



Welcome to the July 2018 Mental Capacity Report. Highlights this month include:

(1) In the Health, Welfare and Deprivation of Liberty Report: an appreciation of Alastair Pitblado, the Mental Capacity (Amendment) Bill, the Joint Committee on Human Rights considers DoLS reform and fluctuating capacity;

(2) In the Property and Affairs Report: the OPG mediation pilot

(3) In the Practice and Procedure Report: court fees reductions and when to join;

(4) In the Wider Context Report: Lady Hale on *Cheshire West* and the CRPD, Parliamentary debates and developments and a major Council of Europe report on attorneys and advance directives;

(5) In the Scotland Report: AWI consultation responses and Sandra McDonald reflects on her time as Public Guardian;

You can find all our past issues, our case summaries, and more on our dedicated sub-site [here](#).

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

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ENGLAND AND WALES

Lady Hale speech

In a fascinating speech to the Royal College of Psychiatrists on 24 June on whether it is a time for another Mental Health Act, Lady Hale ranged widely over a whole host of issues of relevance to readers of this report, giving her reflections not just on the evolution and possible future of mental health law, but also on *Cheshire West* and the implications of the CRPD for both the MHA and the MCA. It is essential reading for all concerned with this area.

Deprivation of liberty and children (again)

Northumberland County Council v MD, FD and RD [2018]EWFC47 (Cobb J)

Article 5 ECHR – Deprivation of liberty

Summary

The issue in this case was whether RD was deprived of her liberty for the purposes of Article 5. RD was

14½ years old and accommodated in a residential placement referred to as Lennox House in Scotland. She did not have the capacity or Gillick competence to give her consent to the care arrangements. Nor could her parents or the local authority do so as she was under an interim care order. The only issue was whether the arrangements satisfied the acid test.

Lennox House was a large detached house in a rural setting accommodating six young people, with a staff ratio of 4:6. Mr Justice Cobb set out the key information:

- i) *RD is given a wake-up alarm call each morning, and then is left to her own devices to dress/wash and prepare for the day;*
- ii) *She has her own room; there is a lock on the door which she can use to lock herself in, or to lock when she leaves for school (or otherwise) so that her belongings are safe; the staff have a*

- master key;¹ I have the impression that the lock is for RD's benefit not the staff's. RD is never locked in her room by the staff, nor are internal doors locked to manage her (or others') behaviour;*
- iii) *RD helps around meal times "which are similar to many households" (per social worker) and she can choose to have free time after her supper with her peers and staff;*
 - iv) *RD can move around Lennox House as she chooses; there are generally staff around the communal areas to support the young people; it is said that the staff do not supervise the young people or place them "under surveillance";*
 - v) *In her leisure time, RD has the freedom to watch television in a communal area; she can have time in her room when she wishes to be alone;*
 - vi) *RD enjoys attending a boxing club; she is taken there (with another young person from Lennox House) by a member of staff;*
 - vii) *RD enjoys shopping and is taken into town by a member of staff who remains with her in town; she enjoys spending time with an animal therapist and enjoys horse riding;*
 - viii) *RD can go out into the grounds of Lennox House alone, but her visits outside the building are monitored by a member of staff watching (generally from within the house); if RD goes outside into the grounds in a group, a member of staff accompanies them to monitor/supervise;*
- ix) *When RD was more settled, she was trusted to make short excursions in daylight hours from Lennox House alone to a local shop in the village; this opportunity has been denied her lately given her recent abscondences;*
 - x) *RD travels the hour to school by car or minibus with the other young people from Lennox House, accompanied by a member of staff. The staff member remains at the school during the hours in which RD is receiving her education, in case there are behavioural issues which require resolution; the member of staff is not generally in the classroom with her;*
 - xi) *RD enjoys fortnightly visits from her family; these visits often take place in the presence of staff, for both supervision and support – there are practical reasons for staff involvement: transport/unfamiliarity of the locality to the family. The family say that they welcome the staff on the visits, and have indicated that they would like this arrangement to remain in place until they feel more familiar with contact taking place in the community, which is unfamiliar to them;*
 - xii) *RD enjoys and seeks out opportunities for adult 1:1 time with a staff member; RD will often try to isolate a member of staff out to obtain this sole attention;*
 - xiii) *RD currently does not have her own mobile telephone (I believe a choice of her parents taken with her), but she*

¹ "I make the important point here that the presence or absence of a lock on the door is not determinative of the issue: see *Ashingdane v United Kingdom* (A/93): (1985) 7 E.H.R.R. 528 at [41]: a compulsory patient is deprived of his liberty in the hospital where he is detained, irrespective of

the openness or otherwise of the conditions there." (footnote in original)

can access the house phone at any time and make calls, which are not supervised; she does indeed call her parents most days, and calls her social worker when she feels the need to do so; there is no restriction (so I understand) on RD having a mobile phone;

- xiv) Internet is available in the unit, but it is regulated by a safety feature which blocks social media and inappropriate sites; RD has access to an iPad on site; iPad use is not supervised; search histories are checked randomly.

