



# Learning Disability and Autism Awareness in Primary Care – Tier 2

**Lecturer Details**

# Session Aims and Objectives

## **During this session you will learn:**

- The definition of learning disability.
- The definition of autism spectrum disorder.
- The importance of awareness of learning disability and autism.
- Why is this relevant to primary care.
- What range of conditions are covered by the term learning disability.
- What are the challenges in primary care when dealing with people with learning disabilities or autism spectrum disorder.
- What reasonable adjustments can help a person with learning disabilities or autism spectrum disorder.
- Where to signpost people and carers for help and support.
- Where to look for further help and advice?

# The definition of Learning Disability?

**Learning Disability** is different for everyone, the main three characteristics in individuals are:

Learning Difficulty is more specific and relates to a problem with reading, writing and/or maths, for example dyslexia.

Severe difficulty in understanding complex information and learning new skills.

Difficulty in looking after themselves or living independently.

A condition that commenced before adulthood with a lasting effect on their development.

# What is Autism Spectrum Disorder?

**Autism spectrum disorder (ASD) is a complex developmental condition that is present from early childhood. ASD severely limits and/or impairs daily living activities and is characterised by:**

Developmental impairments in social interaction and social communication, for example, difficulties in:

- Sharing interests or emotions and engaging in normal conversation.
- Using non-verbal communication in social interactions. This may manifest as a lack of eye contact or a total lack of facial expression when interacting with others.
- Developing, maintaining, and understanding relationships.

Restricted, repetitive patterns of behaviours, interests, or activities, for example:

- Stereotyped or repetitive motor movements, use of objects or speech, and idiosyncratic phrases.
- Inflexible adherence to daily routines or ritualized patterns of behaviour, such as rituals used to greet other people.
- Highly restricted, fixed interests that are abnormal in intensity or focus, such as strong attachment to, or preoccupation with, unusual objects.
- Fascination with sensory aspects of the environment or over/under reactivity to sensations, for example, an adverse response to certain sounds or textures, or an apparent indifference to temperature or pain.

# What is Autism Spectrum Disorder?

**ASD is strongly associated with a number of coexisting conditions that may significantly impact on the wellbeing of the child or young person and their family and/or carers.**

- At least one associated mental health or behavioural disorder occurs in approximately 70% of children or young people with ASD mainly:
  - Anxiety.
  - Attention deficit hyperactivity disorder.
  - Oppositional defiant disorder.
  - Behaviour that challenges.
  - Learning disability — occurs in approximately 50% of people with ASD.
- Functional problems are commonly associated with ASD and include:
  - Sleep problems.
  - Eating problems.
  - Gastrointestinal disturbance, such as diarrhoea, abdominal pain, and constipation.
  - Sensory issues.

**The severity and impact of ASD vary greatly** depending on age, development, and presence or absence of associated conditions.

**Asperger syndrome** is a different form of ASD. People with Asperger syndrome are of average or above average intelligence and do not have the learning disabilities that many people with autism have (although they may have specific learning difficulties). They usually have fewer problems with speech but may still have difficulties with understanding and processing language.

# How common are learning disabilities?

Public Health England (PHE) estimated that in England in 2015, there were almost 1.1 million people with learning disabilities, including 930,400 adults.

PHE reported that in 2015, 70,065 children in England with a primary need associated with learning disabilities had a statement of special educational needs/education health and care plan.

Of these, 44% were identified as having moderate learning difficulties, 41% severe learning difficulties, and 15% profound and multiple learning difficulties.

# Autism Spectrum Disorder

ASD is one of the most common childhood onset neurodevelopmental disorders.

- The estimated prevalence in children is at least 1%.
- ASD affects boys 3–4 times more than girls, although this varies across the spectrum. Girls are more likely to have a learning disability; however, evidence suggests that ASD may be under-recognised in girls without a learning disability.

# What range of conditions are likely to cause learning disabilities?

## **Risk factors for the development of a learning disability include:**

- Chromosomal and genetic anomalies — such as Down's syndrome, William's syndrome, Rhett syndrome, fragile X syndrome.
- Non-genetic congenital malformations — such as some types of spina bifida, hydrocephalus, microcephaly.
- Prenatal exposures — including alcohol, sodium valproate, congenital rubella infection, zika virus.
- Birth complications resulting in hypoxic brain injury/cerebral palsy.
- Extreme prematurity.



# Legal information

The Equality Act (2010) places a requirement on public services to anticipate and prevent discrimination against people with disabilities, and this includes people with learning disabilities and ASD.

The Autism Act (2009) advises that the government would create and update a strategy for meeting the needs of adults in England with autistic spectrum conditions by improving the provision of relevant services to such adults by local authorities, NHS bodies, and NHS foundation trusts.

