



Welcome to the December 2019 Mental Capacity Report – our 100^{th*}. Highlights this month include:

(1) In the Health, Welfare and Deprivation of Liberty Report: an important guest article from Inclusion London, and reflections from Tor and Alex on 100 issues;

(2) In the Property and Affairs Report: a report of an interview with HHJ Hilder and deputyship refunds;

(3) In the Practice and Procedure Report: the administration of appeals, and important judgments shedding light by analogy on fact-finding, costs and vulnerable witnesses;

(4) In the Wider Context Report: assisted dying, Article 2 obligations and informal patients, and reports of developments in Northern Ireland, Jersey and wider afield;

(5) In the Scotland Report: an important judgment on guardianship and deprivation of liberty, a judicial review of conditions of excessive security and further observations on the operation of 'foreign' powers of attorney in England & Wales from the Scottish perspective.

You can find all our past issues, our case summaries, and more on our dedicated sub-site [here](#). If you want more information on the Convention on the Rights of Persons with Disabilities, which we frequently refer to in this Report, we suggest you go to the [Small Places](#) website run by Lucy Series of Cardiff University.

Happy holidays, and we will return in February 2020.

* Confession: there was a numbering glitch a long way back which means that this is no.99 in this series, but in our defence no.1 in fact represented the formalisation of informal updates Tor and Alex had been doing for several months.

Editors

Alex Ruck Keene
Victoria Butler-Cole QC
Neil Allen
Annabel Lee
Nicola Kohn
Katie Scott
Katherine Barnes
Simon Edwards (P&A)

Scottish Contributors

Adrian Ward
Jill Stavert

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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We are not Ps we are People

[In this our 100th issue, we thought that it was most important to start with something written from the point of those to whom the MCA is applied day-in, day-out, inside and outside the Court of Protection; we are therefore very grateful to Svetlana Kotlova of [Inclusion London](#) for her work in coordinating and supporting the following guest article]

There are too many problems with the law and how it doesn't uphold human rights of people with learning difficulties, autism and mental health support needs. It allows discrimination often in the name of protection and making sure people are safe. It often excludes people from making important decisions about their life and it does not address the power imbalance that so many individuals experience no matter where they live and what they do. Many problems are also to do with how the laws are implemented and enforced.

I asked Andrew Lee Director of People First and Christine Spooner Chair of People First to help me write this article. Below we discuss how the Mental Capacity Act works for people who are on the receiving end. We also talk about fundamental problems that underpin our laws and the way people with learning difficulties are treated. We are very grateful for this opportunity to put across our point of view.

Why learning difficulties?

We use the term learning difficulties. We know in law these words have a different meaning. We use this term because we believe in the Social Model of Disability, which says disability is not about impairment, it is the barriers people with impairments face. Learning difficulties describes our impairment and we are disabled by the lack of accessible information, communication, prejudice and discrimination and the lack of support.

Compulsion in the name of caring

Christine told me:

Too many people who come to my house somehow know what's best for me. They start telling me how to do things and what should happen before even talking to me and when I demand they get out of my house, I'm labelled as rude, unreasonable, ungrateful or angry. Yes, I get angry, and so I should be. Just imagine someone came to your house, started telling you what to do straight away, changed things how they wanted without talking to you. You would not be smiling and asking them to come again.

Of course, most people want to help and do good, but somehow still deep down their mind they think they know better what is good for me. They almost treat me like a child. This attitude comes at

every stage, from small decisions to big. Most of the time people do not even understand that what they are doing is wrong. I am used to fighting my corner. I don't care what they think. But it is not easy to live a life where you always have to fight with people who are close to you and are supposed to help you. Why do I have to remind people to recognise me as a person and respect my choices, no matter whether they agree or disagree? I feel the only people who can understand what I am going through are other people with learning difficulties. This is why self-advocacy and peer support are so important.

Compulsion in the name of care is deeply rooted in discriminatory attitude towards disabled people and people with learning difficulties in particular. We have not been seen as "normal" human beings. Society as a whole still doesn't know what to do with us. The support we need can cost a lot and the support that promotes our liberty and our autonomy costs even more.

Andrew says:

Supporting us is a difficult and very skilled job. It is much easier to lock us away in institutions or our homes, make decisions for us and protect us from living a life. And although the laws have changed, discrimination is still there and real life does not resemble what should happen under the law. The choice we have are only the choices we are given, the often have nothing to do with our aspirations and we really want our life to be.. the same as everybody else..

Discriminatory nature of our laws

Only people with learning difficulties, autism and mental health support needs could be detained,

preventatively because professionals think they are a danger to others. We as society would not agree with a proposition to detain all dangerous people, but we accept it when it comes to people with learning difficulties and mental health support needs. And it is often forgotten that there are many of us who experience abuse even in places that are supposed to protect us.

