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Reforming Best Interests: the road towards supported decision making

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Abstract

Decisions under the Mental Capacity Act (MCA) may be made in a person's best interest. This concept is objective, unclear and places discretion in the hands of the decision maker. Currently a person's wishes, feelings, beliefs and values are not accorded primacy status among the checklist of factors to be considered under s.4 MCA. In 2017, the Law Commission in their report on Mental Capacity and Deprivation of Liberty proposed amending the best interest test under s.4 of the MCA to require the decision maker to ascertain wishes and feelings and to also elevate the status of the ascertained wishes and feelings among the other factors under s.4. These proposals contained in a Draft Bill would be of general application under the Act. This paper argues that the trajectory begun by Lady Hale in the Supreme Court in *Aintree* in asserting the individual at the heart of her destiny and the Law Commission proposals are to be welcomed but do not go far enough to be aligned with the principle of supported decision making set out in international frameworks, such as the Convention on the Rights of Persons with Disabilities (CRPD).

Keywords

Key words: Best interests; Capacity; CRPD; MCA; Person's views

Introduction

The Mental Capacity Act 2005 (MCA) came into force almost a decade ago and was hailed as a progressive and ambitious regulatory framework to protect the interests of the intellectually disabled. The core of the Act promotes a decision making model whereby decisions as to medical treatment can be taken by others in the individual's best interests. Determining and defining this test is the key to safeguarding the rights of the incapacitated patients and the intellectually disabled more generally. The problem with the current best interests test is that there is uncertainty as to how much weight decision makers, including courts, should give to an individual's views. The legislative silence in respect of the weighting of this factor, as against the other circumstances, has inevitably led to interpretation and inconsistencies in Court of Protection case law. A number of recent reports

have thrown light on the uncertainty in the application of the best interests test in general as well as the lack of primacy accorded to the individual's wishes and feelings (House of Lords Select Committee on the Mental Capacity Act 2005 2014, Law Commission 2015, para. 12.42).

In a desire to bring greater clarity to the law, in 2013 the Supreme Court decision in *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67 rejected a test predicated on an objective assessment of a reasonable patient. Lady Hale confirmed the primacy to be accorded to the individual's view and wishes when applying the best interests test. Where a patient's wishes could be ascertained, Lady Hale opined these needed to be taken into account in the interests of promoting autonomous choice and free agency.

In 2017, the Law Commission was tasked with examining the legal framework regarding deprivations of liberty involving people who lack capacity. Part of its assessment included wider reform proposals of the MCA regardless of whether a person's liberty was at risk. Building on the momentum of *Aintree*, their laudable intention was clear at the outset: to place the patient or the person for whom decisions are made at the centre of the process (Law Commission 2017, para. 14.1).

The Law Commission have proposed that a more coherent scheme is necessary to clarify the processes of finding out a person's wishes and feelings and in addition to 'bolster' the weight to be given to these wishes (Law Commission 2017, para. 14.16). Their final Report (Law Commission 2017) as well as their earlier interim proposal (Law Commission 2015) while falling short of recommending a full supported decision making modelled on the United Nations Convention on the Rights of Persons with Disabilities (CRPD) provisions do recognise the importance of this international framework. This paper will explore these recommendations against the background of the CRPD directives, and will argue that the trajectory begun by Lady Hale in *Aintree* and the Law Commission proposals, contained in a Draft Bill, are welcomed but do not on their own go far enough in embracing a genuine model of patient participation envisaged by the CRPD. Despite the broad scope of the Law Commission's report, this paper will focus on the best interest reform proposals that will have general application under the MCA.

Before turning to the substantive law, it is worth noting the role of Article 8 ECHR on the protection of people who lack capacity and how it has also been a driver for reform. Article 8 protects the right to 'respect' for 'private and family life'. The European Court of

Human Rights (ECtHR) stated in *Pretty v United Kingdom* [2002] 2 FCR 91 (para. 61) this encompasses personal autonomy, dignity and freedom. In a series of decisions, the European Court of Human Rights has made clear that a stricter scrutiny is required under Article 8, the greater the interference with the autonomous rights of an intellectually disabled person (Law Commission, 2017, para. 1.10; *Shtukurov v Russia* (2012) 54 EHRR 27, para. H8). Set in this context, any reform of the best interests decision making should take into account the principles of proportionality and that the measure ought to be the least restrictive option. The paper will begin with consideration of the MCA and CRPD framework before turning attention to case law on the best interests test and the Law Commission proposals.

MCA Framework

The main principle of the Act, augmented by the Code of Practice, was that it would support and enhance the ability of those who lack capacity to participate in decisions. Capacity is determined on a decision specific basis under a ‘diagnostic test’ and ‘functional test’ and there must be a connection between these two stages (Law Commission 2017, para. 3.4-6). The diagnostic test is set out in s2(1) ‘as an impairment of, or a disturbance in the functioning of, the mind or brain’.

The ‘functional test’ is determined under s3(1) which provides that a person is ‘unable to make a decision’ if he or she is unable to:

- (1) understand the information relevant to the decision;
- (2) retain that information;
- (3) use or weigh that information as part of the process of making the decision; or
- (4) communicate the decision (whether by talking, using sign language or any other means).

Once it has been decided that an individual is unable to make a particular decision at a certain time following a capacity assessment, a decision can be made for them in their best interests (MCA s1(5), s(4)). Best interests is not defined in the Act but section 4 contains a checklist of factors which are not a definitive list. The decision maker must ensure that all the relevant circumstances of the individual case are considered. Under MCA s4(6) a decision-maker must consider: the person’s past and present wishes and feelings (including written statements made when he had capacity), the person’s beliefs and values, and any other factors that the person would be likely to consider if they were able; and consult with others, for example, family and carers.

CRPD and supported decision making

The Convention on the Rights of Persons with Disabilities (CPRD) was ratified by the UK in 2009 and represented a paradigm shift in the protection of the rights of the intellectually disabled. Its aim is the protection of the rights, and to promote the inherent dignity, of people who have long-term physical, mental, intellectual, or sensory impairments. While the CRPD is not incorporated into domestic law, it is recognised by the ECtHR and of course under the terms of the Human Rights Act 1998 domestic courts are required to take it into account when reaching their decisions (2015, para. 3.17).

Article 1 of the CRPD states that: ‘Persons with disabilities include 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.’ This was recently confirmed by a resolution adopted by the Human Rights Council which urged States to actively integrate a human rights perspective into law to ensure full participation on an equal basis (*Human Rights Council Resolution adopted by the Human Rights Council on 28 September 2017 36/13. Mental health and human rights 2017*, para. 5).

