



Welcome to the October 2023 Mental Capacity Report, which is much shorter than last month's blockbuster (to everyone's relief). Highlights this month include:

- (1) In the Health, Welfare and Deprivation of Liberty Report: Brain stem death before the courts and conveyancing;
- (2) In the Property and Affairs Report: the Powers of Attorney Act 2023 gets Royal Assent, and how it will change the Mental Capacity Act 2005;
- (3) In the Practice and Procedure Report: revised guidance for Accredited Legal Representatives and anonymisation of clinicians in cases involving the MCA 2005;
- (4) In the Wider Context Report: a revised online ADRT service and a revised clinical guide for staff working with autistic people and those with a learning disability, and our Irish correspondents highlight two specific aspects of the Assisted Decision-Making (Capacity) Act 2015;
- (5) In the Scotland Report: attorneys as executors.

You can find our past issues, our case summaries, and more on our dedicated sub-site [here](#), where you can also sign up to the Mental Capacity Report.

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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.

## Contents

“Proportional assessments,” remote assessments, the Care Act and the MCA – an update..... 2

Free service to create advance decisions from Compassion in Dying, and advance decisions in the South Asian community ..... 2

Clinical guide for front line staff to support the management of patients with a learning disability and autistic people..... 3

Forced marriages and non-recognition ..... 5

IRELAND..... 7

### “Proportional assessments,” remote assessments, the Care Act and the MCA – an update

We noted last month the [guidance](#) on carrying out proportionate assessments under the Care Act 2014 issued by the chief social worker for adults, Lyn Romeo, and principal social workers have issued. It has been updated to make clear that it is legitimate in some circumstances to carry out assessments under the MCA 2005 without seeing the person:

*Mental capacity assessments should normally be completed in person, but it may be appropriate to carry out the assessment remotely if, for example, it is not possible to visit the person.*

*The principles of the Mental Capacity Act 2005 must underpin assessments where there is a proper reason to doubt that the person has the capacity to make the decision in question. Most deprivation of liberty safeguards assessments should be face to face in order to, for example, meet any communication needs of the person.*

*An important principle of the Mental Capacity Act 2005 is that it must be assumed that the person has capacity*

*unless it is established that they lack capacity. Assuming capacity, however, should not be used as a reason for not assessing capacity in relation to a decision. There should always be an assessment where there is a proper reason to doubt a person’s capacity to make a decision.*

This also gives an opportunity to note that Lyn Romeo CBE will be leaving her role in January 2024, having served since January 2013 as the first chief social worker for adults. We wish her well, and thank her for a huge amount of often unsung and frequently thankless work that she has done in post.

### Free service to create advance decisions from Compassion in Dying, and advance decisions in the South Asian community

The charity Compassion in Dying has updated their free online service to assist people who wish [to make advance decision](#) to refuse treatment. It is available only to people who have capacity, are 18 or over and live in the UK. The service takes people through the form step-by-step (people can also save the document and return to it if they wish), and creates a document that people can execute (this document would need to be signed and witnessed to be valid).

People would also be responsible for sharing copies of the document with their GP or other health provider, and for making family members aware of the fact that they have made an advance decision. The service also has a [template form](#) people can download and prepare by hand, or they can [order the form by post](#) to be sent to them if they do not have access to a printer.

Importantly, Compassion in Dying have made the underlying machinery freely available, so that it can be '[white-labelled](#)' by others, whether that be another charity or a health body working to develop electronic end-of-life records.

Separately, Compassion in Dying has launched a new report on '[Advance Care Planning with people from South Asian Communities](#)' in partnership with Subco Trust and Bristol University's Good Grief Connects project. The South Asian people involved in the project made clear that they face inequities in access to advance care planning and support towards the end of life. People faced significant challenges when talking to healthcare professionals, finding and understanding information, making treatment and care decisions and accessing support.

The experiences Subco Trust members shared demonstrated a clear need to allow people to consider and make informed decisions about planning for the end of their life. Meaningful attention and investment at both a national and local level is needed to provide culturally and linguistically appropriate information and support.

### [Clinical guide for front line staff to support the management of patients with a learning disability and autistic people](#)

NHS England has published new [guidance](#) (updated from predecessor guidance in 2020)

for staff on caring for patients with a learning disability or autism; the guidance specifically notes that it is relevant for all clinical specialities, rather than simply those providing care relating to learning disabilities or autism. The guide is also available in an [easy-read format](#).