In relation to the acid test, his Lordship noted:

29 ... Two phrases fall for scrutiny under the 'acid test': (1) "complete supervision and control" and (2) freedom or lack of freedom "to leave the place where she lives". The second of these phrases on these facts has no application. 'Free to leave' does not mean leaving for the purpose of some trip or outing approved by those managing the institution; it means leaving in the sense of removing herself permanently in order to live where and with whom she chooses. It is accepted wisdom that a typical fourteen or fifteen-year old is not free to leave her home.

The core issue, therefore, was whether RD was under 'complete or constant supervision and control'. The court's view was "that 'complete' or 'constant' defines 'supervision' and 'control' as indicating something like 'total', 'unremitting', 'thorough', and/or 'unqualified'" (para 31). After helpfully setting out the important passages from the case law at para 32, his Lordship made "a finely balanced decision" (para 35), comparing the arrangements with the notional circumstances of the typical child of the same age, station, familial background and relative maturity who is free from disability:

38. The impression I have formed from the statements and reports is that the regime at Lennox House is boundaried, yet

supportive. Naturally the staff keep watchful eyes on the young residents, particularly when they cluster, but I do not discern that this level of monitoring is any more intense or overt than a parent's watchfulness over young adolescent people in a domestic setting, in similar circumstances. The presence of staff in the home is, I am satisfied, in significant measure to give the young people support and attention. These young people, because of their needs, require 1:1 attention and support at times; this is qualitatively different from 1:1 supervision. RD avowedly craves this kind of attention. Contrary to the submission of Mr. Wilkinson, I am not persuaded that the staff ratio indicates of itself that the residents are subject to complete or constant supervision and control.

39. It is the issue of supervision or surveillance and/or control which gives rise to the most difficult question on the facts of this case: i.e. to what extent the 'supervision' of the staff over RD is different from the watchful eye or supervision of a reasonable parent? It is not immaterial to my assessment that RD is described as a 14-year old who appears younger than her chronological age (see [14] above). It is fair to reflect that the degree of supervision may well be greater for her given her 'younger' presentation or late evolving maturity than it would be for a more mature 14-year old. Nor is it immaterial that RD herself does not feel "watched" all the time (see [16] above), which in itself is a reflection of the actual extent of the supervision.

40. The monitoring of RD as she ventures out into the grounds of Lennox House ([18](viii) above) is, it seems to me, ordinary quasi-parental good sense. The fact that Lennox House stands on a busy road would be a matter of concern to any parent; a rash and unthinking excursion onto the road by any young person would place them at risk. As I have earlier indicated, the fact that the staff accompany RD and her parents on some but not all of

her contact visits ([18](xi) above) is more by way of support than supervision, particularly given that the parents have struggled with RD's behaviours in the past; moreover, and not insignificantly, the parents are unfamiliar with the local area, and without transport on their visits.

41. There are restrictions on RD's movement, for sure. She does not enjoy the freedoms to wander in to a town as a 14½ year old young person may have the opportunity to do if living in an urban area. This restriction at least in part (perhaps a significant part) arises because of the geographic location of Lennox House – its distance from the local town and village, its distance from school, and is not in my finding because it is a function of any 'complete control or supervision' of the State. Restrictions of movement in this way do not engage considerations of 'deprivation' under Article 5 (see Guzzardi above). I am satisfied that when the staff regard it as safe for RD to be able to pay a visit independently to the local village shop (involving a walk along the A road in daylight), they let her do so, much as a parent may well do.

*42. Plainly when RD's behaviour (her abscondences, disobediences, and/or her distress) justify some restrictions on her movement, these are appropriately applied and enforced; but every 14-year old is liable to appropriately imposed boundaries and sanctions. One of the obvious consequences of behaviourally acting out (for whatever reason) has been, for RD, the increase in the level of supervision, albeit for a short time. This is not altogether surprising; just as parents may temporarily 'ground' a teenager, or a boarding school head may impose limitations or tighter restrictions on a pupil's ability to leave the campus, there is an element of 'teaching a lesson' as well as promoting future safety (see *Re K* at [32] above). Generally, RD has the freedom to wander around the home, and it seems to me that she enjoys a significant degree of*

autonomy about her recreation there while not at school."