Many people with learning disabilities have support needs that can seriously disadvantage them when they are trying to navigate the healthcare system.

Everyone has different life experiences, strengths, weaknesses, and needs. Many people with learning disabilities will, however, share common characteristics, which, if left unsupported, can make them particularly vulnerable.

# Mortality in people with Learning Disabilities

This results premature mortality of people with learning disabilities.

- Men with learning disabilities are likely to die 13 years earlier than other men in the general population.
- Women with learning disabilities are likely to die 20 years earlier than other women in the general population.

# Why is this relevant to primary care?

People with learning disabilities can struggle with healthcare settings for a variety of reasons including:

- Problems with understanding the language of illness and health (and reliance on written information, including appointment information).
- Challenges with communicating their symptoms, history, and needs.
- Concerns and anxieties about their previous experiences in healthcare.
- Having complex physical needs.
- Diagnostic overshadowing (where symptoms of ill health are misattributed by health professionals to the person's inherent learning difficulty).
- Negative stereotypes and bias against people with learning difficulties or Autism Spectrum Disorders.

This training module outlines the skills, knowledge, and behaviours which constitute competence when interacting with people with learning disabilities and autism spectrum disorder.

# Why is this relevant to primary care?

It is based on the core competencies framework which comprises a range of capabilities:

- Understanding learning disabilities and autism
- Personalised care and support
- Physical and mental health and well-being
- Risk, legislation, and safeguarding
- Leadership and management, education, and research

Each capability comprises the key outcomes of learning or performance. Some of these may be more relevant to some health professionals than others as not all capabilities are essential for all roles.

It is important to recognise that tier 2 training may involve additional education and learning opportunities. This is offered as a recorded webinar.

# Communication

Healthcare professionals should understand their responsibilities when meeting a person with learning difficulties or ASD.

In particular that they have unique communication and information needs which includes both giving and receiving information and the importance of actively including people with learning disabilities or ASD, regardless of their ability to communicate verbally as processing and understanding spoken language is a challenge for many people, especially when they are anxious or in difficult sensory environments, such as a healthcare setting.

You need to be aware how people with ASD may become overwhelmed and need time and quiet space to process and understand information. For example, when overwhelmed some people may 'shutdown' or simply agree to anything said in order to bring the experience to a close.

You should also be aware of and respect the different methods of communication that a person may use.

# Communication Skills

You must actively listen to what a person is 'saying' and be prepared to use patience and perseverance in communication, including being silent to allow time to think and process what is being said.

Be aware that people with ASD often take language literally so it is important to use clear, unambiguous language, responding positively when autistic people use direct language and give direct feedback. Be aware of difficulties and differences in non-verbal communication for example facial expressions, eye contact, and personal distance.

Recognise some key differences in social interaction, for example, processing time, difficulties with small talk, social rules, and understanding and interpreting emotions.

# Interacting with someone with learning disabilities?

Understand the role of trauma in the lives of people with learning disabilities and ASD which can lead to a wide range of mental health problems in later life.

Understand how sensory issues can impact on people with ASD (for example over-sensitivity or under-sensitivity to lighting, sound, temperature, touch, smell) and how anxiety and stress can adversely affect sensory tolerance. Therefore simple changes can optimise an environment for people with ASD, such as turning off unnecessary lights, TV/radio, offering a quiet space, enabling the use of sensory protection such as noise-cancelling headphones or consider the use of an alternative location.

Plan changes in advance whenever possible and provide preparation and information about upcoming events using a variety of communication methods.

Recognise the importance of passionate interests and hobbies, which may be useful in guiding and assisting with the conversation or consultation.

Understand the issue of stimming, which is the repetitive performance of certain physical movements or vocalizations. It is thought to serve a variety of functions, such as calming and expression of feelings.

# Recognize the importance of building trust and consistently put key adaptations into practice, for example:

- Do not spring surprises.
- Do not touch the person without consent.
- Slow down and pause.
- Create or find a calm, quiet environment.
- Explain FIRST, THEN do.

Be aware that behaviour seen as challenging may be a form of communication or an indication of distress.



What are the challenges in primary care when dealing with people with learning disabilities or autism spectrum disorder?

**Behaviour that challenges occur at rates of around 5–15% in educational, health, or social care services and 30–40% in hospital settings, and can encompass:**

- Aggression.
- Self-injury.
- Stereotypic behaviour — including rituals, compulsions, obsessions, perseveration, and repetitive or stereotyped use of language.
- Withdrawal.
- Disruptive or destructive behaviour, which can include violence, arson, or sexual abuse, and may bring the person into contact with the criminal justice system.

