

MENTAL CAPACITY REPORT: HEALTH, WELFARE AND DEPRIVATION OF LIBERTY

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Welcome to the September 2023 Mental Capacity Report, which we think is our largest ever, thanks to judicial hyperactivity over what is usually the (relatively) quiet summer period. Highlights this month include:

- (1) In the Health, Welfare and Deprivation of Liberty Report: the MHA/MCA interface revisited; belief, diagnosis and capacity, and questioning an independent spirit;
- (2) In the Property and Affairs Report: the SRA looks at law firms providing LPA / deputyship services, OPG guidance on completing LPA forms and a shedinar on the MCA and money;
- (3) In the Practice and Procedure Report: transparency in committal hearings and on death, and why belief is not the same as proof when it comes to capacity;
- (4) In the Wider Context Report: the wider MHA context within which many MCA matters arise, the limits of autonomy in medical settings; litigation capacity under the spotlight in both civil and family courts; and the second of our reports from Ireland as the new Act beds in;
- (5) In the Scotland Report: Articles 3 and 2 ECHR in play in the capacity context

You can find our past issues, our case summaries, and more on our dedicated sub-site <u>here</u>, where you can also sign up to the Mental Capacity Report.

We also take this opportunity to bid farewell and thank you to Stephanie David, whose commitments mean that she has to take a step back from the editorial team.

Editors

Alex Ruck Keene KC (Hon)
Victoria Butler-Cole KC
Neil Allen
Nicola Kohn
Katie Scott
Arianna Kelly
Nyasha Weinberg
Simon Edwards (P&A)

Scottish Contributors Adrian Ward Jill Stavert

The picture at the top, "Colourful," is by Geoffrey Files, a young autistic man. We are very grateful to him and his family for permission to use his artwork.

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The MHA/MCA interface revisited – Theis J rolls up her sleeves

Manchester University Hospital NHS Foundation Trust v JS & Others (Schedule 1A Mental Capacity Act 2005) [2023] EWCOP 33 (Theis J)

Mental Health Act 1983 - interface with the MCA

Summary

Theis J has rolled up her sleeves and waded into the thickets of Schedule 1A, hearing the appeal against the decision of HHJ Burrows in Manchester University Hospitals NHS Foundation Trust v JS & Anor [2023] EWCOP 12. In brief terms, she has upheld both the first instance judgment and the test set by Charles J in GJ v The Foundation Trust & Anor [2009] EWHC 2972 (Fam) to be applied by decision-makers to determine whether a person could be detained under the MHA 1983. Whilst much of the judgment turned on an analysis of whether HHJ Burrows had applied the test correctly to the facts of JS's case, of wider relevance are the following parts of her judgment.

Theis J agreed (at paragraph 48) that a useful

structure for practitioners and judges was to answer – in this order – the 'key questions' of:

- (1) Is the person a 'mental health patient'?
- (2) Is the person an 'objecting' mental health patient'?
- (3) Could the person be detained under section 3 MHA 1983? [or I would add, where relevant, s.2]

Theis J was clear that Charles J's analysis of the meaning of 'could' was correct, namely that the decision-maker should ask themselves whether, in their view, the criteria set by, or the grounds in, s. 2 or s.3 MHA 1983 are met (and if an application was made under them a hospital would detain P). The alternative advanced by the Trust of requiring the MCA 2005 decision-maker to defer to the MHA 1983 decision-maker unless their decision is not logical or rational "would probably lead to more uncertainty and risk undermining the purpose of the legislation. Such a development would not be welcome in this area, where the legal landscape needs stability rather than further uncertainty" (paragraph 99)

Theis J identified that a practical step that could be taken in cases where Schedule 1A Case E issues are likely to arise "is for evidence to be provided to address that issue, utilising the GJ framework. That would not only assist the court and the parties, but also focus the minds on what needs to be addressed both in terms of any decisions to date under the MHA 1983, the basis of the application in the Court of Protection and addressing the key questions outlined above" (paragraph 116).

Theis J also endorsed 'practical suggestions' put forward by the Secretary of State for Health and Social Care to address 'stalemate' situations, as follows:

- (1) The MHA and MCA decision-makers should arrange for discussions between the relevant professionals. They should be undertaken in what Ms Kelly describes as 'the spirit of cooperation and appropriate urgency'. This will ensure the relevant professionals have reviewed and considered relevant evidence and if required further inquiries can be made.
- (2) If these discussions do not result in a detention being authorised under the MCA the hospital has a number of choices:
 - (i) It can seek the person's admission under the MHA 1983 to authorise the deprivation of liberty, including on a short term basis while it seeks to advance the person's discharge;
 - (ii) It can seek the person to be detained in an alternative setting, such as a care home, in which Case E has no application with consideration being given to what can be put in place to support the person in the

- community under s 117 MHA 1983 and/or Care Act 2014 duties.
- (iii) It can stop depriving the person of their liberty if it considers the person should not be detained under MHA 1983, even with the knowledge that the person will not be detained under the MCA 2005.
- (3) If the hospital does not consider that an application for assessment or treatment under MHA 1983 is warranted but does consider it is in the person's best interests to be detained in hospital for treatment of a mental disorder, it should consider carefully its reasons for drawing this distinction. The hospital could apply to the Court of Protection for a determination of whether the person is eligible for detention under the MCA 2005.

At paragraph 119, Theis J noted in relation to the last point that she could:

see the sense in the suggestion of an application to the Court of Protection for a determination being a possible route to resolve these issues, but that is not said with any encouragement for such applications to be made unless it is necessary, and only after all other options have been explored. It will be a matter for each individual judge whether such an application is accepted, depending on the particular circumstances of the case.

Specifically in relation to those aged 16 or 17, to whom Schedule A1 does not apply (but to whom Schedule 1A does apply in determining whether or not the Court of Protection can make an order depriving them of their liberty), Theis J identified (at paragraph 123) that the following may provide a guide:

- (1) In any application seeking authorisation to deprive the liberty of a 16 or 17 year old the applicant should carefully consider whether the application should be made in the Court of Protection and, if not, why not.
- (2) If a Schedule 1A Case E issue is likely to arise any evidence filed in support of an application should address that issue, so the relevant evidence is available for the court, thereby reducing any delay.
- (3) In the event that the Court of Protection determines that P is ineligible the professionals should urgently liaise in the way outlined above.

The interface between the MCA and the MHA is a notoriously <u>awful</u> area. Some may find it useful to watch this <u>shedinar</u> where Alex tries to give a way through.

Best interests, life-sustaining treatment and pain

Kings College Hospital NHS Foundation Trust v X and Y [2023] EWCOP 34 (Theis J)

Best interests - medical treatment

Summary

This case concerned an application by Kings College Hospital for permission to withdraw life sustaining treatment from a young man, X, who was 27 years old. The application was opposed by members of his family, with X's father, Y, acting as a family spokesman.

X had been involved in a car accident in January 2023 which had left him with catastrophic brain injuries following a prolonged period of hypoxia. He also sustained damage to his cervical spine and spinal cord. He was resuscitated by

paramedics at the scene of the accident, and admitted to ICU. His treating clinicians, and those from whom they had sought second opinions, considered that he was in a persistent vegetative state (PVS). The Trust considered it was not in his best interests to continue to receive treatment, as they did not consider that there was any prospect of his recovery. The judgment summarises that "[h]e is kept alive by mechanical ventilation, artificial nutrition and hydration and supportive round the clock nursing care involving washing, turning and suctioning of tracheal secretions" (paragraph 2). The Official Solicitor considered that this was a finely balanced case, but ultimately supported the Trust's application.

Y and other family members wanted X to have more time, and felt that X was responding to stimuli, including opening his eyes and moving his head in response to requests. They felt that X would have wished to continue to have life-sustaining treatment, and would wish to "continue to fight to remain with his family" (paragraph 3). The judgment notes the love of X's family, and their mutual devotion to each other. Family members had been granted leave to seek expert evidence, but had ultimately not been able to obtain it, and did not apply to adjourn the hearing to make further attempts to do so.

medical evidence effectively The was unrebutted, and concluded that X had no function above or below his brainstem. The judgment noted that "there is a limited amount of function which controls his blood pressure and heartrate, but there is no ability for him to regain consciousness, or to move again" (paragraph 14). X had been unconscious throughout his time in ICU, and completely dependent on a ventilator to breathe. He had no response on an EEG to painful stimuli, over a six-week period. His pupils had stopped reacting to light and had become fixed and dilated. His physical state appears to have also been negatively impacted, with

medical evidence that "[h]e is colonized with resistant bacteria. His arms and legs are in contractures. He has lost a lot of muscle mass and is not able to move. His skin is fragile and he has developed skin ulcers which are difficult to heal" (paragraph 18). He was considered to have a short life expectancy, and be at risk of infection due to ongoing mechanical ventilation. Second opinion evidence from several specialists (including those who had had sight of videos taken by X's family) confirmed the views of the treating team.

