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Informed consent for capacity assessment

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Abstract

In this paper we examine the role of informed consent to capacity assessment, focussing primarily on the two jurisdictions of England and Wales, and Ireland. We argue that in both jurisdictions, a capacity assessment should be regarded as a distinct intervention, separate from the 'original' intervention at issue, and that specific informed consent to the assessment should generally be sought in advance. As part of this, we consider what information should be provided so as to ensure informed consent. Having established a baseline requirement for informed consent, we also recognise that informed consent to assessment will not always be possible, either because the person is unable to understand the information about assessment or because the person refuses to be assessed and so, in the final part of the article, we explore how to proceed when informed consent is either not possible or not forthcoming, including an analysis of the implications of the statutory presumption of capacity.

Keywords
Decision-making capacity; capacity assessment; informed consent; Assisted Decision-Making (Capacity) Act 2015; Mental Capacity Act 2005; presumption of capacity.

1. Introduction

Notwithstanding the questions raised regarding compatibility with the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (2006),[1] the functional approach to capacity (that capacity should be assessed on the basis of the person's ability to make the decision required at the time required) is now, and looks set to remain, the accepted legal standard across a wide range of jurisdictions (Ruck Keene et al, 2023). There is a substantial literature on how functional capacity assessments should be performed (e.g. MacKenzie and Wilkinson, 2020; Ruck-Keene ed., 2022) and a wide range of structured and semi-structured mental capacity assessment instruments have been developed to assist with the task (e.g. Appelbaum, 2007; Pennington, 2018). In contrast, relatively little attention has been paid to the question of how, when and why the person being assessed should receive an adequate explanation of the assessment process.

[1] See especially Committee on the Rights of Persons with Disabilities, *General Comment No. 1 Article 12 Equal Recognition before the Law* 19 May 2014, CRPD/C/GC/1, para. 15.

In this paper we examine the role of informed consent to capacity assessment. We understand informed consent here to mean consent which legitimates an intervention (what Emma Cave describes as 'valid consent'), rather than the term as understood in respect of the duty to disclose information in the tort of negligence (Cave, 2021). Obtaining informed consent for examination or investigation is also a professional standard expected of doctors by the Irish Medical Council (2024 at 13.1) and the General Medical Council (2024)Our primary focus is the two jurisdictions of England and Wales and Ireland (although some of the arguments are likely to apply in other jurisdictions with a functional approach to capacity). Although there are some relevant differences in the two legal frameworks, we nonetheless argue that in both jurisdictions, a capacity assessment should be regarded as a distinct intervention, separate from the 'original' intervention at issue, and that specific informed consent to the assessment should generally be sought in advance of the assessment. As part of this, we consider what information should be provided in advance so as to ensure informed consent to assessment. Having established a baseline requirement for informed consent, we also recognise that informed consent to assessment will not always be possible, either because the person is unable to understand the information about assessment or because the person refuses to be assessed and so, in the final part of the article, we explore how to proceed when informed consent is either not possible or not forthcoming.

2. The Legal Frameworks

The legal frameworks for capacity law in England and Wales and in Ireland are set out in the Mental Capacity Act 2005 (MCA) and the Assisted Decision-Making (Capacity) Act 2015, as amended by the Assisted Decision-Making (Capacity) (Amendment) Act 2022 (ADMCA) respectively. Both the MCA and the ADM Act are supported by statutory Codes of Practice which provide further detail on the operationalisation of the legislation. In respect of the MCA, there is a single Code: the Mental Capacity Act Code of Practice (2007) (MCA Code) while the ADMCA is supported by no fewer than 13 Codes of Practice. The Code most relevant to our discussion here is the Code of Practice for Supporting Decision Making and Assessing Capacity (2023) (ADM Code).

In both jurisdictions, the legal standard for capacity requires that a person be able to make a specified decision at the time the decision falls to be made (MCA, s. 2(1); ADMCA, s. 3(1)). In both Acts, the abilities required to do this are stated to be: to understand the information relevant to the decision; to retain the information; to use and weigh the information; and, to communicate the decision made (MCA, s. 3(1); ADMCA, s. 3(1)). One notable difference between the two Acts is that the MCA requires that the person's inability to make the decision must be as a result of 'an impairment of, or a disturbance in the functioning of, the mind or brain' (MCA, s.2(1)). This requirement, sometimes referred to as the 'diagnostic threshold', was intended to serve as a form of gatekeeper, protecting the 'normal' (i.e. those without impairments) from being the subject of capacity inquiries (Law Commission, 1993).[2] This kind of threshold does not apply under the ADM Act and so, theoretically, at least, a person may be found to lack capacity notwithstanding the absence of an underlying disability, a position more in line with the equality requirements under the CRPD. It remains to be seen how much (if any) practical difference this different framing of the standard makes. In the recent decision of the Court of Protection in *An NHS Trust v ST and Anor* (2023), the Court found that ST, a 19-year-old woman with a rare degenerative disease, lacked capacity to make decisions about her future medical treatment notwithstanding that there was no evidence that she had an impairment of the mind or brain. Roberts J. found (para. 93) ST to be unable to make a decision about her future medical treatment because 'she does not believe the information she has been given by her doctors' (that she was going to die within a short time). Accordingly, she was unable to use and weigh information 'which has been shown to be both

[2] The Law Commission had in fact recommended that the diagnostic threshold should be the presence of a 'mental disorder'.

reliable and true'. In respect of the diagnostic threshold, Roberts J. found (para. 103) 'on the balance of probabilities that ST's complete inability to accept the medical reality of her position … is likely to be the result of an impairment, or a disturbance in the functioning of, her mind or brain'. This decision suggests that, as Phil Fennell had predicted, if the diagnostic threshold is intended to serve as a gatekeeper, it is 'a gate through which a multitude could pass' (1994: 36).

