

This is an Accepted Manuscript of an article published by in Learning Disability Practice. The final version of the article can be found online - <https://doi.org/10.7748/ldp.2018.e1855>

An update on informed consent to treatment and the impact on the clinical practice of healthcare professionals working with people with learning disability

This article explores issues of capacity and consent in context of new case law, its implications in the field of learning disabilities and practical application in medication prescription and administration.

It is well recognised that people with learning disability in the UK have specific and distinct issues accessing healthcare, experiencing poorer health outcomes and reduced life expectancy compared to the wider population (Emerson and Baines 2011). According to the Article 12 UN Convention on the Rights of Disabled People (2006) people with learning disabilities have the right to expect equal recognition before the law and as such ought to be considered partners in selecting treatment options. In order to achieve this, people with learning disability need to be informed and empowered to be able to discuss and –where needed – able to challenge their treatment with healthcare professionals. Improving health literacy in people with learning disability and their support, using appropriate - wherever possible – bespoke resources may go some way in addressing these issues.

This article seeks to examine new case law which re-balances the relationship between the person and their clinicians, posing questions for all healthcare professionals and what specific adjustments might be required for people with learning disabilities. Medicines Optimisation has been selected for consideration for four reasons:-

1. the current national focus on reducing the over use of antipsychotic medications (NHS England, 2017),
2. the continued increase in non-medical prescribing (Oxtoby, 2016)
3. the day to day implications for people with learning disabilities (NHS England, 2017) and
4. the role the majority of health and social care professionals play in this activity.

Nice guidance on decision making and mental capacity is currently in development.

Mental Capacity Act 2005 (MCA)

The Mental Capacity Act reflects many of previous decisions from the courts. In 1994 C was an inpatient in Broadmoor Hospital and had a diagnosis of paranoid schizophrenia. He was suffering from a gangrenous foot and amputation was

advised by his medical doctor. The court decided he had capacity to refuse this treatment as C comprehended and retained the information, he believed the information to be the truth and he had weighed up the advice in order to reach a decision (Re C 1994). As C satisfied the 'functional stage', his autonomous decision not to have his foot amputated was respected. Simply because C was suffering from a mental disorder did not negate his capacity to consent or refuse medical treatment. However, in the more recent case of NHS v T (2004) where the patient had a borderline personality disorder, the court held that although the patient could satisfy the test in Re C on a superficial level, there was such a 'misconception of reality' that it was sufficient for her autonomy to be displaced in favour of others acting in her best interests.

The Re C case illustrated that simply experiencing a mental disorder does not negate capacity; in doing so it provided a framework for assessing capability to make a decision, and set a precedent safeguarding the autonomy of all who might previously been assumed to lack this ability.

The Mental Capacity Act enshrines the decision in Re C with the assumption that everyone has capacity to make decisions within its first principle. However, health & social care professionals have learnt to be mindful as to whether the person they are working with have any significant disturbance of mind or brain that may have an impact on their capacity, this is known as the two stage test of the Mental Capacity Act.

In many cases where the person has a learning disability, cognitive impairment or dementia the four stage test will need to be applied. By virtue of Section 3 of the Mental Capacity Act, this entails assessing if the individual can:-

- a) understand the information relevant to the decision
- b) retain that information
- c) use or weight that information as part of the process of making the decision or
- d) communicate that decision (whether by talking, using sign language or any other means)'

This act seeks to encourage health and social care professionals to consider presenting information about the proposed choice in a way the person is able to understand (Department of Constitutional Affairs, 2007), therefore encouraging retention and enabling autonomy where possible and where not, safeguarding the rights of those that are unable to make that specific decision at the specific time.

While most significant decisions will be isolated events, prescription and administration of medication will likely have day to day impact for many people with learning disabilities, as such close attention will need to be paid to those that might experience fluctuating capacity as a result of a physical or mental health issue.

In its tenth year, the Mental Capacity Act is currently being reviewed following the publication of the Law Commission's report (2017). Since this time, English law has been significantly strengthened and augmented by the implementation of the Accessible Information Standard (NHS England, 2016) and more widely in practice by frameworks to support the interpretation of the term 'reasonable adjustments' under the Equality Act 2010 (Marsden & Giles, 2017).

What information should healthcare professionals disclose to patients?

The case of *Montgomery v Lanarkshire Health Board* (*Montgomery v Lanarkshire* 2015 UKSC 11), decided by the Supreme Court in 2015, followed decades of judicial decisions involving failure to advise patients of a recognised risk. As a result of the decision in *Montgomery*, the patient is now centre of the decision-making process; a reflection of the principles in the MCA.

