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Transcription of an interview on autism and mental capacity law with Dr Yo Dunn

Qu. Can you tell us how you first became interested in mental capacity law and its impact on autistic people?

I've began quite a few years ago now. I became involved in Adult Social Care Law around community care and social work. The more I read case law in that area, the more I noticed the frequency with which autistic people cropped up in the case law, particularly around mental capacity and the deprivation of liberty. And I became aware really of the very high numbers of autistic people who are deemed to lack mental capacity, and who end up being cared for in situations where they're deprived of their liberty. I basically took it from there.

Qu. Can you tell us a little more about the Mental Capacity Act and the Deprivation of Liberty Safeguards and why they were introduced?

Yeah, the Mental Capacity Act is over 10 years old now, it was introduced in 2005. That came about really, it was a process started by the Law Commission of wanting to codify the existing common law on mental capacity to bring some consistency to decision-making in the area, but also really due to an increasing understanding of disability rights and the importance of disabled people being supported to make our own decisions.

That was sort of the beginning really of the more formal development of Mental Capacity Law, but it was a couple of years after that, that there was a case, the Bournemouth case in the European Court of Human Rights that really began to recognize a difficulty in the care system with adults who were being cared for in quite restrictive circumstances and who might not actually be able to give their informed consent to that care.

That case then led to the introduction of the Deprivation of Liberty Safeguards in 2009, and the intention there was to insure that where an adult is cared for in a way that interferes with their right to liberty that that's just looked at, checked up on by an independent person to say, yep that is the right thing to do here.

Qu. Can you tell us about the Cheshire West Case and its impact?

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Yeah, so after the Deprivation of Liberty Safeguards were introduced, not terribly long after that, there was a very important case that ended up in front of the Supreme Court, and it was actually more than one case, involving a number of disabled adults with a variety of disabilities, and the decision that the Supreme Court came to in that case was actually really seminal for disability rights.

It essentially said that looking after an adult in a way that interferes with their rights or deprives them of their liberty, if that's happening and they don't have the full rights that other adults in society would have, then that needs to be looked at legally, it's not an inevitable consequence of their disability. We can't say, oh well because someone's disabled it's as normal a life as they can expect, so that's alright then, which was sort of what we were doing up to that point.

But the other intended consequence of that ruling has been that the system that was set up with the Deprivation of Liberty Safeguards simply was never get to handle the sheer volume of adults who we now recognise as being deprived of their liberty, and so right at the moment and today, the system is completely overwhelmed and is not in practise working at all as it should.

Qu. How are autistic adults impacted by the law around mental capacity?

Fundamentally, the law around mental capacity at present means that quite a number of autistic adults are judged to lack the mental capacity to make decisions in their own lives for themselves.

The problems for autistic people specifically with this, are that, in my experience, the quality of assessment of whether someone has the capacity to make decisions for themselves are often quite poor, often the people carrying out those assessments don't necessarily have a good understanding of autism, and what ends up being assessed is quite often a person's ability to communicate verbally about their understanding rather than necessarily their actual understanding. So I think that's one of the significant problems.

Another area of difficulty is that where someone is judged to lack capacity decisions are then taken in their best interest. Now the Mental Capacity Act is actually very good about what that means but practise is a very long way behind. On the ground very often best interest is seen as code for what professionals think ought to happen, and there's not enough respect for the views and wishes that an adult might have, their feelings and their needs.

And finally a problem in the law itself, with the current state of Mental Capacity Law in England, is that it's an all or nothing. So, someone either has the capacity to make adult decisions entirely by themselves or they don't have that capacity at all. The difficulty with that is that, unfortunately, England is lacking behind the rest of the world now in the development of supported decision-making and legal mechanisms to enable disabled adults to empower people who are helping or supporting them to assist them with making decisions. So I think it has quite a major impact really on the lives of autistic adults.

Qu. How are autistic adults impacted by the law around the deprivation of liberty?

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That's a picture which is really very complicated by its history as much as anything. That in some areas the law, certainly the Cheshire West judgement, has moved well ahead of where practise is. And unfortunately in day-to-day practise there are many autistic adults who are cared for in circumstances that deprive them of their liberty with a very high level of restrictions, quite often those restrictions may not really be necessary and that sometimes isn't looked at hard enough, often due to poor understandings of autism there's an overuse of inappropriate medication to manage challenging behaviour, and also a very high use of seclusion and restraint, and as I said, really high level of restrictions without really consideration of whether those are fully appropriate.

Now, the law is very supportive of the right of adults to be cared for in the least restrictive circumstances possible. But unfortunately at the moment, the Deprivation of Liberty Safeguards, are functioning so poorly in practise, and access to the court's protection is also severely limited and encountering serious problems at the moment. So the reality is that there are many autistic adults who are being cared for in perhaps inappropriately restrictive circumstances and that's not really being appropriately challenged and subject to sufficient independent review.

Qu. How can autistic adults who may find decision making difficult be best supported?

Yeah, actually there's an awful lot that can be done, and it doesn't necessarily take an enormous amount of expert knowledge. Very often adults can be very well supported to make their own decision simply by being given more time to process the information, to understand and weigh up the issue without also having to communicate about it. So just allowing lots of processing time can really help.

Another crucial step that can be taken to help autistic adults with decision-making is to provide information and to collect information from adults in forms of communication other than speech. I'm not just talking about adults who may not use speech at all, but right across the autistic spectrum it can be helpful to have the information about a decision provided in other formats as well, whether that's pictures, writing, things like that. And also, for other people to recognise communication and understanding that may be communicated in non-verbal ways, say through someone's behaviour.

The final step I think that would make a really big difference is just a deeper respect for genuine equality in society. Unfortunately very often, adults with disabilities are simply assumed, on the basis of diagnosis, to be unable to make decisions for themselves, and often even quite basic support for decision-making is lacking.

Now, autistic people in particular, may have difficulty sometimes working out the unwritten rules, the sorts of information that we may find it difficult to pick up. And quite often autistic decision-making is considered faulty because of a failure to anticipate for example, how other people might react. But actually, Mental Capacity Law says that, an adult should only be judged to lack capacity whether unable to use and weigh the information relevant to a decision. So actually it shouldn't be up to the autistic adult to guess how other people might react, or where is a safe area of town to go late at night on one's own. It should be the responsibility of people supporting them to provide that sort of information, to explain how other people might react, and then see whether the autistic person can make a decision on the basis of that information.

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Qu. Please could you tell us about the proposals for reform of the deprivation of liberty safeguards in England

Yes well, the Law Commission undertook a very thorough review, and there were a number of people with a great deal of experience in Mental Capacity Law involved in that, and they had a very deep look at the Deprivation of Liberty Safeguards and consulted widely in the social care sector as to what form of system would strike the correct balance between protecting people's human rights and being proportionate, being manageable, for day-to-day decision-making about social care placements.

They came up with a system that they've called the Liberty Protection Safeguards, which for starters is a much better name because it makes it clear that the aim here is to protect people's freedoms, not take their freedoms away. But it's also a system which proposes, crucially I think, to look at whether the proposed restrictions are necessary, whether they are proportionate to the risks that someone's being protected against, and to think about that at the point of making initial decisions about a placement rather than the situation that we currently have where placement is made first and then those safeguards kick in later.

So, the reform proposals in themselves, are very largely a very positive step. The difficulty is that we have yet to hear from the government on whether, let alone when, those safeguards might actually be brought into law, and given the current political climate and other priorities such as Brexit, it has to be said that it seems unlikely that we will see a new system really in place any time soon.