The guidance emphasises that approximately 2.5% of people in England have a learning disability, and approximately 1-1.7% of the population has autism. It notes that people with a learning disability have higher rates of death from avoidance causes and tend to die at a younger age, and there is also evidence of premature mortality for people with autism. It highlights the following 'key points' which should be addressed when assessing or treating a person with a learning disability or autism:

**Be aware of diagnostic overshadowing:** *This occurs when the symptoms arising from physical or mental ill health are misattributed to a person's learning disability or autism leading to delayed diagnosis or treatment. People with a learning disability and autistic people have the same illnesses as everyone else, but the way that they respond to or communicate their symptoms may be different and not obvious.*

**Pay attention to healthcare passports:** *Some people with a learning disability and some autistic people have a healthcare passport giving information about the person and their health needs, preferred method of communication and other preferences. Ask the person or their accompanying carer if they have one of these.*

**Ensure that clinical decisions around care and access to treatment are made on an individual basis:** *People should not have a DNACPR (do not attempt cardiopulmonary resuscitation) recorded on their clinical record simply*

because they have a learning disability or are autistic. Every person has individual needs and preferences which must be taken account of, and they should always have high quality standards of care. It is also important not to make generalised judgements or assumptions about people's vulnerability or frailty based on their dependence on others for support in daily living.

**Listen to parents and carers:** Families and carers have a wealth of information about the individual and how their health has been, including any comorbidities and the medication that the person is taking. Listen to them as well as the person you are caring for. They know the person well and how to look after them when they are not in hospital. They also know how the person's current behaviour may differ from usual, as an indication that they are unwell. The family or carer may have short videos of the person to give you an idea of their usual self. Remember that the carer they come into hospital with may not be their usual carer at this unusual time. You may wish to talk to their usual carer as soon as is practicable.

**Make reasonable adjustments:** It is a legal requirement to make reasonable adjustments to care for people with a disability under the Equality Act (2010). Getting the reasonable adjustments right is important to help you make the correct diagnostic and treatment decisions for an individual. You can ask the person and their carer or family member what reasonable adjustments should be made. Adjustments aim to remove barriers, do things in a different way, or to provide something additional to enable a person to receive the assessment and treatment they need. Possible examples include allocating a clinician by gender, taking blood samples by thumb prick rather

than needle, providing a quiet space to see the patient away from excess noise and activity.

**Communication:** Communicate with and try to understand the person you are caring for. Check with the person themselves, their family member or carer or in their hospital or communication passport for the best way to achieve this. Use simple, clear language, avoiding medical terms and 'jargon' wherever possible. Some people may be non-verbal and unable to tell you how they feel. Pictures may be a useful way of communicating with some people, but not all.

**Understanding behavioural responses to illness, pain and discomfort:** A person with a learning disability and some autistic people may not be able to articulate their response to pain in the expected way: for example, they may say that they have a pain in their stomach when the pain is not there; may say the pain is less acute than you would anticipate; or not say they are in pain when they are. Some may feel pain in a different way or respond to it differently: for example, by displaying challenging behaviour; laughing or crying; trying to hurt themselves; or equally may become withdrawn or quiet. People who use a wheelchair may have chronic pain. Understanding what is 'normal' for that person by talking to them, their family and carers, is crucial to helping with assessment and diagnosis. You can use pictures to help establish whether a person is in pain and where that pain is.

**Mental Capacity Act:** People with a learning disability and autistic people should be assumed to have capacity in line with the principles of the Mental Capacity Act. Assess their capacity to make a decision about their treatment or care in line with the person's communication abilities and needs and

*follow the principle of the Mental Capacity Act in making appropriate efforts and adjustment to enable decision making wherever possible. Remember that capacity is time and decision-specific. Refer to the MCA Code of Practice for guidance.*

**Ask for specialist support and advice if necessary:** *Your hospital learning disability team or liaison nurse can help you with issues of communication, reasonable adjustments, and assessment of pain. You may also want to make contact with your local community learning disability team if your Trust does not have a learning disability liaison nurse.*

**Training on how to support people with a learning disability and autistic people:** *The Oliver McGowan Mandatory Training on Learning Disability and Autism is the government's preferred and recommended training for health and social care staff. Access the [e:learning on: The Oliver McGowan Mandatory Training on Learning Disability and Autism](#).*

