Version 1.2 – November 2024

The Oliver McGowan Mandatory Training on Learning Disability and Autism Tier 2

Delegates’ pre-course reading

Contents

Introduction

This pre-course reading contains important information about key legislation and standards which cannot be covered in depth on the course itself. Please read this booklet before attending the 1-day Tier 2 training.

These standards and legislation are also key to understanding Oliver's story and how to provide good care and support to people with a learning disability. Delegates can speak to their employer if they need further training on these for their roles.

The text in red boxes is quotes from Paula McGowan taken from the draft code of practice on statutory learning disability and autism training. Paula's quotes from Oliver's story have been included as a reminder of the very real human impact of these laws and how following them can save lives.

The text in blue boxes is from the Learning from Lives and Deaths report (LeDeR, 2022). This is a service improvement programme which reviews the lives and deaths of people with a learning disability and autistic people who have died in England each year. The learning from LeDeR is summarised in annual reports. LeDeR aims to improve healthcare, reduce health inequalities and prevent early deaths of people with a learning disability and autistic people.

Human Rights Act

Human rights are the basic rights and freedoms which include key values such as freedom, fairness, dignity, equality and respect. Our human rights are protected in UK law by the Human Rights Act 1998 which sets out the fundamental rights and freedoms to which everyone in the UK is entitled. All public authorities such as health and social care providers – and this includes all staff working for them – must follow the Human Rights Act. It gives legal protection of our 16 human rights.

For example, the **right to liberty and security** (Human Rights Act 1998, Article 5) prevents significant restrictions being placed on people's movement, except in specific circumstances which are allowed by law, such as a Deprivation of Liberty authorisation or detention under the Mental Health Act 1983. Whenever there are restrictions on a person's liberty, the law requires there to be human rights safeguards in place. The safeguards mean that people are held accountable for their actions if they interfere with another person's liberty.

Interfering with a person's liberty includes being restrained or administering tranquilising psychiatric medication to address behaviours of concern. It also includes placing a person under continuous supervision or control or not giving the person freedom to come and go from a place (British Institute of Human Rights, 2016). If restrictions are thought to be both necessary and proportionate, then legal safeguards such as in the Mental Capacity Act (2005) and in the Mental Health Act (1998) must be in place. We each have a duty to uphold a person's human rights, irrespective of their behaviour or mental health condition.

Another example is the right to **respect for private life** (Human Rights Act 1998, Article 8) which protects a person's autonomy including having control over their own life, care and treatment.

OLIVER'S CAMPAIGN

"[The] hospital was very intolerant of Oliver's autistic and learning-disabled behaviours. They had no understanding of sensory crisis or overload. They refused to take any direction from us or the learning disability nurse. Horrifically, the use of physical restraint was increased with up to 8 staff being involved. Oliver was suddenly not allowed any privacy with his personal care. He had 3 staff members sit around his bed and he was kept in a darkened room."

Paula McGowan, 2023

The Mental Capacity Act 2005

> 'The Mental Capacity Act 2005 is a vitally important piece of legislation, and one that will make a real difference to the lives of people who may lack mental capacity. It will empower people to make decisions for themselves wherever possible and protect people who lack capacity by providing a flexible framework that places individuals at the very heart of the decision-making process. It will ensure that they participate as much as possible in any decisions made on their behalf, and that these are made in their best interests. It also allows people to plan ahead for a time in the future when they might lack the capacity, for any number of reasons, to make decisions for themselves.' (Lord Falconer in Foreword to The Mental Capacity Act 2005 Code of Practice)

What is capacity?

'Capacity [refers to] the ability to understand and use information to make a decision, and communicate any decision made. A person lacks capacity if their mind is impaired or disturbed in some way, and a capacity assessment establishes that the person does not have the mental capacity to make the specific decision at the time it needs to be made.' (NHS, 2022)

What does lack of capacity mean?

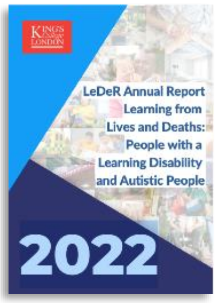
'Whenever the term "a person who lacks capacity" is used, it means a person who lacks capacity to make a particular decision or take a particular action for themselves at the time the decision or action needs to be taken.' (The Mental Capacity Act 2005 Code of Practice)

The Mental Capacity Act 2005 (MCA)

The purpose of this legislation is to empower a person to make their own decisions and protect those who may not be able to make their own decisions. It sets out a legal framework of how to act and make decisions on behalf of a person (aged 16+) who has been assessed as lacking capacity to make specific decisions for themselves. It is up to us to support and empower patients to make their own decisions whenever possible, even when they are unwell or distressed.