X's family felt strongly that X "would not want to give up on life. He is not the sort of person to let go. Why I say that is because he would say he wants to live for his family, and especially for his children" (paragraph 31). Y produced four videos taken while X was in ICU in which Y felt demonstrated that "X moves his head, following requests to do so from his father, and is able to open his eyes. These videos were taken between the end of May to end of June. He confirms that although X was not a practising Christian he was brought up in the Christian faith, which is important to his wider family and that faith does not support the Trust's application as they believe people should go naturally" (paragraph 32). X's family also felt that he had opened his eyes in response to hearing his grandmother's voice. Y felt that X "has some level of consciousness and disagrees with the assessment that X's pupils are fixed and dilated, he has observed X look at him" (paragraph 34). Y's request was that X "be given more time" (paragraph 35). The evidence of the medical staff was that what his family had seen was "reflexive, and consistent with X being in a The movements are not vegetative state. purposeful discriminating behaviour" or (paragraph 39).

Theis J granted the Trust's application. She accepted the medical evidence that X was in a Persistent Vegetative State, and further accepted

the medical evidence that the evidence relied on by X's family were "spontaneous and reflexive movement which is compatible with a vegetative state, rather than any level of consciousness by X" (paragraph 48). Theis J accepted the strong presumption of sustaining life, and acknowledged that X would likely have wished to be with his family, and that sustaining life would be in keeping with his Christian religious beliefs. Theis J noted that there was no direct evidence that X was in pain, but considered that

51...By definition there are intrinsic burdens to being cared for on ICU and the interventions that are necessary in such care. In this case there is evidence of relative stability in one sense due to the interventions, but there is equally evidence of considerable instability regarding X's condition as part of his care, such as the frequent drops in heart rate.

52. I agree with the final analysis of the Official Solicitor that in the light of the evidence regarding the X's medical condition, his lack of awareness and factoring in the likely wishes he would have to be with his family, the strong presumption of sustaining life and the limited evidence of pain, there is, in my judgment, overall no benefit to X in continuing the treatment, due to his lack of awareness and the bleak medical prognosis. In those circumstances, his best interests are met by the withdrawal of treatment.

Comment

This tragic case includes a helpful discussion of (1) the perceptions of family members that a person is reacting, and the medical evidence as to why this might be occurring; and (2) where a person's best interests may lie where there is no evidence that a person is in pain (an issue covered in some depth in *Guy's And St Thomas'*

NHS Foundation Trust v A & Ors [2022] EWHC 2422 (Fam)). X's family perceived various movements as being reactive to their presence; these were reviewed by a number of specialists, who were consistent in their views that these were spontaneous. The family's evidence (including video evidence) was put before the court, but ultimately (and with the assistance of medical evidence on point) did not persuade Theis J that X was able to react to this surroundings.

What place diagnosis? Learning Disability, deafness and the Court of Protection

TW v Middlesbrough Council [2023] EWCOP 30 (Katie Gollop KC, sitting as a Tier 3 Judge)

Mental capacity – assessing capacity

This case raises an important issue about diagnosis in the context of Learning Disability (the term being capitalised for reasons which will become clear) especially in the presence of profound deafness.

For many years, professionals concerned with a man Katie Gollop KC called 'Tony' had supported him on the basis that he had a mild learning disability. However, in the context of an application determining questions of residence, internet and social media, 1 that diagnosis was called into question by expert evidence provided by Dr O'Rourke, a consultant clinical psychologist, in May 2022 after she undertook psychometric testing and identified that Tony's IQ was in the low average range, meaning that he did not meet one of the three mandatory diagnostic criteria. Conversely, she was equally clear that Tony's ability to understand information relevant to the matters in issue, and to comprehend the consequences of his decisions, meant that in

relation to the relevant matters, he functioned as if he has a Learning Disability.

As Katie Gollop KC identified at paragraph 3, by the time that the application came before the court in June 2023, the parties had had the benefit of MacDonald J's decision in *North Bristol NHS Trust v R* [2023] EWCOP 5 for some months, explaining why a formal diagnosis of a mental health condition or brain injury is not a necessary prerequisite to a finding that a person lacks capacity to make a decision about a matter for purposes of the MCA 2005. However, at paragraph 4, Katie Gollop KC explained that:

that the lack of a formal diagnosis of Learning Disability was actively causing Tony problems in his everyday life. Tony has a long history of using the internet to access images of child sexual abuse. (I am grateful to the Official Solicitor for alerting me to the fact that it is not refer appropriate to to pornography", and that this is the preferred and appropriate term.) The latest discovery of such behaviour was in November 2019 when police were involved and removed three internet enabled devices. Tony's care was transferred to the Council's Forensic Disability Service and its Forensic Social Care Team in around February 2021.

It had been intended that Tony move to 'Placement 2,' a five bedded residential care home exclusively for male adults at risk of coming into contact with the criminal justice system as a result of their offending behaviour. Tony had visited Placement 2 on a number of occasions and expressed a desire to move there. However, Placement 2's registration with the Care Quality Commission required that its service was accessible only by male residents

current placement, but were clearly then reconstituted more broadly.

¹ The proceedings initially started as a s.21A challenge by Tony to the restrictions in place upon him at his

with Learning Disability. In light of Dr O'Rourke's conclusion, Placement 2's position was that it would not accept Tony unless he had a formal diagnosis. Further, Tony's continued access to the Forensic Disability Service was in jeopardy because there was doubt about whether it could properly be said that he has a mental health disability at all.

At the end of the hearing, Dr O'Rourke was asked whether she would endorse a formulation that in the context of having an IQ on the fourteenth centile, Tony has a longstanding impairment of the mind or brain, acquired before his eighteenth birthday as a result of prolonged deprivation of communication, education and life experience, which was best termed "a functional learning disability" (it is not entirely clear whether it was one of the parties, the judge or Dr O'Rourke who came up with this term). She said that she would. This, on its face, appeared to satisfy Placement 2, although it is not entirely clear whether it would also satisfy the Forensic Disability Service. The parties all therefore agreed that Tony lacked capacity in the relevant domains, but Katie Gollop KC agreed to give a written judgment because the evidence revealed "some unhelpful differences of approach to the diagnosis of Learning Disability amongst healthcare professionals, and the case concerns the effect of deprivation on mental development in the context of profound deafness."

This meant giving a pen picture of Tony. He was born with cerebral palsy which affected the movements of his head, trunk and hands in particular. He was also born profoundly deaf. In 2017 he fractured his spine and he had been a wheelchair user since then. He deployed a variety of methods of communication including British Sign Language, some Makaton, and other

signs of his own devising which supplemented with occasional written notes. He had some useful speech sounds and lip patterns. He therefore had some communication with hearing people generally, but opportunities for exchange of information and development of understanding were better with someone who had some BSL qualifications, and optimal with a person who was BSL fluent. He had been placed into care of the local authority by his parents when a small baby; and between birth and the age of 20, went to nurseries and schools as far apart as Leeds, Sussex, Kent and Clwyd, Wales. Though he was taught a form of signing, all of these establishments were for hearing children because priority was given to meeting his physical rather than his communication needs. Tony therefore grew up with no exposure at all to his deaf peers. When he went aged 20 to live in a facility for deaf people, he was described as lacking an identity.

Issues around Tony accessing images of child sex abuse started in 2014, and included, in 2021, assessing by a group of professionals from the Adult Learning Disability team, including an interpreter and a social worker who knew him well and who was able to sign, completed an assessment of his capacity to use the internet. The group agreed that he was unable to understand and weigh up the consequences of looking at such images and took the view that functionally he had a learning disability. The police were involved and a COP9 application form recorded in the judgment stated that Tony was served with a Sexual Risks Order² and that there were court hearings.

Dr O'Rourke, an expert in the field of mental health and deafness, assessed Tony's capacity in accordance with the 2015 <u>Guidance</u> on the

on him by the Sexual Risk Order, because they should only be granted where this is the case.

² Parenthetically, it would have been interesting to understand whether there had been consideration of whether Tony could understand the conditions placed

Assessment and Diagnosis of Intellectual Disabilities in Adulthood published by the British Psychological Society ("the BPS Guidance"). As Katie Gollop KC identified at paragraph 17.

Of note is the fact that the BPS Guidance deprecates the use of screening tools, and reliance on just one part of the assessment process. Further, recommends that "a judgement as to whether or not an individual has an intellectual disability should only be made when all three components of the assessment are carried out by an appropriately qualified professional, who is able to justify their opinion in accordance with this guidance. This would reduce confusion for individuals, families and services." The appropriately qualified professional will be a psychologist.

The three criteria necessary to an assessment of learning disability are:

- a) a significant impairment of intellectual functioning; and
- b) a significant impairment of adaptive behaviour (social functioning); with
- c) both impairments arising before adulthood.