**Mental wellbeing and emotional distress:** *It is estimated that 40% of people with a learning disability experience mental health problems ([Mental health problems in people with learning disabilities: prevention, assessment and management](#)) and research suggests autistic people may be more likely to experience depression than non-autistic people ([Depression \(autism.org.uk\)](#)). Change in routine can have a big effect on people's emotional and mental wellbeing. A hospital setting may make people with a learning disability and autistic people more anxious or lead to adverse behaviours, such as hurting other people, hurting themselves or damaging property. Do not assume that this is an indication of mental illness and do your best to work*

*with the person who is unwell, their carer or family member to find out how best to keep them calm and relaxed.*

### Disagreements about the care of critically ill children

The Nuffield Council on Bioethics has [published](#) the report of the review it was commissioned in December 2022 to carry out by the Secretary of State for Health and Social Care, on the causes of disagreements between parents and healthcare teams about the care of critically ill children (i.e. children unwell enough to be treated in intensive care). Unsurprisingly they found that one of the key causes of disagreements was communication issues. Mismatched expectations (i.e. about what is medically possible, what medical information is or is not significant, or about what is involved in the provision of palliative care) was also found to be very influential on the development of disagreements. Conversely, they found that where healthcare professionals had built relationships with parents, had understood their needs and communicated accordingly, this had a positive impact on parents. Equally they found that where uncertainty was communicated honestly, this was seen to have a positive impact on relationships and the building of trust between parents and healthcare professionals.

They made a number of recommendations about resolving disputes, including that:

- Guidance should be produced for clinical ethics committees (CEC) on how to ensure that parents', and where appropriate children's, views are taken into account in CEC discussions and that parents are supported to provide input to CEC meetings.
- NHS trusts in England should inform families within three calendar days of taking the decision to initiate court proceedings in

order to give them sufficient time to seek independent legal advice and collate necessary information to disclose to the court.

The report was lukewarm on mediation between parents and healthcare professionals, finding that it can be helpful in some situations to facilitate open conversations, but that there is no current evidence to support mandating its use in every case or in disagreements that would otherwise go to court.

It is of interest to note that the report does not recommend a change in the 'best interests' test applied by the courts in cases concerning children. It is also perhaps important to note two developments that the report was not able to incorporate in what is otherwise an extremely comprehensive review of a very complicated area. The first is the coming into force of the removal of means-testing for parents involved in cases concerning life-sustaining treatment of children, with effect from 3 August 2023 (rather earlier than the report authors had feared). The second is that the Supreme Court have agreed to hear the appeal by the Trusts involved in the *Abbasi* and *Haastrup* cases in relation to reporting restrictions relating to medical professionals, an issue identified as being one of concern to professionals in the report.

### Deprivation of liberty and children

The Nuffield Family Justice Observatory has published its key findings from 12 months of research at the national deprivation of liberty court. It makes for sobering reading. They found that:

- 1,249 children had been subject to a Deprivation of Liberty (DoL) order and between July 2022 and March 2023, there were almost 10 times as many applications to deprive children of their liberty under the

inherent jurisdiction than there were applications for secure accommodation orders.

- The children have multiple and complex needs, including mental health problems, behavioural and emotional difficulties, and difficulties with education – which they are not receiving adequate support for.
- Their behaviours are often associated with experiences of early and ongoing childhood adversity (such as abuse and neglect, but also poverty and racism) and complex trauma.
- While it is often intended as a temporary measure, many children will continue to have their liberty deprived for many months while living in what are often unsuitable – and illegal – placements far from home and their communities. The restrictions imposed on them are often severe and multiple.

The report considered the reason why there has been such a huge increase in the number of applications. It was multifactorial, including a reduction in places in children's secure homes and in child mental health beds, as well as an increase in the number of children in care and in the complexity of their presenting needs. For lawyers who do this kind of work, the finding that children have limited opportunity to participate or have their voices heard in deprivation of liberty proceedings is something that must be addressed as a matter of urgency.

### Forced marriages and non-recognition

For those who want to continue to track through the complexities of forced marriages and non-recognition, we recommend the paper by Sir Nicholas Mostyn responding to the decision of the Court of Appeal in *Re SA (Declaration of Non-Recognition of Marriage)* [2023] EWCA Civ 1003

we covered in brief in our last issue.

### Australian Disability Royal Commission reports

The Australian Disability Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, established in 2019, has reported, making 222 recommendations on how to improve laws, policies, structures and practices to ensure a more inclusive and just society that supports the independence of people with disability and their right to live free from violence, abuse, neglect and exploitation.

