amendments to the MHA: see ADMA, s. 144.
[66] See the *Report of the Expert Group* n. 14 above.
[67] On the impact of these principles on healthcare decision-making, see text following n. 105 below.
[68] [2015] IESC 83, [32].
[69] *Ibid* (citing Clarke J).

Director of Decision Support Services (DDSS) and the second is the role of the courts. The success of the ADMA in delivering an improved legal framework in practice will depend to a large extent on how issues are dealt with by these bodies.

The DDSS, who is not yet in place at the time of writing,[70] has a range of statutory functions, including promoting public awareness of the ADMA and supervising the people performing support and substitute decision-making functions.[71] S/he may also receive complaints about these people and, if s/he considers appropriate, instigate an investigation.[72] The DDSS is also empowered to develop, or approve codes of practice on the operation of the ADMA.[73] Relevant codes for healthcare decision-making include a code on assessing capacity; a code on urgent treatment; and a code for healthcare professionals.[74] These codes, together with HSE Guidance,[75] will provide more detail on how the ADMA is to be operationalised in practice. Inevitably, however, these will not be able to address all the issues which will arise in practice. Therefore references to court are likely to increase at least in the early stages of the operation of the ADMA. [76]

Any person with a *bona fide* interest in the welfare of a relevant person may make an application to court under the ADMA.[77] This would clear include the HSE, an individual hospital or healthcare provider.[78] For the vast majority of applications, the relevant court is the Circuit Court[79] and these applications will be heard by specialist judges.[80] Two kinds of application may only be heard by the High Court. The first is any decision regarding the donation of an organ from a living donor, which must always be approved by the High Court.[81] The second is an application relating to the withdrawal of life-sustaining treatment. As originally drafted, this had seemed to suggest that the withdrawal of life-sustaining treatment would always require High Court approval,[82] something which would have been extremely traumatic for the dying person and his or her loved ones as well as wasteful of

[70] S/he is to be appointed by the Mental Health Commission: ADMA, s. 94(1).
[71] ADMA, s. 95(1).
[72] ADMA, s. 96(1).
[73] ADMA, s. 103(2) lists eleven possible codes. In the absence of the DDSS, the function of drafting codes is currently being undertaken by the National Disability Authority.
[74] ADMA, s. 103(2). Note that there will also be a code on advance decision-making which is to be published by the DDSS following recommendations of a multidisciplinary working group established by the Minister for Health: ADMA, s.91(3) .
[75] This is being developed by the HSE Assisted Decision-Making Steering Group.
[76] A notable (and largely unexpected) outcome of the introduction of the MCA was a very substantial increase in court applications (which has increased rather than reduced as the MCA has become more established).
[77] ADMA, s.36(1).
[78] Note however that the prior consent of the court is required for such an application: ADMA, s.36(3) requires prior court consent unless the applicant is the relevant person or his or her spouse or decision-making support/representative or the DDSS.
[79] ADMA, s. 4(1).
[80] These specialist judges are the cohort of judges originally appointed to administer the Personal Insolvency Act 2012 (the uptake on the insolvency jurisdiction was not as extensive as expected and so there is spare capacity).
[81] ADMA, s. 4(3)(a)
[82] See ADMA Bill 2013, s. 4(2) read together with s. 54(1).

resources.[83] The relevant provision now makes clear that, while the High Court has sole jurisdiction over cases concerning the withdrawal of life-sustaining treatment from a person lacking capacity, this does not require that all such decisions must have the approval of the High Court. [84]

Applications to court must be heard with the least amount of formality consistent with the proper administration of justice and must be heard other than in public.[85] The *in camera* requirement raises important issues. While there is an undoubted need to protect the privacy of the people in respect of whom applications are made, there is also a significant need for transparency and of justice being seen to be done. Moreover, given (as discussed below) the very broad way in which the principles underpinning the ADMA are formulated, there is a clear need for further clarification and for judicial guidance to be made available to those people, including healthcare professionals, who are dealing with the ADMA in practice. In England and Wales, the relevant court – the Court of Protection – received a great deal of criticism in its early days because of its lack of transparency and in 2014, the President of the Court issued Practice Guidance for increased transparency in the Court. This Guidance emphasised the publication of (anonymized) judgments as a source of guidance and transparency.[86] It is essential both to the reputation of the courts and to the effective delivery of the ADMA that a similar model is put into effect in respect of both Circuit and High Court judgments under the ADMA.

Healthcare Decision-Making: The Key Changes in the ADMA

Although it will take time for the full impact of the ADMA changes to become apparent, there are several key changes (and some continuities) in the legal framework in respect of healthcare decision-making which are likely to be significant. Before considering these, it is worth noting that, although the ADMA Bill as originally drafted provided explicit statutory protection for informal decision-making, including in the healthcare context,[87] this is not contained in the ADMA as enacted. This means that the pre-ADMA position (and its uncertainties) continues.[88] In the absence of legislative clarification of the matter, there is now a very strong case to made for judicial clarification of the scope and application of the professional defence in the context of informal healthcare decision-making under the ADMA.