Dr O'Rourke's conclusions on capacity in her initial report were that:

- a) Tony's nonverbal skills were within the normal range;
- b) however his acquisition of knowledge and skills was poor as a result of deafness leading to lack of access to information and learning;
- c) that lack of access is not unusual among deaf people but it had been exacerbated in Tony's case as a result of him being in schools for hearing children in his formative years and thus without access to

- effective communication with his peers;
- d) consequently, he had poor understanding of matters that would be understood by most individuals with his nonverbal skills
- e) that inconsistency was explained by educational and experiential deprivation, not organic impairment;
- f) the fact that his intellectual potential was within the normal range raised the question of whether the diagnostic test of the MCA was met.

In July 2022, Dr O'Rourke provided answers to questions put by the parties. By this time, she had had access to additional records and the 2014 WAIS scores. She explained that on proper analysis of the 2014 test results, and when she administered the updated tests in 2022, he scored in the low average range for IQ, on the fourteenth centile, and therefore did not meet the criteria in the BPS Guidance for a diagnosis of Learning Disability. She elaborated on this: "The fact that he can learn computer skills, adapt his signing to meet my needs, understand humour and answer questions involving 'why?', all support the notion that he does not have a learning disability. However, there are clear deficits in understanding of more abstract and complex matters and impairments in adaptive functioning, most notably a lack of insight into his own needs and matters concerning risk." She went on to say that "this discrepancy and his very obvious difficulties in adaptive functioning are a result of lack of access to formal and incidental learning, lack of opportunity and impoverished linguistic environments which did not afford him the opportunity to develop."

As Katie Gollop KC noted, two other clinicians considered that Tony could be diagnosed with a Learning Disability, the first being a GP assessing him as part of the DOLS process (but who then

backed down advising that it was not within her expertise to make a diagnosis of Learning Disability), and the second being a psychiatrist, who diagnosed a mild Learning Disability, although with an explanation of how he reached that conclusion. This led Katie Gollop KC to comment that:

26. The reported diagnoses of the GP and psychiatrist, in the face of Dr O'Rourke's assessment of IQ, are important because they illustrate the confusion identified by the BPS Guidance, and the pertinence of the recommendations it makes with regard to the need for assessment of Learning Disability to be made by a trained psychologist in accordance with the Guidance. When Dr O' Rourke was asked how she thought it was that a GP and a psychiatrist disagreed with her expert opinion, she said that in her experience most (though not all) psychiatrists are not trained to administer the WAIS tests. and may not be fully cognisant with or fully appreciate them their significance.

27. It may be that some healthcare professionals assume an IQ below 70 where the adaptive behaviour criterion is clearly met. Alternatively, there may be a linguistic issue. The term "learning disability" may be being used as a descriptor of functional incapacitous decision making, without an intention to connote a formal diagnosis. Whatever the explanation, the present case demonstrates there will be occasions when P's welfare is compromised if there is confusion about whether all three criteria are met, and a lack of robust evidence supporting diagnosis. Further, if the practice of referring to a person provided with adult social care as having "mild learning disability" where that person's IQ is properly assessed as being over 70 is widespread, that practice may undermine the validity of the diagnosis. It may mean that the potential of people who have the capability to gain capacity is not being maximised, or that their strengths and weaknesses are not being analysed in the way envisaged by the BPS Guidance (see paragraph 5.7) with deleterious effect. It may perhaps be helpful if healthcare professionals recording that a person has a learning disability (with or without capital letters) go on to state whether that assessment is "within BPS Guidance" or "outside BPS Guidance".

On the basis of the evidence before her, Katie Gollop KC expressed herself satisfied that Tony lacked capacity in the relevant domains, and in relation to each decision:

30. [...] the inability exists by reason of an impairment in the functioning of his mind or brain. The impairment, which operates as a functional learning disability, is the result of stunted mental development, occurring before the age of 18 years, as a result of prolonged deprivation of communication. education, social learning and life in combination experience, institutionalisation. That impairment renders Tony unable to understand why accessing images of child sexual abuse is wrong, the potential consequences for him if the police are involved, and the harm caused to children directly and to wider society indirectly by his actions when he is allowed unrestricted, unsupervised internet access.

Amongst the orders that Katie Gollop KC made in consequence were:

33. [...] interim orders which permit support workers to supervise Tony's access to the internet and social media, and prevent him from accessing images of child sexual abuse, or any other material they consider may be illegal or

which may make those viewing or possessing the images liable to criminal prosecution. I declined to accede to the Official Solicitor's application to bring what were described as "crime adjacent" images of children within the ambit of that interim order. I was told that in the past, when Tony has access to a device with software that prevents him from accessing images of child sexual abuse, he may seek out pictures or video of, for example, children in swimming costumes in a paddling pool. It appeared to me that viewing or possession of such images may not be unlawful, that such a measure could be unduly restrictive, and in any event may be difficult to justify in circumstances where Tony is currently choosing not to use a screen at all whilst supervised. This is a matter that is properly ventilated and determined at the final best interests hearing, where a proposed Care Plan is likely to be available.

Comment

Amongst the many troubling issues that the case shines a light on is the 'gatekeeping' function of diagnosis as access to services. Debates about whether or not diagnoses are 'valid' or 'stigmatic' are vigorous and very heated. But for so long as services are diagnosis-based, as this case illustrates, not having a formal diagnosis can be as problematic as having one. And, indeed, it is not entirely clear whether such matters as access to the Forensic Disability Service were going to be solved in Tony's case by the judge's ingenious creation (or endorsement) of a concept of 'functional learning disability.'

The case also highlights the vital, and potentially disabling, role of environment. Had Tony been brought up in an environment which responded to his communication needs, it is likely that the picture before the court regarding his capacity would have been very different – indeed, it may

well have been the case that his circumstances would have been sufficiently different that court involvement simply would not have been needed.

When does disbelieving your doctor shade into incapacity? And what place diagnosis in the MCA test?

An NHS Trust v ST & Anor [2023] EWCOP 40 (Roberts J)

Mental capacity – assessing capacity – medical treatment

This desperately sad provides an example of how far the courts have come in terms of thinking about capacity since the early days of the MCA 2005, and poses some perhaps challenging questions about its future. ST was 19, and had spent the past year as a patient in an intensive care unit. She had a rare mitochondrial disorder which is a progressively degenerative disease. According to the clinical evidence before the court, there was no cure which might have enabled ST to resume her life outside the clinical setting of the intensive care unit. She was mechanically ventilated through a tracheostomy. She was fed through a percutaneous endoscopic gastrostomy tube and was undergoing regular haemodialysis. Her disease had resulted in a number of related health problems including impaired sight and hearing loss, chronic muscle weakness, bone disease and chronic damage to her kidneys and lungs. The collective view of her treating team was that ST was in, or was fast approaching, the final stage of her life.

Her treating Trust's plan was to move to a treatment plan of palliative care. That path would involve a much less invasive regime for ST. Dialysis would end and there would be no further attempts to resuscitate her in the event of a further major respiratory arrest such as had already occurred twice. As Roberts J identified at paragraph 2 of the judgment:

Her treating clinicians are keenly aware of the need to involve ST as far as possible in how she would wish to be cared for and what steps might be taken to ensure that her last days or weeks of life were as comfortable and pain-free as possible. In preserving respect for her personal autonomy to make these choices, they have met with a fundamental obstacle which, on the case advanced by the Trust, is her apparent refusal or inability to accept that her disease will result in her early, if not imminent, death. It is that inability, or "delusion", which the Trust relies on as rendering her incapacitous to make decisions for herself [in relation to future medical treatment].

The questions before the court were (1) whether that was the case, and (2) whether ST had capacity to conduct the proceedings.

As Roberts J further identified at paragraph 4:

At the heart of the issues in this case is what ST and her family perceive to be a ray of hope in the form of an experimental nucleoside treatment outside the United Kingdom which might offer her hope of an improved quality of life, albeit a life which is likely to end prematurely in terms of a normal life expectancy. She has told her doctors that she wants to do everything she can to extend her life. She said to Dr C, one of the psychiatrists who visited her last week, "This is my wish. I want to die trying to live. We have to try everything". Whilst she recognises that she may not benefit from further treatment, she is resistant to any attempt to move to a regime of palliative care because she wants to stay alive long enough to be able to travel to Canada or North America where there is at least the prospect that she may be accepted as part of a clinical trial.

Unusually, perhaps, the Trust sought to advance the case that ST lacked capacity in the material domains in the face of evidence from two psychiatrists involved (there independent experts instructed). Both the liaison psychiatrist involved in ST's case and a consultant psychiatrist instructed by the Trust considered that ST had capacity to make decisions about her future medical treatment, and neither considered that ST had an impairment of or disturbance in the functioning of her mind or brain. However, the consultant leading her care, Dr A, whilst accepting that he could find no evidence of psychological disturbance or brain damage, was concerned that "she is unable to weigh up the pros and cons of what he described as 'a dignified death'. As such he believes that she is suffering from a delusion which derives from a false reality in that she cannot contemplate her own death" (paragraph 31).