Both Acts impose broadly similar obligations on capacity assessors. Both include a statutory presumption of capacity (MCA, s.1(1); ADMCA, s. 8(2)) and both require that a person is not to be considered unable to make a decision unless 'all practicable steps' to help the person have been taken without success (MCA, s. 1(3); ADMCA, s. 8(3)). Both Acts also prescribe that a person is not to be considered to be unable to make a decision in respect of a matter merely because the person makes or proposes to make an 'unwise decision' (MCA, s. 1(4); ADMCA, s. 8(4)). These statutory requirements are further elaborated on in the accompanying Codes.

3. What is a capacity assessment?

'Capacity assessment' usually means – and that is what we mean in this article - an interview or series of interviews between an assessor and person in which the former seeks to determine whether the person has the capacity to make a specified decision/s (O'Keeffe, 2022). Such encounters are ideally face-to-face although remote assessments became more common during the COVID-19 pandemic and, in England, these are formally recognised to be acceptable if conducted appropriately (Guidance on Proportional Assessment, 2023). Ultimately, the assessor will need to reach and to document their conclusion regarding the person's capacity. The assessment of capacity needs to be distinguished from both a 'capacity judgement' and a determination of capacity. A capacity assessment is a clinical opinion as to the person's capacity; a capacity judgement is a conclusion reached by the person who proposes to provide an intervention for the person whose capacity is at issue, usually based on the outcome of a capacity assessment; and a capacity determination is a conclusion made by the courts.

3.1 Formal and Informal Assessments

The MCA Code views capacity assessments as operating on a continuum ranging from informal to formal. Less formal assessment is needed for day-to-day decisions, such as agreement to being bathed or having a dressing changed (MCA Code, para. 4.38). Although the Code is clear that all capacity assessments must follow the underlying principles of the MCA, formal, written assessments are not needed is these situations. However, 'more complex decisions are likely to need more formal assessments (MCA Code, para. 4.42). The Code identifies a requirement for a formal assessment where: a person's capacity to sign a legal document (e.g. a will) could later be challenged; it needs to be established if the Official Solicitor should be involved; when the matter is going before the Court of Protection; and, if the courts are required to make a decision about a person's capacity in other legal proceedings (MCA Code, para. 4.45). In between these two ends of the continuum, the Code identifies situations involving 'complex or major' decisions where the person assessing capacity may need to get a 'professional opinion' (MCA Code, para. 4.51). The Code proposes that a professional opinion may be needed where: the decision is complicated or has serious consequences; the person challenges an assessment of lack of capacity; family members, carers or professionals disagree about the person's capacity; there is a conflict of interest between the assessor and the person assessed; the person being assessed is expressing different views to different people; someone might challenge the person's capacity to make the decision; someone has been accused of abusing a vulnerable adult who may lack the capacity to make decisions to protect

themselves; or, the person repeatedly makes decisions that put them at risk or could result in suffering or damage (MCA Code, para. 4.53).

Drawing a distinction between an informal and formal assessment is not always easy especially when the assessment is carried out by someone caring for the person. However, we would suggest the heuristic that, if the sole or main purpose of an interaction is the assessment of capacity, this should be seen as a formal intervention. So, for example, where a different professional to the one who is proposing an intervention is asked to perform a capacity assessment perhaps because of their expertise (such as a psychiatrist, geriatrician or neuropsychologist) or just as a second opinion in difficult cases, this is clearly a formal intervention.

3.2 Difference in scope between the MCA and ADM

In contrast to the MCA Code, the ADM Code does not refer to informal assessments and instead envisages the full formal assessment process to apply to all capacity assessments. This difference in approach reflects the differing underlying scope of the two Acts. The MCA provides a statutory basis and accompanying protection for those who provide care and treatment for a person (referred to in the MCA as 'P'). Under s. 5(1) of the MCA, a person may provide care and treatment to P, provided that s/he has taken 'reasonable steps' to establish whether P lacks capacity in relation to the matter in question and 'reasonably believes' that P lacks capacity in relation to the matter and that it will be in P's best interests for the act to be done. Thus, in this respect, the MCA is an all-encompassing statute, establishing the complete applicable legal framework for the provision of care and treatment where a person lacks capacity.

