Version 2.0 July 2024

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

Autism session

Delegate handbook

Contents

Overview

Background

The training is named after Oliver McGowan. Oliver was a young man whose death shone a light on the need for staff to have training to better understand and respond to the needs of autistic people and people with a learning disability. Its ambition is to ensure health and social care workforce have the right skills and knowledge to provide safe, compassionate and informed care to autistic people and people with a learning disability.

Developed as a result of "Right to be Heard", the government's response to the consultation on mandatory training on learning disability and autism for health and social care staff.

In the Health and Care Act 2022 the government introduced a requirement for CQC-registered service providers to ensure their employees receive learning disability and autism training appropriate to their role.

Course aim

Enhance learners' understanding of autism, best practice in a health and social care setting and understand how this is supported by current legislation.

Learning outcomes

- Understand why autism is described as an invisible condition
- Reflect on our own values and beliefs
- Recognise potential differences, strengths and challenges for autistic people
- Identify potential triggers for anxiety
- Identify reasonable adjustments and ways to adapt your practice
- Be familiar with legislation and resources for inclusive enabling services

Session outline

- Neurodiversity
- Intersectionality
- What is autism
- Areas of difference
- Stress and anxiety
- Final thoughts

Autism training session

Oliver's story
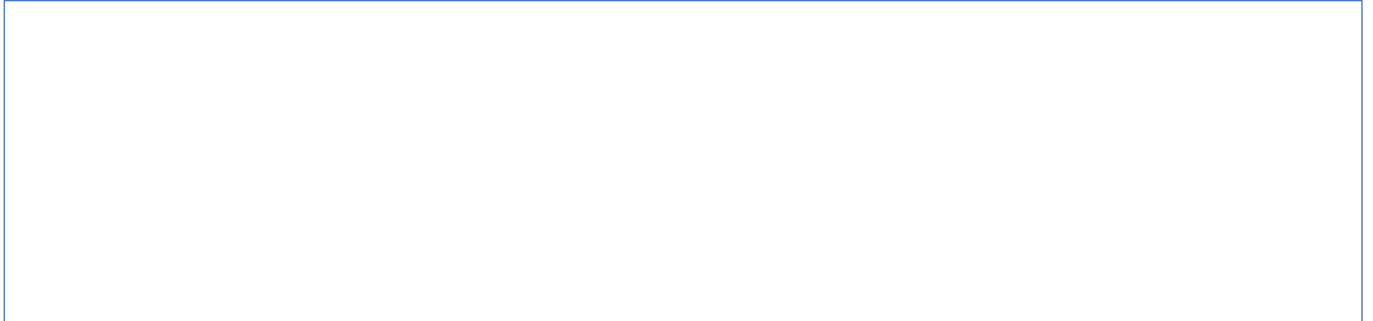
The Equality Act

A duty on organisations to make reasonable adjustments in order to remove barriers faced by people with a disability. This may be small changes in:

- The way a system is set up
- The way someone works or interacts with another person
- The way an environment is set up

Reasonable adjustments should be anticipatory, and needs-, not diagnosis-led.

Autism and neurodiversity

Autistic people experience this world differently, particularly in relation to:
- Communicating and relating to others
- Processing information from the world, including sensory processing.

We are all different with different personalities and life experiences. We live in a neurodiverse world where everyone has their own strengths and challenges.
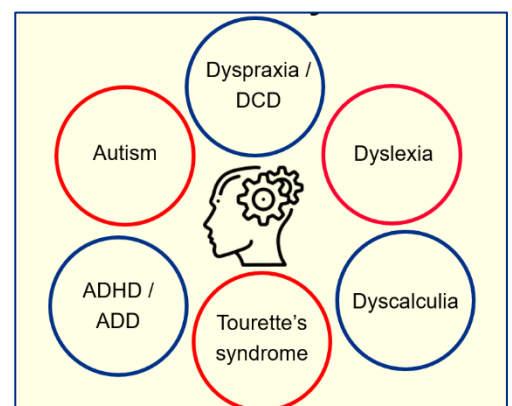
Intersectionality

Alongside being autistic, some people may have other identities too. This includes their gender, race, sexuality, religion, class etc.