As Roberts J identified, the starting point was the decision that ST had to make, and the information relevant to that decision, which at paragraph 77 Roberts J set out as being:

- (i) the nature of her disease and the fact that her disease is responsible for the deterioration in her respiratory condition;
- (ii) the assessment of her medical team as to prognosis;
- (iii) the available options in terms of active treatment including the likelihood of that treatment being available and its chances of success;
- (iv) the fact that a small insult arising in the course of her care or management or the further development of her disease (such as another respiratory arrest) may cause potentially fatal clinical instability.

She then made clear that she considered that:

78. In terms of the functional test of capacity, a person's ability to understand, use and weigh information as part of the process of making a decision depends on him or her believing that the information provided for these purposes is reliable and true. That proposition is grounded in objective logic and supported by case law in the context of both the common law and the interpretation of MCA 2005.

The case law Roberts J referred to was *Re MB* (Medical Treatment) [1997] 2 FLR 42, Local Authority X v MM [2007] EWHC 2003 (Fam) and Leicester City Council v MPZ [2019] EWCOP 64, Roberts J noting at paragraph 83 that:

Whilst it is clear that the strict terms of the MCA 2005 omitted a 'belief' requirement from the wording of ss. 2 and 3, it is clear from Local Authority X v MM that the approach taken by Munby J subsumes the requirement for belief the statutory limbs of within understanding, using and weighing as part of the decision-making process. In this context, and in terms of a patientcentred approach, it is important in my judgment for the court to consider the extent to which the information provided to a person is capable of being established objectively as a "fact" or a "truth". The less certain the fact or truth, the more careful the court must be when determining whether the presumption of capacity is rebutted.

Applying this to the facts of ST's case, Roberts J continued:

84. In this case I accept that ST is aware of the nature of her disease in terms of it being a mitochondrial depletion syndrome which is rare. She knows that she is one of few people in the world to have the disease. I further accept that

she knows the disease by its nature is progressive and she recognises that, at some point in the future, she may succumb to its effects and die. What she fails to understand, or acknowledge, is the precariousness of her current prognosis. She does not believe that her doctors are giving her true or reliable information when they tell her that she may have only days or weeks to live. She refuses to contemplate that this information may be true or a reliable prognosis because she has confounded their expectations in the past despite two acute life-threatening episodes in July this year and because she has an overwhelming desire to survive. whatever that may take.

85. As to the 'truth' or reliability of the information which ST is being given by her doctors, I am quite satisfied on any objective basis from the body of medical evidence before the court that it is the mitochondrial disease which is causing the progressive failure of her respiratory muscles and the general deterioration in her overall condition. It is not the residual after-effects of long-Covid as ST believes it to be.

86. Because she clings to hope that her doctors are wrong, she has approached decisions in relation to her future medical treatment on the basis that any available form of treatment is a better option than palliative care which is likely to result in an early death as active treatment is withdrawn. In my judgment she has not been able to weigh these alternatives on an informed basis because (a) she does not believe what her doctors are telling her about the trajectory of her disease and her likely life expectancy, and (b) she does not fully comprehend or understand what may be involved in pursuing the alternative option of experimental nucleoside treatment. Whilst I accept that she recognises that it may not be

successful in terms of the outcome which she wishes to achieve, she has failed to factor into her decision-making that there are, as yet, no concrete funded offers of treatment, far less offers which might offer her even the smallest prospect of a successful outcome.

In the circumstances, Roberts J found:

93 [...] ST is unable to make a decision for herself in relation to her future medical treatment. including the proposed move to palliative care, because she does not believe the information she has been given by her doctors. Absent that belief, she cannot use or weigh that information as part of the process of making the decision. This is a very different position from the act of making an unwise, but otherwise capacitous, decision. An unwise decision involves the juxtaposition of both an objective overview of the wisdom of a decision to act one way or another and the subjective reasons informing that person's decision to elect to take a particular course. However unwise, the decision must nevertheless involve that essential understanding of the information and the use, weighing and balancing of the information in order to reach a decision. In ST's case, an essential element of the process of decision-making is missing because she is unable to use or weigh information which has been shown to be both reliable and true.

Roberts J accepted the proposition advanced by the Official Solicitor that "an individual who expresses hope that they will survive, or even a belief based on that hope, does not, without more, become incapacitous simply because they disagree with the medical advice they are given." However, on the facts of the case before her, Roberts J found that:

94. [...] ST's fundamental distrust in, and refusal to accept, the information she is given by her doctors as to the likely timescales of her deterioration, do not simply operate to impair her ability to make a decision. They prevent her from understanding, using and weighing the information in the context of the options available to her in terms of future care planning. Dr A expressed himself to be entirely open to discussing these options with ST. Indeed, he saw it as an essential part of the care he was providing as her lead treating clinician. She was unwilling to engage with him at all on the subject because she does not trust the information he has given her. Dr D [the liaison psychiatrist] did not raise with ST the question of alternative options and what palliative care might look like in terms of an alternative. Dr C [the consultant psychiatrist] confirmed in his evidence that ST was unable to weigh up any decision about palliative care because she failed the functional test

That then brought Roberts J on to consider whether ST's inability to make the decision was caused by an impairment of or disturbance in the functioning of her mind or brain. Roberts J, relying on the observations of MacDonald J in *North Bristol NHS Trust v R* [2023] EWCOP 5, reminded herself that:

97. That issue is a question of fact for the court to determine. The wording of s.2(1) MCA itself does not require a formal diagnosis before the court can be satisfied as to whether an inability of a person to make a decision in relation to the matter in issue is because of an impairment of, or a disturbance in the functioning of, the mind or brain. This test is not further defined in the Act. As the court made clear in the North Bristol NHS case, to require a specific diagnosis would not only be undesirable, it would constrain the application of the

Act. The court, instead, is fully entitled to have regard to the wide range of factors that may act in any individual case to impair functioning of the mind or brain and, most importantly, to the intricacies of the causal connection or nexus between lack of ability to take a decision and the impairment in question (see paragraph 47). There is thus no requirement for the court to be able to formulate precisely the underlying condition or conditions which constitute the impairment.

It was accepted, Roberts J further reminded herself, that ST did not suffer from any recognised psychiatric or psychological illness. However, having reviewed the evidence before her, Roberts J continued:

103. In my judgment, and based upon the evidence which is now before the court, I find on the balance of probabilities that ST's complete inability to accept the medical reality of her position, or to contemplate the possibility that her doctors may be aiving her accurate information, is likely to be the result of an impairment of, or a disturbance in the functioning of, her mind or brain. Her vulnerability has been acknowledged by Dr C. I need no persuading that she has been adversely impacted by the trauma of her initial admission to hospital. That trauma is likely to have been exacerbated by the length of her stay in the ITU unit. Her brother acknowledges that she has been surrounded by patients dying around her on the unit as the months have gone by. Whilst she has been sustained by the near continuous presence of her mother and, to a lesser extent, the other members of her close family, she has endured almost a year of intensive medical and surgical intervention which has been both painful and distressing for her. She is frightened by the prospect of dying and clings to her desire to

survive what her doctors have repeatedly told her is an unsurvivable condition. The cumulative effect of her circumstances over such a prolonged period, her profound inability to contemplate the reality of her prognosis, and a fundamentally illogical or irrational refusal to contemplate an alternative are all likely to have contributed to impaired functioning notwithstanding resilience which ST has displayed in her determination to carry on fighting. It is not necessary for me to seek to further define the nature of that impairment. I am satisfied that it exists and that it operates so as to render her unable to make a decision for herself in relation to her future medical treatment.

The Official Solicitor was clearly concerned about such an approach, submitting that "the Trust's reliance on the same beliefs which impair ST's decision-making ability under the first limb of the test in s.2(1) MCA to found the existence of an impairment under that section is circular and undermines the importance of the second question in s.2(1)." However, Roberts J identified that:

104. [...] In my judgment that is to misunderstand the Trust's position and the basis of my finding that, on the balance of probabilities, the impairment functioning has ST's been established. It is not simply the failure to believe the advice she is receiving and thus her inability to understand, use and weigh information in the decisionmaking process which informs the finding of impairment. It is informed by a holistic evidence-based overview of ST's lived experience on the ITU and the trauma she has suffered as a result of the intensive treatment she has required over the past twelve months. That trauma has manifested itself in acute episodes of distress and anxiety and a presentation which suggests a hypervigilant state where she is continuously watching for her mother and requiring her constant support on an almost daily basis.

Roberts J found that she could not see what further steps could be taken to help ST to make a decision, such that future decision-making must take place on a best interests basis.