Unlike the MCA, the ADMCA provides only part of the applicable legal framework where a person lacks capacity. The ADMCA allows a person whose capacity is in question or may shortly be in question to appoint supporters to help them make decisions as specified in the appointment and to make advance appointments of decision-makers to come into effect if and when the person loses capacity (Donnelly, 2016; Kelly, 2017). It also allows an application to be made to the Circuit Court for a declaration that a person lacks capacity in respect of a specified matter/s (ADMCA, s. 37) and for the Court to either make a decision on behalf of the person or to appoint a Decision-Making Representative to whom the Court grants decision-making authority in respect of the matter/s in question (ADMCA, s. 38). However, the ADMCA does not address decision-making outside of these contexts and the legal basis for intervention in such circumstances remains subject to the body of judge-made law, generally referred to as the common law (Donnelly, 2016).[3]

Unfortunately, the Irish courts have not yet provided a clear articulation of the common law position in respect of non-emergency care and treatment where a person lacks capacity, including when an application to court is required. It may reasonably be expected that the Irish courts would adopt a position broadly similar to the expanded understanding of the common law doctrine of necessity which was set out by the House of Lords in *Re F (Mental Patient: Sterilisation,* 1990) (Donnelly, 2016). This decision, subsequently statutorily enshrined in the MCA, permitted the provision of care and treatment to a person lacking capacity on the basis that this was in the person's best interests. The Supreme Court has recognised the doctrine of necessity in respect of short-term deprivation of liberty where a person lacks capacity (*AC v Hickey*, 2019) and this could be extended to incorporate the provision of care and treatment in some situations. Rather than the best interests standard (which is not a part of Irish law post-ADMCA), the obvious basis for the operation of an extended doctrine of necessity would be the principles set out in the ADMCA. Although there is a long list of

[3] The Assisted Decision-Making (Capacity) Bill 2013 as initiated had included a provision allowing for 'informal' decision-making (s. 53) along the lines of s. 5 of the MCA. However, this was removed following objections by disability organisations.

applicable principles, those most relevant for the discussion in this article are the requirement that the person providing an intervention must act at all times in good faith and for the benefit of the person and that they must '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' (ADMCA, s. 8).

4. Informed Consent to Capacity Assessment

Neither the MCA nor the ADMCA contain an express reference to a requirement for consent to assessment of capacity. However, the ADM Code is clear that an assessor must obtain informed consent from the relevant person before undertaking a capacity assessment and must inform that person that they have a right to refuse to undergo the assessment or may stop the assessment at any stage (ADM Code, para. 5.3).

This explicit identification of a requirement for advance informed consent is in line with the legislative position in some other jurisdictions. The Adult Capacity and Decision-making Act 2017 (Nova Scotia) provides that an assessor may conduct an assessment only if the adult has not refused to undergo or continue with the assessment and the adult has either consented, if the assessor considers the adult to capable of consenting, or the assessor has reasonable grounds to believe that the adult is not capable of consenting to the assessment (s. 9). The Court may also order an adult to undergo a capacity assessment, including admitting the assessor to the adult's place of residence or attending at another place for the assessment (s. 10). The Substitute Decisions Act 1992 (Ontario) takes a somewhat different approach. It does not require that the person consent to being assessed but it sets out a legal right for the person to refuse the assessment (s. 78(1)). The 1992 Act also requires that before carrying out the assessment, the assessor must explain to the person assessed the purpose of the assessment, the significance and effect of a finding of incapacity, and the person's right to refuse to be assessed (s. 78(2)).

The MCA Code reflects aspects of the Ontario approach. The Code does not include a requirement for advance informed consent, but it does state that '[n]obody should be forced to undergo an assessment of capacity' (para. 4.59). However, the Code does not identify an obligation to inform the person that they may refuse nor does it include specific requirements regarding information provision. The furthest the Code goes is that statement that 'it may also be helpful' to '[m]ake every effort to communicate with the person to explain what is happening' (para. 4.45). The emphasis here, we suggest, is on explanation as a procedural step for assessors rather than as something essential for the understanding of the person being assessed. The NICE guideline on Decision-Making and Mental Capacity (2018) states that '[w]here consent has been provided, health and social care practitioners should identify people who could be spoken with in order to inform the capacity assessment' (para. 1.4.13). Although this could be taken to imply that consent should be sought for some aspects of preparation for assessment, it does not expressly require practitioners to seek consent for the assessment.

Two decisions of Hayden J., the former Vice-President of the Court of Protection, provide a degree of support for a requirement for informed consent in respect of formal assessments in England and Wales. *London Borough of Wandsworth v M & Ors* (2017) concerned the living arrangements for three children, all of whom were living in residential units at the time, and specifically whether they should return to live with their mother. Although the case came before the Family Division of the High Court, the issue of capacity arose in respect of J, who would shortly reach his 18th birthday. J had indicated that he would choose to live with his mother, a decision which social services

considered to be damaging and risky for him. Hayden J. considered the application of s. 48 of the MCA which allows the Court of Protection to make an interim order where 'there is reason to believe P lacks capacity' in relation to a matter. This requires a lower standard of proof than the balance of probabilities required for a declaration of lack of capacity made under s. 15 of the MCA (*Barnet Enfield v Mr K*, 2023). A capacity assessment was presented to the Court which concluded that that 'due to J's "*lack of insight*" and "*inflexibility of thought*", he "*on the balance of probabilities lacked mental capacity to make the decision as to where he should live*"' (para. 45, original emphasis). Notwithstanding the application of the lower standard of proof, Hayden J. was not convinced by this assessment, concluding that it 'displayed insufficient rigour to justify its conclusion' (para. 46). He continued by expressing his concern that the purpose of the assessment had not been explained to J, stating:

> It seems to me that a prerequisite to evaluation of a person's capacity on any specific issue is at very least that they have explained to them the purpose and extent of the assessment itself. Here, that did not happen. In my view, it is probably fatal to any conclusion. In any event, it, at least, gravely undermines it (para. 49).