Richardson argues cogently that the CPRD ‘represents a radical, paradigm shift in thinking about disability’. One, she argues, moves from medical to social norms of decision making (Richardson 2012, p. 351). The traditional medical model of disability wherein the individual is seen as someone who needs to be fixed in some way has given way to an emerging one that is driven by human rights norms. In the medical model the focus is on an individual’s diagnosis and dysfunction, which needs to be corrected or managed by medical intervention. The Human Rights framework postulated by the CRPD is predicated on viewing disability from a social model lens; one that is concerned with how the individual is involved with their environment or as Lucy Series describes how the environment adapts to disability (Series 2015, p. 80). According to the social model, disability is an expression of the individual’s relationship with their environment (Dinerstein 2011, p. 9). It is society’s failure to accommodate the needs of people with disabilities rather than the inherent condition which needs attention (Bach and Kerzner 2010, p. 14). The societal imposition of disadvantage is the issue rather than the impairment itself (Clough 2017, p. 475). The CRPD’s aim to pursue a social model is expressed in the preamble wherein it recognises how ‘attitudinal and environmental barriers’ hinders effective participation in society (section (e) to preamble). Viewed through this lens, the historical legacy of assuming the disabled need to be protected

from themselves and others, gives way to a shift of emphasis whereby individuals have full legal capacity and a legal framework in which to enjoy and enforce their rights.

Article 12 Section 2 of the CRPD says ‘States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.’ Underpinning this article is the idea that states should provide everyone with the necessary support so that they may exercise legal capacity (Gooding 2015, p. 46). The principle enshrined in the CRPD of ‘universal’ legal capacity in accordance with Article 12 are driven by the goal of enhancing individual autonomy, justice as well as providing a mechanism for a more rational and structured form of decision making (Gooding 2015, p. 47).

The UN Committee on the Rights of Persons with Disabilities (“Committee”) which monitors the Convention implementation, in their 2014 General Comment suggested that this article had generally not been understood and in simple terms its effect would involve that a human rights-based model of disability involve the transition from substitute decision making to a supported one (Committee on the Rights of Persons with Disabilities 2014, para. 3).

The UN General Comment states:

The present general comment reflects an interpretation of article 12 which is premised on the general principles of the Convention, as outlined in article 3, namely, respect for the inherent dignity, individual autonomy — including the freedom to make one’s own choices —, and independence of persons; non-discrimination; full and effective participation and inclusion in society; respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; equality of opportunity; accessibility. (Committee on the Rights of Persons with Disabilities 2014, para. 4)

This new framework would prioritise the individual’s will and preferences as well as their autonomy (Committee on the Rights of Persons with Disabilities 2014, para. 29), and is underpinned by the preamble statement that people with disabilities have the freedom to make their own choices (Convention on the rights of persons with disabilities 2006, preamble para. (n)).

They also pointed out that notions of legal and mental capacity can be distinguished and that a mental impairment should not used to suspend legal capacity (Freeman *et al.* 2015, p. 845, Series 2015, p. 80).

The Committee declares that: ‘Legal capacity and mental capacity are distinct concepts. Legal capacity is the ability to hold rights and duties (legal standing) and to exercise those rights and duties (legal agency)’ (Committee on the Rights of Persons with Disabilities 2014, para. 13). Legal agency means making treatment choices. Therefore the upshot of article 12 is that persons with mental disabilities have the right to make their own decisions (Scholten and Gather 2017, p. 3). The Committee further states: ‘...all persons, regardless of disability or decision-making skills, inherently possess legal capacity’ (Committee on the Rights of Persons with Disabilities 2014, para. 28), thereby ensuring that the exercise of legal capacity is not an outcome of determining mental capacity and these two concepts should not be conflated (Scholten and Gather 2017, p. 3).

The crux of this interpretation is that people with mental disabilities have full legal capacity and therefore the right to make decisions, including unwise ones (Scholten and Gather 2017, p. 3). This leads to the conclusion that the CRPD requires a move from substituted decision-making structures towards a supported decision-making approach, in which treatment decisions are made by the individual with support from others (Craigie 2015, p. 399). The shift is encapsulated in article 12(3) which requires States to ‘take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.’ Under this interpretation the best interest’s model and diagnostic test for incapacity under the MCA would not meet the CRPD standard (see Cave 2015, p. 12 for further discussion, Craigie 2015, p. 399).

Recently, in his Annual Report on mental health and human rights, the UN High Commissioner for Human Rights confirmed the human rights-based approach to disability in the context of mental health (*Annual report of the United Nations High Commissioner for Human Rights: Mental Health and Human Rights* 2017, para. 22). Significantly the robust interpretation of article 12 in respect of legal agency and the application of this principle ‘in the exercise of free and informed consent’ was made to ensure that individuals make their own decisions. The Commissioner made clear that States should ‘repeal legal frameworks allowing substitute decision makers to provide consent on behalf of persons with disabilities and introduce supported decision-making, ensuring its availability for those who request it’ (para. 26). To facilitate this process, providing adequate information and communication to people with disabilities would be paramount (para. 27).

Article 12 prohibits using the best interest test in respect of adults with disabilities (Committee on the Rights of Persons with Disabilities 2014, para. 29(b)). Efforts should be made to find out the person's will and preferences and where this is not possible then the principle of 'the best interpretation of will and preferences of the individual' must be upheld and carried out in good faith could be used rather than applying the best interests test (Committee on the Rights of Persons with Disabilities 2014, para. 21). This was described by the UN committee as the 'will and preferences paradigm' and would necessitate a move away from best interests decision making (Committee on the Rights of Persons with Disabilities 2014, para. 21). Opining on this shift, Bach and Kerzner, in a report for the Law Commission of Ontario state, 'the question can no longer be: Does a person have mental capacity to exercise their legal capacity? . . . Rather, the question is: What types of supports are required for the person to exercise his or her legal capacity?' (p. 58)

Supported decision-making is based on the concept of providing support to a person to enable them to make their own decisions wherever possible. It is premised upon the individual exercising capacity to make decisions where they are supported to do so (Law Commission 2017, para. 14.43). The rationale here is the idea that people are autonomous agents who navigate their own choices, with support if necessary (Devi *et al.* 2011, p. 253). Support could then assist the individual with understanding information and communicating their decision, but ultimately the decision will be based on the individual's preferences (Devi *et al.* 2011, p. 255). Supported decision making will facilitate their personal development and participation (Devi *et al.* 2011, p. 255). Advantages of this model are that supported decision making upholds the individual's right to full expression and choice. Bach and Kerzner put it this way: 'The ability to make one's own decisions based on personal values and in the context of meaningful choices is a defining feature of what it means to be a person and a full citizen' (p. 6). Pragmatic advantages include facilitating efficient and ensuring more appropriate decisions are made (Davidson *et al.* 2015, p. 62).