Intersectionality is when various aspects of an autistic person's identity intersect and interact to shape their experiences.

Intersectionality can lead to the person experiencing different forms of discrimination related to their different identities.

> "As a gay autistic man, it's almost as if I have two identities. I have my LGBTQ+ identity and my autistic identity. Sometimes they both merge well together, and sometimes they don't."
>
> **Tom Moran**

> "I love being an autistic, Muslim Pakistani woman. My identity in itself is so diverse, which I am really proud of! It does make it harder to live so freely however, with all of the stigma and discrimination that surrounds both autistic people and Muslims. Race and autism intersect a lot and talking about race in autism conversations is so important."
>
> **Iqra Babar**

Language

- Language is a personal choice – ask the person what their preferred language is
- It is now generally accepted that identity-first language is used, i.e. autistic person or person on the autism spectrum

> "Autism is a part of who I am, it is a core part of my personality. I do not 'have' autism. I am an autistic person."
>
> **Olivia**

What is autism?

- A neurological difference
- An invisible condition
- Lifelong
- Clinically defined as a disability
- A spectrum condition with varying profiles, including Asperger's Syndrome (a term we don't use diagnostically any more)

Double empathy

The concept that neurotypical people and autistic people struggle to empathise with each other.

Autistic people often talk about being able to relate to, and better communicate with, other autistic people.

Society accepting and accommodating difference would lead to better outcomes for autistic people.

The autism spectrum

- Social communication and interaction
- Certainty, routine and familiarity
- Sensory processing differences

Autism + environment = outcome

Dr Luke Beardon

Spiky profiles

"My work calls for me to interview many household names – actors, authors, celebrity chefs and models, amongst others. Perversely, I can do this as easily as others might do the weekly shop. Equally perversely, I do not know how to do a successful weekly shop."

Laura James

Co-occurring conditions

Autistic people can present in many different ways.

Co-occurring conditions are common and might include:

- Learning disability
- Demand-avoidance
- Mental health issues
- Other neurodivergence, such as ADHD, dyslexia, dyspraxia, etc
- Physical health conditions, e.g. cardiovascular, chronic pain, hypermobility, gastrointestinal issues, etc.

Every autistic person will have their own, unique presentation and profile.

Important statistics

- Prevalence – at least 1 in 100 people
- Current male/ female ratio – 3:1

- Autism and learning disability – 33%
- Employment – only 22% of autistic people are in any type of employment
- Mortality – on average autistic people die 16 years earlier
- Suicide rates – 9 x higher than non-autistic population
- Autism and ethnicity – underdiagnosis

Masking

- Masking or camouflaging is common in many autistic people
- It takes a lot of effort and is mentally draining
- Long-term impact on mental health

"As a woman I had this experience in my younger years, I felt lonely and worked so hard to be like the other girls but never felt like any of them were my real friends. I felt disconnected and was often bullied for being different. I became very good at mimicking other people's voices and mannerisms."

Kayleigh

Strengths

"…my autism also makes it easy for me to do things a lot of non-autistic people may struggle with. I work intensely when I'm painting, writing, composing or doing anything creative.

I think being autistic also contributes to my aptitude in problem solving and pattern recognition, which can help me research a highly specialised subject and give talks on it."

Patrick Samuel

Stress and anxiety

Many autistic people experience consistently high levels of anxiety.

"Reality to an autistic person is a confusing, interacting mass of events, people, places, sounds and sights. There seem to be no clear boundaries, order or meaning to anything.

A large part of my life is spent trying to work out the pattern behind everything. Set routines, times, particular routes and rituals all help to get order into an unbearably chaotic life. Trying to keep everything the same reduces some of the terrible fear."