The Role of Capacity

In many respects, the role of capacity under the common law is replicated under the ADMA. Capacity continues to play a gatekeeper role in determining how healthcare decisions are made: a patient with capacity can make his or her own decisions while decisions are made

[83] See B. Lyons, 'Improving End-of-Life Care in Intensive Care Units' in M. Donnelly and C. Murray, *Ethical and Legal Debates in Irish Healthcare: Confronting Complexities* (Manchester: Manchester University Press, 2016), pp. 237-8.
[84] ADMA, s. 4(3)(b)
[85] ADMA, s. 36(10).
[86] See Transparency in the Court of Protection: Publication of Judgments, Practice Guidance, 16 January 2014.
[87] ADM Bill 2013, s.53 (1). There is a broadly similar measure in the MCA, s. 5.
[88] See text to n. 34 above.

for a patient who has been found to lack capacity (albeit that these are made in accordance with the ADMA principles, discussed below).[89] There is also continuity in several aspects of the test for capacity. The ADMA gives statutory effect to the functional test for capacity (i.e. that capacity is assessed in the context of the particular decision to be made at the time that the decision has to be made)[90] and to the presumption of capacity,[91] both of which had been established in *Fitzpatrick and Anor v K and Anor*.[92] The standard for capacity is also broadly in line with that adopted in *Fitzpatrick*. As in *Fitzpatrick*, there are no diagnostic criteria (i.e. no requirement that the patient have some form of mental illness/disability) to be met before the test for capacity is applied.[93] Under the ADMA, a person lacks capacity to make a decision where s/he is unable:

(a) to understand the information relevant to the decision,
(b) to retain that information long enough to make a voluntary choice,
(c) to use or weigh that information as part of the process of making the decision, or
(d) to communicate his or her decision (whether by talking, writing, using sign language, assistive technology, or any other means) or, if the implementation of the decision requires the act of a third party, to communicate by any means with that third party.[94]

The only substantive difference from *Fitzpatrick* is the identification of an inability to communicate (albeit tightly subscribed) as a ground for a finding of lack of capacity.[95]

While there are many similarties, there are also some notable changes introduced by the ADMA. In the main, these derive from the inclusion of several measures intended to reduce the possibility that a person will be found to lack capacity. The ADMA requires that a person is not to be regarded as unable to understand information if s/he is able to understand an explanation given in a way appropriate to his or her circumstances[96] and that the fact that a person is able to retain information for a short period only does not prevent

[89] In this respect the ADMA does not comply with the interpretation in GC1 of Art. 12 of the CRPD: see text to n. 50 above.

[90] ADMA, s. 3(1). The functional approach is reinforced by s. 3(5) which states that the fact that a person lacks capacity in respect of a matter at a particular time does not prevent him/her from being regarded as having capacity in respect of the same matter at another time and s. 3(6) which states that the fact a person lacks capacity in respect of one matter does not prevent him/her from being regarded as having capacity to make decisions on other matters.

[91] ADMA, s. 8(2).

[92] [2008] IEHC 104. This test has been applied in several subsequent cases: see eg. *HSE v R and Ors* [2016] IEHC 445; *Governor of X Prison v PMcD* [2015] IEHC 259; *HSE v KW* [2015] IEHC 215; *HSE v JB* [2015] IEHC 216.

[93] Contrast the position under the MCA where the inability to make a decision must arise from 'an impairment of, or disturbance in, the mind or brain': MCA, s. 2(1). This is clearly discriminatory as well as contrary to the CRPD: see. Bartlett above n. 47, 762-3.

[94] ADMA, s. 3(2). Information relevant to a decision is defined as information about the reasonably foreseeable consequences of (a) each of the available choices at the time the decision is made, or (b) failing to make the decision: s. 3(7).

[95] In *Fitzpatrick*, Laffoy J. held that a patient is incapable of making a treatment decision if s/he has not comprehended and retained the treatment information; has not believed the information; and has not weighed the information in the balance in arriving at the decision. Although the ADMA does not refer to belief, the belief element is subsumed into the 'use and weigh' requirement: it is not possible to use and weigh information if one does not believe it.

[96] ADMA, s. 3(3). Examples given are: using clear language; visual aids or any other means.

him/her from being regarded as having capacity.[97] Furthermore, the principles underpinning the ADMA require that a person shall not be considered unable to make a decision unless all practicable steps have been taken, without success, to enable him or her to do so[98] and that a person may not be considered unable to make a decision merely by reason of making, having made, or being likely to make, an unwise decision.[99] And, finally, the decision-making support mechanisms (discussed below) allow a person to draw on others to assist them so that they can reach the standard for capacity. If these aspects of the ADMA are applied properly (alongside the presumption of capacity) it would seem reasonable to expect that, post-ADMA, there should be a reduction in determinations that a person lacks capacity. Unfortunately though, because we do not have reliable data on how frequently people are found to lack capacity prior to the commencement of the ADMA, it will be difficult to develop a comparative analysis of the impact of these measures in practice.