The risk of  
'behaviour  
that  
challenges'  
is increased  
by factors  
including:

- A severe learning disability.
- ASD.
- Dementia.
- Communication difficulties.
- Visual impairment (which may lead to increased self-injury).
- Physical health problems.
- Age (incidence peaks in the teens and twenties).
- Abusive or restrictive social environments.
- Environments with little or too much sensory stimulation and those with low engagement levels.
- Developmentally inappropriate environments (for example, a curriculum that makes too many demands on a child or young person).
- Environments where disrespectful social relationships and poor communication are typical or where staff do not have the capacity or resources to respond to people's needs.
- Changes to the person's environment (for example, significant staff changes or moving to a new care setting).

# What are the challenges in primary care when dealing with people with learning disabilities or autism spectrum disorder?

**Around 50% of people with learning disabilities have a comorbid physical health condition. This is thought to be due to a combination of factors, including:**

- Increased rates of obesity and of being underweight due to dietary factors, lack of physical exercise, and difficulties accessing healthy lifestyle advice and support.
- A 20-fold increased risk of epilepsy compared with background population rates.
- Increased risk of difficulty swallowing (dysphagia) leading to eating and drinking problems and aspiration pneumonia.
- Increased rates of visual and hearing impairment.
- Increased rates of constipation, dyspepsia, thyroid disorders, eczema, and Parkinson's disease or Parkinsonism compared with background population rates.
- Difficulties accessing healthcare and communicating needs.

# Mental Health

**In the UK, mental health problems are experienced by 40% (or 28% if problem behaviours are excluded) of adults and around 36% (or 24% if problem behaviours are excluded) of children and young people with learning disabilities. These can include:**

- Anxiety.
- Depression.
- Phobias.
- Psychosis.
- Bipolar disorder.
- Schizophrenia.
- Dementia — rate of 22% compared with 6% in the general population.

# Social Inequality

in the UK, a person with a learning disability or ASD is more likely than a person in the background population to:

- Live in housing that is rented and/or overcrowded and/or of a poor standard — around 60% of children and young people with learning disabilities live in poverty.
- Be exposed to tobacco smoke.
- Be bullied and/or physically, sexually, or emotionally abused — children with a learning disability are often socially excluded and 8 out of 10 are bullied.
- Have less social support.

# Premature Death

A 2012 confidential enquiry based on data from 142 males and 105 females found that men with a learning disability died on average 13 years sooner than men in the background population, while women died 20 years sooner than the female population average.

- Conditions associated with a learning disability (such as epilepsy, aspiration pneumonia, chromosomal disorders and associated congenital heart problems) can increase the risk of premature death.
- A higher risk of inadequate or inappropriate care may also be a contributory factor to the increased mortality risk.

## What reasonable adjustments can help a person with learning disabilities or autism spectrum disorder?

- According to the Equality Act (2010) healthcare services are legally required to make '**reasonable adjustments**' for people with learning disabilities or ASD to ensure equal and fair treatment.
- Examples of reasonable adjustments include:
  - Provide easy to read information.
  - Reduce distractions when talking to a person with learning disabilities.
  - Give longer appointment times.
  - Give the person time to respond to questions.
  - Look for non-verbal responses as well as verbal ones.
  - Encourage the person to show you as well as tell you what they are thinking.
- Health professionals should also seek information from and listen to the families and support staff of people with learning disabilities, when appropriate.

# What are my responsibilities?

As a healthcare professional you should:

- Understand that people with learning disabilities or ASD are individuals, each with their own background, culture, preferences and experiences.
- Demonstrate positivity, recognising the strengths and abilities of people with learning disabilities and ASD.
- Gain an understanding of each person's perspective and personal preferences.
- Be patient and actively listen to what is being communicated by a person with learning disabilities or ASD.
- Recognise the presentation, behaviour, and identity of people with learning disabilities or ASD - and respond with respect and compassion, without judging them or labelling their behaviour in unhelpful ways.



# Healthcare professional's responsibilities

Value and acknowledge	Value and acknowledge the experience and expertise of people with learning disabilities or ASD, their families and support networks, enabling choice and autonomy and protecting people's human rights.
Act	Act with integrity, honesty, and openness, seeking to develop mutual trust in all interactions with people with learning disabilities and ASD, their families, carers, and communities.
Be	Be committed to integrated current and future care and support through working in partnership with people, teams, communities and organisations.
Value	Value collaborative involvement and co-production with people with learning disabilities or ASD to improve person-centred design and quality of services.
Recognise, respect, and value	Recognise, respect, and value people's differences and challenge negative stereotyping.
Take	Take responsibility for one's own learning and continuing professional development and contribute to the learning of others.