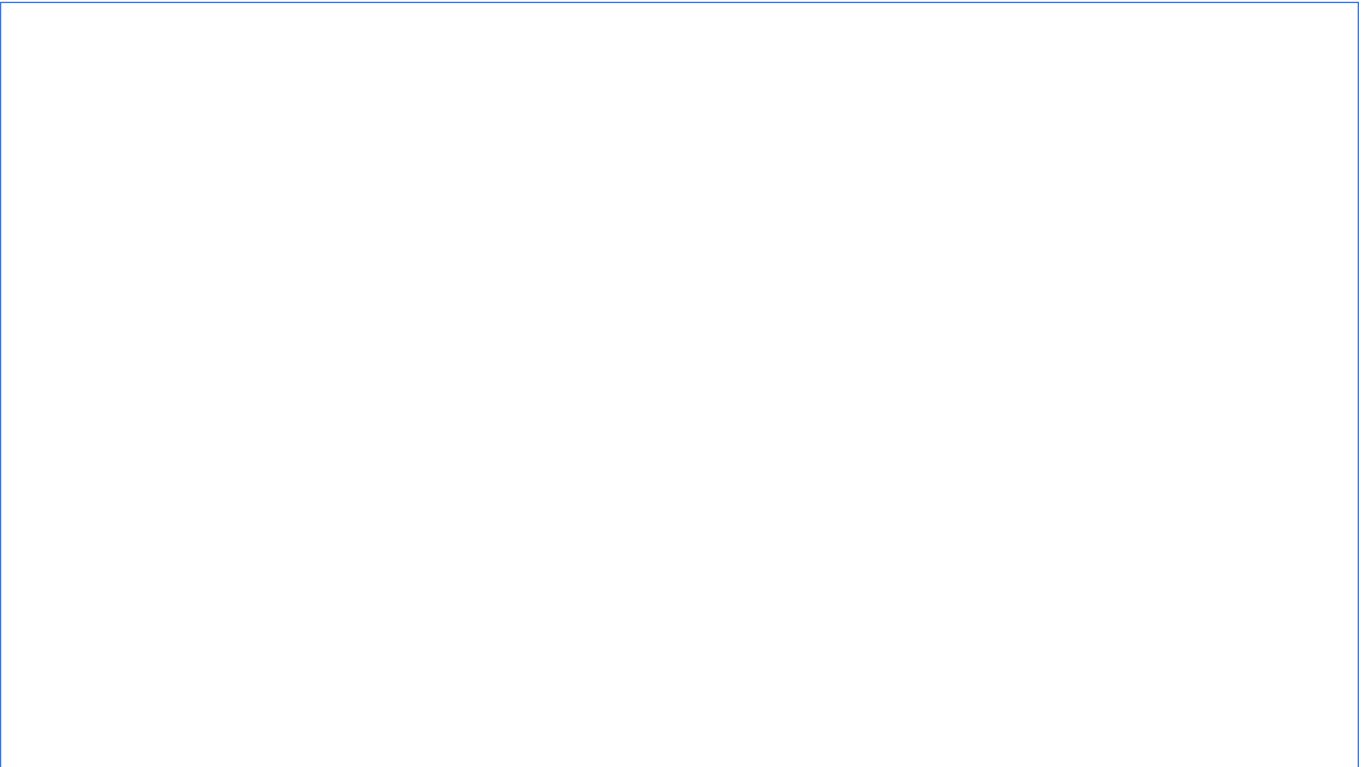**Therese Jolliffe**

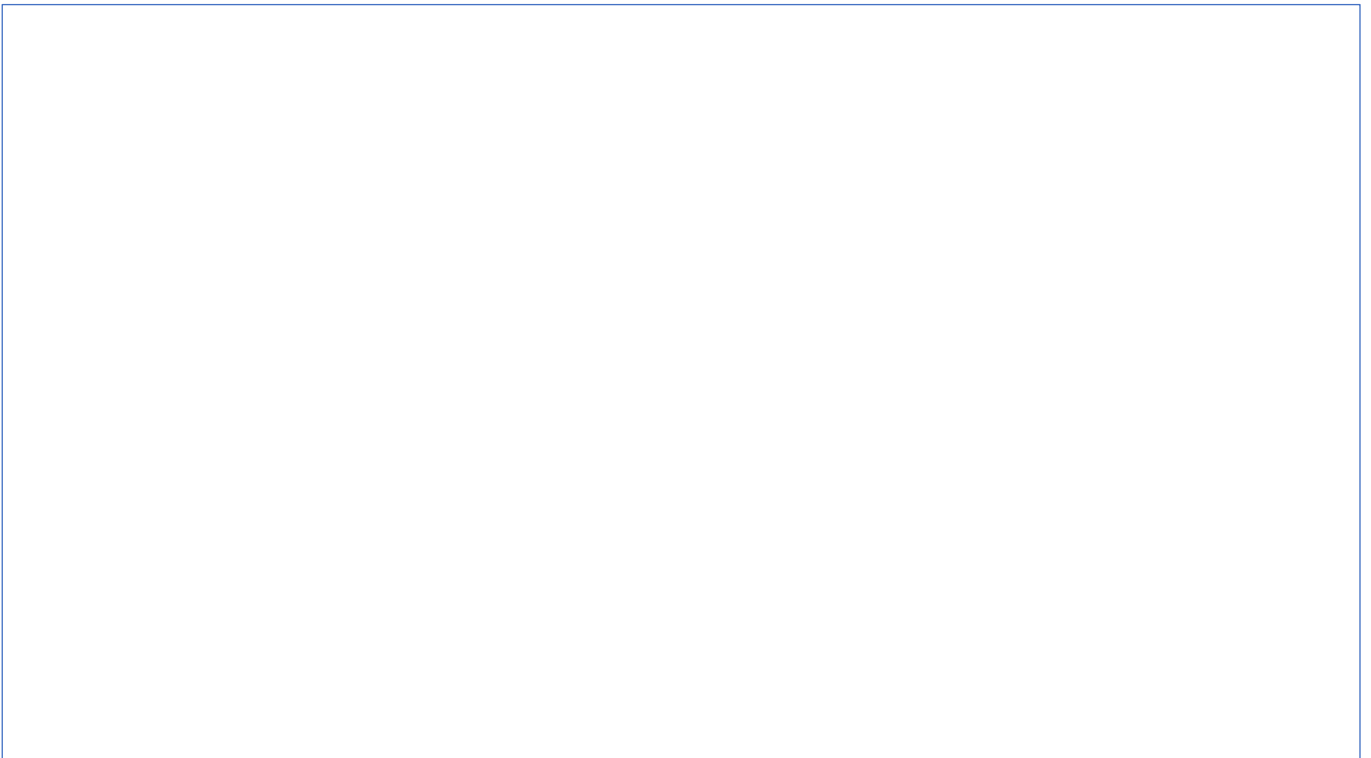# Areas of difference

Group work and exercise notes section.

Your group's topic:

Communication and interaction discussion notes:

Sensory processing discussion notes:

Routines and certainty discussion notes:

Film: *Communication – good practice*

- What good practice have you identified in the film?
- What have you noticed that may not have worked for another person?
- What would you do differently?

Communication support strategies

- Clear and direct communication language
- Visual support – objects of reference, photos, symbols, words, email, text, messaging
- Sign language – e.g. Makaton
- Processing time

Certainty – important considerations

- Provide structure and predictability – preferably visually
- Offer to give written instructions
- Prepare for and explain changes to plans
- Respect the person's need to engage in stimming
- Include people's interests
- Be guided by the individual – some people may not want (or need) this support

Self-regulatory behaviours

"Researchers would eventually discover that autistic people stim to reduce anxiety – and also simply because it feels good. In fact, harmless forms of self-stimulation (like flapping and fidgeting) may facilitate learning by freeing up executive-functioning resources in the brain that would otherwise be devoted to suppressing them."

Steve Silberman

2015 *Neurotribes: The Legacy of Autism and the Future of Neurodiversity*

The senses

- Sight (visual)
- Sound (auditory)
- Touch (tactile)
- Taste (gustatory)
- Smell (olfactory)
- Balance (vestibular)
- Body awareness (proprioception)
- Inside body (interoception)

Film: *Recognising sensory needs – good practice*

Note all the things the professional is considering and providing adjustments for that help the autistic patient cope with the situation and environment.

Sensory sensitivities

As a result of sensory differences, autistic people may:

- Prefer not to hug or shake hands/need to hug tightly, be very tactile
- Have very high anxiety around clinical procedures – e.g. vaccinations, blood pressure being taken
- Need to move/pace around
- Show sensitivities with clothing materials
- Stand in close proximity to you
- Experience alexithymia

Personal perspective

"Think of a noise you can't stand. The kind of noise that sends shudders through your soul or sets your teeth on edge. Maybe its nails down a blackboard or squeaky breaks. Everybody has one of those noises. I have thousands. Feet scraping on gravel. Sweeping. Machinery. Electricity in the walls. Cutlery scraping on plates. The list is endless."