However Richardson counsels caution that to avoid it resulting in denigrating the intellectually disabled to the wishes of their supporters, and for it to work properly, the issue of conflicting preferences and the issue of resources need to be examined carefully (Richardson 2012, p. 352). Davidson *et al.* point out that as well as time and resources, changes of attitudes by health care professionals, need to be overcome before effective implementation (Davidson *et al.* 2015, p. 64). Looking ahead at future reform, it is notable that the UN General Comment is not without critique. Freeman *et al.* argue that a universal

presumption of legal capacity co-existing with supported decision making must have exceptions or it may in fact damage an individual's health care. He argues that if people with mental disability are left untreated in the community, this may in fact lead to increased stigma and discrimination against them thereby undermining rights of liberty, justice and health. They argue that a model must have some exceptions in order to be workable in practice for the protection of the individual and others (Freeman *et al.* 2015, p. 845) Researchers have noted other concerns for instance there are some who cannot communicate their wishes. Concerns have also been voiced that it will in fact damage the autonomy and safety of the individual, as well as the problem of eliciting their 'will and preferences' and so expose them to the dangers of influence by supporters (Scholten and Gather 2017, p. 4). The interests between patient and supporter may not be clear and it will be difficult to monitor any undue influence. They further point to the risk of abuse as the responsibility for the decision (however unwise) will fall on the patient, thereby leaving the supporter difficult to hold accountable (Scholten and Gather 2017, p. 4). The Committee notes: 'new, non-discriminatory indicators of support needs are required in the provision of support to exercise legal capacity' (Committee on the Rights of Persons with Disabilities 2014, para. 29(i)). This passage is vague, open ended and it maybe that the present systems of competence criteria and delineating capacity is fair, and more cost efficient (Scholten and Gather 2017, p. 5).

Currently the best interests model under the MCA does not provide sufficient recognition of this new framework. To give effect to the international framework, a supported decision making model which protects the autonomy of and gives effect to human rights of the individual should be implemented (Law Commission 2015, para. 12.40). The CRPD article 12 (the right of disabled people to enjoy legal capacity on an equal basis with others) requires national laws to provide a framework of supporting individuals to facilitate respect of their will and preferences. This more subjective approach is at odds with the objectification of best interests.

The logical application of this new paradigm therefore is to bring the individual centre stage in their world and to assist in the means necessary to navigate through their lives (Richardson 2012, p. 350). In a practical context this would ensure they had help in arriving at the best decision for their medical treatment. In the legal sphere this would ensure that mechanisms are in place to provide support to enable individuals to assert their full legal capacity in the way that the non-intellectually disabled person would (Series 2015, p. 80). It is inevitable therefore that there might be a collision course between the current best interests

test enshrined in the MCA, which at its heart, is decision making on behalf of another with asserting the primacy of the individual in asserting or giving full effect to their wishes.

Substituted decision making essentially allows another (surrogate) to make decisions on behalf of a person on the premise of what they would have wanted (Donnelly 2009, p. 18) There is some uncertainty, perhaps as product of terminology, in whether the MCA reflects this model. For example, Donnelly argues that the MCA, although having a flavour of substituted decision making with its reference to past wishes, took a different approach by focusing on best interests (Donnelly 2009, p. 16). She argues that it represents a compromise between objective and subjective tests (Donnelly 2011, p. 313). Certainly this is the view favoured in some cases which will be discussed below. In their consultation paper, the Law Commission took the view that the MCA postulates a substituted decision making model (Law Commission 2015, para. 3.20). Regardless, it is clear that the current law is not clearly reflective of supported decision making approach. It is the case that subjective wishes of the person may be overlooked by decision makers in coming to an objective medical-legal assessment. There may also be a temptation for decision makers to stamp their views on the individual. Dresser suggests:

[T]hey sometimes construct a mythical, generalized competent person to inhabit the body that lies before them (...) We should seek amore reciprocal relationship with these patients. Rather than making them the mirror of our own fears about debilitation and the end of life, we should attempt to ascertain their point of view, their perspective, on what is to be decided. (Dresser 1993, pp. 612–613)

Supported decision making is recognised somewhat in the Act in s1(3) which states: ‘a person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.’ This provision is augmented by the Code of Practice which lists the type of support individuals may need to assist them with making a decision (*Mental Capacity Act 2005 Code of Practice 2007*, para. 2.7, 5.23). It is also recognised by the provision of rights to an independent advocate under the Care Act 2014. However, the support mechanisms envisaged in the MCA are not altogether clear and decision makers are arguably therefore left with uncertainty in its application. The House of Lord’s Select Committee, tasked with a post legislative scrutiny of the Act, found evidence pointing to participatory mechanisms being rarely used and not being followed through effectively. Many professionals viewed the Act simply as enabling decisions to be made for

others (House of Lords Select Committee on the Mental Capacity Act 2005 2014, para. 79). The participatory intention was either not implemented or professionals were not aware of it, with evidence adduced before the Committee of an atmosphere of protection and paternalism rather than genuine involvement of the individual (House of Lords Select Committee on the Mental Capacity Act 2005 2014, para. 79). The inadequacy of social resources, time and training were drawn to their attention by several organisations including the Law Society (House of Lords Select Committee on the Mental Capacity Act 2005 2014, para. 82). However, examples of good practice were gleaned from learning disability nurses in acute hospitals in making ‘small adjustments’ and parallels drawn with the requirements of making reasonable adjustments under the Disability Discrimination Act 2005. The point was made that requirements under s1(3) ought not in practice place undue burdens on time and resources to front line professionals (House of Lords Select Committee on the Mental Capacity Act 2005 2014, para. 82). Although it is clear that a more involved model of supported decision making would have some resource implications.

The Law Commission acknowledged the importance of supporting a person so that they were able to act on their legal capacity, although this, they opined, could not be an unqualified right (Law Commission 2017, para. 14.45). To encourage a transition from a paternalistic culture focused on safeguarding towards a more empowering model, the Law Commission, in their consultation paper, had suggested a formal legal process in which a person could appoint a supporter to assist with making decisions, thereby enabling them to exercise their legal capacity. The Supporter would be someone in a relationship of trust with the patient (Law Commission 2015, para. 12.27). This, they hoped, would overcome the criticism of the uncertainty of the supported decision making process for all involved in the process but they formed no definitive view on whether the supporter would be a professional or a non-professional family member nor did they propose a limit to the type of decision they could assist with (Law Commission 2015, para. 12.12;12.22). It is important to note that this proposal would not seek to replace the best interests decision-making, rather reinforce existing mechanism under the Act (Law Commission 2015, para. 12.13). Another approach considered was the co-decision maker model where a co-decision maker could make decisions. Interestingly, the Law Commission rejected this approach reasoning it would be a form of substituted decision making in essence giving away power to override the individual’s autonomous choices (Law Commission 2015, para. 12.25).