There are many non-disabled people who would benefit from medical treatment, but it is only us who could be forced to undergo the treatment we do not want. On the other hand we often have to fight for the help and support that we really need and that would really help us.

We need support and sometimes protection, that increase our choice and promotes our freedom, but we get protection and care that forces us to accept things we don't want.

People with learning difficulties are subjected to unbelievable levels of scrutiny. Take parents with learning difficulties, who have to prove they are good parents and battle for support, when non-disabled parents have to do something seriously wrong before anyone gets involved.

Many of us have to battle hard to have relationships or live where we want, while non-disabled people take it as normal part of life.

And the Human Rights Act allows all this.

And of course the Mental Capacity Act with all its protections and presumption of capacity still allows others to make decisions for us, override our wishes and decide what is good for us. In reality people are not supported to make decisions, they are not given accessible information or real choices, what they get to

choose from depends on what information they get given, time is not taken to see and understand what they want. Moreover, since many individuals need support their choices are often limited by decisions made by local authorities or CCGs about their support packages. Supporting people to make decisions requires time, commitment, skill and the right attitude. In a day-to-day life it is much easier and cheaper to just make decisions for them.

There is a huge imbalance of power in our lives; we often depend on people who make decisions for us. And when we disagree, the onus is on us to dispute through the Court of Protection... the very system we cannot access.

It feels like when the system was designed, no one really thought it through from our point of view. How is it supposed to work in practice for every person and every decision? How would it work for a friend of mine who was told by a care home manager they cannot have a relationship? Many of us need support to get support, not everyone has relatives who will fight for us, not everyone has an advocate. Most people would not know where to start and what to do. The process is so complex and inaccessible even for non-disabled people and it is just an illusion that we can challenge decisions about our capacity or best interests. We can only challenge when others around us are prepared to help us.

Decision makers and legal systems don't have credibility with people with learning difficulties as the promises they have made, and make again, especially after scandals such as Winterbourne View and more recently Whorlton Hall, are never followed through.

The Court of Protection feels more like a place where other people argue what is good for us, often without us. I was shocked that the law and the lawyers call us "P". I know it is legal language, but there is a life, a real person, Joe, Sarah, whose life is on the cards, not just a P. I was also shocked to find out the lawyers who represent us will not always argue what we want. They will argue what they think is best for us. So who is there to represent our voice? It would be scandalous if something like this was happening to non-disabled people.

The advocacy that people with learning difficulties set up for themselves, and still use, needs to be accepted by the legal system – advocates recognised by the legal system such as barristers and lawyers are not always 'our' advocates.

The whole system is not fit for the XXI Century. It needs to be accessible, it needs to hear our voice and give us a real opportunity to exercise our rights.

The change we need

There are international human rights standards like the UN Convention on the Rights of Persons with Disabilities. Which talks about supported decision-making, it prohibits detention on the basis of disability and calls for respect for integrity of every disabled person. It requires support to be put in place in community to ensure we have choice and control in our lives. These standards challenge ways of thinking and working and this is why there is still a lot of scepticism among the professionals. It is worth remembering that UNCRPD is probably the only document which was developed with such extensive and meaningful input from disabled people. We therefore ask everyone to accept

these standards, aspire to achieve them and focus on what to do to make it happen, rather than thinking and talking why it is impossible to achieve this.

We need support to make decisions ourselves. We need our wishes and views to be heard and respected in decision-making processes. We need supporters and allies who would help us advance our human rights and who would support and enable us to speak out for ourselves be it in court or when bigger policies are developed by the government.

Last year, when the Mental Capacity Amendment Act was going through Parliament we spoke to many people with learning difficulties about the Mental Capacity law and UNCRPD. We published a report which highlights some important issues for us. You can read the report [here](#).

DoLS statistics

The DoLS statistics for 2018-9 have been published by NHS Digital. Headline points are that:

- There were 240,455 applications for DoLS received during 2018-19, relating to 200,225 people. The number of applications has increased by an average of 15.0% each year since 2014-15.
- The number of applications completed in 2018-19 was 216,005. The number of completed applications has also increased each year, by an average of 36.3% each year since 2014-15.
- The reported number of cases that were not completed as at year end was 131,350. This

is higher than in previous years, however the gap between the volume of applications and those completed within each year has narrowed from 54.5% in 2014-15 to 10.2% in 2018-19.

- The proportion of completed applications in 2018-19 that were not granted was 45.9%. The main reason was given as change in circumstances, at 58.1% of all not granted cases; in 31,130 cases, the application was not granted because the person had died.
- The proportion of standard applications completed within the statutory timeframe of 21 days was 22.0% in 2018-19. The average length of time for all completed applications was 147 days.