The second question before the court was as to ST's capacity to conduct the proceedings. ST was represented by the Official Solicitor, but also present in court were leading and junior counsel who were instructed directly by a solicitor on ST's behalf as (as Roberts J described them at 9) her 'informal' paragraph as legal representatives. They cross-examined the medical witnesses and made final written submissions in relation to ST's capacity to make the substantive decisions required of her and to conduct the proceedings. As matters turned out, the final position of the Official Solicitor and the position of ST's informal representatives were more or less aligned. Given Roberts J's conclusions as to ST's capacity to make decisions about her medical treatment, however, she could not allow the quantum indeterminacy position of representation to continue, and had to make a determination as to whether, in fact, ST had or lacked litigation capacity. Her conclusion was clear:

106. Despite the view of Dr C and the position urged on me by Mr Garrido KC and Mr Quintavalle [ST's informal representatives], I am satisfied that this is a case where ST lacks capacity to litigate without the assistance of a litigation friend. Capacity to litigate includes not only an understanding of the issues in the case but an ability to understand, use and weigh the arguments on the evidence so as to give instructions in relation to the arguments of other parties who may take an opposing position. Given my findings in

relation to subject matter capacity, it is difficult to conceive of circumstances where ST might be said to have full litigation capacity but lack subject matter capacity. I am concerned about the lack of information in which Mr Foster of Moore & Barlow came to be instructed and whether the origin of that instruction was ST herself or her family. I offer no criticism of their involvement in this hearing. They attended at the invitation of the court in order that the court might have the benefit of full argument. In that respect. attendance of Mr Garrido KC and Mr Quintavalle at this hearing has been of considerable assistance to the court.

Comment

It is important to emphasise that the decision in this case was fact-specific, and it should not be read (as the Official Solicitor was clearly concerned that the approach adopted could be read) as equating to the simple formula: "patient believes what doctor is saying => patient has capacity; patient does not believe what doctor is saying => patient does not have capacity." However, Roberts J's observations about the continuing importance of the concept of belief within the structure of the functional test contained in the MCA are of wider relevance: see further here for more on how the language of the MCA maps onto clinical and social work realities.

Some might well be challenged – as it appears was the Official Solicitor – by the approach taken to the so-called (but, as this case shows, entirely inaccurately so-called) 'diagnostic test.' It is entirely understandable that, having reached a conclusion that ST could not – functionally – make the decisions required of her, Roberts J sought then to explain why that was the case within the four walls of the MCA 2005. The alternative (as the liaison psychiatrist, Dr D, appears to have considered) would have been to identify that this was a case falling within the

scope of the inherent jurisdiction. At that point, however, very difficult questions would have arisen as to the circumstances under which it would have be legitimate to deploy the <u>inherent jurisdiction</u> of the High Court to make decisions in relation to medical treatment in circumstances where it could not be said (on the face of the material recorded in the judgment) that ST was subject to undue influence or coercion.³

It is therefore entirely understandable why Roberts J sought to bring the case within the scope of the MCA 2005. At that stage, it is one thing to say that there does not need to be a formal diagnosis before the court (or indeed anyone else) can reach a conclusion that someone lacks capacity for purposes of the MCA 2005. However, Roberts J appeared to be (and I would say rightly) aware that she was engaged in a sensitive task of, in effect, having to set out a formulation of an impairment / disturbance⁴ in the face of clinical evidence that one did not exist. It would be interesting to speculate whether the involvement of a psychologist would have assisted here in terms of clarifying matters. And, to reiterate, her conclusions were fact-specific, and did not represent a general invitation simply to 'invent' an impairment or disturbance in difficult situations.

More broadly, the case does throw into sharp relief the question of the place of the 'diagnostic' test – a test which has been abandoned by the Republic of Ireland in its newly implemented Assisted Decision-Making (Capacity) Act 2015. Its history and purpose is summarised in section V of this <u>article</u>, but, as the article suggests, revisiting that test must be a matter for Parliament, rather than the courts.

Finally, in relation to litigation capacity, it is very unusual indeed, but on the facts of this case clearly an appropriate exercise of the court's wide case-management powers, to have a situation in which P has both 'formal' and 'informal' representation. One anticipates that this would not have been a step that the court had been taken had there not been evidence before it to suggest that there was at least an arguable case that P had litigation capacity.

Dialysis and different realities – the Court of Protection has to decide

Nottingham University Hospitals NHS Trust v JM & Anor [2023] EWCOP 38 (Hayden J)

Best interests - medical treatment

Hayden J has helpfully reminded us of the fact that a person with cognitive impairments may be operating within a very different reality to everyone else does not mean that it is a reality which can simply be ignored.

The case concerned a 26 year old man, JM, who was diagnosed as autistic at the age of 5, but had received very little support for it. His childhood experiences were described by Hayden J as having been characterised by trauma. He was diagnosed with chronic kidney disease in January 2021 and had acquired Thrombotic Thrombocytopenic Purpura ('TTP'). He required regular at least 4 hourly sessions of haemodialysis for a minimum of three times per week. The clinical consensus was that JM would die within 8-10 days if he did not receive treatment.

JM did not accept a diagnosis of chronic kidney disease or his need for dialysis. His mother –

evidence before the court summarised in the judgment, to have many of the features of 'adjustment disorder.'

³ Although see <u>here</u> for an examination of how subtle interpersonal influences might be.

 $^{^{\}rm 4}$ At the risk of engaging in remote (and lay) diagnosis, it might be thought that ST's presentation had, on the

who had been diagnosed with schizophrenia – did not accept this either. Hayden J noted in this regard (at paragraph 4) that, "though they share the same view, which is irrational, Dr C [the independent psychologist] is persuaded that they each independently hold the same view and JM's belief structure has not been superimposed upon him"

In the context of proceedings relating to the future placement of JM, the matter was restored urgently to court, JM having been found in bed at home covered in blood from his dialysis line, there being "very little doubt" that it was JM himself who had cut the line. The line was removed, and JM refused have a replacement line inserted.

Capacity not being in issue, the question was what steps it was in JM's best interests to take. Hayden J's analysis was sufficiently crisp but nuanced that it requires (to use one of the judge's catchphrases) to be set out in full:

The situation for JM has progressively deteriorated. I remind myself that in early 2023 when JM was clinically stable in hospital, the proceedings were concerned with finding a placement from which he could be encouraged to attend for dialysis three times per week. The situation is plainly now far graver. Restraining JM to reinsert a new dialysis line against his will might in and of itself be justifiable. However, JM's objection is not merely to the reinsertion of the line but to the life sustaining dialysis it would provide. It follows, inevitably, that the restraint required for the reinsertion would be a harbinger for repeated and extensive restraint on a weekly basis and indefinitely. JM's erratic compliance and distorted thinking, now over many months, effectively discounts him, I have been told, from eligibility for a donor organ. Such transplant would

need compliance with a fairly rigorous regime of support which is very unlikely to be complied with. Moreover, that too may involve an extensive period of haemodialysis.

44. JM's belief system in respect of dialysis is so plainly distorted as to manifestly rebut the presumption of capacity, erected by the MCA 2005. However, even though his reasoning is unsound, JM's confidence and belief in his own judgment is well-established and as the chronology of the case has demonstrated, unmoveable. The fact that an individual's views may be misconceived does not, however. deprive him of the right to hold them. To approach this otherwise particularly discriminate against the incapacitous, as well as more generally. JM's views on dialysis arise from the complex interplay of his psychological functioning and his life experiences. This is no doubt true for all of us but in JM's case, both are disordered. The nature and extent of JM's autism coupled with the extent of trauma that he has endured, serves to disable him from processing his thoughts and experience in an effective way. Nonetheless, JM's own reality, even though it greatly differs from ours, requires to be respected. It is in this way that the autonomy of the incapacitous is respected. That does not mean that their views prevail but it does mean that they must be afforded weight. As I have set out above [in North West London Clinical Commissioning Group v GU [2021] EWCOP 59], "human dignity is predicated on a universal understanding that human beings possess a unique value which is intrinsic to the human condition".

45. For the reasons which I have set out, I am clear that forced restraint either in the face of JM's expressed opposition or at a time when he is no longer able to

resist, would compromise his dignity. By agreement and because Roberts J had previously met with JM on a number of occasions, I spoke with him on a private video link from which the public and lawyers were excluded. The solicitor for the Official Solicitor took a note. With outstanding efficiency, the note was available to the parties within 20 minutes of my concluding the meeting. Judges, I suspect, vary greatly in their approach to meeting with P. Video conferencing platforms have changed the landscape. It seemed to me, ultimately unthinkable, that I should not meet with JM and tell him the important decision I had made. I found him, as has everybody else involved in his care, to be a very pleasant young man. His conversation with me reinforced Dr C's assessment of him. As both Dr F and Dr C have said, JM does not want to die. When I told him of my decision and the fact that he would die, he told me without prompt or question that he did not want to. I formed the impression that he very much wanted to live. Ultimately, all I could do was tell him that the decision was his.

Hayden J also expressly paid tribute to the doctors and nursing staff, as well as JM's mother and sister, noting in respect of JM's mother that, though she "struggles to understand the realities of JM's situation due to her own mental health difficulties, she has an impressive and, I sense, strongly maternal instinct that the use of restraint to compel dialysis would be inimical to his welfare. Those instincts, to my mind, are sound and also require to be factored in to this decision" (paragraph 46).