Opponents of reform argued that a supporter could potentially cause confusion with the resulting multiplication and diffusion of roles. How, for example, would they be distinguished from an advocate or deputy currently maintained by the Act? There was also a fear of a conflict of interest if the person was associated with the care or treatment (Law Commission 2017, para. 14.49-14.50). In their final report, the Law Commission was persuaded by these opposing arguments, opining that a clear demarcation of role would be necessary for the scheme to work. Faced with a lack of evidence, in the event, they shied from making any legal proposals and instead incorporated into the draft Bill (clause 12) a power to make regulations enabling the Government, after further consultation, to establish a scheme in respect of personal welfare and/or property matters as well as to investigate lessons on ‘assisted decision-making’ and ‘co-decision-making’ incorporated into the recent Assisted Decision-Making (Capacity) Act 2015 in Ireland (Law Commission 2017, para. 15.53-54).

As matters currently stand the Law Commission considers that departing from the best interests test politically unfeasible and that such a radical move would be matter for the Government (Law Commission 2015, para. 12.44).

Further reforms on the shape of the model therefore need to take account of these powerful arguments. It is likely that as primary decision maker, a patient whose values, opinions and concerns have been attended to is more likely to feel included in their treatment and respond better. Herring notes that values such as a right to dignity, which is broader than autonomy, is upheld when guiding action through what the person wants and is part of what it is to be a human being (Herring 2009, p. 14). Dignity and individual worth are likely to be enhanced by this paradigm shift and therefore in themselves are worth striving for. Since a full supported decision making model has not been adopted by the Law Commission, the section below turns to case law under the MCA to properly locate the Law Commission proposals on reforming the best interests test.

Case Law

Before discussing the significant Supreme Court case of *Aintree*, it is worth exploring judicial interpretation of the weight to be attached to a person’s views in deciding treatment. Before the MCA, best interests was judged according to the Bolam test which simply required a treatment proposal be supported by a reasonable body of medical opinion. However, in *Re A (Medical Treatment: Male Sterilisation)* [2000] 1 FCR 193 the Court of Appeal moved towards a wider test stating the Bolam standard used in negligence cases was

not determinative of the best interests test but rather the start. In doing so the court effectively separated the best interests standard from Bolam. Butler-Sloss P in *Re A* suggested a broader role: 'best interests encompasses medical, emotional and all other welfare issues' (p. 200). Thorpe LJ spoke about a balance sheet approach whereby the judge would list the benefits and disadvantages of the proposals and then allow the application to proceed if the gains exceeded the losses (p. 206).

Following the enactment of the MCA, Lewinson J in *Re P* [2009] EWHC 163 (Ch) opined that parliament's intention was that it was for the court to determine best interests taking into account all the evidence. It was not about enquiring what the individual would have decided if they were able (para. 26). In support he cited the explanatory notes to the Mental Capacity Bill which stated: 'Best interests is not a test of "substituted judgement" (what the person would have wanted) but rather it requires a determination to be made by applying an objective test as to what would be in the person's best interests.' (para. 37)

The focus he noted was on the individual's wishes and feelings held currently by the person lacking capacity. He described the test as a 'structured decision making process' and 'these include encouraging P to participate in the decision' (para. 38). In respect of the individual's views he stressed:

That is not to say that P's expressed wishes should be lightly overridden. On the contrary, the Act expressly requires them to be considered; and for particular consideration to be given to wishes expressed by P when he had capacity. (para. 40)

In an earlier case, *Re S and Another (Protected Persons)* [2008] EWHC 816 (Fam) (para. 55), Judge Marshall QC suggested that the individual's views and wishes 'carry great weight'. Further in weighing all the relevant circumstances, the judge stated: 'having his views and wishes taken into account and respected is a very significant aspect of P's best interests' (para. 56). Having asserted this Judge Marshall then introduced some qualifications. Where the individual's view and wishes were rational, practical and responsible, she stated, 'then that situation carries great weight, and effectively gives rise to a presumption in favour of implementing those wishes unless there is some potential sufficiently detrimental effect for P of doing so which outweighs this' (para. 57).

It is interesting that, although not unqualified, the court was prepared to elevate a person's views into a presumption that ought to be followed. The idea of a presumption may gain traction should the best interests test be reformed.

However, while endorsing many of HH Judge Marshall QC's sentiments, Lewinson J in *Re P* felt that she had 'overstated' the weight to be given to the individual's views as they were only part of the balance. Referring to what the individual might have wanted he thought was tantamount to 'substituted judgment' (para. 41). He cited in support the Code of Practice which explains at para 5.38:

In setting out the requirements for working out a person's 'best interests', section 4 of the Act puts the person who lacks capacity at the centre of the decision to be made. Even if they cannot make the decision, their wishes and feelings, beliefs and values should be taken fully into account - whether expressed in the past or now. But their wishes and feelings, beliefs and values will not necessarily be the deciding factor in working out their best interests. Any such assessment must consider past and current wishes and feelings, beliefs and values alongside all other factors, but the final decision must be based entirely on what is in the person's best interests. (para. 41)

A gap in the legislative scheme is that there is no guidance on the weight to be attributed to the factors (Law Commission 2017, para. 14.4). Indeed the lack of any priority in the weighting of the factors suggests a deliberate intention by Parliament to leave a residual degree of discretion and flexibility in the Act's application. This pragmatic approach has some advantages and indeed may permit one factor to become 'magnetic' to determine the case (*Re M* [2009] EWHC 2525 (Fam), para. 52). In *Re M* Mr Justice Munby (as he was then) made a number of observations. He suggested there was a lack of 'hierarchy' between the issues to be taken into account given that the overriding principle was that the courts assessment of the best interest was determinative.

As regards the weight to be attached to the individual's wishes and feelings, he endorsed the sentiments of Judge Marshall QC in *Re S* and then by Lewison J in *Re P* at para 41 and also added the following propositions: First, among them that P's wishes and feelings will always be a significant factor to which the court must pay close regard. He stated that in line with the test of incapacity the weight to be attached to the individual's wishes and feelings will be issue-specific. (*Re M*, para. 34). In considering the weight and importance to P's wishes, Courts would have regard to all the relevant circumstances, including, the degree

of P's incapacity, the strength and consistency of P's views; the impact on P of knowledge that her wishes and feelings are not being given effect to; the extent to which P's wishes and feelings are, or are not, rational and pragmatically capable of implementation; and the extent to which P's wishes and feelings, if given effect to, can properly be accommodated within the court's overall assessment of what is in her best interests. (para. 35)

The final point does place a limitation on the weight to be attached to the individual's views as they would need to defer to the judicial assessment of their best interests. This may be seen as incompatible with the CRPD calls for supported decision making which seeks to place the individual at the heart of the process.