The case concerned Mrs Montgomery, a slight pregnant woman with diabetes. Although Mrs Montgomery's obstetrician and gynaecologist Dr McLellan advised her she was having a larger than average baby, Mrs Montgomery was not advised of the risk of shoulder dystocia; a condition where the baby's shoulders are unable to pass through the mother's pelvis. Although it was accepted by Dr McLellan that shoulder dystocia was a significant risk, she did not routinely advise patients of the risk, partly because the risk of serious injury to the baby was small and partly because her patients would ask for a caesarean section which was not Dr McLellan's preferred practice. Once Mrs Montgomery was in labour, shoulder dystocia occurred, and Mrs Montgomery gave birth to a severely disabled boy and sued the Health Board for compensation.

The Supreme Court redefined the law on informed consent which now imposes a duty of any healthcare professional who treats a patient 'to take reasonable care to ensure that the patient is aware of any material risks involved in any recommended treatment and of any reasonable alternative or variant'.

The Supreme Court defined a material risk as one where 'a reasonable person in the patient's position would be likely to attach significance to the risk, or a doctor is or should reasonably be aware that the particular patient would be likely to attach significance to it' (*Montgomery v Lanarkshire* 2015 UKSC 11 para 87)

With regards to Mrs Montgomery, it would appear clear that a 9-10% risk of shoulder dystocia was a risk that she would attach significance to, particularly in relation to the smaller but still present risk of serious harm to the baby, should shoulder dystocia occur. Had she been advised of the risk, she may have asked for a caesarean section to eliminate that specific risk. Not being advised of the risk meant she could not provide informed consent.

In reality, the court's judgment largely reflects GMC guidelines (General Medical Council 2008) that have been in place since 2008 and which many healthcare

practitioners adhere to, but close attention should be paid to these issues as failure to advise of risk in itself, can now result in a patient's claim in negligence.

Whilst this judgment is the source of many academic articles and debate, the emphasis is now on what a reasonable adult with capacity would want to know, rather than what a reasonable healthcare professional would disclose. The court emphasised the method for achieving this would be present in the dialogue between the patient and the healthcare professional in order that the patient:

- a) understands the seriousness of her condition
- b) and the anticipated benefits and risks of her condition and
- c) any reasonable alternatives

so that the patient can provide informed consent (Montgomery v Lanarkshire 2015 UKSC 11 para 90).

This -in itself- could be described as more person centred shared decision making process, but has implications for people with issues with verbal communication – of which people up to 90% (Bhaumik et al 2008) of people with learning disabilities might experience.

In situations where the individual states they do not wish to know the risks, or the decision maker believes it would be to the detriment of the person's health to share the full risks, the rarely used 'therapeutic exception' could be made . Since this judgment applies across the whole health economy, including primary care, acute trusts and mental health providers, we need to look at how people with learning disability are supported in all these areas to make informed choices.

The implications of Montgomery case law are a welcome rebalancing away from medicalised paternalism, toward a partnership in decision making, so that the risk factors are based on the individuals lifestyle choices, rather than a prescribed list of percentage risk factors. This has a reliance on a dialogue between the health/social care professional and the person, which at best will likely further reduce the time and quality of the choice to be made based on the greater time required to discuss, reflect and understand on the part of the person.

Communication is a key factor as a barrier to accessing healthcare. Healthcare professionals across the whole health economy, should consider reviewing their communication strategies involving people with learning disability in order that the patient is fully informed of the material risks and available alternative treatments.

Accessible Information standard 2016

The Accessible Information Standard (AIS) amended in August 2017 (DCB1605 Accessible Information) initially came into force for all publicly funded providers of adult and social care on 31st July 2016 in England.

The AIS is defined as 'information which is able to be read or received and understood by the individual or group for which is intended' and aims to ensure that people who have a disability or sensory loss receive information they can access and understand together with any communication support they might need, which could be in the form of easy read material or appropriate verbal communication.

The recently amended guidance states 'promoting equality and addressing health inequalities are at the heart of NHS England's values', and that the 'information standard has 'had due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it' and has 'had regard to the need to reduce inequalities between patients in access to, and outcomes from, healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities '.

Compliance with the information standard is a legal duty under section 250 of the Health and Social Care Act (2012) and the information standard both conforms with and supports the Equality Act (2010).

Under section 1, when a public authority makes strategic decisions about how to exercise its functions it has a statutory duty to reduce 'inequalities of outcome which result from socio-economic disadvantage'. Disability is a protected characteristic under the Act which states that a person has a disability if a) P has a physical or mental characteristic and b) the impairment has a substantial and long term adverse effect on P's ability to carry out normal day to day activities. Furthermore, a person is discriminated against, if because of this protected characteristic, he is treated less favourably than someone without this protected characteristic. Importantly, the amended AIS describes disability (rather than defines disability) with reference to Article 1 of the United Nations Convention on the Rights of Persons with Disabilities where 'persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others' (UN).

The reference to the Convention on the Rights of Persons with Disabilities is important as the UK, which has ratified the Convention has committed to promoting and protecting the human rights of disabled people and acting in a way that ensures they have equality before the law, which includes access to medical treatment.