There may be one further difference between the common law and the ADMA. This relates to whether the gravity of the decision the person proposes to make is relevant in assessing his or her capacity. In *Fiztpatrick*, Laffoy J. stated that '[i]n assessing capacity … the assessment must have regard to the gravity of the decision, in terms of the consequences which are likely to ensue from the acceptance or rejection of the proffered treatment'.[100] This meant that, in applying the civil law standard of proof (i.e. the balance of probabilities), 'the weight to be attached to the evidence should have regard to the gravity of the decision, whether this is characterised as the necessity for "clear and convincing proof" or the enjoinder that the court "should not draw its conclusions lightly"'.[101] This approach was affirmed in *Governor of X Prison v PMcD*, where Baker J. applied Laffoy J's statement that the Court should not 'draw its conclusions lightly' in determining the capacity of a prisoner on hunger strike.[102] It is unclear whether this approach to evidence will continue following the ADMA.[103] There is nothing explicitly stated in the ADMA to indicate either that there should be a variation in the approach to evidence depending on the gravity of the decision proposed or that there should not. On the one hand, it might be argued that adopting a more rigorous approach to evidence where the consequences of the decision are grave makes it more likely that people making unreasonable or risky decisions will be found to lack capacity and therefore that this approach fails to show sufficient respect for their right of autonomy. However there is a counterargument that respect for other rights, including the right to life, dignity, bodily integrity and the highest attainable standard of health, require that greater care should be taken in situations of grave risk so to ensure that any conclusions regarding capacity or lack of capacity are made on basis of the best possible evidence.[104]

[97] ADMA, s. 3(4).
[98] ADMA, s. 8(3).
[99] ADMA, s. 8(4).
[100] [2008] IEHC 104.
[101] Ibid.
[102] [2015] IEHC 259, [57].
[103] The matter may be dealt with in the Rules of Court required under the ADMA, s. 92(6).
[104] See arguments (made in the context of the more controversial issue of a variable standard for capacity – as opposed to a variable approach to evidence of capacity) in M. Donnelly, *Healthcare Decision-Making and the Law: Autonomy, Capacity and the Limits of Liberalism* (Cambridge: Cambridge University Press, 2010), pp. 114-119.

A Principles-Based Approach to Decision-Making in Incapacity

One of the most immediately striking features of the ADMA is that it contains no reference to the 'best interests' standard that has provided the basis for decision-making in wardship and under the inherent jurisdiction. Instead, the ADMA requires that, in respect of any 'intervention' (which includes the provision of medical treatment), the 'intervener'[105] must 'give effect' to a set of principles. On closer reading, it is evident that several of these principles are identical to the best interests standard as set out in the MCA (although this standard differs substantially from the traditional, objective approach to best interests).

Five of the ADMA principles (which are further sub-divided) are relevant to healthcare decision-making where a person has been found to lack capacity.[106] As is usually the case with principles, the application of these rarely leads to straightforward resolutions in difficult situations. Moreover, because the principles are wide-ranging and diffuse, they leave a good deal of discretion to interveners and create a clear need for careful and considered guidance, including judicial guidance. The first relevant principle is that there may be no intervention at all unless this is necessary having regard to the circumstances of the relevant person.[107] This principle raises interesting questions, especially in the context of non-therapeutic treatments.[108] It would seem excessively medico-centric to assume that only treatments which are therapeutically advised are 'necessary' within the meaning of the principle. However, it is not clear how what is 'necessary' will be interpreted outside of this context.

Secondly, an intervention must be made in a way that minimises the restriction to the person's rights and freedom of action and must have due regard to the need to respect the person's right to dignity, bodily integrity, privacy, autonomy and control over his or her financial affairs; be proportionate to the significance and urgency of the matter; and, be as limited in duration as practicable.[109] The sheer breadth of this principle makes its application in practice difficult to predict. Respect for the listed rights alone may lead simultaneously in different directions. In the healthcare context, however, it can be expected that this principle should have significant implications for how treatment is actually provided to a patient, especially in cases where a patient is unenthusiastic or resistant. It is difficult to envisage many situations – other than immediate emergencies - in which the use of force to administer treatment to a resistant patient could be consistent with this principle.[110]

---

[105] An intervention is an action taken under the ADMA in respect of a relevant person by the Circuit or High Court; a decision-making assistant co-decision-maker, decision-making representative, attorney or designated healthcare representative; the DDSS; a special visitor or general visitor; or, a healthcare professional. An 'intervener' is any one of these people: ADMA, s. 2(1).