Hayden J reinforced the need to 'clearly explain the purpose of the assessment' in *DP* v *Hillingdon* (2020). This case concerned an appeal of an interim order that the 'protected person' lacked capacity to make decisions as to his care and residence. Once again, the lower standard of 'reason to believe' applied. A difficulty arose because the capacity assessor had introduced himself as being there to assess the person's care and support needs, rather than to perform a capacity assessment (2020: para. 10). While recognising the inaccuracy of this description, the judge at first instance had found that it was 'unlikely to have impacted on the assessment itself' (2020: para. 18). Hayden J. did not have the same confidence, finding that the first instance judge had erred in not taking steps to investigate further when this inaccuracy had emerged (2020: para. 41). He found that the failure to inform P of the purpose of the assessment would 'probably be "*fatal to"* or, at least, "*gravely undermine" the* reliability of any conclusion" (2021: para. 61, original emphasis). This did not mean that the requirements under s. 48 could not be met – this was a decision for the judge, having looked at 'the wider canvas of the available evidence' and considered 'those aspects of the report that might survive its failings' (2021: para. 61). Nonetheless, the flaws in the evidence were clear.

While these cases do not expressly impose a requirement for consent to formal capacity assessment, they do provide strong support for the obligation to provide clear information about that nature of the assessment in advance. We suggest that a requirement for consent to assessment is the logical next step, setting out our reasons for this view below.

4.1 The Argument for a Consent Requirement

Hayden J is not explicit about <u>why</u> it is so fundamental to the assessment process that the person is adequately informed such that a failure to do so may be 'fatal to any conclusion' (2017, para. 49). We believe that there are two reasons, one instrumental and one principled, why informed consent to assessment is required.

At an instrumental level, we begin from the premise that a capacity assessment is, fundamentally, a human interaction. A person may engage differently with a capacity assessment, and assessor, if aware of the purpose of the assessment (O'Keeffe, 2022). This is likely to result in a 'better' capacity assessment, one which is fairer to the person and more reflective of their abilities and values and beliefs. For example, it may be that the person was bored, tired or distracted during prior discussions about an intervention, and it was this that led to concerns about their capacity to make a decision about the intervention. Their willingness to take in and balance relevant information about the decision might improve if they knew that they may lose the right to make their own decision

without such engagement. However, we recognise that this argument has limitations. It can be seen as simply an aid for assessors – in this case to get capacity assessment 'done' in a better way. Moreover, it can also be argued that an awareness of the nature and implications of a capacity assessment could lead to the person being more upset and less able to engage with the decision at issue or will lead to a refusal of assessment.

There is however also a principled reason why information (and consent) is required. In setting out this argument, we begin from the premise that capacity assessment is a separate intervention (to adopt the language of the ADMCA), distinct from the intervention proposed. From the perspective of the person, the risks and benefits of agreeing to or refusing a capacity assessment are distinct, even if related, from those of the substantive decision. The separate benefit of the assessment is that it may allow the person access to the decision-making support they need. Under the ADMCA, for example, a capacity assessment is a pre-requisite for entering into a Co-Decision-Making Agreement (ADMCA, s. 21(4)(f)) or creating an Enduring Power of Attorney (ADMCA, s. 60(1)). Under both the MCA and the ADMCA, depending on the outcome, assessment may also allow the person to make decisions about their lives without external interference or alternatively may provide them with access to protection, including from the consequences of their own unwise decisions. However, capacity assessments also have risks, the most significant of which is that the person may find that someone else will make a decision on their behalf. This risk has been reduced in both jurisdictions discussed in this article by the greater legal acknowledgement of the person's past and present wishes and feelings/will and preferences in situations where they have been found to lack capacity to make a decision (MCA, s. 4(6); *Aintree NHS Trust v James* (2013); ADMCA, s. 8 (7)). Nonetheless, it remains a genuine risk. A person may reasonably find the possibility that they will lose a fundamental right held by other citizens to be upsetting and unacceptable of itself, irrespective of the nature of the particular substantive decision. We can see this play out in *Wandsworth*, where Hayden J was sceptical that a proper explanation had been given to J because:

> J …is fiercely and politically resistant to what he considers to be disproportionate state intervention in private life…[I]f it had been properly explained to J that an assessment of his capacity to take decisions as an autonomous adult was being tested I would have expected a voluble and unambiguous response on his part, none is recorded (2017: para. 49).