The first 100 issues: Tor's thoughts

You might remember that 2010 was the year of the Conservative/Liberal Democrat coalition government, the election of Ed Miliband as Labour leader rather than his brother, and, even more significantly, the publication of the first formal 39 Essex (St) Mental Capacity Newsletter.

Back in 2010, we had about 50 people who were sent our case summaries by email every three months or so. The first formal edition, in August 2010, covered the familiar topics including deprivation of liberty and the appointment of welfare deputies. It was a mere 13 pages long, with only 2 editors, and no photos. Nor were there any neutral COP citations for the cases.

Fast forward to the 100th edition, and we have 8 editors, 2 Scottish contributors, reports that sometimes seem more like short books than newsletters, and, at the last count, 11,390

individual subscribers! It is a huge task to pull the report together each month, and Alex bears the brunt of it. But we are all committed to continuing the report, as we know how useful people find it – not just lawyers, but social workers, health professionals and others with an interest in this area of the law. Here's to the next 100 editions!

The first 100 issues: Alex's thoughts

At the risk of sounding like an Oscar's speech, I am going to use my slot to give thanks:

- That Tor had the thought to start this off almost 10 years ago rather than 10 weeks ago, so that it has been possible to build a database of cases and materials gradually, rather than attempt the impossible task of starting now from scratch;
- To those who read, comment and send in materials to us, not just from England, Wales and Scotland, but increasingly from the other two jurisdictions within these islands, and from the wider world;
- To the marketing team in Chambers who have over many years cheerfully and patiently supported a project that – if it works – frequently works to ensure that situations do not get to the point where barristers within Chambers have to be asked to advise or represent people or bodies; and, above all
- To the members of the editorial team for their hard work in keeping up contributions month after month. They never fail to respond to the monthly email from me asking for volunteers, and from the times that the emails are sent in response I know how often their work is being done on top of a very demanding day job.

Who knows where we will be in another 100 issues' time? Reporting upon a 'fused' mental capacity and mental health law? Reporting upon separate Welsh mental capacity legislation? Reporting upon a law that moves entirely beyond mental capacity? We can, though, promise that we will continue to keep up reporting developments as and when they occur.

Editors and Contributors

**Alex Ruck Keene: alex.ruckkeene@39essex.com**

Alex is recommended as a 'star junior' in Chambers & Partners for his Court of Protection work. He 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 Wellcome Research Fellow at King's College London, and created the website www.mentalcapacitylawandpolicy.org.uk. To view full CV click [here](#).

**Victoria Butler-Cole QC: 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. Together with Alex, she co-edits the Court of Protection Law Reports for Jordans. She is a contributing editor to Clayton and Tomlinson 'The Law of Human Rights', a contributor to 'Assessment of Mental Capacity' (Law Society/BMA), and a contributor to Heywood and Massey Court of Protection Practice (Sweet and Maxwell). To view full CV click [here](#).

**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. To view full CV click [here](#).

**Annabel Lee: annabel.lee@39essex.com**

Annabel has experience in a wide range of issues before the Court of Protection, including medical treatment, deprivation of liberty, residence, care contact, welfare, property and financial affairs, and has particular expertise in complex cross-border jurisdiction matters. She is a contributing editor to 'Court of Protection Practice' and an editor of the Court of Protection Law Reports. To view full CV click [here](#).

**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 2019). To view full CV click [here](#).

Editors and Contributors



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](#).



Katherine Barnes: Katherine.barnes@39essex.com

Katherine has a broad public law and human rights practice, with a particular interest in the fields of community care and health law, including mental capacity law. She appears regularly in the Court of Protection and has acted for the Official Solicitor, individuals, local authorities and NHS bodies. Her CV is available here: To view 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: adw@tcyoung.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

Jill Stavert is Professor of Law, Director of the Centre for Mental Health and Capacity Law and Director of Research, The Business School, Edinburgh Napier University. Jill is also a member of the Law Society for Scotland's Mental Health and Disability Sub-Committee. She has undertaken work for the Mental Welfare Commission for Scotland (including its 2015 updated guidance on Deprivation of Liberty). To view full CV click [here](#).

Conferences

Conferences at which editors/contributors are speaking

Approaching complex capacity assessments

Alex will be co-leading a day-long masterclass for Maudsley Learning in association with the [Mental Health & Justice](#) project on 15 May 2020, in London. For more details, and to book, see [here](#).

Other conferences of interest

Safeguarding and the Care Act 2014 - Self-neglect

Continuing the SALLY (safeguarding and legal literacy) series, this day-long seminar at Keele University on 31 January focuses on self-neglect. For more details, and to book a free ticket, 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.

Our next edition will be out in February 2020. 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.

Michael Kaplan
Senior Clerk
michael.kaplan@39essex.com

Sheraton Doyle
Senior Practice Manager
sheraton.doyle@39essex.com

Peter Campbell
Senior Practice Manager
peter.campbell@39essex.com



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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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