[106] The other principles are relevant to the assessment of capacity: ADMA, s. 8(2),(3) and (4) and to informational privacy: s. 8(10).

[107] ADMA, s. 8(5).

[108] The ADMA expressly provides that one non-therapeutic treatment (non-consensual sterilisation) cannot be authorised: ADMA, s. 4(4).

[109] ADMA, s. 8(6).

[110] The use of force to impose medical treatment is, of course, also problematic under the European Convention on Human Rights: see eg. *Storck v Germany* (2005) 43 EHRR 96.

The third principle relates to the obligations of an intervener, in making an intervention.[111] It requires that the intervener must permit, encourage and facilitate insofar as practicable, the relevant person to participate or to improve his or her facility to participate in the intervention. The intervener must also give effect, in so far as is practicable, to the past and present will and preferences of the relevant person, in so far as these are reasonably ascertainable; take into account the beliefs and values of the relevant person (in particular those expressed in writing), in so far as these are reasonably ascertainable, and any other factors which the person would be likely to consider if s/he were able to do so. The intervener must also, unless s/he reasonably considers it is not appropriate or practicable to do so, consider the views of any person named by the relevant person and any decision-making assistant; co-decision-maker; decision-making representative or attorney for the relevant person. S/he must act at all times in good faith and for the benefit of the relevant person. Finally, s/he must consider all other circumstances of which s/he is aware and which it would be reasonable to regard as relevant. Much of this wide-ranging principle resonates with the best interests standard under the MCA.[112] And, like this standard, this principle can simultaneously lead in more than one direction. So, for example, a person's past and present will and preferences may not be consistent with each other, nor may the views of people consulted. Moreover, the inclusion of the seemingly objective requirement that an intervener must act at all times 'for the benefit of' the relevant person raises the question of how benefit is to be determined. And, the already considerable potential for discretion is further increased by the inclusion of the 'catch-all' that the intervener must consider 'all other circumstances' of which the intervener is aware. In this context, there is a risk that the 'will and preferences' element of the principle may be overlooked. Yet, this aspect of the principle is most closely aligned with requirements under the CRPD[113] and a strong case may be made that respect for will and preferences, insofar as this is possible,[114] should be prioritised in guidance, including judicial guidance.

The fourthly principle relates to consultation by the intervener. It provides that the intervener may consider the views of any person engaged in caring for the relevant person; any person who has a bona fide interest in the welfare of the relevant person; or healthcare professionals.[115] This principle, which is facilitative rather than mandatory, reflects the way many healthcare decisions involving people lacking capacity are made in practice. Oddly, the principle does not state the subject on which the views of the person/s consulted should be sought. In light of the other principles and in particular the focus on the will and preferences/beliefs and values of the relevant person, it might be presumed that this should

[111] ADMA, s. 8(7).

[112] See in particular MCA, s 4(4) and 4(6) (although the MCA refers to the person's 'wishes and feelings' rather than 'will and preferences'): on the ambiguities in the MCA standard, see M. Donnelly, 'Best interests, Patient Participation and the MCA' (2009) 17 *Med L Rev* 1.

[113] See text to n. 45 above.

[114] On the normative case in favour of prioritising the will and preferences of a person with impaired capacity (but not affording this determinative status), see M. Donnelly, 'Best Interests: Time to Say Goodbye?' (2016)24(3) *Med L Rev* (forthcoming).

[115] ADMA, s.8(8).

be the focus of the inquiry.[116] However, it would have been preferable if this had been clearly stated.[117]

The final relevant principle is that regard should be had to the likelihood of the recovery of the relevant person's capacity in respect of the matter concerned and the urgency of making the intervention prior to the recovery.[118] This could be significant in cases of fluctuating capacity, which may be especially relevant for some patients with mental disorders.

Formalising Decision-making Supports

One of the most innovative elements of the ADMA is the introduction of provision for decision-making supports which can be used by a person who believes that his/her capacity is in question or may shortly be in question ('the appointer') and allow the appointer to avoid being found to lack capacity.[119] Provision is made for two forms of support.[120] The first is where the appointer enters into a decision-making assistance agreement and appoints a person/s as his or her decision-making assistant/s (DMA) in respect of a particular decision/s.[121] The DMA assists the appointer in obtaining and explaining relevant information; ascertaining the appointer's will and preference; making and expressing a decision; and ensuring that the decision is implemented.[122] However, the DMA may not make a decision on behalf of the appointer[123] and any decision made is deemed to be the decision of the appointer.[124]

The second, and more extensive, form of support involves the appointer appointing a co-decision maker/s (CDM).[125] Reflecting the higher level of support involved (and the accompanying risks), the process of making a co-decision-making agreement is more complex and formal than that for the appointment of a DMA. So, for example, the Co-Decision-Making Argeement must include a statement by a registered medical practitioner and by such other healthcare professional as prescribed that appointer has capacity to make a decision to enter into the agreement; that s/he requires assistance in making decisions