It is true that capacity assessment as a separate intervention does not involve a physical component and so, unlike the usual understanding of a valid consent (Cave, 2021), the purpose of consent here is not to prevent an action in battery. Nonethelessit must be recognised that the nature of a capacity assessment makes this a potentially threatening clinical encounter for patients. Assessment can involve probing patients' emotions, experiences, goals and values (Rafcliff, 2020). They are being asked to open the 'cognitive bonnet', expose the inner workings of their mind (to the degree that this can ever be possible) and to justify and explain their decisions and reasoning. Depending on the nature of the underlying decision to be made, the assessment may be intrusive on the person's privacy. An assessor may conduct collateral interviews with others and seek to examine medical or financial records (Kapp, 2010; Jones, 2020). Capacity assessment in such cases can be more than just an investigation into a person's decision-making abilities; it is an investigation into his or her life.

Given that the stakes for the person are so high, it is a reasonable supposition that people would expect to be told why an assessment is being performed and the purpose and potential outcomes of such an assessment. In healthcare, professionals will know of the possible implications if a patient is judged to lack decision-making capacity. Most patients will not; they will be familiar with assessments by professionals for a therapeutic or diagnostic purpose but not necessarily with assessments that could result in a loss of decision-making autonomy. Thus, there is an inevitable

informational asymmetry as between the two parties to the assessment, with one party having substantially more power and knowledge.

4.2 A Challenge for Health Professionals?

We recognise that emphasising a requirement for consent to capacity assessment is potentially challenging for some professionals and that it can give rise to ethical concerns. Sandip Talukdar points out that providing an explanation about the assessment 'may cause a patient to react negatively, which may impede therapeutic engagement' (2021: 1). In this, Talukdar is almost certainly correct. Indeed, in *Wandsworth*, Hayden J was concerned about the assessment precisely because the person wasn't given the opportunity to have a negative reaction. However, as Talukdar also recognises there is also a possibility that a person will have feelings of betrayal and breach of trust if they learn that their capacity has been covertly assessed, with consequent harm to the therapeutic relationship (2021: 9). Moreover, as Talukdar also notes, doctors have a history of using therapeutic exceptions to avoid the 'pains of telling the truth' (2021: 10). For this reason, we are unconvinced that the threat to therapeutic engagement justifies an expansive use of a therapeutic exception although we recognise that there may be situations where such an exception might apply. If this were the case, we would argue that the fact that the person was not informed about the assessment, and why should be noted in any court application. We would also have some concerns about Talukdar's argument regarding how 'the use of skilful language could reduce patient disengagement' (2021: 10). Talukdar explains that:

> There is a difference between the patient being informed that their decision-making capacity would be assessed and telling them that the doctor would ask some further questions to confirm that they had understood all relevant information for making their own decision. The latter option would sound less confrontational on its face, though there is no difference in the underlying purpose of the questioning (2021: 10).

While this would indeed be likely to be less confrontational, the difficulty is that, even if the questions asked are the same, the intention of the interaction is different, and so, this kind of depiction runs the risk of being essentially deceptive and ultimately disrespectful of the rights of the person whose capacity is being assessed.

Talukdar also argues that capacity assessment has now become 'ubiquitous in contemporary healthcare' (2021: 1) and that professionals are frequently obliged to perform a capacity assessment (2021: 4). We agree that psychiatrists, and some other specialists such as geriatricians, may be particularly attuned to possible impairment of decision-making capacity. Also, it seems true that the observational skills of specific groups of healthcare professionals can't be turned off and on at will: many dermatologists, for example, report the experience of noting that a skin lesion on a stranger in the street might be malignant and wondering whether they should say something to the person. Thus, it is to be expected that a sensitivity to possible impairment of decision-making capacity when talking to a patient may result in a judgement that their capacity to decide may be in question. However, it is important that this doesn't morph into a stealth capacity assessment. For example, when professionals find themselves mentally ticking off the four-step functional capacity test, they should stop and inform the person what is happening and seek consent to a formal assessment.

5. Informed Consent to Capacity Assessment: Practical issues

5.1 Providing Information

Valid consent requires that the person must receive sufficient information about the nature and purpose and potential risks and benefits of the proposed intervention and that they must understand that they have a choice in the matter (i.e. the decision must be free or voluntary) (Faden and Beauchamp, 1986). We have argued above that there is no reason that consent for a capacity assessment should not meet the same standard. This means that the person needs to know why their capacity is being called into question, including telling (or reminding for those who have memory problems) the person of incidents where problems have occurred. They also need to know that they can refuse a capacity assessment, even if that may have consequences that they will need to be told about. The person should also receive a truthful explanation of the potential benefits as well as the reasonably foreseeable risks entailed—including the risk that they may lose the right to personally make certain decisions.

The risks and benefits inevitably depend on why the assessment is being carried out. The relevant question from the person's perspective is: 'What's in it for me? And at what potential cost?' For a person who wishes to create a support arrangement or advance decision such as a Co-Decision-Making Agreement or Enduring Power of Attorney (under the ADMCA) or a Lasting Power of Attorney (under the MCA), the benefits are obvious. If the person is not assessed, they cannot make the chosen arrangement and will not be able to avail themselves of the support provided by the arrangement.