⁵ The language used in <u>General Comment 1</u> on the right to equal recognition before the law contained in Article 12 CRPD. Pedantically, Article 12(4) talks of the need for measures relating to the exercise of legal capacity to respect the <u>rights</u>, will and preferences of the person. It

Comment

We anticipate that paragraph 44 may well be quoted to and by other judges in the same way as the earlier, pithy observation of Peter Jackson J (as he then was) in the Wye Valley case that in some cases "the wishes and feelings, beliefs and values of a person with a mental illness can be of such long standing that they are an inextricable part of the person that he is. In this situation, I do not find it helpful to see the person as if he were a person in good health who has been afflicted by illness. It is more real and more respectful to recognise him for who he is: a person with his own intrinsic beliefs and values. It is no more meaningful to think of Mr B [the subject of that case] without his illnesses and idiosyncratic beliefs than it is to speak of an unmusical Mozart."

More broadly, the concept of 'best interests' is often challenged, especially by those associated with the Committee on the Rights of Persons with Disabilities, as being code for medical paternalism, as well as a licence (if, indeed, not even a mandate) to discriminate against those with cognitive impairments. It is against this backdrop that calls are made to base all decisions upon the autonomy, will and preferences⁵ of those with disabilities. There is no doubt that it is all too easy to point to decisions made up and down the country on a best interests basis that merit the strong criticism leveled against the concept. However, in line with the clear trend in the case-law of the Court of Protection, this decision shows that the concept is capable of being interpreted in a very different way. If the decision is constructed outwards from the person, on the basis of their reality, it is difficult to see how the end result

is not obvious that 'autonomy' is synonymous with all the rights that are guaranteed by the CRPD. For more about the CRPD, we strongly recommend the work of Lucy Series.

does not comply with the requirement of Article 12 CRPD that it respects their rights, will and preferences.

When should questioning an 'independent spirit' stop? Capacity, contact and the limits of the inherent jurisdiction

Re RK (Capacity; Contact; Inherent Jurisdiction) [2023] EWCOP 37 (Cobb J)

CoP jurisdiction and powers – interface with family proceedings – mental capacity – assessing capacity

Summary⁶

The case name helpfully captures what this difficult case was about. It concerned RK (identified in the body of the judgment as 'R'), a 30 year old woman with Down's Syndrome, a moderate to severe learning disability (described in the documents as a significant cognitive impairment), who was partially sighted. She had a full-scale IQ of 60, and had some expressive and receptive communication difficulties. She was also an accomplished swimmer, having competed national and European championships and actor (she had been on national TV in a well-known series). R lived in supported living accommodation called (for purposes of the judgment) 'Castle Hill,' her care needs being provided by a provider identified for purposes of the judgment as 'Signia,' contracted by the relevant local authority, XCC.

Cobb J had previously made determinations that R lacked capacity to litigate, and to manage her property and affairs, but that she had capacity to engage in sexual relations, to make the decision to remain at Castle Hill, and to make decisions about what support she needs on a day-to-day basis with an adequately supported

environment. He was now asked by R's family to declare that she lacked capacity to make decisions about contact, that she was susceptible to undue influence, and measures need to be put into place to protect her from this; and that she lacked capacity to revoke the LPA created in respect of property and affairs and health and welfare. In the alternative, if he found that R had capacity to make decisions about contact, he was asked to make an order under the inherent jurisdiction in relation to supporting contact between her and her family. R's family, in essence, wanted to have implemented a supportive framework to encourage R to repair and maintain her relationship with her immediate and wider family and friends.

In support of their application, R's family sought unsuccessfully to persuade Cobb J to embark on a fact-finding inquiry, but 'inevitably' had regard to some of the factual issues set out in a 73-page schedule of proposed facts which they argued required determination. The length of the schedule gives a clue to the long and difficult prehistory of the case, set out in considerable detail in the judgment. To summarise very crudely, R had lived at Castle Hill since 2015 and, between 2015-2020, arrangements had run smoothly and the family were able to work reasonably well with Signia. Matters became problematic when at some point in 2018 or 2019 R formed a relationship with a male resident at Castle Hill, SA (a relationship which was now said to be at an end). As Cobb J noted at paragraph 18:

The relationship generated no small amount of anguish for R's family, and their concerns about it led to dispute with Signia. R was clear that SA made her feel happy; whilst she may not have been able to articulate the intricacies of this relationship, she recognised and

⁶ Tor was involved in the case, but has not contributed to the summary or comment.

responded to the emotional value this relationship brought her. Those supporting them believed them to have a loving and nurturing relationship from which they both equally benefited. The anguish focused on whether R had capacity to engage in sexual relations with him.

The relationship between the family and Signia then broke down entirely during the lockdown, when R could not be persuaded to leave Castle Hill in the face of her family's desire for her to return home to live with them, having spent some time there at the start of lockdown. Matters went from bad to worse, as detailed by Cobb J, but crucially (at paragraph 22):

From about this time, R ceased contact with her parents; she left the family WhatsApp group (something which the family do not believe she could have done without help), and rarely (if ever) responded to text or e-mail messages. She initiated no contact with her family, and made herself unavailable if family members or friends called in at Castle Hill unannounced; she cancelled prearranged visits. The family say that she missed all of the family birthdays, something which she would generally not have done.

Contact was never resumed, despite mediation, and – as is sadly often the case – allegation followed allegation about the care provider, as well as R's family raising a safeguarding alert with the police including alleged financial abuse and concerns about sexual abuse, leading to a visit by two police officers to speak to R and SA (a step that it is clear that R's family had not anticipated, and were troubled by). In Autumn 2020, R also stopped the range of activities that she used to enjoy, including 1:1 piano lessons, swimming, a drama group and attending a project which offers a range of activities including drama (the latter two had continued

online during lockdowns); the family believed that this – again – was the result of pressure from Signia.

Cobb J identified that he was satisfied that from all that he had read that R "fundamentally loves her family, and wishes to be a part of the family" (paragraph 75), but:

76. That said, she has for some time (probably since the late summer of 2020) been steadfast – at least in her discussions with Signia staff with whom she has her most regular relationship – that she does not want to see her parents. I find that she is currently highly conflicted in this regard. Dr McKay described her as "ambivalent". R's independent advocate for the Talking Project advanced a similar perspective in an e-mail to PB in October 2022:

"I sense that there are deep rooted issues that the family has with [Signia] that remain unresolved. However. this is an issue they have with [Signia] and not with their daughter although she senses it and I believe this is what holds her back from reaching out to the family." (Emphasis by underlining added).

Dr McKay [the jointly instructed expert psychologist] went on in her evidence, to demonstrate R's ability to 'use or weigh' the relevant information, to remark that:

"R did not have polarised views of her family. We see many people who only see good or bad but this is not the case with her... she suggested lots

of positive attributes in the family".

- 77. I find, having heard all of the evidence, that R feels great empathy towards her family but she is also angry with them because she believes inter alia that they are trying to control her. Ironically, R's parents are firmly of the view that it is the Signia staff who are controlling and coercing R. She senses their anger with Signia, and she does not like being caught in the middle of that.
- 78. The origins of R's anger with her parents and sister, and her strong sense that the family are controlling her or trying to do so, is not entirely clear, but they may well lie in the time when they applied pressure on her in relation to losing weight. This, at least, is what she told the previous social worker, and this was associated in time with the family's stated wish to remove her from Castle Hill (where she was/is happy and has friends) to live at home. Her relatively recent experience of living at home during the early phase of the COVID-19 lockdown in the spring 2020 may have a bearing on this too.
- 79. I am satisfied that her current antipathy towards her family is real; the feelings are, in my judgment, neither confected nor are they the result of pressure (improper or otherwise) from those who currently support and care for R. It is R's view that the family exercise inappropriate control of her in relation to:
 - i) The proceedings, which they initiated and about which she is unhappy; within the proceedings, R has been assessed, questioned and interviewed repeatedly over the same issues. It is possible that her answers in interview for the court have been affected by her unhappiness with the process. The fact that she has been

- repeatedly questioned may have left her wondering whether her views count for nothing, and this may well have made matters worse;
- ii) Her money; she wishes them not to know about her spending;
- iii) Her weight; she senses that they are trying to control what she eats and impose rules around her diet (I was directly aware of her sensitivity about this when I visited her, from comments which she made while we stood together in the kitchen);
- iv) Her relationship with SA.

By contrast, Cobb J was not persuaded that Signia had exerted undue pressure on R:

81. I have seen no evidence which suggests that the Signia staff have acted in such a way as to sap R of her free-choice to meet with them; on the contrary, I was impressed by Ms TB [the managing director of Signia] and accept PB's assessment of the quality of care which they offer to R. I accept Dr McKay's persuasive view that if the staff had conveyed to R deeply negative views about R's family, R herself would not hold or communicate positive thoughts about her family. Dr McKay is of the view that R has a desire to reconcile with her family, but lacks confidence that it will be a positive experience; the recent attempt would confirm this. I am satisfied that PB [R's social worker] in particular has made concerted efforts to persuade R to see her family, but those efforts have been in vain. In the current circumstances, I am not surprised.