When RD had temporarily absconded, she returned voluntarily or by persuasion and, not being distracted by the protective or "comparative benevolence" of Lennox House and RD's general compliance with its regime, the court held:

45. All children are, or should be, as I have discussed subject to some level of restraint, adjusted to their degree of maturity; so too is RD. It is against that background that I assess RD's situation. Having reviewed all the circumstances, and for the reasons which I have set out above, I have reached the conclusion, on a fine balance, that the regime at Lennox House does not possess the "degree or intensity" of complete control or supervision of RD which justifies the description of 'deprivation' of her liberty. In my judgment, insofar as the staff impose limits or boundaries on her movements and freedoms, these represent restrictions of the type which a child of her age, station, familial background and relative maturity would have placed upon her.

Accordingly, there was no deprivation of liberty so it was not necessary to present a petition to the *nobile officium* of the Court of Session in Scotland (i.e. the exercise of the equivalent of the inherent jurisdiction) for its authorisation.

Comment

This is the latest in a series of cases which have tackled the implications of the *Cheshire West* decision for those under 18. One of the most challenging aspects of the law is in identifying the "notional circumstances of the typical child of the same age, station, familial background and relative maturity who is free from disability". The level of detail provided in this judgment helpfully enables practitioners to determine those circumstances for someone aged 14, with other general rules of thumb for 10-12 year olds available in *Re A-F* [2018] EWHC 138.

When, and why, does false imprisonment not equate to deprivation of liberty?

R (Jollah) v Secretary of State for the Home Department [2018] EWCA Civ 1260 (Court of Appeal (Davis LJ; Hickinbottom LJ; Sir Stephen Richards))

Article 5 ECHR – Damages

Summary

This case concerned an award of damages for false imprisonment in the context of immigration detention. The Secretary of State appealed against an award of damages for false imprisonment of a foreign national (IJ) arising out of the imposition of a curfew. IJ cross-appealed against the quantum of damages.

Following his release from prison, IJ was detained in an immigration detention centre. He was granted bail by the First-tier Tribunal and the bail conditions included a requirement that he reside at a specific address. When the bail came to an end, the Secretary of State imposed a curfew between 11pm and 7am every day and IJ was fitted with an electronic tag from 3 February 2014 and 14 July 2016. IJ challenged the lawfulness of the curfew and the Secretary of State accepted that he had no power to impose a curfew. The judge determined that IJ was entitled to damages for false imprisonment quantified at £4,000.

On appeal, the Court of Appeal emphasised that the concept of deprivation of liberty was not identical to the tort of false imprisonment; in fact, whilst recognising that *“the underpinning rationale is similar in each case”*, nonetheless, *“the approach to be adopted with regard to Article 5.1 claims is significantly different from that to be adopted by domestic courts in dealing with claims in false imprisonment.”* The court explained at paragraph 30 that:

...in Article 5.1 cases the courts tended to look at the restraint in question in the context of the whole picture: a distinction

between deprivation of liberty and restriction on liberty was maintained, involving an assessment of the whole range of factors present including nature, duration and effects of the restraint, and the manner of implementation and execution and so on. Thus, even extensive curfew requirements... might not necessarily involve an infringement of Art 5...”

There could therefore be deprivation of liberty without false imprisonment and vice versa. What had occurred in this case constituted imprisonment for the purposes of the tort of false imprisonment and IJ was right not to have pursued a claim by reference to Article 5(1).

As to the quantum of damages, the Court of Appeal noted that many cases involving an assessment of damages for false imprisonment in an immigration detention context have eschewed the setting of a general tariff and each case was left to be decided by reference to its own facts and circumstances. In this case, the restrictions on IJ’s liberty were not complete or total, and there was no finding that the curfew interfered with IJ’s chosen lifestyle in some kind of wholesale way. The Court of Appeal concluded that the award of £4,000 was not plainly wrong such that it should be interfered with.

Comment

Although this is not a decision heralding from the Court of Protection, it is nonetheless interesting for its discussion of the principles separating unlawful deprivation of liberty for the purposes of Article 5 and the tort of false imprisonment at common law. It is also relevant to the vexed issue of damages.