Sometimes, however, the need for assessment is identified by a healthcare professional and the balance of benefit and risk for the person is less obvious. We can distinguish here between two common scenarios. In the first, the person agrees to a proposed intervention but their capacity to consent is in question. Here, a capacity assessment has clear benefits for the person providing the care and treatment in that it provides them with a statutory protection under the MCA and protects them if an adverse outcome occurred and there was doubt regarding the validity of the person's consent. However, the benefit from the perspective of the person being assessed is less obvious. The intervention will proceed whether or not they are found to have decision making capacity, but agreeing to the capacity assessment runs the risk, which they may consider important, that they will not be the decision-maker. In the second scenario, the person does not agree to a proposed intervention but their capacity to refuse consent is in question. Although making an unwise choice should not of itself lead to a presumption of incapacity, it is a common trigger causing capacity to be called into question. If the intention, if incapacity is proven, is to overturn the person's original 'unwise' decision, this should be made clear in seeking consent for the assessment. Answering the 'what's in it for me?' question and seeking to persuade someone to undergo a capacity assessment is going to be 'a hard sell' when the message is in effect: 'if you agree to the capacity assessment and we find you lack decision-making capacity, we will seek to provide the intervention you declined earlier, on the grounds that it is in your best interests (MCA) or for your benefit (ADMCA). Nonetheless, we argue that this information must be provided for valid consent to assessment.

5.2 Absence of Consent

We can distinguish two situations in which consent to assessment is not forthcoming. The first is where the person is unable to consent and the second is where the person refuses to do so We should, however, note at the outset that the distinction between the two may not always be clearcut. We can see this in *Nottingham University Hospital NHS Trust v RL* (2023). RL was a man in his thirties, serving a life sentence for murder. He had exhibited signs of psychosis and had been refusing food to the point where he was severely malnourished. RL had stopped communicating and was described by the consultant psychiatrist for the Trust as 'virtually stuporous and mute' (2023, para. 10). His consultant psychiatrist believed him to be seriously mentally ill and suffering from psychosis. However, although she had met with him many times, save for one very limited

communication, he had not communicated with her at all (2023, para. 9). RL's mother stated that he was a completely changed person and that he had deteriorated greatly and was not engaging with his family. Sir Jonathan Cohen noted that '[h]e simply has made it impossible for anyone to know what his wishes are because he will not express himself' (2023, para. 12). Based on the evidence of RL's consultant psychiatrist and his mother, Sir Jonathan found that, on the balance of probabilities, RL was unable to weigh up the relevant information as part of making a decision (about whether to commence nasogastric feeding) and that he was unable to communicate his decision (2023, para. 12).

The person's inability to consent is addressed in both statutory Codes. The MCA Code states that where a person 'lacks capacity to agree or refuse', the assessment can normally go ahead so long as person does not object to the assessment and it is in their best interests (MCA Code: para. 4.90). The ADM Code states that where the relevant person is not able to consent, the assessor must consider 'whether the assessment is required at this time and if it will benefit the relevant person' taking into account the purpose of the capacity assessment, the seriousness of the decision to be made and the likely consequences of delaying the assessment. If the assessor considers that the assessment is required at that time, and the relevant person does not object to the assessment, the assessor may carry out the assessment if it is for the benefit of the person, encouraging the person to participate as far as possible (ADM Code, para. 5.3.1). We agree that the approach taken by the Codes is a reasonable way to proceed where a person is unable to consent although we suggest that the framing in the ADM Code is preferable, first because it does not begin from the conclusion that the person, who has not been assessed, lacks capacity as the MCA Code does and secondly because it incorporates the question of whether the assessment can be delayed.

The second situation is where the person refuses to have their capacity assessed. Some people do not agree to undergo a capacity assessment (and we suspect that more would refuse if the potential consequences were explained fully and if they understood they had a choice). Both statutory Codes are clear that refusals must be respected. The ADM Code requires that, where a person refuses to consent to assessment, the assessor should try to establish the reasons for the refusal and address any concerns. Beyond this, however, '[t]he assessor should not persist in trying to assess the relevant person but should document the refusal and actions taken in trying to facilitate the assessment' (ADM Code, para. 5.3.3). The MCA Code states that, in cases of refusal, 'it might help to explain to someone refusing an assessment why it is needed and what the consequences of refusal are'. This reference to 'the consequences of refusal' might be seen as one sided and somewhat threatening, especially given that the Code does not similarly require that the consequences of acceptance are explained. Nonetheless, the Code continues with a clear statement that 'threats or attempts to force the person to agree to an assessment are not acceptable' (MCA Code, para. 4.89).

5.3 Responding to Refusal of Consent

A person's refusal to be assessed will leave the professional who proposed the underlying intervention with limited options. Sometimes, the reasonable choice will simply be to accept a person's decision not to be assessed and that this means that the proposed intervention cannot be provided. This may be the case, for example, where the benefits of the proposed intervention are limited and the intervention is clearly contrary to the persons wishes and feelings/will and preferences. However, there will also be situations where the consequence of not providing the intervention are such that it is neither ethically nor legally appropriate simply to let the matter rest.