Importantly – and unusually – Cobb J had before him very clear evidence from R herself as to what

she wished from the litigation, set out in a letter that she had sent to him. As Cobb J noted, he found comfort in the letter because it signaled ways in which the situation could improve:

- i) The disclaimer of the LPA [a matter which Cobb J had identified earlier in the judgment had been agreed to by her parents] will signal the moment when her parents cannot "make decisions" about her life, particularly money;
- ii) R can and should be told that her parents had good reason for referring their concerns to the police about SA and genuinely did not expect the police to visit Castle Hill; R should be told that the mother described to me how she recognised R's upset and distress;
- iii) It would be possible for R's parents to apologise (again) to SA [R's former partner]. If they feel that they have already done this, they could repeat it in such a way that R knows and understands that the apology has been issued;

As Cobb J noted:

84. There is no doubt in my mind that R desperately wants the proceedings to be over. PB expressed it well thus:

"This independent spirit, this determination to set her own store has been continuously undermined and undervalued time and time again. R has been assessed, questioned and interviewed repeatedly over the same issues which have left her feeling that her words and feelings count for little. That her views have been ignored or diminished, her experiences, her feelings and more importantly her own decisions, disregarded".

85. It is against this backdrop that Ms TB expressed herself to be "... optimistic that when the Court case is concluded and if [R]'s wishes are respected, that she will feel able to reunite with her family". I cautiously share that optimism.

Against this context, Cobb J had to decide whether R had capacity to make decisions about contact. He had the benefit of expert reports from Dr Claudia Camden-Smith, a jointly instructed consultant psychiatrist with a particular interest in Neurodevelopmental Disability Psychiatry, and Dr Katherine McKay, a Consultant Clinical Psychologist with a specialism in learning disabilities. Dr Camden-Smith was clear that R lacked capacity; Dr McKay considered that she had capacity. Cobb J preferred the evidence of Dr McKay, noting amongst other matters – that she had met R on a number of occasions previously, which was a great advantage: she was able to begin her assessment with some pre-existing knowledge and experience of R's abilities and limitations.

Cobb J declared himself satisfied that R:

103. [...] understands the issues, and has been able to use or weigh the information relevant to the decision on contact. She knows her family well and she loves them, but has been hurt by them (for the many reasons which I have discussed above) and deeply so; she feels it very keenly. I do not think that the family see how badly they have hurt R and this is perhaps in part why they cannot accept that she can make a capacitous decision in this regard. R has been clear in saying that she would like to see her family on Zoom initially; this is perfectly understandable. I further sense

that she is not saying that she will not want to see her family ever again; she is very clear that a number of impediments to contact need to be cleared first – the disclaimer of the LPAs, and the end of these proceedings being the most important.

104. The fact that R has vacillated in recent times (reference 17 November 2022 and June 2023) over seeing the family (or members of them) is perfectly understandable, and utterly predictable; it is not evidence of inappropriate pressure being applied on her to change her mind. Nor is that that she does not understand the information relevant to a decision on whether to see her family. She does understand that information; she can use and weigh that information; she can retain it, and can communicate her views. But - and this is the key - I find that she is deeply conflicted, very aware that she is caught in the crossfire of the dispute between her family (which fundamentally she loves) and Signia (in whose care she lives, and whose relationship she values). She may say to people that which she thinks they want to hear. That of itself is not an indicator of a lack of capacity; many fully capacitous people do exactly that. Her vacillation is not, or not necessarily, an indicator that she is coming under pressure, let alone undue pressure, from external sources.

That was not the end of the matter, though, because Cobb J had then to go on to consider whether to make orders under the inherent jurisdiction. He conducted a detailed review of the authorities, "to demonstrate that while the inherent jurisdiction is available in the right case, it is not 'all-encompassing' and there are clear limits to its applicability" (paragraph 120). Importantly, he further noted that:

119. The burden falls on the Applicant and Third Respondent to prove in this

case that R's will has been and/or is being overborne by those who are caring for her, and that she is the subject of constraint, coercion, undue influence or other vitiating factors. It is a serious allegation to make; the more so, it may be thought, when the accusation is against professional care made providers. I have considered the the balance allegations on probabilities; and I approach my task on the basis that if the party who bears the burden of proof fails to discharge it, the fact is treated as not having happened. If he does discharge it, the fact is treated as having happened (Re B [2008] UKSC 35). I found it useful to reconnect with what Lord Nicholls said in re H (Minors)(Sexual Abuse: Standard of Proof) [1996] AC 563, at 586D-H:

"When assessing the probabilities the court will have in mind as a factor, to whatever extent is appropriate in the particular case, that the more serious the allegation the less likely it is that the event occurred and, hence, the stronger should be the evidence before the court concludes that the allegation is established on the balance of probability".

Having reviewed the material before him Cobb J reached the following conclusions:

133. [...] As I mentioned above, in Re SA, Munby J declined to define the categories of person for whom the inherent jurisdiction may be invoked, but it is nonetheless clear from his judgment (and from DL which followed) that those for whom it would apply are those who are under constraint, subject to coercion or undue influence or otherwise (for some other reason) deprived of the capacity to make a relevant decision, or disabled from making a free choice (see above). In my judgment, this has not been R's experience in her placement.

134. I reject the suggestion by the Applicant that there has been any deliberate attempt at, or actual, alienation of R against her family by members of the Signia staff; I further reject the allegation of 'environmental alienation' - i.e. Signia creating an environment or eco-system in which R is not able to speak positively about her family and/or where all conversation about her family is negative. In my judgment it is likely that, once R's family started making allegations about Signia and the care it was offering R, Signia staff will have found it difficult actively to encourage R to engage with her family; it may well be that R picked up on Signia's sense of unhappiness at being on the receiving end of a wide range of allegations.

135. It is clear that R has recently made free choices, and these are choices which have brought her into contact with her family – i.e., she agreed to take part in the Talking Project [mediation]; she agreed to a meeting with her family in November (albeit that this did not happen), and agreed again to the café meeting on 9 December 2022.

136. I view with some sympathy the 'supportive framework' proposals advanced by the parties; indeed in the next section of the judgment I discuss them and actively encourage those with responsibility for R's care closely to consider them. But it is not 'necessary' for me to make orders in relation to them in order to liberate R to make decisions freely, nor is it 'proportionate' ([66] and [76] of DL) that I should. I am conscious of the need to guard against adopting an overly paternalistic attitude to a vulnerable adult who is the subject of the proceedings, and to make orders in (what McFarlane LJ referred to as) the "hinterland" of the MCA 2005 which

undermine the very concepts of the MCA 2005 itself.

As presaged above, this left Cobb J with no "jurisdictional peg" upon which to hang any ruling about R's care arrangements going forward. However, not least because the parties jointly urged him to do so, he gave a number of observations about future arrangements, including an observation that Signia should remain in place providing care for R, and identified some key features of an "impressive" 21 point supportive framework plan put forward by the family as having "particular merit" for incorporation in any plan going forward.

In his conclusions, Cobb J identified that

151. [...], there is at least one conclusion which it has not been difficult to reach in this case. And that is that these proceedings should now come to an end. R has repeatedly said that she is unhappy by the court's involvement; I am sure that she blames her parents for having initiated the litigation, and that this very issue in itself undermines the efforts which have been made to promote reconciliation. I accept the evidence that R has regularly lost sleep with worry about the court's involvement in her life, and that for a time she was "struggling... crying every night" because of them.

152. I agree with PB and Ms TB that R does show a good level of interest in, and empathy for, her family, but she is clearly conflicted; she has feelings of love and obligation towards them, but a strong desire to pursue her own interests and be free from what she sees as their 'control'. I find that she has been relatively steadfast in the last three years in her view on the issue of reconciliation; she has attempted to meet the many demands placed upon her by professionals, and has been

frustrated by having to answer repeatedly many similar questions, when she has already made clear her position. I share the optimism of Ms TB that when the litigation has ended, and particularly if R's wishes are respected and hostilities cease between Signia and the family, R will feel freer to explore the options around seeing her family. I also agree that this may take time, and perhaps some third-party help from a personal counsellor for R.

153. Other issues raised by the parties at this hearing have not yielded answers with the same ease. While the Court of Protection is accustomed to making important decisions about an individual's capacity to make decisions, and declarations about their best interests, it is not able to order or declare how people should think, or what they should do to get on better with each other. And that, in large part, is what needs to change in this case for the situation to move on.

Cobb J also proposed to write a short letter to R to explain that the proceedings have ended, and to set out some key outcomes, and also to give R an opportunity to meet with him again, should she wish to do so.

Comment

The summary above does not do full justice to the detail and nuance of the judgment, which is noteworthy even by the high standards of Cobb J. Above all, and to sadly still perhaps unusual extent, one gets a sense of the person at the heart of the proceedings, and the deep sense of conflict that troubled her.

As with all decisions, it is fact-specific, but there are undoubtedly patterns which are depressingly familiar to those who work (in whatever capacity) in this area. And Cobb J's observation at paragraph 153 about the inability of the court to

declare how people should think or what they should do to get on better with each other is one made with a perhaps weary sense of familiarity with cases of this nature.