Although the Court of Appeal resolutely maintained the distinction between false imprisonment and deprivation of liberty, it was interestingly suggested that an argument could be advanced that the concept of imprisonment for the purposes of the tort of false imprisonment could be aligned with the contempt of deprivation of liberty for the purposes of Article 5. However, this argument was not pursued although

the Secretary of State reserved his position to argue it elsewhere. For the time being, false imprisonment and deprivation of liberty continue to be treated differently. We note that this means that it is entirely possible, therefore, that a self-funder in a private care home/hospital may well have no recourse against the care home/hospital which does not seek a DOLS. If they do not meet the rather tighter test for false imprisonment, they could not bring a claim for deprivation of liberty under the HRA 1998 against the care home/private hospital. It is not obvious why this gap in protection is justified.

In relation to damages, the Court of Appeal in this case, like many courts previously, declined to lay down any general guidelines for quantum of damages, but rather recounted the mantra that “*each case is left to be decided by reference to its own facts and circumstances.*” Whilst this does provide flexibility for litigants to argue for or negotiate damages relatively unconstrained by prior cases, it does pose difficulties for practitioners attempting to advise on what damages might be awarded by a court if a claimant is successful at trial. The inherent uncertainty in assessing quantum of damages for false imprisonment and unlawful deprivation of liberty claims will likely continue.

Short Note: Assisted dying

On 27 June, the Court of Appeal rejected ([2018] EWCA Civ 1431) Mr Conway’s appeal against the Divisional Court’s determination that the ban in s.2(1) Suicide Act 1961 did not represent a disproportionate interference with his rights under Article 8 (1) ECHR. An application for permission to appeal to the Court of Appeal has been lodged.

Short Note: Article 2 procedural obligations, medical treatment and dementia

R (Parkinson) v HM Senior Coroner for Kent [2018] EWHC 1501 (Admin) was an application for judicial review of the decision by a Coroner that the death of

an elderly woman in hospital did not engage Article 2 ECHR. Mrs Parkinson was 91 years old at the time of her death, and had a diagnosis of dementia. She was diagnosed with a chest infection and taken to hospital. On arrival, the treating doctor formed the view that Mrs Parkinson was dying.² Mrs Parkinson’s son disagreed and wanted further tests and investigations to be conducted. The judgment reports that he attempted to give her mouth to mouth resuscitation. At the inquest, he argued that his mother had been subject to neglect and that Article 2 ECHR was engaged. The Coroner found that Mrs Parkinson had been at an advanced stage of dying when she arrived at hospital and that it would have made no difference if further investigations and tests had been carried out. Her son challenged the Coroner’s decision on various grounds, including that Article 2 was engaged, but his claim was rejected by the High Court.

Giving judgment, the court helpfully summarised the principles that are now to be applied in respect of Article 2 in medical treatment cases following the decision of the Grand Chamber of the ECtHR in *Lopes de Sousa Fernandes v Portugal* [2017] ECHR 1174:

82. Article 2 imposes both substantive positive obligations on the state and procedural obligations.

83. The primary substantive positive obligation is to have in place a regulatory framework compelling hospitals, whether private or public, to adopt appropriate measures for the protection of patients’ lives.

84. The primary procedural obligation is to have a system of law in place, whether criminal or civil, by which individual failures can be the subject of an appropriate remedy. In the law of England and Wales that is achieved by having a criminal justice system, which can in principle hold to account a healthcare

² For a direct but sensitive discussion of the realities of natural dying and in particular the effect on breathing, read

the excellent new book “[With The End in Mind](#)” by Dr Kathryn Mannix.

professional who causes a patient's death by gross negligence; and a civil justice system, which makes available a possible civil claim for negligence. We note that, in the present case, there is in fact an extant civil claim which has been brought by the Claimant against the NHS Trust which ran the hospital (which is the First Interested Party in the present judicial review proceedings).

85. The enhanced duty of investigation, which falls upon the state itself to initiate an effective and independent investigation, will only arise in medical cases in limited circumstances, where there is an arguable breach of the state's own substantive obligations under Article 2.

86. Where the state has made adequate provision for securing high professional standards among health professionals and the protection of the lives of patients, matters such as an error of judgment on the part of a health professional or negligent coordination among health professionals in the treatment of a particular patient are not sufficient of themselves to call the state to account under Article 2.

87. However, there may be exceptional cases which go beyond mere error or medical negligence, in which medical staff, in breach of their professional obligations, fail to provide emergency medical treatment despite being fully aware that a person's life would be put at risk if that treatment is not given. In such a case the failure will result from a dysfunction in the hospital's services and this will be a structural issue linked to the deficiencies in the regulatory framework. At the risk of over-simplification, the crucial distinction is between a case where there is reason to believe that there may have been a breach which is a "systemic failure", in contrast to an "ordinary" case of medical negligence.