In considering how to respond to such cases, we must begin with the statutory presumption of capacity (MCA, s. 1(2); ADMCA, s. 8(2)). In *Wandsworth*, Hayden J. emphasised the importance of

the presumption, describing it as central even when applying the lower standard of proof under s. 48 of the MCA(2017: para. 70).In the case in question, the failure to explain the purpose of the assessment to J; the 'superficial and incomplete' analysis of J's understanding and the 'vague and unsatisfactory' reasoning underpinning the conclusions led Hayden J. to find that the presumption had not been rebutted, even on an interim basis (2017: para. 71). Reiterating this point in *London Borough of Tower Hamlets v PB*, Hayden J. was clear that the presumption may only be 'displaced by cogent and well-reasoned analysis' (2020: para. 22). The implications of this for an assessor are drawn out in *AMDC v AG and CI* (2020) where Poole J. identified the requirement that '[a]n expert report should not only state the expert's opinions, but also explain the basis of each opinion', noting that '[t]he court is unlikely to give weight to an opinion unless it knows on what evidence it was based, and what reasoning led to it being formed' (2020: para. 28).

This then leads to the question of what kind of evidence might be relied upon where a person refuses to be assessed. To answer this, we need to look more closely at the nature of the presumption of capacity. Isabel Astrachan and colleagues identify two ways in which the presumption might be understood. With the first, until it is established that the person lacks capacity, it must be presumed that they have capacity. This creates the logical conundrum that 'an evaluation of [capacity] is indicated only where it has already been established' that the person lacks capacity (Astrachan et al, 2023:2). It also allows responsible bodies, such as local authorities, to avoid taking responsibility for vulnerable people on the basis that they must be presumed to be making capacitous choices unless the contrary is established (Astrachan et al, 2023: 2). The second way of understanding the presumption adopts a staged approach. This begins with the default position that the person has capacity and that evidence is needed to 'justify any upset or challenge to this default'. Where this evidence is such that there is sufficient uncertainty about the person's capacity, the presumption is suspended. At this point, there is still no conclusion about capacity. Rather, the assessment continues but without the operation of the presumption. This then allows a determination about the 'truth-value of the presumption's content' to be made. If there is evidence that P has capacity, the presumption is restored; if not, it is rebutted (Astrachan et al, 2023: 3). Astrachan et al argue, and we agree, that this latter understanding of the presumption is the only way to avoid the presumption serving as an ethical and legal dead-end.

Although Astrachan et al do not specifically address the issue of refusal of assessment, their staged approach assists in formulating a way to respond to such refusals. The person refusing must be presumed to have capacity but if sufficient evidence is available such that there is uncertainty about the person's capacity, the presumption is suspended. In some such situations, an assessor may reach a conclusion regarding capacity even in the absence of an adequate assessment. Their expert report should acknowledge when an adequate assessment has not occurred and will still be required to explain the basis of their opinion based on the statutory criteria.

It seems clear that the simple fact that the person did not agree to a capacity assessment should not, of itself, be seen as sufficient to suspend the presumption. As we have set out above, refusing a capacity assessment is an obviously rational choice for some people. If someone is very committed to seeing their underlying decision respected, to being respected as a decision-maker irrespective of the actual underlying decision, or both, it makes perfect sense to refuse a capacity assessment that might lead to the underlying decision being overthrown or to the person not being the decision maker. As Jeffrey Spike describes, one of the paradoxes of capacity is that '[a] patient's defiance and refusal to talk to psychiatry may be prima facie evidence of capacity' (2017: 99). Spike continues by noting that while refusing to talk to psychiatry is not proof of capacity, it is 'certainly more evidence of "understanding and appreciation" of what was going on than evidence of confusion' (2017: 99).

The fact that a person refuses to explain how they used and weighed information in making a choice may be more relevant. It is undoubtedly the case that, as Hurst describes, 'the fact that an ability cannot be assessed does not mean that the patient lacks it' (2005: 1757). Even if it seems clear that the person did not deliberate about a decision and has no adequate reason, for example, if they refuse to hear the relevant information before deciding, this does not necessarily mean they are unable to deliberate or use reason. However, the lack of evidence in this respect may, in some circumstances, be sufficient to suspend the presumption of capacity. This may combine with other evidence, for example, evidence that the person is making an obviously unwise choice. Natelie Banner gives the example of someone at the kerbside who is warned that a lorry was speeding towards him, where there was every reason to believe he hears and understands the warning and who proceeds to step directly into the lorry's path. While accepting the need to avoid 'a strongly prescriptive "ought" that would imply a person is only using or weighing information if he makes a decision seen as "good"', she concludes:

> Without being able to delve into his reasoning, I would judge that this person had failed to use or weigh the information I had given him, because he did not respond to that information in the way that he ought to (taken with the assumption that he had an interest in preserving his own life) (2012: 1040).