[116] Note that this is the approach advocated in the HSE *National Consent Policy*: see n. 32 above.
[117] Compare MCA, s. 4(7) which specifically relates the consultation to the best interests standard and the wishes and feelings/values and beliefs of the person.
[118] ADMA, s. 8(9).
[119] Similar support models are operational in several Canadian jurisdictions: see M. Bach and L. Kerzner, *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity* (Law Reform Commission of Ontario, 2010), pp 53-56 and are being piloted in Australia: see T. Carney, 'Supported Decision-Making for People with Cognitive Impairments: An Australian Perspective?' (2015) 4(1) *Laws* 37.
[120] Further detail on the applicable procedures in establishing these supports will be contained in Regulations, which the ADMA requires be introduced: ADMA, s. 10(4) and s. 31.
[121] An appointer may appoint different DMAs for different decisions: ADMA, s.10(1) and appoint more than one DMA for the same decision: ADMA, s. 10(5).
[122] ADMA, s. 14(1).
[123] ADMA, s. 14(2)
[124] ADMA, s. 14(3).
[125] ADMA, s. 17(1). An appointer may appoint different CDMs for different decisions; however, s/he may not appoint more than one person as CDM in the same co-decision-making agreement or appoint a CDM in respect of a relevant decision which is the subject of another co-decision-making agreement: ADMA, s. 17(8). Where an appointer has more than one CDM, each of the CDMs must exercise his or her functions in a manner which is not inconsistent with the functions exercisable by another CDM: ADMA, s. 19(7).

specified in the agreement; and that s/he has capacity to make these decisions with the assistance of the co-decision-maker.[126] The CDM jointly makes decisions with the appointer.[127] S/he is also required to explain relevant information and considerations to the appointer; ascertain the appointer's will and preferences and assist the appointer with communicating these; assist the appointer in obtaining relevant information; discuss with the appointer the known alternatives and likely outcomes of a decision; and make reasonable efforts to ensure that the decision is implemented as far as practicable.[128] Although the decision is jointly made, a CDM must acquiesce with the wishes of the appointer in respect of the decision and where the decision requires a document (e.g. a consent form) to be signed,[129] the CDM may not refuse to sign the document unless it is reasonably foreseeable that such acquiescence or signature will result in serious harm to the appointer or another person.[130]

It is unclear at this point how many people will choose to avail themselves of these support mechanisms. For those who do, these new measures provide a legal grounding for the kind of support which, in ideal situations, is already part of decision-making in practice. Most people (whether their capacity is impaired or not) make healthcare decisions in conjunction with other people.[131] The advantage of the new framework is that the chosen support person will now have legal standing. This requires healthcare professions to engage with the patient in the context of his or her relationship with his or her chosen support person. Where this relationship is good, this offers potential for improved and enhanced healthcare decision-making by patients with impaired capacity and allow patients a greater degree of control.

Because the person providing support has been chosen by the patient, it would seem reasonable to presume that most of the time, the relationship will be good and that the support mechanisms will facilitate good healthcare decision-making. Certainly, they are preferable to the next-of-kin system as currently operated in practice. However, inevitably, not all support relationships will proceed as planned and healthcare professionals may have concerns about how the support dynamic is operating in a particular situation. Such concerns are most likely to come to the fore where the patient, with support, reaches a decision with which a healthcare professional does not agree. The ADMA makes provision for a complaint to be made to the DDSS about either a DMA or a CDM (with a more extensive list of grounds for complaint in respect of a CDM).[132] Clearly, the mere fact of disagreement does not justify a complaint; however, if there are factors which indicate that the patient is being unduly influenced by his or her supporter and would suffer harm as a result, the duty of care which a healthcare professional owes to his or her patient requires steps to be taken, whether in the form of a complaint to the DDSS or a reference to court.

[126] ADMA, s. 21(f).
[127] ADMA, s. 17(1) and s. 19(1)(e).
[128] ADMA, s. 19(1).
[129] Documents which require a signature must be signed by both the appointer and the CDM: ADMA, s. 23(3).
[130] ADMA, s. 19(5).
[131] See R. Gilbar, 'Family Involvement, Independence and Patient Autonomy in Practice' (2011) 19(2) *Med L Rev* 192.
[132] ADMA, s. 15(1) (complaints in respect of DMAs) and s. 30(1) (complaints in respect of CDMs).