It was submitted on behalf of the son that since Mrs Parkinson had dementia and “lacked mental

capacity,”, she was in the same position as a vulnerable mental health patient and so within the scope of Article 2. That submission was quickly rejected by the High Court. The High Court also rejected any suggestion that because a DNACPR notice was put in place at the hospital, this was evidence of a denial of appropriate medical treatment. The High Court noted that “*It was a matter for the clinical judgement of [the treating doctor] but it will be readily apparent that the administration of CPR can be harmful to the interests of a patient, in particular an elderly patient.*”

‘Seni’s Law’ passes Third Reading in Commons

After an unexpected hitch, Steve Reed MP’s Mental Health Units (Use of Force) Bill has progressed through its Third Reading in the House of Commons and now moves to the Lords. Named ‘Seni's law’ in memory of Olaseni Lewis, who died in September 2010 after being restrained by 11 police officers at Bethlem Royal Hospital in south-east London, this Private Member’s Bill is supported by the Government so has a realistic chance of becoming law. It makes provision about the oversight and management of use of force in relation to patients in mental health units and similar settings, introducing statutory requirements in relation to the use of force in mental health units; and require service providers to keep a record of any use of force, have a written policy for the use of force, commit to a reduction in the use of force, and provide patients with information about their rights. In the case of death or serious injuries following the use of force, the Bill would require mental health units to have regard to all relevant NHS and Care Quality Commission (CQC) guidance. This would have the effect of putting NHS England’s Serious Incident Framework on a statutory footing.

The Bill also places a new duty on the Secretary of State to produce an annual report on the use of force at mental health units. At present, data on this is not routinely published.

In addition to provisions on the use of force in mental health units, the Bill also includes provisions on the use of body cameras worn by police officers who attend mental health units for any reason.

Acquired Brain Injury debate

Towards the end of last month, and shortly after Brain Injury Awareness Week, the House of Commons held a debate on acquired brain injury (“ABI”) chaired by the parliamentary under-secretary of state for health and social care (Steve Brine). As the debate noted, the number of people currently living with ABI is thought to be between 500,000 and 1 million with some 1500 patients with traumatic brain injury attending A&E departments in the UK each day. The “total cost” of brain injury, however that is calculated, is estimated to be at least £1 billion.

In an interesting debate, in which a large and perhaps surprising number of MPs volunteered very personal experiences of ABI, the prevalence of ABI was discussed as well as the need for better rehabilitation.

MPs noted the research of the United Kingdom Acquired Brain Injury Forum which calculates that the average cost of the initial rehabilitation programme for ABI is offset by savings in the cost of ongoing care within just 16 months and that this leads to an average saving over a lifetime in care costs of £1,475,760. Neuro-rehabilitation was accordingly described as “*one of the most cost-effective services the NHS provides and one of the few services in medicine that result in long-term decreased costs to the economy.*”

It was also observed that research carried out at HMP Leeds showed that when screening of every prisoner arriving in through the door was carried out, 47% were discovered to have an ABI, that 76% of those had several and that 30% of those had more than five brain injuries. There was also discussion of figures showing that five children in every primary school class in this country will have an ABI, with some research suggesting this figure is between 3 and 4.3 times higher in poorer areas

The government expressed recognition of the fact that “*neglecting rehabilitation is a false economy*” and highlighted its current investments in ABI:

- £100 million over 5 years in biomedical research in Cambridge;
- £5 million to co-fund the surgical reconstruction and microbiology centre in partnership with the Ministry of Defence
- £2 million over three years through NIHR’s global health research group on neurotrauma

In the context of national health budgets, these sums are, of course, fairly limited.

Transforming Care programme debate

In an embarrassingly poorly-attended back bench debate brought by Norman Lamb MP on 5 July, detailed consideration was given by those MPs present of the current – very problematic – state of the Government’s Transforming Care programme, designed to secure the move from hospitals such as Winterbourne View into the community of those with learning disability and autism. At the end of the debate, those MPs expressed the view that:

this House is concerned at the slow progress made under the Transforming Care programme, which was set up to improve the care and quality of life of children and adults with a learning disability and/or autism who display behaviour that challenges; recognises that a substantial number of people with learning disabilities remain trapped in, and continue to be inappropriately admitted to, Assessment and Treatment Units rather than living with support in the community; is further concerned at the lack of capacity within community services; notes evidence of the neglect, abuse, poor care, and premature deaths of people with learning disabilities; believes that the Transforming Care programme is unlikely to realise the ambitions set out in the Building the Right Support strategy before it ends in March 2019; calls on the

Government to establish, prioritise, and adequately resource a successor programme that delivers a shift away from institutional care by investing in community services across education, health and social care; and further calls on the Government to ensure that such a programme is based on lifelong support that protects people's human rights and promotes their independence and wellbeing.