The Final Report consists of 12 Volumes plus an additional introductory volume, which includes the Chair's foreword, the Commission's vision for an inclusive Australia, an executive summary and the full list of recommendations. All volumes of the Final Report are available in various accessible formats [here](#). The Royal Commission has also published [A brief Guide to the Final Report](#). This guide explains how information is organised in the Final report. It is for a broad audience including people with disability, their families and carers, other members of the Australian community, disability advocates, service providers and people looking to quickly find the information they need.

Additionally, the Royal Commission has published a brochure called [Listening to First Nations people with disability](#). This brochure describes what the Commission heard from First Nations people with disability and their families and communities about the issues and challenges they face. It also describes some of the changes needed to create an Australia where First Nations people with disability are included.

Whilst the focus of the Report is on Australia, there is much that those working in other

jurisdictions can – and should – draw upon.

### IRELAND<sup>1</sup>

#### Co-Decision-Making Agreements

With very little in the way of capacity law happening over the long vacation, we thought this a perfect opportunity to highlight one of the rather unique features of the newly commenced capacity legislation in Ireland, namely a co-decision-making agreement. This agreement sits above a decision-making assistance agreement which offers simply assistance to the appointer, and beneath a decision-making representation order which is a relationship of agency following court appointment. A co-decision-making agreement is a mid-level decision-support mechanism under the Assisted Decision-Making (Capacity) Act 2015. It can be made either at the behest of a person whose capacity is or may soon be in question, or following a declaration that the person lacks capacity unless they have such an agreement. The core feature is that decisions must be made jointly by the appointer and the co-decision-maker.

#### *Criteria for Co-Decision-Makers*

A co-decision-maker must adhere to the appointer's wishes but can refuse to sign a document if it could lead to serious harm, and their authority is limited to decisions explicitly outlined in the agreement. A person is deemed suitable to act as a co-decision-maker if they meet two criteria: (i) they must be a relative or friend with whom the appointer has a trusting relationship, established through significant personal contact over time; and (ii) they must be capable of fulfilling the roles and responsibilities as outlined in the co-decision-making agreement and the legislation. An appointer can appoint

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<sup>1</sup> Prepared by our Irish correspondents, Emma Slattery BL and Henry Minogue BL.

multiple co-decision-makers, but with limitations; within a single agreement, only one co-decision-maker can be appointed.

#### *Court Declarations and Applications*

In a capacity application or a discharge from wardship application, the applicant can seek a court declaration under section 37(1)(a) or section 55(1)(b)(i) that the relevant person lacks the capacity to make certain decisions unless assisted by a suitable co-decision-maker. If such a declaration is made, the relevant person is given time to register a co-decision-making agreement. Alternatively, the process for creating a co-decision-making agreement begins with the appointer submitting an 'Application to Register a Co-Decision-Making Agreement' form to the Decision Support Service.

#### *Application Review Process*

Upon receiving the application, the Decision Support Service reviews it and sends back a draft agreement, a capacity statement, character references, declarations, and notice forms. A capacity report confirms the appointer's capacity to enter into the agreement. Two character references are also required for the co-decision-maker, and both parties must sign declarations that are witnessed by two individuals.

#### *Notification and Objections*

The appointer and co-decision-maker are required to notify specific parties, such as spouses or adult children. Objections to the registration can be raised within five weeks on various grounds, including the appointer's lack of capacity or the co-decision-maker's unsuitability. An application to register a co-decision-making agreement must be submitted within five weeks of signing the agreement and is accompanied by a €90 fee. The Director either registers the agreement if all criteria are met or refuses registration, in which case the applicants must

notify specific parties such as spouses or adult children, and an appeal can be filed within 21 days.

#### *Legal Implications of Registration*

Once a co-decision-making agreement is registered, decisions made within its scope are binding and cannot be challenged based on the appointer's capacity. For decisions requiring the signature of documents, both the appointer and the co-decision-maker must sign them, with exceptions made if the appointer is unable to sign. Importantly, a joint decision does not equate to joint liability. The Director of the Decision Support Service is responsible for establishing and maintaining a register of these agreements. Various professionals and public bodies, including medical practitioners and legal professionals, have the right to inspect this register. Authenticated copies can be issued by the Director for a fee and serve as evidence of the agreement's content and any variations.