Substitute Decision-Making

The ADMA operates on the basis that for some people, there may be a point where notwithstanding all the mechanisms to enhance and support decision-making capacity, a person may be found to lack capacity. In such circumstances, the ADMA provides for two general forms of substitute decision-making (i.e. the appointment of someone to make decisions for the person in accordance with the ADMA principles) and one form specific to the healthcare context (discussed in the next section). The two general forms are first, decisions made by a court-appointed decision-making representative (DMR)[133] and secondly, decisions made by an attorney appointed by the person while s/he had capacity.[134] Both a DMR and an attorney may have authority (albeit limited in some respects) in respect of healthcare decision-making for the person lacking capacity. In addition, the Court may to make an order making a decision for a person lacking capacity where it is satisfied that the matter is urgent or that it is otherwise expedient for it to do so.[135]

The scope of a DMR's authority depends on the terms of his/her court appointment.[136] Where the DMR is given authority to make personal welfare decisions (which includes healthcare decisions[137]), the Court must have regard to the terms of any advance healthcare directive and ensure that the terms of the order are not inconsistent with this.[138] Similarly, the Court must have regard to the terms of any enduring power of attorney.[139] Where the DMR makes decisions for the relevant person, s/he acts as agent for the relevant person in this regard.[140] In making such decisions, s/he must, insofar as possible, ascertain the will and preferences of the relevant person and assist him or her in communicating these.[141] From a healthcare perspective, there are some important restrictions on the decisions which a DMR may make. First, a DMR may not refuse consent to the carrying out or continuation of life-sustaining treatment or give consent to the withdrawal of such treatment.[142] Secondly, the DMR may not do an act intended to restrain the relevant person or authorise another person to do this unless there are exceptional emergency circumstances, the DMR reasonably believes the relevant person lacks capacity and the act of restraint is

[133] A DMR is appointed by the Court following a determination that the person lacks capacity: ADMA, s. 38(2)(b). More than one DMR may be appointed and if this happens, the order must clarify how the DMRs are to operate: ADMA, s. 38(10). In making an appointment, the Court is required to have regard to the known will and preferences of the relevant person; the desirability of preserving existing relationships within the family of the relevant person; the relationship (if any) between the relevant person and the proposed DMR and their compatibility; whether the proposed DMR will be able to perform the functions assigned; and, any conflict of interest: ADMA, s. 38(5).

[134] ADMA, s. 59(1).

[135] ADMA, s. 38(2)(a).

[136] ADMA, s. 38(2)(b).

[137] ADMA, s. 2(1).

[138] ADMA, s. 38(3).

[139] ADMA, s. 38(4).

[140] ADMA, s. 41(2).

[141] ADMA, s. 41(1).

[142] ADMA, s. 44(4).This limit is subject to the terms of any advance healthcare directive made by the relevant person and to the relevant powers exercised by a designated healthcare representative appointed under such a directive.

proportionate to the likelihood of harm.[143] Restraint, in this context, is defined as using or indicating an intention to use force to secure the doing of an act which the relevant person resists; intentionally restricting the relevant person's freedom of voluntary movement; administering medication with the intention of controlling or modifying the relevant person's behaviour or ensuring that s/he is compliant or not capable of resistance.[144]

Although it has been possible to appoint an attorney to make decisions post-incapacity since the enactment of the Powers of Attorney Act 1996, this possibility did not extend to healthcare decision-making. This is changed by the ADMA. A person with capacity[145] ('the donor') may appoint an attorney with either general authority to act on the donor's behalf in relation to property and affairs or with authority to do specified things on the donor's behalf in relation to personal welfare (which can include healthcare decision-making) or property and affairs or both.[146] However, as with DMRs, attorneys are restricted in the personal welfare/healthcare decisions which they may make. Like DMRs, attorneys are restricted in the use or authorisation of restraint.[147] The donor is also precluded from included in an enduring power of attorney a decision relating to refusal of life-sustaining treatment or a decision which is the subject of an advance healthcare directive.[148] This means that that the only way a person can provide an advance authorisation to someone to refuse life-sustaining treatment if they subsequently lack capacity is through the use of the advance decision-making mechanisms discussed in the next section.

Advance Healthcare Decision-Making

Legal frameworks for advance decision-making have been common in the United States since the early 1990s; in Australia and New Zealand since the late 1990s and in Europe, since the 2000s. Although the Irish courts had, in principle, recognised the enforceability of advance healthcare decisions prior to the ADMA,[149] the introduction of a formal (and carefully calibrated[150]) mechanism for such decision-making is a significant contribution of the ADMA.