Two points of broader relevance perhaps arise from the judgment. The first related to Cobb J's observation about the mediation that took place during the course of the proceedings:

50. Although the mediation showed some signs of promise, it was not in fact a success. Signia did not play a significant part in the mediation, having been given a clear expectation (it is said) that they would be expected to participate in the mediation on the basis full disclosure and open communication. Signia felt that it could not in good faith sign up to this, give the status of R's capacity and her views. R had been very clear with Signia (so it was reported) that she did not wish any information about her service or her personal circumstances to be shared with her family. Signia had understood at that time (from XCC) that R was assumed to have the capacity to make that decision following a capacity assessment undertaken by the previous social worker. A further concern to Ms TB, and a deterrent to successful engagement in the mediation, was that during this period in which mediation was being attempted, the family ignited fresh allegations of fraud which on no account would be amenable to mediation, and which would inevitably complicate the relationships further.

As important as mediation is, the observation about the position where the subject of the proceedings is understood to have capacity to make decisions about information-sharing is a very important reminder that mediation cannot either lead to a process or a result which might suit everyone else except for that person.

The second is in relation to the inherent jurisdiction, as this case adds to the body of case-law (and, importantly, this time, as an actual decision, rather than 'obiter' comments) pointing towards the limits of the inherent jurisdiction as a tool to coerce – however benignly – a capacitous individual to take steps that they resist.

DoLS statistics – the crisis continues to deepen

The DoLS statistics for England for the year 1 April 2022 to 31 March 2023 were <u>published</u> on 24 August 2023. They show that, despite heroic efforts by local authorities up and down the country, they continue to fight a losing battle actually to secure that all those requiring the safeguards are provided with them.

In headline terms:

- There were an estimated 300,765 applications for DoLS received during 2022-23. This is an increase of 11% compared to the previous year, which is closer to the rate of growth seen before COVID-19 (between 2014-15 and 2019-20 the average growth rate was 14% each year) following an interim period of relatively small increases in numbers of applications.
- The number of applications completed in 2022-23 was estimated to be 289,150. The number of completed applications has increased over the last five years by an average of 10% each year.
- However, the reported number of cases that were not completed as at year end was an estimated 126,100, 2% more than the end of the previous year, and the proportion of standard applications completed within the statutory timeframe of 21 days was 19% in 2022-23; this has fallen from 20% in the previous year. The average length of time for

all completed applications was 156 days, compared to 153 days in the previous year.

Tellingly, 56% of applications were not granted, but only 3% were not granted because one or more of the DoLS criteria were not met. The reasons for most applications not being granted was due to a change in the person's circumstances, for example being discharged from a short term stay in hospital following an urgent authorisation. And the stark fact is that almost 50,000 people died whilst waiting for a DoLS authorisation to be considered.

The DoLS statistics only tell part of the story, because the framework does not apply where the person is not yet 18, or is deprived of their liberty other than in a care home or hospital. There were 872 applications to the Court of Protection for judicial authorisation of deprivation of liberty in the <u>first quarter</u> of 2023 (down from 1,002 applications the <u>quarter before</u>), but it is very difficult to get a sense of by a factor of how many this number is short of the number of applications that should be made.

The Court of Protection is reviewing the Re X application procedure at the moment; Alex would also suggest that there is an urgent need to discuss whether and how it is possible to operate the DoLS framework in a more proportionate fashion - in line with the guidance from the Chief Social Worker for Adults and Principal Social Workers in relation to Care Act assessments. An extremely useful starting point for the discussion - in our view is this guest post on Alex's website by Lorraine Currie

Editors and Contributors



Alex Ruck Keene KC (Hon): alex.ruckkeene@39essex.com

Alex has been in cases involving the MCA 2005 at all levels up to and including the Supreme Court. He also writes extensively, has numerous academic affiliations, including as Visiting Professor at King's College London, and created the website www.mentalcapacitylawandpolicy.org.uk. To view full CV click https://example.com/here-numerous-num



Victoria Butler-Cole KC: vb@39essex.com

Victoria regularly appears in the Court of Protection, instructed by the Official Solicitor, family members, and statutory bodies, in welfare, financial and medical cases. She is Vice-Chair of the Court of Protection Bar Association and a member of the Nuffield Council on Bioethics. To view full CV click https://example.com/hem-ex-regular/



Neil Allen: neil.allen@39essex.com

Neil has particular interests in ECHR/CRPD human rights, mental health and incapacity law and mainly practises in the Court of Protection and Upper Tribunal. Also a Senior Lecturer at Manchester University and Clinical Lead of its Legal Advice Centre, he teaches students in these fields, and trains health, social care and legal professionals. When time permits, Neil publishes in academic books and journals and created the website www.lpslaw.co.uk. To view full CV click here.



Arianna Kelly: Arianna.kelly@39essex.com

Arianna practices in mental capacity, community care, mental health law and inquests. Arianna acts in a range of Court of Protection matters including welfare, property and affairs, serious medical treatment and in inherent jurisdiction matters. Arianna works extensively in the field of community care. She is a contributor to Court of Protection Practice (LexisNexis). To view a full CV, click here/beta/fig/



Nicola Kohn: nicola.kohn@39essex.com

Nicola appears regularly in the Court of Protection in health and welfare matters. She is frequently instructed by the Official Solicitor as well as by local authorities, CCGs and care homes. She is a contributor to the 5th edition of the Assessment of Mental Capacity: A Practical Guide for Doctors and Lawyers (BMA/Law Society 2022). To view full CV click here.



Katie Scott: katie.scott@39essex.com

Katie advises and represents clients in all things health related, from personal injury and clinical negligence, to community care, mental health and healthcare regulation. The main focus of her practice however is in the Court of Protection where she has a particular interest in the health and welfare of incapacitated adults. She is also a qualified mediator, mediating legal and community disputes. To view full CV click here.



Nyasha Weinberg: Nyasha.Weinberg@39essex.com

Nyasha has a practice across public and private law, has appeared in the Court of Protection and has a particular interest in health and human rights issues. To view a full CV, click here



Simon Edwards: simon.edwards@39essex.com

Simon has wide experience of private client work raising capacity issues, including *Day v Harris & Ors* [2013] 3 WLR 1560, centred on the question whether Sir Malcolm Arnold had given manuscripts of his compositions to his children when in a desperate state or later when he was a patient of the Court of Protection. He has also acted in many cases where deputies or attorneys have misused P's assets. To view full CV click here.



Adrian Ward: adrian@adward.co.uk

Adrian is a recognised national and international expert in adult incapacity law. He has been continuously involved in law reform processes. His books include the current standard Scottish texts on the subject. His awards include an MBE for services to the mentally handicapped in Scotland; honorary membership of the Law Society of Scotland; national awards for legal journalism, legal charitable work and legal scholarship; and the lifetime achievement award at the 2014 Scottish Legal Awards.



Jill Stavert: j.stavert@napier.ac.uk

Conferences

Members of the Court of Protection team regularly present at seminars and webinars arranged both by Chambers and by others.

Alex is leading a masterclass on approaching complex capacity assessment with Dr Gareth Owen in London on 1 November 2023 as part of the Maudsley Learning programme of events. For more details, and to book see here.

Alex is also doing a regular series of 'shedinars,' including capacity fundamentals and 'in conversation with' those who can bring light to bear upon capacity in practice. They can be found on his <u>website</u>.

Advertising conferences and training events

If you would like your conference or training event to be included in this section in a subsequent issue, please contact one of the editors. Save for those conferences or training events that are run by non-profit bodies, we would invite a donation of £200 to be made to the dementia charity My Life Films in return for postings for English and Welsh events. For Scottish events, we are inviting donations to Alzheimer Scotland Action on Dementia

Our next edition will be out in October. Please email us with any judgments or other news items which you think should be included. If you do not wish to receive this Report in the future please contact: marketing@39essex.com.

Sheraton Doyle

Senior Practice Manager sheraton.doyle@39essex.com

Peter Campbell

Senior Practice Manager peter.campbell@39essex.com

Chambers UK Bar Court of Protection: Health & Welfare Leading Set

The Legal 500 UK Court of Protection and Community Care Top Tier Set

clerks@39essex.com • DX: London/Chancery Lane 298 • 39essex.com

LONDON

81 Chancery Lane, London WC2A 1DD Tel: +44 (0)20 7832 1111 Fax: +44 (0)20 7353 3978 MANCHESTER

82 King Street, Manchester M2 4WQ Tel: +44 (0)16 1870 0333 Fax: +44 (0)20 7353 3978 SINGAPORE

Maxwell Chambers, #02-16 32, Maxwell Road Singapore 069115 Tel: +(65) 6634 1336 KUALA LUMPUR

#02-9, Bangunan Sulaiman, Jalan Sultan Hishamuddin 50000 Kuala Lumpur, Malaysia: +(60)32 271 1085

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