Dementia Guidance

The Government has published new guidance (with an easy read version) in relation to people with dementia and learning disabilities and the need to make reasonable adjustments. It notes that age-related dementia of all types is more common at earlier ages in people with learning disabilities than in the rest of the population and that those with Down's syndrome are at particular risk of early onset dementia. It also notes that data from GPs has suggested dementia in the general population is 5.1 times the number anticipated.

INTERNATIONAL DEVELOPMENTS OF RELEVANCE

Council of Europe report: Powers of attorney and advance directives for incapacity

[Adrian Ward has recently completed a major report as consultant to the Council of Europe reviewing Recommendation CM/Rec(2009)11 on principles concerning continuing powers of attorney and advance directives for incapacity, looking both at how powers of attorney and advance directives are operating in practice across member states in the Council of Europe, and making proposals suggestions for future action. We reproduce below the executive summary, edited to remove cross-references, but strongly recommend reading the report in full both to see how states across the Council use (or do not use) these tools, and also – importantly – for how they can be re-tooled to make them more effective and more compliant with the principles of the CRPD.]

Across Europe, implementation of Recommendation CM/Rec(2009)11 is work-in-progress. Achievements to date by member states are commendable. Much has been done, and continues to be done, by member states towards promoting self-determination for their citizens, by providing and refining voluntary measures, and encouraging their use.

The picture across Europe is however that outcomes envisaged by the Recommendation are only at an early stage of development, leaving most member states still with much to be done. It is also a picture of diversity, ranging from unavailability of continuing powers of attorney (“CPAs”) and/or advance directives, through to relatively wide-ranging provision for CPAs, and at least some provision for advance directives. There is also diversity in that some member states have legislation in force and in full operation, some have passed legislation which is not yet in operation, some have proposals before their legislatures, and some have proposals which are not yet before their legislatures. [...] Where CPAs and advance directives are available to citizens, there is diversity among member states as to the length of time for which they have been available, and remarkable diversity in the extent to which – so far as statistics have been provided – they are used. [...]

As at 1 September 2017, nine member states currently had in force all of the areas of relevant provision of (1) CPAs to cover economic and financial matters, (2) CPAs to cover health, welfare and other personal matters, and (3) advance directives as defined in Principle 2.3 of the Recommendation. One more state will have all of those areas of provision when legislation already passed comes into force. Only one member state, when legislation already passed comes fully into force, will have implemented all of the Principles identified as fundamental in this report.

Completed questionnaires [...] were received from 26 member states. They contributed a wealth of information, which has been correlated and analysed

in this report. These responses to questionnaires (“Responses”) reflect great care and enthusiasm with which member states have analysed and addressed relevant issues in recent years. In addition to Responses, one abbreviated form, and further information from two further member states, were received [...].

The Principles in the Recommendation remain highly relevant. In a time of dynamic development across our continent, guided by the common Principles in the Recommendation, this report seeks to provide a starting-point for further collaborative progress. Member states are encouraged to continue to share information, initiatives and experience. Member states are encouraged to contact the Secretariat to the Directorate General of Human Rights and Rule of Law (“DGI Secretariat”) with proposals for joint projects, conferences and the like.

As well as the general need to continue collaboratively the work of full implementation of the Recommendation, particularly significant conclusions emerging from this review include:

- Provision for advance directives, compared with CPAs, is under-developed. Nowhere is there clear legislative provision maximising the scope of self-determination by advance directives, so as, in conjunction with CPAs, to maximise the total range of provision for self-determination.
- There are insufficiently strong requirements to ensure that, in accordance with the UN Convention on the Rights of Persons with Disabilities, during operation of CPAs granters are informed and consulted, and their wishes and preferences identified and respected.
- Europe-wide, there is insufficient clarity as to how to balance expressions of self-determination when voluntary measures are created, with inconsistent expressions when they are subsequently in operation.
- Promotion of self-determination requires not only availability in legislation of voluntary

measures, but availability of fully inclusive forms of document and procedures to establish them; proactive promotion of use of voluntary measures; and removal of barriers to their effective operation, both within member states and in cross-border situations. All of these aspects require to be developed further in many member states.

This report contains six proposals designed to address the foregoing issues, and 30 suggestions [...], four of them directed to both Council of Europe and member states, and the remainder to member states. Some of those suggestions are at least partly supplementary to the proposals. The majority are free-standing.