One can see that this combination of refusal to engage and an evidently bizarre decision could be sufficient in some cases to suspend and possibly ultimately rebut the presumption of capacity. However, care must be taken not to veer into an outcome-based approach to capacity. The applicable legislation in both jurisdictions statutorily prohibits a determination of lack of capacity 'merely' because a person makes an unwise decision (MCA, s. 1(4); ADMCA, s. 8(4)). And, as Peter Jackson J. (quoted with approval by Hayden J. in *Wandsworth* (2017: para. 49)) identified in *PC and Anor v City of York Council* (2013) 'there is a space between an unwise decision and one which an individual does not have the mental capacity to take and … it is important to respect that space, and to ensure that it is preserved, for it is within that space that an individual's autonomy operates'.

The Irish case of *In the Matter of JD* (2022) provides another possible basis on which the presumption of capacity might be rebutted notwithstanding that the person refuses to be assessed. JD was a 19-year-old man with bipolar disorder and a disrupted family history. He was already subject to a detention order, granted under the inherent jurisdiction of the High Court and the application before the Court sought his admission to wardship[4] and the continuation of detention. JD resisted the application and indicated his desire to live independently. Evidence was provided to the Court of his refusal to comply with his medical regime to manage his bipolar disorder as well as aggressive and sexually inappropriate behaviour toward staff (2022: para 39). Although the ADMCA had not yet come into force at the time of the case, JD's capacity to make decisions in respect of his medication and residence was assessed by the medical experts using the functional standard for capacity in the ADMCA (rather than the all-encompassing standard of 'unsound mind' for admission to wardship).[5] The medical experts disagreed as to whether JD had the capacity to make the

[4] Prior to the ADMCA coming into force (on 26 April 2023), there were two legal mechanisms for formal decision-making where a person lacked capacity: admission to wardship under the Lunacy Regulation (Ireland) Act 1871 and an application to the High Court under its inherent jurisdiction. All new applications for admission for wardship ceased when the ADMCA came into force although proceedings already commenced could be completed: AMDCA, s. 56(3) as ins by Assisted Decision-Making (Capacity) (Amendment) Act 2022, s. 47. The inherent jurisdiction of the High Court is unaffected by the ADMCA: ADMCA, s. 4(5) as ins by Assisted Decision-Making (Capacity) (Amendment) Act 2022, s. 5.

[5] The application of the functional test for capacity in wardship applications had become standard practice in the Irish High Court prior to the coming into force of the ADMCA (Donnelly, 2023).

decisions in question. In making a determination of capacity, Hyland J. looked to JD's behaviour, commenting that:

> Where possible, a court should look not just at the person's identified wishes but also at their conduct in relation to those spheres of decision making. Often, in cases necessitating a capacity assessment, a court will have available to it evidence relating to a person's behaviour in respect of those spheres. Past behaviour may be highly relevant to a capacity analysis (2022: para. 5).

She was also clear about the importance of adopting a subjective approach in reaching conclusion about behaviour, noting 'I must also bear in mind that JD is a young man just having turned 19 and therefore his actions and approach to decisions should be evaluated from that point of view' (2022: para. 33).

Applying this standard, Hyland J. found that JD's actions in failing to take his medication consistently indicated that he did not fully understand the information relevant to this decision, including 'the absolute necessity of him taking his medicine if he is to keep his illness at bay' (2022: para. 76). She reached a similar conclusion with regard to JD's capacity to decide where to live, finding that JD's ongoing engagement in physically and sexually aggressive behaviour indicated that he lacked the capacity to understand, or alternatively to use and weigh, the relevant information that this kind of behaviour would 'torpedo his aim' to live independently (2022: para. 102).

This decision suggests that evidence of behaviour could play a role in determinations of capacity in situations where assessment is refused. However, as with bizarre and unexplained decisions, care needs to be taken not to use behaviour as an alternative to a capacity assessment in cases of refusal. The decision does not support such an approach. Rather, Hyland J. explains 'JD's articulation of his understanding of issues and intentions in relation to same is of course important. However, JD's behaviour is also critically important in determining his capacity' (2022: para. 34). Thus, an evaluation of behaviour is part of and not a substitute for a capacity assessment. It should also be noted that there was an unusually rich body of evidence in this case regarding JD's behaviour over a 20-month period.

6. Conclusion

In this article, we have argued that informed consent is a legal and ethical requirement in formal capacity assessments. This means that a person should be informed in advance of the nature and consequences of the assessment and told that they have a right to refuse to be assessed. We are not aware of any data regarding the extent to which this requirement is observed in practice although we suspect that it is more frequently honoured in the breach. We recognise that the operationalisation of the consent requirement may create practical difficulties for assessors. However, the consequences of a capacity assessment are too important to allow for assessment by stealth. We recognise too that providing information about assessment may result in some people refusing to have their capacity assessed. While this may sometimes have the effect that the intervention does not proceed, we have also argued that refusal of assessment does not necessarily constitute a legal dead-end and that in some circumstances, the presumption of capacity may be rebutted notwithstanding that assessment has not taken place. We have, however, also identified the need for care in such situations to avoid conclusions based solely on outcomes or behaviours.

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