In *Aintree*, Lady Hale, in rejecting a test predicated on an objective assessment of a reasonable patient, confirmed the primacy to be accorded to the individual's view and wishes. She said:

The purpose of the best interests test is to consider matters from the patient's point of view. That is not to say that his wishes must prevail, any more than those of a fully capable patient must prevail. We cannot always have what we want. Nor will it always be possible to ascertain what an incapable patient's wishes are. Even if it is possible to determine what his views were in the past, they might well have changed in the light of the stresses and strains of his current predicament. ... But insofar as it is possible to ascertain the patient's wishes and feelings, his beliefs and values or the things which were important to him, it is those which *should be taken into account* [emphasis added] because they are a component in making the choice which is right for him as an individual human being. (para. 45)

Lady Hale noted that the Act gives limited guidance about best interests; every case is different:

The most that can be said, therefore, is that in considering the best interests of this particular patient at this particular time, decision makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude to the treatment is or would be likely to be; and they must consult others who are looking

after him or are interested in his welfare, in particular for their view of what his attitude would be. (para. 39)

It is of interest that she uses the words ‘should be taken into account’. Arguably these do not go far enough and that creating a presumption that the individual’s wishes and views are given effect, unless there was good reason not to, would support and enable full participation.

Recent Court of Protection case law continue the theme of the fact-specific nature of the exercise in determining what weight should be attached to a person’s wishes and feelings. In *X NHS Trust v B* [2015] EWCOP 60 at para. 11 Jackson J pointed out: ‘It would therefore be wrong in principle to apply any automatic discount to their point of view.’ Further adding:

I think, important to ensure that people with a disability are not - by the very fact of their disability - deprived of the range of reasonable outcomes that are available to others. For people with disabilities, the removal of such freedom of action as they have to control their own lives may be experienced as an even greater affront that it would be to others who are more fortunate. (para. 12)

In refusing to authorise the life saving amputation of a 73-year-old man’s severely infected leg against his wishes, he opined that Mr B’s right to freedom of religion protected under article 9 ECHR would be as relevant as any other person. Evidence was adduced that Mr B heard angelic voices advising him on whether to take his medication. His strongly held views, which could be described by some as ‘religious delusions’, were nonetheless given effect to in the same way a person who had legal capacity would have their wishes respected. Despite the fact that Mr B lacked capacity, it was held it would not be in his best interests to force the surgery upon him (para. 42).

Despite these enlightening judgments, it is evident however that there remains some residual uncertainty as to how much weight decision makers, including courts, should give to this provision. The legislative silence in respect of the weighting of this factor as against the other circumstances listed in MCA s4 has inevitably led, as we have seen, to interpretation and inconsistencies in Court of Protection case law.

The House of Lords Select Committee found there were problems in the Act’s implementation as well as in reaching its overarching principle of empowerment. Further they wrote ‘the prevailing cultures of paternalism (in health) and risk-aversion (in social care)

have prevented the Act from becoming widely known or embedded'. In addition, and perhaps of more concern, they pointed out how the rights of the intellectually disabled have failed to be fully upheld and the duties enshrined in the provisions not fully met (House of Lords Select Committee on the Mental Capacity Act 2005 2014, p. 6).

They opined that decision making was led by professionals without adequately consulting carers and family members about the individual's wishes (House of Lords Select Committee on the Mental Capacity Act 2005 2014, para. 107). The consulting provisions are found in s4(7) of the Act and arguably seek to augment the 'listening to others' ethos that the framers of the law set out to achieve. Whether the lack of regard to consulting is deliberate or simply a matter of lack of knowledge of the ethos of the Act is a moot point but one which the Committee considered ought to be rectified by means of a programme of raising awareness among end users as well as professionals (House of Lords Select Committee on the Mental Capacity Act 2005 2014, para. 109). In more strident language the Committee opined that a change of emphasis and priority was necessary away from paternalism to as they put it to 'enablement and empowerment' (House of Lords Select Committee on the Mental Capacity Act 2005 2014, para. 108). This empowerment theme was also emphasised in the final Law Commission Report (Law Commission 2017, para. 4.27).

The Law Commission accepted that best interests determinations accorded little weight or priority to patient's views, specifically in the context of their remit in examining arrangements to deprive people of their liberty, but also in all decision making under the MCA (Law Commission 2017, para. 1.26). Driven by a concern to emphasise an individual's wishes and feelings, the Law Commission's consultation paper had proposed provisionally that decision-makers begin with the assumption that the person's past and present wishes and feelings should be determinative of their best interests but this assumption could be overridden where there were good reasons (Law Commission 2015, para. 12.47).

In their final report the Law Commission acknowledged that most consultees agreed with this proposal. Evidence ranged from perceptions that professionals ignored patient wishes to reporting that, driven by medical and paternalistic views, there was a culture of selecting factors based on the preferred outcome of the decision (Law Commission 2017, para. 14.7). Perceptions about the Court of Protection's bias in this respect were also raised, in that they afforded a superficial recognition of wishes and feelings on the one hand, only to subsequently gloss over them (Law Commission 2017, para. 14.7). Opponents of reform,

however, argued that fully applying the provisions of the MCA was adequate and/or the primacy of patient's views could be signalled by a reformed Code of Practice rather than embark on statutory change (Law Commission 2017, para. 14.10). Evidence was heard that it was often difficult to gauge a person's views where they were 'unclear or fluctuated'. This practical problem was compounded by some members of the judiciary arguing that a change of wording would lead to semantic discussion of what constituted a 'good reason' to depart from the assumption (Law Commission, 2017, para. 14.9; *X NHS Trust v B*, para. 17).

Jackson J, for example, in *X NHS Trust v B*, while sympathetic to the desire for reform, did not agree it would promote certainty or that elevating one strand above the others would lead to better judicial determination of the facts. His view was that a 'proper' application of the Act would protect the rights of the individual (para. 17). Certainly there is force in these views in cases such as *Re C; Kings College Hospital NHS Foundation Trust v C* [2015] EWCOP 80 (discussed below) where judges have signalled that a more robust application of the current law alone may achieve the desired enhanced participative model. Followed logically, these arguments also sit comfortably with the House of Lords Select Committee's call for a programme of education, awareness and training in the ethos of the Act.