The proposals set out below, and the suggestions appearing later in this report, have been drawn by the consultant from the information provided in this report, and from matters within his own knowledge. These proposals and suggestions are solely those of the author and do not necessarily reflect the views of CDCJ, the Council of Europe or its member states.

The proposals are:

PROPOSAL 1:

(A) – That all member states should, on an ongoing basis, continue to review and develop provisions and practices to promote self-determination for capable adults in the event of future incapacity by means of CPAs and advance directives.

(B) – That in doing so, member states should have regard to such assistance as may be provided by the solutions to issues, and experience in practice, of other states as described in this report; should continue to share information, initiatives and experience; and should where appropriate, and in conjunction with Council of Europe, promote joint projects, conferences and the like.

PROPOSAL 2:

(A) – That member states consider, in particular, developing provision for advance directives, as a

component in the overall promotion of self-determination in conjunction with CPAs, having regard to the full potential scope of application of advance directives to all health, welfare and other personal matters, to economic and financial matters, and to the choice of a guardian should one be appointed; and with appropriate distinction between the categories of instructions given and wishes made.

(B) – That Council of Europe should consider promoting research and consideration at a European level, and issue of guidance or recommendations, with a view to assisting member states in implementing Proposal 2 (A).

PROPOSAL 3:

That member states review laws relating to CPAs to ensure –

(A) That in relation to all acts and decisions in their role as attorneys, attorneys are required to take all practicable steps to ascertain the will and preferences of the granter, or failing that the best interpretation of the will and preferences of the granter.

(B) That in their acts and decisions on behalf of the granter attorneys are required to give effect to the will and preferences of the granter (or best interpretation thereof) except only where stringent criteria for doing otherwise, set forth in law, are satisfied. (C) That the requirement to inform and consult the granter on an ongoing basis includes a requirement (i) to present to the granter, in the form that the granter is most likely to understand, the information necessary to enable the granter to formulate and communicate his or her will and preferences, (ii) to provide the granter with all reasonable support towards enabling the granter to formulate and communicate the granter's will and preferences, and (iii) to keep the granter informed of acts and decisions taken and implemented.

PROPOSAL 4:

That Council of Europe give consideration to promoting discussion and research with a view to clarifying matters relevant to situations of conflict

between the terms of a continuing power of attorney or advance directive, on the one hand, and on the other the apparent will and preferences of the granter at time of exercise of powers conferred by a CPA, or of implementation of instructions in an advance directive, or when wishes expressed in an advance directive are to be followed.

PROPOSAL 5:

(A) – That member states facilitate and encourage the use of continuing powers of attorney and advance directives in forms helpful to people with disabilities, including in easy-read form, and the maximisation of support to enable people with disabilities to exercise their legal capacity by granting CPAs and issuing advance directives.

(B) – That member states facilitate and encourage the incorporation of supported decision-making and co-decision-making provisions in continuing powers of attorney.

(C) – That Council of Europe develops and issues guidance or recommendations to assist member states in implementing Proposals 5 (A) and (B).

PROPOSAL 6:

That member states should:

(A) – Educate citizens about CPAs and advance directives, and proactively promote the granting of CPAs and the issue of advance directives.

(B) – Assess whether financial savings achieved by higher levels of uptake of CPAs and advance directives would make it economically prudent to fund such public education and promotion, and/or to subsidise the costs of granting CPAs and issuing advance directives.

(C) – Review whether all available involuntary measures comply with international human rights requirements, and whether they avoid inhibiting uptake of voluntary measures.

(D) – Review and address any barriers, internally or in cross-border situations, to the full recognition and

effectiveness in practice of CPAs and advance directives.

Can values, wishes and beliefs determine the meaning of death?

In June 2018, the Ontario Supreme Court (not the highest appellate court in Ontario) gave judgment in *McKitty v Hayani*, a tragic case concerning a 27 year old woman who suffered serious brain damage following a drug overdose and was declared to be brain stem dead by doctors. In Ontario, as in many other places, there is no statutory definition of death, but the diagnosis of death is generally left to medical professionals. Ms McKitty's parents argued that where a person's religious beliefs conflicted with the medical definition of death, those religious beliefs should prevail, and that "[t]he determination of death requires an assessment of not only medical considerations but also the values, wishes and beliefs of the individual patient."

There are different ways in which death can be described – the cessation of the circulatory system (the heart and lungs) and the cessation of neurological function. In contrast to a prolonged disorder of consciousness, in brain stem death, there is no flow of oxygen to the brain and so no brain activity, even at the level of reflex. The heart of the brain stem dead person can continue to beat and, if supported by ventilation, the person can continue to be kept 'alive' for a period of time.