Sara Gibbs

Sensory differences

These are some things to consider:

- Understanding and acceptance – e.g. stimming
- Minimising background noise - quiet spaces
- Preparation, e.g. sensory maps, virtual tours
- Helpful equipment, e.g. headphones, earplugs, etc
- Consider yourself as part of the environment

Stress and anxiety

Many autistic people experience consistently high levels of anxiety.

How will you know?

- Sometimes no visible signs
- Increase in repetitive behaviour
- 'Meltdown/shutdown'
- Continual talking/questions
- Becoming non-speaking
- Leaving suddenly without explanation

How might you support?

- Consider your communication
- Be aware of the environment
- Make yourself more predictable
- Slow everything down
- Reassure
- Give time and space

Mental health

- Autism is not a mental health condition
- Autistic people are more likely to experience mental health difficulties
- Research shows that increased levels of stress and anxiety and the different experience of those impacts on the mental health of autistic people
- These include higher rates of depression, suicide and other mental health conditions

Resources

- National Autistic Society: "Good practice guide for professionals delivering talking therapies for autistic adults and children"
https://s2.chorus-mk.thirdlight.com/file/24/asDKlN9as.klK7easFDsalAzTC/NAS-Good-Practice-Guide-A4.pdf
- Stopping the over-medication of people – STOMP: A resource for autistic people and their families
https://s2.chorus-mk.thirdlight.com/file/24/neg-kxjnX-21a6ne8KUndNOKKi/Stopping%20the%20over-medication%20of%20people%20%28STOMP%29%20a%20resource%20for%20autistic%20people.pdf
- Autistica: "Autism and mental health. A guide to looking after your mind"
https://www.autistica.org.uk/downloads/files/Mental-health-autism-E-LEAFLET.pdf
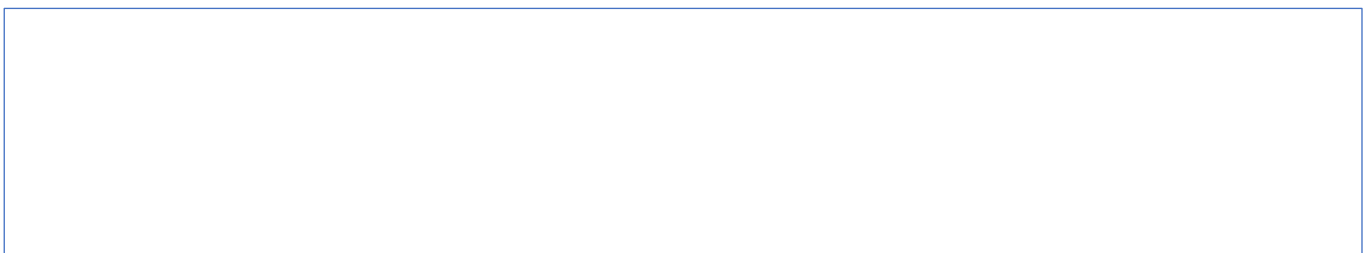
SPELL framework

Enabling support through adapting environment and approaches.

- Structure – using structure to make the environment and processes more predictable, accessible and safe.
- Positive approaches and expectations – recognising potential and strengths.
- Empathy – understanding, experiencing and relating to autistic perspectives.
- Low arousal – adjusting the environment and approaches.
- Links – forming partnerships, sharing information and working alongside.

Documents to support a person-centred approach:

- Hospital passport
https://www.nhs.uk/Livewell/Childrenwithalearningdisability/Documents/Hospital%20Passport%20Template%20example%20from%20South%20West%20London%20Access%20to%20Acute%20Group.doc
- My autism passport
https://www.autism-anglia.org.uk/autism-passport#:~:text=Our%20Autism%20Passport%20is%20for,councils%20and%20for%20employment%20purposes.
- Autism alert card – police
https://www.npaa.org.uk/launch-of-tri-force-autism-alert-card-scheme/

Film: *Attending a care review meeting*

National Autism Strategy

The strategy aims to:

- Help people understand autism
- Help autistic children and young people at school
- Help autistic people find jobs
- Ensure health and care services equal for autistic people
- Ensure autistic people get help in their communities
- Help autistic people in the justice system

What changes can you make?