The Code of Practice provides guidance to anyone who is working with and/or caring for adults who may lack capacity to make particular decisions. It describes their responsibilities when acting or making decisions on behalf of individuals who lack the capacity to act or make these decisions for themselves. In particular, the Code of Practice focuses on those who have a duty of care to someone who lacks the capacity to agree to the care that is being provided. (The Mental Capacity Act 2005 Code of Practice)

> "Nobody discussed this medication with Oliver, who had full capacity, or [with] us."
>
> Paula McGowan, 2023



LeDeR Annual Report
Learning from
Lives and Deaths:
People with a
Learning Disability
and Autistic People
2022

> The main area of concern within the statutory duties category was lack of adherence to the MCA and its principles. In primary and community care, there were examples of lack of use of the MCA affecting several types of decision including sometimes complex decisions around screening and preventative healthcare and treatment for long-term conditions.
>
> Learning from Lives and Deaths, 2022

The MCA five principles

There are **five principles** of the Mental Capacity Act. Principles 1, 2 and 3 are about the person and how they are supported to make a decision. Principles 4 and 5 of the MCA are all about what to do if the person lacks capacity.

Principle 1 – **An assumption of capacity**. Every person has the right to make their own decisions if they have the capacity to do so. Family carers and healthcare or social care staff must assume that a person has the capacity to make decisions, unless it is established that the person does not have capacity.

Principle 2 – **Individuals must be supported to make their own decisions.** Every effort should be made to find ways of communicating with someone, to support them to understand their options and to make their own decisions. A decision cannot be made that someone lacks capacity until all practicable steps have been made to support them to make their own decision.

Principle 3 – Unwise decisions. A person who makes a decision that others think is unwise should not automatically be considered as lacking the capacity to make the decision.

How can we assess capacity?

The Mental Capacity Act expects us all to learn to assess capacity, and to be able to assess capacity in relation to our own roles. Speak to your employer if you need more support with this.

The test of capacity includes the following questions:

1. Is the person **able to understand the information relevant to the decision?** Are they able to weigh up the information, the options, and make and communicate their decision (the functional test)? Looking FOR capacity, not looking to disprove it.

2. **Are they able to retain information that is relevant and weigh up this information and communicate their decision?** Even when we can show that we have tried to support them to make the decision, we need to consider if an inability to make a decision is caused by an impairment of, or disturbance in the functioning of a person's mind or brain, no matter how caused, temporary or permanent. This could be due to long-term conditions such as mental illness, dementia, or a learning disability, or more temporary states such as confusion, unconsciousness, or the effects of drugs or alcohol (the diagnostic test).

3. **Does one cause the other?** The diagnostic issue may not be the cause of the functional problem, so a causal link must be shown (the 'causative nexus').

The MCA says that a person is unable to make their own decision if they cannot do one or more of the following four things:

- Understand the information given to them that relates to the decision.
- Retain that information long enough to be able to make the decision.
- Weigh up the information available to make the decision.
- Communicate their decision – this could be by talking, using sign language or even simple muscle movements such as blinking an eye or squeezing a hand.

Consent and capacity

In the NHS and social care, we must seek a person's consent before carrying out any care or treatment. Any intervention or treatment should start by discussing with the person what is being proposed, as well as why, when, how, and where the proposed care or treatment could take place. The discussion should include identifying the risks and benefits, the alternatives and what would happen if no intervention or treatment happens.

Then we need to seek the consent of the person, ensuring the person is able to give their informed consent, and that the consent is given voluntarily.

If we have any concerns about the capacity of the person, for example, if they appear not to understand or not to be able to weigh up the information, then we should carry out a capacity assessment. Doubt about capacity to consent to care or treatment is the gateway to using the MCA 2005.

Principle 4 –Decisions can only be made on behalf of an individual once it has been established that they lack capacity. The person's best interest must be at the heart of all decisions made on behalf of a person who has been found to lack capacity on the specific issue.

The **best interest checklist** outlines what needs to be considered before taking an action or making a decision on behalf of someone else who has been assessed as lacking capacity. The checklist contains the following factors:

- Consider past, present and future wishes.
- Involve the person.
- Can the decision wait until the person has regained the mental capacity to make the decision.
- Involve others where appropriate.
- Consider all information, consider options.
- Make no assumptions.