In Ms McKitty's case, a number of doctors had assessed that she was dead by applying neurological criteria – there was no flow of oxygen to the brain and no electrical activity in the brain. She had displayed some movements which were documented by her family, but the court accepted that these were spinal reflexes not mediated by any brain activity.

In the course of its judgment, the court considered the position in the UK, observing that "*The common law of the United Kingdom recognizes death by neurologic criteria, which is defined as death of the brainstem.*" Overall, the court summarised the global jurisprudence in the following terms:

Courts have made findings of death when cardiorespiratory function has been maintained by mechanical ventilation;

- Courts have accepted brain death as death;
- This definition of death has evolved from a traditional reliance on cardio-respiratory failure as a result of scientific and medical advancements;
- It is left to the medical community to determine the criteria or guidelines to establish brain death;
- There is no decision where the court has found that an individual's views, wishes and beliefs must be considered as part of the determination of death;
- There is no decision where the court has found that a body that may be physiologically and biologically functioning, in the presence of brain death, is alive.

The court, unsurprisingly, followed this approach and determined that Ms McKitty was dead. The court was anxious about the wider implications of the family's position:

126. The applicant is proposing a radical and significant change to the definition of death and, in essence, the concept of life. It is not the role of this court to engage in a social policy analysis that engages significant bioethical and philosophical considerations regarding the recognition of physiological functioning of the body as life.

127. There are also policy issues that would have to be considered which are beyond the role of this court. For example, according to Dr. Baker and Dr. Truog, given medical technology, a body can be maintained for an indefinite period of time after a declaration of brain death. That could have a significant financial impact on the health care system if a body that is biologically or physiologically functioning is to be

maintained on mechanical ventilation until such time as the heart stops beating, at the request of the individual or their family, based on their personal values and beliefs. There could also be an indirect impact on those who require medical services or treatment if staffing and medical resources are required to maintain those who believe that a biologically functioning body is life. Lastly, there could also be adverse consequences to the organ donation system in Canada. Although no evidence was led regarding any possible impact on the organ donation system, a reasonable conclusion is that if more individuals are maintained on mechanical ventilation beyond the determination of brain death, there could be fewer possible donors. This ripple effect of consequences flowing from a recognition of biological functioning as life requires careful consideration by the legislature.

128. *Furthermore, if a choice can be made that a physiologically functioning body must be maintained on mechanical ventilation, do medical services have to extend to providing other interventions to maintain that functioning body? For example, if Ms. McKitty's kidney function fails, will dialysis be required? Should she be treated with antibiotics to fight infection? If her bowels fail, should there be interventions to provide her with a colostomy for so long as her heart is beating? If her heart stops beating, is medical intervention required to attempt to restart the heart? What medical services and to what extent must those services be provided to maintain a physiologically functioning body if that is considered life? These are all issues that cannot be resolved by this court but are best dealt with by the government which is well-suited to address such policy issues. Unlike the court, legislatures are better able to determine questions with many diverse input factors that affect a variety of constituencies in the decision-making process.*

The court also found that the Canadian Charter did not apply to Ms McKitty as it applied only to living persons, but held that in any event, the principles of the Charter were not inconsistent with an approach to brain death which did not factor in the religious beliefs of the individual.

Comment

There are two reported decisions in England and Wales concerning brain stem death – *Re A* [1992] 3 Med LR 303 and *Re A (A child)* [2015] EWCA 443 (Fam). In both, the mainstream medical approach was accepted. The uncertainties involved in this area, including the persistence of movement and the recording of electrical activity after the cessation of brain function, may well mean that the issue arises again. The recent case of *Jahi McMath* has highlighted that different regions in the USA have a different approach to religious objections to brain stem death. Greater public knowledge of this option could lead to a situation where permission is sought to take a child or adult out of the jurisdiction for continued ventilation in another country.

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Conferences

Conferences of interest

Costs and summer drinks reception

On 26 July a training event and summer drinks reception will be hosted by London CoPPA in association with Hardwicke Chambers covering hot topics in the world of Court of Protection costs. For more details, see [here](#).

Towards Liberty Protection Safeguards

This conference being held on 24 September in London will look at where the law is and where it might go in relation to deprivation of liberty. For more details, and book, see [here](#).

5th International conference on capacity: ageing, sexuality & human rights

Capacity Australia is hosting this fascinating-looking conference in Rome on 3 October. For more details see [here](#).

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.

We are taking a summer break (from this, but not from the world of mental capacity law, which is going to be a very busy one over the next few months). Our next edition will be out in early September. 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.

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