In pairs identify three main adjustments that you could make when you go back to your work place

Consider adjustments in relation to:

- processes
- place
- people

Key points to remember:

- Autistic people often have poorer life outcomes
- Reasonable adjustments are needed so autistic people and those with learning disabilities are not disadvantaged
- Relatives and carers often know their son or daughter better than anyone
- Good practice is thinking creatively and flexibly about how best to deliver care and support

Enabling autism inclusive interactions:

- Empathy and understanding – our values
- Communication – make adjustments
- Think about the different sensory experiences
- Consider stress and anxiety
- Be consistent
- Develop an inclusive approach

Appendices

Further resources and signposting

- Oliver's Story: https://www.olivermcgowan.org/
- The Oliver McGowan Mandatory Training webpages: https://www.hee.nhs.uk/our-work/learning-disability/current-projects/oliver-mcgowan-mandatory-training-learning-disability-autism
- NHS England: https://www.england.nhs.uk/
- Skills for Care: https://www.skillsforcare.org.uk/Home.aspx
- The National Autistic Society: https://www.autism.org.uk/
- Mencap: www.mencap.org.uk
- Autism and learning disability: https://www.autistica.org.uk/what-is-autism/signs-and-symptoms/learning-disability-and-autism
- BAME autistic people and their families: https://www.autism.org.uk/advice-and-guidance/professional-practice/bame-families
- Diagnostic overshadowing: https://www.gmc-uk.org/ethical-guidance/ethical-hub/learning-disabilities
- Employment: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/outcomesfordisabledpeopleintheuk/2020
- Language: https://www.autism.org.uk/what-we-do/help-and-support/how-to-talk-about-autism
- Mortality rates: https://www.autistica.org.uk/downloads/files/Personal-tragedies-public-crisis-ONLINE.pdf
- Women and girls: https://www.autism.org.uk/advice-and-guidance/what-is-autism/autistic-women-and-girls

Local resources information

- NHS webpage: https://www.nhs.uk/conditions/autism/support/
- The National Autistic Society services directory: https://www.autism.org.uk/directory

Legislation and guidance

Accessible Information Standard

The Accessible Information Standard (AIS) was introduced by the government in 2016 to make sure that people with a disability or sensory loss are given information in a way they can understand.

It is now the law for the NHS and adult social care services to comply with AIS.

https://www.mencap.org.uk/accessible-information-standard

Ask Listen Do

Ask Listen Do supports organisations to learn from and improve the experiences of people with a lived experience of learning disability, autism or both as well as their families and carers when giving feedback, raising a concern or making a complaint. It also makes it easier for people, families and paid carers to give feedback, raise concerns and complain.

https://www.england.nhs.uk/learning-disabilities/about/ask-listen-do/

Autism Act and Think Autism strategy

The Autism Act 2009 committed the government to publishing an adult autism strategy to transform services for autistic adults. This commitment was met in 2010 with the publication of the first ever strategy for improving the lives of adults with autism in England. It was reviewed in 2014 (Think Autism strategy).

https://www.legislation.gov.uk/ukpga/2009/15/contents

https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy

All-Age Autism Strategy 2021

The updated strategy outlines the government's plans to improve services and support for autistic people (children and adults). This covers mental health, diagnosis, employment, education, public understanding and the justice system.

Key elements:

- Helping people understand autism
- Helping autistic children and young people at school
- Helping autistic people find jobs
- Making health and care services equal for autistic people
- Making sure autistic people get help in their communities
- Help for autistic people in the justice system

https://www.gov.uk/government/publications/national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026

https://www.autism.org.uk/what-we-do/news/new-autism-strategy

Care Act

The Care Act helps to improve people's independence and wellbeing. It makes clear that local authorities must provide or arrange services that help prevent people developing needs for care and support or delay people deteriorating such that they would need ongoing care and support.

https://www.legislation.gov.uk/ukpga/2014/23/contents/enacted

Core Capabilities Frameworks

Capabilities frameworks describe the skills, knowledge, and behaviours which people bring to their work and are used to:

- support development and planning of the workforce
- inform the design and delivery of education and training programmes

Core capabilities frameworks for supporting autistic people and/or people with a learning disability are relevant to those working in any sector and all staff working across health and social care.

https://skillsforhealth.org.uk/info-hub/learning-disability-and-autism-frameworks-2019/

Human Rights Act

The Human Rights Act protects people from discrimination in connection with your human rights. This means people's human rights mustn't be breached or protected differently because of certain things like sex, disability and race. This protection is wider than that of the Equality Act 2010.

https://www.legislation.gov.uk/ukpga/1998/42/contents

Learning from Lives and Deaths Review

The Learning from Lives and Deaths Review (LeDeR) (previously the Learning Disability Mortality Review) programme was established to support local areas across England to review the deaths of people with a learning disability (and from 2021 has included the deaths of autistic people), to learn from those deaths and to put that learning into practice.

https://www.england.nhs.uk/learning-disabilities/improving-health/mortality-review/

Mental Capacity Act 2005

The Mental Capacity Act (MCA) is designed to protect and empower people who may lack the mental capacity to make their own decisions about their care and treatment. It applies to people aged 16 and over. It covers decisions about day-to-day things like what to wear or what to buy for the weekly shop, or serious life-changing decisions.

The MCA is underpinned by five key principles (Section 1, MCA). It is useful to consider the principles chronologically: principles 1 to 3 will support the process before or at the point of determining whether someone lacks capacity. Once you've decided that capacity is lacking, use principles 4 and 5 to support the decision-making process. The MCA 5 principles are:

- Principle 1: A presumption of capacity
- Assume a person has the capacity to make a decision themselves.
- Principle 2: Individuals being supported to make their own decisions
- Wherever possible, help people to make their own decisions.
- Principle 3: Unwise decisions
- Do not treat a person as lacking the capacity to make a decision just because they make an unwise decision.
- Principle 4: Best interests
- If you make a decision for someone who does not have capacity, it must be in their best interests.
- Principle 5: Less restrictive option
- Treatment and care provided to someone who lacks capacity should be the least restrictive of their basic rights and freedoms.

The MCA sets out a 2-stage test of capacity:

1. Does the person have an impairment of their mind or brain, whether as a result of an illness, or external factors such as alcohol or drug use?
2. Does the impairment mean the person is unable to make a specific decision when they need to?

People can lack capacity to make some decisions but have capacity to make others. Mental capacity can also fluctuate with time – someone may lack capacity at one point in time but may be able to make the same decision at a later point in time.

The person is determined as unable to make a decision if they are unable to:

a. understand information given to them
b. retain that information long enough to be able to make the decision
c. weigh up the information available to make the decision
d. communicate their decision

References and further training:

- Social care institute for excellence – Mental Capacity Act
- NHS.uk – Mental Capacity Act
- Gov.uk
- elearning for healthcare – Mental Capacity Act

National Institute of Clinical Excellence

NICE provides evidence-based recommendations developed by independent committees, including professionals and lay members, and consulted on by stakeholders. They are not statutory but provide a framework for diagnosing, working with and supporting autistic people.

https://www.nice.org.uk/guidance

Right to be heard

This is the Government response to the consultation on proposals for introducing mandatory learning disability and autism training for health and social care staff, which was published on 13 February 2019 and closed on 26 April 2019.

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/844356/autism-and-learning-disability-training-for-staff-consultation-response.pdf

STOMP – STAMP

STOMP stands for stopping over medication of people with a learning disability, autism or both with psychotropic medicines. It is a national project involving many different organisations which are helping to stop the over use of these medicines. STOMP is about helping people to stay well and have a good quality of life.

STAMP was launched in December 2018 by NHS England and The Royal College of Paediatrics and Child Health. It focuses on how children and young people with a learning disability, autism or both be supported with medication better.

https://www.england.nhs.uk/publication/stomp-stamp-pledge-resources/

Transforming Care

Transforming care is all about improving health and care services so that more people can live in the community, with the right support, and close to home.

Building the Right Support, which is a national plan published in October 2015, sets out how this change happens.

https://www.england.nhs.uk/learning-disabilities/care/

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