In the event, the Law Commission was persuaded by perceptions of the apparent vagueness of the legislative scheme which permitted any outcome, as long as the procedures had been followed. Additionally, the Law Commission recognised that international human rights frameworks warranted a change in the law. Specifically, the CRPD requirement that 'greater account to be taken of the wishes and feelings (or will and preferences) of the individual concerned' (Law Commission 2017, para. 14.11-14.12). They therefore concluded that a more coherent scheme would be necessary to clarify the processes of finding out a person's wishes and feelings and in addition to 'bolster' the weight to be given to these wishes (Law Commission 2017, para. 14.16).

Rebuttable Presumption

In respect of the precise weight to be accorded to the patient's wishes and feelings, various options were available to the Commission: these include making them a 'primary consideration' or a harder 'rebuttable presumption' that wishes and feelings should be followed (with departure only occurring if there were 'compelling reasons' or 'serious adverse consequences') (Law Commission 2017, para. 14.18). The logistical difficulties with elevating it to a rebuttable presumption, they opined, was that it may then tilt the weight into

a substantive requirement overriding the best interests test thus requiring the amendment of s1 MCA (Law Commission 2017, para. 1.41).

The provisional proposal in the consultation paper was one they described as an intermediate option: decision makers would begin with the assumption that the person's wishes and feelings should be determinative of their best interests decision (Law Commission 2015, para. 12.45). In their final report, in an effort to bring certainty in both ascertaining the wishes and feelings and according them more weight, they concluded that the current requirement to 'consider, so far as is reasonably ascertainable' the person's wishes and feelings in s4(6) was insufficient. They proposed that s4(6) of the Mental Capacity Act should be amended to require that the individual making the best interests determination must ascertain, so far as is reasonably practicable, the person's wishes and feelings, beliefs and values in relation to the matter. The process of finding out the wishes would be augmented by a new Code of Practice. Moreover, this emphasis would be accompanied by an additional measure in requiring decision makers to explain reasons for not following the ascertainable wishes (Draft Bill, cl 8(2) and (3)) (Law Commission 2017, para. 14.16). In particular, section 5 which permits a defence of acting lawfully in the giving of care and treatment to those unable to consent, would not be available unless this condition was complied with (Draft Bill, cl 9) (Law Commission 2017, para. 14.19). In this way a new 'stick' approach of the scheme would be introduced. Significantly, once views were ascertained, at the stage of making the determination, the decision maker 'must give particular weight to any wishes or feelings ascertained' (Draft Bill, cl 8(4)) (Law Commission 2017, para. 14.19).

It is clear then that wishes and feelings would now be an elevated factor within the scheme. Whilst refraining from defining 'particular weight', they pointed out that the stronger the wishes, the greater the weight that should be accorded and reasoned that it 'would evidently give ascertained wishes and feelings a higher status than all the other factors which a decision-maker is required to consider under section 4(6)' (Law Commission 2017, para. 14.17). On the thorny issue of departing from the wishes, the Law Commission took the view that this will be justified where it was necessary and proportionate in accordance with the obligations under Article 8(1) of the ECHR. In making their assessments, decision makers would be aided by factors listed in the new Code of Practice to include, for instance, family views and risk of harm to the patient (Law Commission 2017, para. 14.18).

In summary, the options available were: retain the status quo, make the person's views a rebuttable presumption or a half way option. The Law Commission in selecting the latter measure have not embraced the principle of placing the individual at centre stage and in charge of her destiny which an arguable interpretation of supported decision making model under the CRPD would require. If elevating her views to a presumption would subvert the best interest test, then there is force in making such a change to uphold values of autonomy and free agency. It would also be more aligned to the CRPD framework which prioritises the notion that preferences are respected, instead of an objective best interests system predicated on substituted decision making. If there were factors that made it difficult or impossible to ascertain views, then support should be given to correspond with the most likely estimation of their wishes. The logical trajectory of such a scheme would be to place the best interests test at a lower stage in the decision making process. Indeed as the Law commission in their consultation paper noted adjusting the weight of preferences would not be sufficient to achieve CRPD goals (Law Commission 2015, para. 12.40). Such a reform would also bolster the existing requirement under MCA s4(3) to encourage the person to participate as fully as possible in the decision before making it for the person. In these respects, a substantive change to MCA s1 is justifiable.

Although a step in the right direction, ultimately measures contained in the draft Bill would still place a person's views, albeit strengthened, as one among many factors to consider and therefore facilitate departure from them. Moreover the inclusion of the word 'particular' weight is arguably too vague and also a watered down version of Mr Justice Munby's formulation in *Re M* of 'significant factor' or even 'serious'. Decision makers would retain a considerable 'elbow room' of discretion under these proposals.

The Law Commission proposed cases where wishes were 'inconsistent or unclear', or the patient was unable to communicate them at all would be designated as not being reasonably practicable to ascertain. The effect of this designation would release the need to give them any particular weight. In those cases, the decision would fall to be determined under the current best interest checklist without reference to any statutory weighting (Law Commission 2017, para. 14.21). Arguably these proposals present a loophole and are problematic from the true free agency and empowerment principles espoused by Lady Hale. For instance, an example they presented of an 'inconsistent' decision is where 'the person expresses different views on their care and treatment to different members of the family' (Law Commission 2017, para. 14.20). Potentially this may be interpreted in giving

precedence to family members' views. In sterilisation cases, for example, this may be problematic, where the application to sterilise is initiated by family members themselves and the interests of the intellectually disabled person are in danger of being conflated with that of their family (see further *A Local Authority v K (by the Official Solicitor)* [2013] EWHC 242 (COP), *An NHS Trust v DE* [2013] EWCH 2562 (Fam), *Re A (Medical Treatment: Male Sterilisation)*)).

One question to be addressed is whether a person's previous or current wishes should be followed. The MCA does not provide an express answer although there is a nod in the direction of the individual's current wishes and feelings in the validity and applicability of the advance directive framework under s25 (Donnelly 2009, p. 27, Law Commission 2015, para. 12.46). Donnelly argues that this approach is reflective of an 'endorsement' that present preferences will be favoured under s4(6), and should take effect, particularly in refusal of treatment cases (Donnelly 2009, p. 27). This is especially so where 'capacity falls towards the upper end of the (in)capacity continuum.' Although she points out that recognition of autonomy demands that previous sentiments should not be entirely ignored (Donnelly 2009, p. 29). Views, attitudes and values may change as a response to life events and there is force in giving expression to current wishes. The literature on the CRPD supports the idea that current will and preferences are to be respected and this is in keeping with the proposals for facilitating full legal capacity (see for instance Craigie 2015, p. 399, Scholten and Gather 2017). There is some cogent reasoning for prioritising current views rather than relying on outdated previous statements, particularly so when medical treatment progresses and the Law Commission in its earlier consultation paper had also leant in this direction, while not coming to a firm proposal, opining that it could be fleshed out in guidance rather than needing to amend the statutory scheme (Law Commission 2015, p. 12.46).