The ADMA allows a person, over the age of 18 years, who has capacity (which may be achieved using the ADMA support mechanisms), to make an 'advance healthcare directive' (AHD).[151] The AHD must be in writing[152] and contain designated details.[153] It must also be

[143] ADMA, s. 44(5)
[144] ADMA, s. 44(6).
[145] Note the appointment must include confirmation by a registered medical practitioner and by a healthcare professional of a class to be specified that the donor has capacity to understand the implications of creating the power of attorney at the time of its execution: ADMA, s. 60(1).
[146] ADMA, s. 59(1).
[147] ADMA, s. 62(1).
[148] ADMA, s. 62(5).
[149] See *JM* v. *St Vincent's Hospital* [2003] 1 IR 321.
[150] For an argument that the Irish model is superior to the much blunter model adopted in the MCA, see M. Donnelly, 'Developing a Legal Framework for Advance Healthcare Planning: Comparing England & Wales and Ireland' (2017) *European Journal of Health Law* (forthcoming).
[151] ADMA s. 84(1).
[152] ADMA s. 84(4).
[153] ADMA s. 84(5). These include the name, date of birth and contact details of the directive-maker and of the DHR (if any).

signed by the directive-maker[154] and the designated healthcare representative (DHR), if one is appointed.[155] It is not necessary that the person making the AHD includes a confirmation of capacity nor that s/he consult with a healthcare professional about the choices made. The AHD may relate to either the refusal of treatment (including life-sustaining treatment) or a request for treatment, although the enforceability of the AHD differs depending on the nature of the instruction.

Advance Refusal of Treatment

A refusal of treatment must be complied with provided that the relevant conditions are met (unless the refusal falls within one of three designated exceptions).[156] The relevant conditions are first, that the AHD is valid and secondly, that it is applicable. An advance directive is not valid if the directive-maker did not make the directive voluntarily; or if while s/he had capacity, s/he has done something clearly inconsistent with the relevant decision outlined in the directive.[157] An AHD is not applicable if, at the time in question, the directive-maker still has capacity to give or refuse consent to the treatment in question; the treatment in question is not materially the same as the specific treatment set out in the directive; or, at the time in question, the circumstances set out in the directive are absent, or not materially the same.[158] These conditions are notably more limited in scope than those in other jurisdictions, including the MCA. They should result in Irish AHDs being more robust and reliable (from a patient's perspective) than has been the case under the MCA.[159]

There are three exceptions to the requirement that an advance refusal must be respected. First, the AHD may not refuse the administration of 'basic care'.[160] This is defined as as including (but not limited to) 'warmth, shelter, oral nutrition, oral hydration and hygiene measures'[161] but, crucially, does not include artificial nutrition and hydration (ANH).[162] Secondly, the AHD does not have to be complied with in respect of treatment for a mental disorder (only[163]) where the directive maker has been made subject to the MHA.[164] This

[154] ADMA s. 84(5)(b). Someone may sign on behalf of the directive-maker but only if the directive-maker is unable to sign and the signature is completed in the presence of the directive-maker and at his or her direction.

[155] The directive-maker and the DHR (if appointed) must sign in each other's presence and in the presence of two witnesses: ADMA s. 84(6). Each witness must be over the age of 18 years and at least one witness must not be an 'immediate family member' of the directive-maker

[156] ADMA s. 84(2). Note that the requirement to comply with the refusal extends to refusal of life-sustaining treatment; however, that the AHD will not be applicable to such treatment unless it includes an express statement that it is to apply to the treatment in question even if the directive-maker's life is at risk: ADMA, s. 85(3).

[157] ADMA s. 85(1).

[158] ADMA s. 85(2).

[159] The MCA model has not been especially successful: data cited to the House of Lords Select Committee review suggested a take-up rate of only 3 per cent of the public as well as confusion among healthare professionals about the role and status of advance decisions: see House of Lords Select Committee, *Mental Capacity Act 2005: Post Legislative Scrutiny* (London: The Stationary Office, 2014), para. 193.

[160] ADMA s. 85(4)(a).

[161] ADMA s. 85(4)(b).

[162] ADMA s. 85(4)(b). The differential treatment of oral and artificial nutrition and hydration reflects the decision in *Re a Ward of Court* [1996] 2 IR 79 and the Medical Council's ethical guidance on the matter: see Guide above n. 2, para. 45.2.

[163] ADMA, s.85(7)(b) expressly states that the directive must be complied with in respect of treatment for a physical illness not connected with the amelioration of the mental disorder.

runs counter to the increased recognition that the provision of mechanisms for advance care planning around mental health is important both as a protection for patient rights and as part of an effective recovery process.[165] Such mechanisms are generally provided within the context of mental health, rather than mental capacity, laws, not least because of the need to ensure some degree of consistency between the legal treatment of advance and contemporaneous decisions. As argued above, this matter needs to be reviewed and reformed in the context of a wider review of the interaction between the ADMA and the MHA.[166] The third exception derives from the constitutional protection afforded to the 'right to life of the unborn' under Art. 40.3.3 and applies where the decision-maker is pregnant. Where the woman has not specifically stated whether she intended a refusal of treatment to apply if she were pregnant and the healthcare professional involved in her care considers that the refusal of treatment would have a deleterious effect on the unborn, the ADMA establishes a presumption that the treatment should be provided or not withdrawn.[167] Rebuttal of this presumption would almost inevitably require court involvement. Where the AHD specifically states that the refusal is to apply in cases of pregnancy, and the healthcare professional involved in the woman's care considers that the refusal of treatment would have a deleterious effect on the unborn, the matter must be referred to the High Court to determine if the refusal should be upheld.[168] In determining the application, the Court must consider the potential impact of the refusal on the unborn; the invasiveness and duration of the treatment and risk of harm to the directive-maker; and, any other matters the Court considers appropriate.[169] Given the elevated status of foetal rights arising from Art. 40.3.3,[170] it is difficult to envisage many circumstances in which the refusal would be upheld under the current constitutional framework.

