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

Delegates' pre-course reading

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Introduction

This pre-course reading contains very important information about key legislation and standards which can not be covered in depth on the course itself. Delegatges must 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.

Human Rights Act

Human rights are the basic rights and freedoms which we all have which are protected in UK law by the Human Rights Act 1988. This Act sets out the fundamental rights and freedoms that everyone in the UK is entitled to. All public authorities such as health and social care providers need to follow the Human Rights Act. The Act gives legal protection of our 16 human rights, such as our right to life and right to liberty.

Examples of our right to liberty could include a right to not be detained in an inappropriate place, for public officials to not using excessive restraint for long periods, being told you are not allowed to leave or being physically prevented from leaving a place (like a care home or hospital) when you are not formally detained under the Mental Health Act or have not had your deprivation of liberty authorised under the Mental Capacity Act. (British Institute of Human Rights).

OLIVER'S CAMPAIGN

'This 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)

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The Mental Capacity Act

The Mental Capacity Act (MCA) is designed to empower people to make their own decisions and protect people 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 people (16+) who lack capacity to make specific decisions for themselves. Having mental capacity means that a person is able to make their own decisions.

OLIVER'S CAMPAIGN

'…Nobody discussed this medication with Oliver, who had full capacity, or [with] us.' (Paula McGowan, 2023)



'A main area of concern is there continues to be a lack of adherence to the MCA and its principles particularly around the '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)

When should capacity be assessed?

A person may be unable to make a particular decision at a particular time because their brain is affected by an illness or disability, so in these instances you may need to assess their capacity. Their lack of capacity may a temporary or permanent condition. (SCIE)

What is mental capacity and when might you need to assess capacity?

There are **five principles** of the Mental Capacity Act. Principles 1, 2 and 3 are all about the person and how they are supported to make a decision.

Principle 1 – Start by thinking they **can** make a decision. You cannot assume someone lacks capacity just because of their diagnosis, age or appearance alone.

Principle 2 – Do all you can to help them make a decision. Every effort should be made to find ways of communicating with someone before deciding that they lack capacity to make a decision based solely on their inability to communicate. Also, you will need to involve family, friends, carers or other professionals.

Principle 3 – You must not say they lack capacity just because their decision seems **unwise**.

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If the person does not have capacity…

Principles 4 and 5 of the MCA are all about what to do if the person lacks capacity.

Under the Mental Capacity Act, you are required to make an assessment of capacity before carrying out any care or treatment if you have reasonable belief someone lacks capacity – the more serious the decision, the more formal the assessment of capacity needs to be. (SCIE)

Principle 4 – Use a **best-interest checklist** for them if they cannot make a decision. The checklist asks you to…

- Consider past, present, future wishes.
- Involve the person.
- Consider whether they are likely to regain capacity.
- Involve others.
- Consider all information.
- Make no assumptions.

Principle 5 – Check the decision being made does not stop their freedom more than needed.

How do you assess capacity?

There is a two-stage test. In order to decide whether an individual has the capacity to make a particular decision, you must answer two questions. This is sometimes referred to as the 'acid test'.

Stage 1 – Is the person unable to make a particular decision (the functional test)?

Stage 2 – Is the inability to make a decision caused by an impairment of, or disturbance in the functioning of, a person's mind or brain? This could be due to long-term conditions such as mental illness, dementia, or learning disability, or more temporary states such as confusion, unconsciousness, or the effects of drugs or alcohol (the diagnostic test) (SCIE).

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 information given to them.
- 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.

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Advance Care Planning

Advance care planning is used to plan for future care, support and even medical treatments while you still have capacity to do so. An advance care plan can be used by a person when they are getting very ill and will not get any better. It can make the difference between a future where a person makes their own decisions and a future where others do.

'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.'

There are six universal principles of advanced care planning

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.

The Mental Capacity Act 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)

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Do Not Attempt Cardiopulmonary Resuscitation – DNACPR

DNACPR is sometimes called DNAR (do not attempt resuscitation) or DNR (do not resuscitate) but they all refer to the same thing. Sometimes making an advance care plan includes thinking about and making a DNACPR decision. Discussions about DNACPR preferences should take place as part of a wider conversation about the person's preferences, wishes and needs for their future care.

- 1 in 10 people accessing health, care and support services experienced a DNACPR being placed on their file without consultation or with pressure to agree to it.
- Over 1 in 3 staff members had experienced pressure to put a DNACPR in place without involving the person in the decision. (British Institute of Human Rights, 2020)



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 in 2022 had a DNACPR in place at the time of death.

Reviewers judged that this was correctly followed 63% of the time. Compared to 61% of the time in 2021 (LeDeR, 2022)

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