Principle 5 – Less restrictive option. Someone making a decision or acting on behalf of a person who lacks capacity must consider whether it is possible to decide or act in a way that would interfere less with the person's rights and freedoms of action, or whether there is a need to decide or act at all. (SCIE, 2022)

Advance care planning

The Mental Capacity Act (2005) ‘also allows people to plan ahead for a time in the future when they might lack the capacity, for any number of reasons, to make decisions for themselves.’ (The Mental Capacity Act 2005 Code of Practice)

Advance care planning is used to plan for future care, support and even medical treatments while a person still has capacity to do so. An advance care plan can be used by a person when they are becoming ill. It can make the difference between a future where a person makes their own decisions and a future where others do.

There are six universal principles of advance care planning (NHS England, 2022):

1. The person is central to developing and agreeing their advance care plan including deciding who else should be involved in the process.
2. The person has personalised conversations about their future care focused on what matters to them and their needs.
3. The person agrees the outcomes of their advance care planning conversation through a shared decision-making process in partnership with relevant professionals.
4. The person has a shareable advance care plan which records what matters to them, and their preferences and decisions about future care and treatment.
5. The person has the opportunity, and is encouraged, to review and revise their advance care plan.
6. Anyone involved in advance care planning is able to speak up if they feel that these universal principles are not being followed.

OLIVER’s CAMPAIGN

> “Oliver had made an advance verbal decision to ambulance staff and to doctors in A&E that he did not want to be given antipsychotic medications, giving good reason, saying, “They mess with my brain and make my eyes roll up.” He had the capacity to remember the dystonic reaction back in the children’s hospital several months earlier.”
>
> Paula McGowan, 2023
> (Oliver McGowan draft code of practice)

The Mental Capacity Act 2005 and advance care planning

'Where a person has capacity, as defined by the Mental Capacity Act, this advance care plan should always be discussed with them directly. Where a person lacks the capacity to engage with this process then it is reasonable to produce such a plan following best interest guidelines with the involvement of family members or other appropriate individuals.' (Joint statement on advance care planning Royal College of General Practitioners, 2020)

Advance Decisions to Refuse Treatment

An advance decision to refuse lifesaving treatment (MCA 2005) is made by a person, 18 and over, who has capacity. It is made, in writing, signed and witnessed and states their refusal to consent to such treatment at a time in the future when they may lack the capacity to declare their refusal to consent. This decision may be about refusing resuscitation, but it may also be about refusing other forms of treatment - such as refusing chemotherapy for example. Where an advance decision is judged to be 'valid' and 'applicable' then clinicians are expected to abide by it.

Cardiopulmonary resuscitation recommendations

DNACPR is sometimes called DNAR (do not attempt resuscitation) or DNR (do not resuscitate) but they all refer to the same thing.

LeDeR reviews into deaths of people with a learning disability and autistic people have found that sometimes a cardiopulmonary decision has been put in place without the person's or their family's knowledge or consent. This has led to the NHS making the following statement.

'The NHS is clear that it is unacceptable that people have a DNACPR decision on their record simply because they have a learning disability, autism or both. The terms "learning disability" and "Down's syndrome" should never be a reason for DNACPR decision making, nor used to describe the underlying, or only, cause of death. Learning disability itself is not a fatal condition; death may occur as a consequence of co-occurring physical disorders and serious health events.' (NHS, 2023)

A ReSPECT form can be used, which is a specific type of advance care plan which considers all aspects of care and treatment in an emergency, including decisions around resuscitation. ReSPECT stands for Recommended Summary Plan for Emergency Care and Treatment. It is a process which creates a personalised recommendation for clinical care in emergency situations where the person is not able to make decisions or express their wishes.

In **hospital in-patient** care, issues related to Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) were raised as concerns in several cases. This included DNACPR decisions being made without consultation with the family or key professionals, decisions being made inappropriately on the grounds of a learning disability diagnosis "rather than any clinical condition", and DNACPR orders and advance care plans not being followed.

74% of people who died [with a learning disability or autism] in 2022 had a DNACPR in place at the time of death. Reviewers judged that DNACPR documentation and processes were correctly completed and followed for 63.3% of the deaths in 2022 where a DNACPR was in place. Compared to **61%** of the time in 2021.

LeDeR, 2022

Conclusion

In this section we have highlighted some key aspects of working within the law, with people who have learning disabilities. Some of the key messages are to support and empower people to make their own decisions wherever possible, and to make best interests decisions only when this support has not enabled the person to make a capacitous decision for themselves. At that point we need to make best interests decisions, following the best interest checklist, to always consider the person's wishes and feelings, and to always consider whether our proposed interventions are less restrictive of a person's freedoms and rights.

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