Unwise decisions

Interestingly, the Law Commission noted other general perceptions of the MCA, including hearing evidence of 'blanket' assessments of capacity. For instance they stated:

Family members reported that hospital and care home workers were often too ready to use restrictive forms of intervention (such as restraint and sedation). One consultee described the Mental Capacity Act as a 'tool' used by professionals to 'bully' and 'side line' vulnerable people and their families. (Law Commission 2017, para. 14.25)

This section will discuss wider aspects of the MCA which have a bearing on the effectiveness of the participatory mechanisms. These issues tied to the definition of capacity, are worthy of attention in their own right, particularly in the way they may result in the conflation between capacity and best interest determinations. In any future move towards supported decision making the MCA as a whole would need to be carefully reviewed, including the concept of capacity.

An important aspect of the participatory model of decision making is rooted in MCA s1(4) which states: ‘A person is not to be treated as unable to make a decision merely because he makes an unwise decision.’ This section is intended to ensure that decision makers do not equate an unwise decision with evidence of incapacity, although the insertion of the word ‘merely’ is interesting in this regard. It is well established that a competent individual can make a decision, for example, to refuse medical treatment if it would lead to their death or even the death of a viable foetus (*Re C; Kings College Hospital NHS Foundation Trust v C, Re MB (An Adult: Medical Treatment)* [1997] 2 FCR 541). A decision not in keeping with societal norms ought not therefore to be used to coerce individuals into accepting treatment nor to circumvent consent processes. MCA s1(4) is also interwoven with one of the factors in the best interest checklist under s4(1) whereby a decision maker should not make their determination merely on the basis of the age or the appearance of the person, or on the basis of unjustified assumptions from the person’s condition or behaviour.

It is pertinent in this regard to heed the warnings of Mr Justice Peter Jackson in *Heart of England NHS Foundation Trust v JB* [2014] EWHC 342 COP about arriving at unjustified assumptions.

The temptation to base a judgment of a person’s capacity upon whether they seem to have made a good or bad decision, and in particular on whether they have accepted or rejected medical advice, is absolutely to be avoided. That would be to put the cart before the horse or, expressed another way, to allow the tail of welfare to wag the dog of capacity. (para. 7)

This case concerned a refusal by a woman who suffered from paranoid schizophrenia to undergo a knee amputation. In declaring that it had not been established that she lacked the capacity to decide whether to have the surgery, the judge opined, ‘The freedom to choose for oneself is a part of what it means to be a human being.’ (para. 1)

In a similarly thoughtful judgement in the context of a middle-aged woman's refusal to accept life saving renal dialysis following an unsuccessful suicide attempt, Mr Justice MacDonald in *Re C* stated:

To introduce into the assessment of capacity an assessment of the probity or efficacy of a decision to refuse life saving treatment would be to introduce elements which risk discriminating against the person making that decision by penalising individuality and demanding conformity at the expense of personal autonomy in the context of a diverse, plural society which tolerates a range of views on the decision in question. (*Re C; Kings College Hospital NHS Foundation Trust v C*, para. 30. See also *Mental Incapacity (1995)* (Law Comm No 231) (HC 189), para 3.4)

In this case, C's lifestyle revolved around her looks, social life and material possessions. She was adamant that she did not want to grow old and feared she would lose her 'sparkle'. The stakes in this case could not be higher yet the court was mindful of not conflating capacity with outcome and therefore upheld her values to 'live life on her own terms' as C had indeed herself put it. This is despite judicial recognition that her values may not accord with reason, logic or the principle of the sanctity of life.

Aware of the dangers of confusing irrational or even bizarre thoughts with incapacity, in a similar vein, Holman J held in another Court of Protection case that a woman was able to consent to a termination, despite having 'skewed thoughts and paranoid or delusional views' (*Re SB (A Patient; Capacity to Consent to Termination)* [2013] EWHC 1417 (COP), para. 41). These cases signal that judges in the Court of Protection are aware of the dangers of leaping to conclusions and labelling a person 'incapable' where their viewpoint may not accord with what the majority would deem reasonable. They might also provide evidence that as long as the participatory mechanisms in the MCA are applied robustly, the Act may not need amendment, rather just applied properly as intended.

Researchers have warned of the conflation between the outcome of a decision and triggering a capacity assessment (Taylor 2016, p. 176). There is evidence that a capacity assessment may be undertaken in the face of a refusal of treatment (see generally Wildeman 2013, p. 59 for a useful discussion, Cave 2015, p. 7). Certainly there is evidence of this occurring in cases where women have refused caesarean sections in the face of foetal danger. For instance, in one case a woman's desire to have a natural childbirth despite complications, including pre-eclampsia, triggered an assessment and eventual detention under the Mental

Health Act (*St George's Healthcare NHS Trust v S; Regina v Collins* [1999] Fam 26). Under the MCA as currently formulated, if an individual refuses treatment or chooses one over another treatment which is at odds with the preferred medical view, a capacity assessment maybe triggered resulting in treatment being authorised under the objective best interests test. The conflict between paternalism and autonomy are stark in this debate. The stigma attached to those labelled as lacking capacity justifies a paternalistic intervention on individual liberty in circumstances where the state would not countenance interfering in those with mental capacity (Cave 2015, p. 7). Indeed some researchers note this form of intervention may itself induce a 'vulnerability' and disempowerment in the patient (Clough 2017, p. 475).

Taylor points out that there may be a tendency for health care professionals to practise defensively to avoid potential claims in negligence. The argument is that a fear of breaching a duty of care may therefore deny an individual's autonomous choices (Taylor 2016, pp. 187–189). Certainly there may be a natural tendency in seeking to protect and progressing treatment where the outcome may be death or serious harm, without it.

In their empirical research in respect of data from a national study regarding the operation of the best interests principle, Williams et al describe the issue as a 'concertina effect'. As they put it: 'Rather than allowing the "unwise" principle to prevail, practitioners regularly framed a person's decision as proof of lack of capacity...' They continue: '...a capacity assessment was often part of a wider process driven by an awareness of the risks faced by an individual; what emerged was a phenomenon we labelled the "concertina effect", in which practitioners moved between the best interests decision itself and the assessment of capacity, generally portraying both as an interaction with the person, conducted over time.' (Williams *et al.* 2014, p. 82)

The danger of this conflation of the best interests and capacity test is that it strips the individual of the safeguards and mechanisms built into the Act, eroding autonomous choices and potentially leading to decision making premised on the clinical viewpoint. In turn this may diminish the broader welfare issues and is at odds with the process set in motion by the courts in moving away from *Bolam* to include wider interests than purely medical (*Bolam v Friern Hospital Management Committee* [1957] 2 All ER 118, *Re A (Medical Treatment: Male Sterilisation)*, *Re MM; Local Authority X v MM and KM* [2007] EWHC 2003 (Fam)).