#### *Remuneration, Annual Reviews and Codes of Practice*

Co-decision-makers are entitled to reimbursement for fair and reasonable costs and expenses incurred while performing their duties, although they are not entitled to remuneration. These costs must be evidenced and reported to the Director. Co-decision-makers are also required to adhere to relevant codes of practice. The Director reviews each registered co-decision-making agreement annually. These reviews involve consultations with the appointer, co-decision-maker, and any visitors on behalf of the Director who have had contact with them. A capacity report confirming the appointer's continued need for decision-making support is also required.

#### *Variations and Revocations*

Both the appointer and the co-decision-maker



may mutually vary the terms of a co-decision-making agreement, subject to specific signing and witnessing requirements. A varied agreement must be registered, accompanied by a fee of €90 and supporting documents, including a capacity report confirming the appointer's capacity. The application for such a variation cannot be made earlier than six months from the initial registration and subsequent applications must be at intervals of no less than 12 months. In addition, a co-decision-making agreement can be either totally or partially revoked by either party or both.

### *Conclusion*

While it remains to be seen what the uptake of co-decision-making agreements will be, co-decision-making agreements offer a useful middle ground for people who require some form of decision-making support, without the requirement to resort to substitute decision-making.

*Emma Slattery*

### **Decision Support Service (DSS) and Codes of Practice**

The Decision Support Service ('DSS') is the statutory service established by the Assisted Decision-Making (Capacity) Act 2015 (as amended) ('the Act'). The DSS provides an essential service for people who face difficulties in exercising their decision-making capacity.

In the run up to the initiation of the Act, and over the course of 2022, the DSS implemented a [public consultation process](#) on several of the draft codes of practice on the Assisted Decision-Making (Capacity) Act 2015.

Following ministerial approval, on the 24<sup>th</sup> of April 2023 the Codes of Practice were published in tandem with the commencement of the Act. There were 13 Codes of Practice were published

by the DSS, providing guidance as to functions and responsibilities under the Assisted Decision-Making (Capacity) Act 2015 (as amended) (See [link here](#)).

While similar in function to the Mental Capacity Act 2005 Code of Practice, covering England and Wales, the position of Codes of Practice in Ireland goes into much more granular detail for each distinct area of support underlined in the Act.

### *Codes of Practice*

These 13 Codes of Practice can be broken down into three categories, the first gives general guidance to any person involved with a relevant person, especially when the person must make an important decision. The other five are for the various tiers of decision supporters and health care representatives. The remaining seven pertain to specific professionals when working with a relevant person, e.g., general visitors, legal practitioners, financial professionals etc.

The codes of practice are generally drafted with the same emphasis and wordings, but for this edition of the Report, we will consider guidance given to legal practitioners.

### *Code of Practice for Legal Practitioners*

The code for legal practitioners covers many various areas, such as:

- Assessing capacity for a specific decision;
- Advising a client on decision support arrangements;
- Record keeping;
- Interacting with the Decision Support Service; and
- Court matters, etc.

An example of such guidance of the code for legal practitioners' is directions around interacting with the relevant person, which is given in the following terms<sup>2</sup>:

*When interacting with a person who needs to make a decision, you must presume they have capacity to make that decision at the time it needs to be made. A relevant person must not be considered unable to make a decision until all such steps set out in this code and all practical steps have been taken to help them to make that decision.*

The code also underlines the responsibilities of legal practitioners when they hold a belief that the relevant person's decision supporter, is not performing their duties to the required level.

*Where you believe [the practitioner] that a relevant person's decision supporter is not performing their functions appropriately or is acting beyond the scope of their authority, you may make a complaint to the Decision Support Service. This includes complaints about attorneys appointed under the Powers of Attorney Act 1996 in addition to all decision supporters appointed under the 2015 Act.*

Of note to practitioners, the section discussing taking instructions from a decision supporter is of particular importance:

*A decision supporter may seek to instruct you in relation to court proceedings involving or on behalf of a relevant person. Court proceedings may be included as a property and affairs decision within a decision support arrangement. You should check the authority of the decision supporter to take this action on behalf of the relevant*

*person, as described in section 3.2. A decision supporter may only instruct you if such a decision is within the scope of the decision support arrangement.*

### Conclusion

Overall, the codes are very discrete and condensed documents, most of which vary from 22-25 pages in length, and are formulated in plain English. In addition, the DSS have compiled several user friendly walk-through videos available on YouTube for consultation (See Playlist [Link here](#)).

Henry Minogue

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<sup>2</sup> This is also in line with the 'guiding principles' section of the Act.

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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](#).



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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](#).



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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.

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## 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 [website](#).

### **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.

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Our next edition will be out in November. 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](mailto:marketing@39essex.com).

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