The AIS aims to ensure that people who have a disability or sensory loss receive information they can access and understand, together with any communication support they might need. This could be easy read material or verbal communication.

Easy read material regarding medication that can be accessed via internet searches, may be of variable quality. Standards for the easy read itself may vary and there is

the risk of over simplified information not of a sufficient standard in order to inform of all material risks.

Practical issues for prescribing and administering medication

O'Dwyer et al (2016) identified that over 90% of adults over the age of 41 take regular medication, finding that with increasing age and severity of disability the greater the risk of polypharmacy, in some cases to excess. This would indicate that the prescription, dispensing and administration of medication are part of medical treatment that many health and social care practitioners will be involved on a day to day basis. With this in mind, capacity, consent and the outcomes of the Montgomery case have implications for practitioner's communications – as part of their assessment and account - with individual service users and the other stakeholders.

The prescriber (GMC, 2013) has a number of assessing activities to undertake; along with identifying the persons condition, the risks and benefits of a proposed treatment in context of the persons medical history and lifestyle choices and plans, the prescriber will now want to make detailed notes of these conversations, and be considering the individual's capacity to make a choice about this treatment. While accessible information formats (Choice and Medication, 2017) are more readily available to aid this task, the Montgomery case and AIS challenge practitioners to identify individualised processes to attend to the above areas in a timely fashion.

These legal updates also have implications for those that administer, support and monitor the treatment which extends beyond the eradication of medication errors. In many cases prescribed medications will have an impact on the individual's capacity, whether that be antibiotics for an infection that has caused delirium, or an antidepressant that has the individual better able to understand, retain or weigh up their treatment choices. In these situations evidence of changes of decision making ability will want to be monitored to enable the individual to take a full role in decision making and proactively plan for the future.

Conversely, a decline in individual's physical or mental health could cause a reduction in capacity to choose to take the medication. This could result in the individual either continuing or refusing to take the medication; in both cases the medication administrator will want to continue to encourage the individual to take the medication, urgent advice from the prescriber will need to be sought, and in both cases a renewed capacity assessment and a best interests decision making process may need to be convened, and –as a last resort - a plan for covert administration in line with national guidance and evidence (NICE, 2015, Kelly-Fatemi, 2016) be implemented.

As evidence indicates that mental health issues are more prevalent in people with learning disabilities compared to the general population (Emerson & Bains, 2011), it

could be assumed that health and social care professionals in this field will have more experience of individuals who have fluctuating capacity. As such Gergel & Owen (2016) advocate proactive (advanced) care planning with the individual when well, which would include a framework for monitoring capacity for medication administration along with other medical treatments, similar to participatory researchers proactive process consent models (Dewing, 2002, 2007 & Lord, 2013).

Application to Practice

Hertfordshire Partnership University NHS Foundation Trust provides Intensive Support Teams aligned with NHS England's (2017b) service specifications. Integral to this is the Learning Disability Nurses responsive care and support that works effectively with local people, partners and agencies to reduce admissions. Acknowledging current initiatives (NHS England, 2017a), the judicious use of anxiolytic and antipsychotic medications can play an important part in the rehabilitation of people with learning disabilities, behavioural and mental health issues, as such a good understanding of psychopharmacology is essential for the role.

Aligned to enablement model (Beebee & Abdulla, 2014) the nurse's goal is to enable independence wherever possible; in Hertfordshire, nurses work toward self-administration. This will often require multi-disciplinary assessment of the risks, the context, the environment and lifestyle. A good assessment of the individual's receptive and expressive communication is essential, in empowering individuals to understand the reasons for the treatment and potential side effects, identifying tools, techniques, and bespoke information to support successful ingestion, and in some cases contributing to more formal assessments of capacity. Where capacity cannot be established nurses support service providers with administration, monitoring compliance and facilitating care through ensuring critical information and advice is shared with the prescriber.

Conclusion

It is clear that shared decision making has been elevated by the Montgomery case from good practice guidance to be legally binding and its implementation with people with learning disabilities will require some consideration. The balance of capturing the dialectic evidence required with treating in a timely manner, will likely pose challenges to practitioners, as such it would be salient to monitor the numbers of people with learning disabilities being identified as lacking capacity, and the numbers of therapeutic exceptions being employed, as greater anticipatory adjustments under the equality act might be required.

With non-medical prescribing becoming more widespread, health and social care professionals will want to examine how they fully engage individuals with fluctuating capacity in their treatments, how they account for identifying the risks and benefits of a treatment and who they may have to engage to reach the preferred outcome.

While proactive planning will be beneficial to ensure -when well- individual can be involved in planning for care when unwell or lacking capacity; with so many experienced practitioners and experts available, this is a ripe area for further reflection, practice development and research.

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