Requests for Treatment

Requests for treatment are not legally binding under the ADMA. Rather, they must be 'taken into consideration' during any subsequent decision-making process 'if that specific treatment is relevant to the medical condition for which the directive-maker may require treatment'.[171] If the request is not complied with, the healthcare professional concerned must record the reasons for not complying with the request in the directive-maker's notes and give a copy of these reasons to the person's DHR (if such an appointment has been made).[172] The ADMA approach recognises that there is an ethical difference between refusal of treatment and requests for treatment[173] and avoids intervention in clinical

---

[164] ADMA, s.85(7)(a).

[165] See P. Weller, *New Law and Ethics in Mental Health Advance Directives: The Convention on the Rights of Persons with Disabilities and the Right to Choose* (Hove: Routledge, 2013); P. Weller, 'Psychiatric Advance Directives and Human Rights' (2010) 17 *Psychiatry, Psychology and Law* 218; F. Morrissey, 'Advance Directives in Mental Health Care: Hearing the Voice of the Mentally Ill' (2010) 16(1) *Medico-Legal Journal of Ireland* 21.

[166] See text to n. 66 above.

[167] ADMA, s. 6(a).

[168] ADMA, s. 6(b).

[169] ADMA, s. 6(c).

[170] In addition the constitutional protection of the 'right to life of the unborn', the decision in *PP v Health Service Executive* [2014] IEHC 622 lends support to a hitherto unrecognised concept of foetal best interests.

[171] ADMA s. 84(3).

[172] ADMA s. 84(3)(b). The reasons must be provided as soon as practicable and no later than 7 working days after they have been recorded.

[173] See K. Manson and G. Laurie, 'Personal Autonomy and the Right to Treatment', *Edinburgh Law Review* 9(1) (2004) 123.

judgement regarding the appropriate delivery of care. However, it affords patients the opportunity to record their views formally and by requiring healthcare professionals to take account of these, the ADMA offers patients some degree of control over post-incapacity healthcare decisions.[174]

Designated Healthcare Representative

One of the most useful elements of the ADMA framework is the possibility of designating a person in the AHD to act as a DHR.[175] The DHR has the power to ensure that the terms of the advance directive are complied with.[176] The AHD may also confer on the DHR the power to advise and interpret the directive-maker's will and preferences about treatment, including life-sustaining treatment, based on the advance directive.[177] This potential to empower a trusted person to deal with issues which may subsequently arise offers a richer and more integrated approach to advance healthcare planning than a simple written instruction.

Conclusion

There can be no doubt that the legal change brought about by the ADMA is overdue. The current legal framework fails to meet any international/European human rights standards. It is also wholly inadequate in protecting the interests of people with impaired capacity and in empowering them to maximize their potential. The ADMA is not perfect but it offers the potential for a vastly improved healthcare decision-making process for people with capacity impairments. However, the extent to which the ADMA will actually deliver substantive improvements will depend on many factors, including effective implementation and adequate resourcing. It will also require a significant culture shift in the way services are delivered to people with impaired capacity. This shift will undoubtedly pose challenges in practice. Yet without it, there is a risk of 'legalism',[178] with changes in practice driven by technical compliance with the ADMA rather than by a commitment to providing the most effective protection for the rights and interests of people with impaired capacity. Healthcare decisions can be among the most important decisions which any of us make in our lives. This is why ensuring that people with impaired capacity are facilitated, to greatest extent possible, to make such decisions in line with their values and preferences is a goal worth pursuing, notwithstanding the challenges ahead.

[174] Compare the more blunt approach under the MCA which does not permit any advance requests for treatment.

[175] ADMA s. 87(1)(a). This is subject to the agreement in writing of the DHR who must sign the directive to confirm his or her willingness to act in accordance with the known will and preference of the directive maker as determined by reference to the directive: ADMA, s. 87(1)(b).

[176] ADMA s. 88(1)(a).

[177] ADMA s. 88(1)(b). There are also consultation requirements with DHR in circumstances of ambiguity: ADMA s. 85(5).

[178] The term 'legalism' is most closely associated with Judith Shklar, *Legalism* (Cambridge, Mass: Harvard University Press, 1964) who defines it (*ibid*, 1) as 'the ethical attitude that holds moral conduct to be a matter of rule following and moral relationships to consist of duties and rights determined by rules'.