Even with wholesale reform of the capacity and best interest test, it is debateable whether a move towards a full supported decision making model would resolve this difficult

area. Critics point out that under article 12, unwise or damaging consequences of decisions would need to be given effect to once legal and mental capacity is de-linked (Richardson 2012, p. 349). As Craigie questions does genuine autonomy then include the rights to make poor choices or bad decisions (Craigie 2015, p. 403)? A specific and difficult example of the dilemma posed in the literature is the anorexic who refuses to eat but does not wish to die. Richardson for instance argues in cases of repeated pattern of self destructive behaviour that there is a 'moral obligation' to override autonomous choices. There is otherwise a risk that 'support' would cloak coerced decision making thereby obliterating the difference between supported and substituted decision making (p. 349). The balance between steering a course between paternalism and autonomy in these hard cases is one of the issues which will need to be confronted. The difficult path to navigate if supported decision making is fully implemented in the future is to ensure there is the appropriate balance between facilitating the person's preferences, and with ensuring their general well being is enhanced by it without undermining their choice or as Craigie puts it, 'helping the person make a "good" decision' (p. 403).

Risk

Another interesting feature explored by Williams et al was the notion of risk and how capacity could become as they put it 'interwoven with the capacity to manage one's life without risk' (Williams *et al.* 2014, p. 78). There is judicial recognition of risk taking and outcome, particularly, in recent cases where courts were clear that the outcome should not be used to pre-determine whether a person is capable of making their own decisions.

For example, in *Re Z* [2016] EWCOP 4, in assessing the capacity of a 20-year-old woman with autism, Cobb J described the dangers of equating dangerous or unhealthy risks (which all adolescents are prone to take) with lack of capacity. Indeed, he pointed out that the one of the hallmarks of autonomous choices was the freedom to make unwise decisions. He said 'It is tempting for the court to take a paternalistic, perhaps overly risk-averse, approach to Z's future; but this would be unprincipled and wrong' (para. 67).

The House of Lords Select Committee heard evidence from professionals that a capacity assessment often followed what was described as a 'perception of risk' and considered this as 'attitudinal barrier' preventing implementation of the Act (House of Lords Select Committee on the Mental Capacity Act 2005 2014, para. 78). They noted that the right to make unwise choices conflicted with dominant themes of protection and paternalism in

health care (House of Lords Select Committee on the Mental Capacity Act 2005 2014, para. 84). Further, evidence to the Committee alluded to principles of ‘safeguarding’ or ‘risk aversion’ as general impediments to this shift to individualising rights and a model which seeks to uphold autonomy and dignity as the primary focus (House of Lords Select Committee on the Mental Capacity Act 2005 2014, para. 85). Arguably the right to make unwise decision and choices about health and lifestyle or to take risks should not be denied to the intellectually disabled. By continuing themes of protection and safeguarding, the medical model of decision making although eschewed in recent decades continues as the main force in healthcare.

Conclusion

The Law Commission noted how the requirements of article 12 CRPD on supported decision making fell short in the MCA provisions which rely in part on substituted decision making. Currently under the MCA wishes and viewpoints of the individual are one of the relevant factors but are not given any primacy over any other aspect of evidence (Law Commission 2015, para. 3.20). While they drew attention to criticism of the extent to which the individual’s wishes were given sufficient accord, they made clear that the essential framework of the best interests decision making was clear, sound and were unwilling to countenance replacing it altogether. Such politically sensitive policy matters, they opined, belonged in the hands of Ministers (Law Commission 2015, para. 12.44).

The recent reports considered in this paper clearly point to how the person’s wishes and feelings are overlooked in favour of medical judgment or other factors, including resources. The net effect has been that these other considerations have tended to tip the scales in arriving at best interests determinations. The legislative intention behind the MCA and judicial approach is to apply the best interests checklist, taking into account all the circumstances, and to not give any one factor weight above another.

Proposals under the draft Bill that in all best interests decisions under s4, the decision maker would be required to establish the person’s wishes and feelings, beliefs and values are welcomed as a positive step forward. Once views have been ascertained the duty to give particular weight to these wishes and feelings kicks in. Residual uncertainty remains as to how the term ‘particular weight’ will be interpreted and will no doubt give rise to judicial discussion. Although these proposals and the draft Bill have merit in moving towards securing a more supported and inclusive decision making model, they do not go far enough.

Reform should elevate, and in so doing, actually give effect to, the intellectually disabled persons wishes and feelings as a presumption. The arguments for strengthening patient views in to a rebuttable presumption are compelling. Furthermore, as we have seen there is a wider discussion to be had about the conflation of capacity assessments and the best interests test in respect of making unjustified assumptions and risk taking and so a wider more fundamental review of MCA s1-4 in line with international calls is warranted when the issue of supported decision making powers is picked up by Ministers.

It is the case as Donnelly points out that patient participation can be problematic where it is not possible to understand the wishes and feelings of a person who lacks capacity (Donnelly 2009, p. 17). It is also the case that views may not be able to be communicated at all. In those cases, a test predicated on a more objective assessment of clinical need may be inevitable. However, in other cases international calls for a new way of operating are to be welcomed and a vision which empowers the individual and puts them on an equal footing with those who have capacity is a goal towards which the law can evolve. The current objective test is too unclear, vague and a clearer test modelled on subjectivist and individualist principles is the way forward.

Looking ahead at reform supported decision making models have proposed by Bach and Kerzner for the Law Commission of Ontario (see Bach and Kerzner 2010 for more detail). The crux of this model is the abandonment of the notion of mental capacity in favour of a 'disability neutral state' linked to legal capacity (Richardson 2012, p. 351). In their three-tiered model, in a few cases facilitated decision making using a type of substituted decision making would be activated at a later point. On a more general note, diagnosis of significant disabilities will no doubt provide a challenge if any wholesale reform is adopted. Scholten and Gather therefore propose a combined model in order to play to the advantages of both systems which accommodate a role for substituted decision making where a patient is unable to make an informed decision, such as serious psychosis or late stage dementia (see Scholten and Gather 2017, p. 5 for more details of their scheme).

The wider trend which views disability protection through the human rights lens suggests a more dynamic process orientated vision where the intellectual disabled person is moved centre stage in taking control of their destiny, thereby also securing better outcomes. The principle of equal treatment dictates that all human beings, irrespective of capacity, should be able to exercise the principle of free agency. If views are ascertainable, there is no

reason for them not to be given the respect and value that a person with capacity currently enjoys. Equality demands that all voices are indeed heard equally and a level playing field suggests a more robust reform of the law towards a supported decision model is the way forward in line with human rights norms.

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