## Providing personalised support

In order to provide support clinicians need to understand:

- How to identify practical strategies to offer person-centred support to people with learning disabilities or ASD in a range of day to day situations.
- The importance of meeting an individual's unique communication and information needs including using visual information (photos, diagrams, symbols), use of IT, autism alert cards and written information (e.g. text or email) when this works for the individual.
- That communication is about both giving and receiving information and the importance of including people with a learning disability in conversations about them.
- The key barriers to communication for people with a learning disability.
- How to go about finding out someone's communication needs.
- How to avoid the tendency to underestimate the capabilities of less verbal individuals and overestimate the capabilities of those who are more verbal.
- Stimming, including why it can be helpful as a form of expression and where to seek support if it seems to be becoming harmful.

# Providing personalised support

- That any change in a person's presentation or behaviour may be a sign of a health or emotional problem, distress or sensory overload. Do not assume it is simply an inevitable part of autism even if it presents differently than in other people.
- How behaviour may indicate stress and avoid assumptions about what a person's behaviour may be trying to communicate.
- The specific supports that autistic people may need with communication and proneness to anxiety and high arousal and differences in sensory experiences.
- The activities that people adopt to 'self soothe' or 'self-regulate' or just 'calm down' and make sure people can do these things when they need to.
- How to access further support within one's own organisation to ensure people's communication needs are met.
- That carers and supporters have expertise and experience that will help you communicate with an individual and include them.
- How to signpost people with a learning disability and their families and carers to other services and support.

# Prescribing

In England, between 30,000 and 35,000 adults with a learning disability, autism or both are taking a prescribed antipsychotic, an antidepressant or both without appropriate clinical indications.

- 17.0% were taking prescribed antipsychotic drugs.
- 16.9% antidepressants.
- 7.1% drugs used in mania and hypomania.
- 4.2% anxiolytics.
- 2.7% hypnotic.

Many may have been prescribed these medications to manage behaviour that challenges. It is clear that a substantial proportion of people have their drugs reduced or withdrawn.

NICE advise that specialists only consider prescribing antipsychotic medication to manage behaviour that challenges if:

- Psychological or other interventions alone do not produce change within an agreed time or,
- Treatment for any coexisting mental or physical health problem has not led to a reduction in the behaviour or,
- The risk to the person or others is very severe (for example, because of violence, aggression or self-injury).

# Prescribing

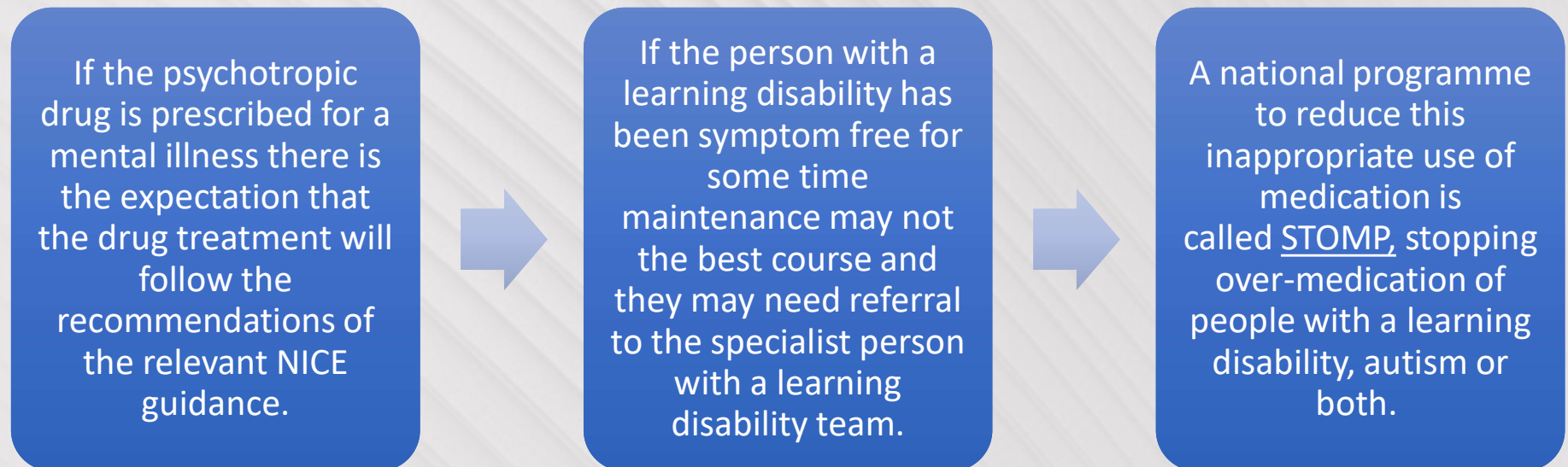
Only offer antipsychotic medication in combination with psychological or other interventions.

If there is a positive result the specialist needs to conduct a full multidisciplinary review after three months and then at least every six months covering all prescribed medication (including effectiveness, side effects and plans for stopping).

If prescribed for behaviours that challenge there is the expectation that the drugs will stop unless:

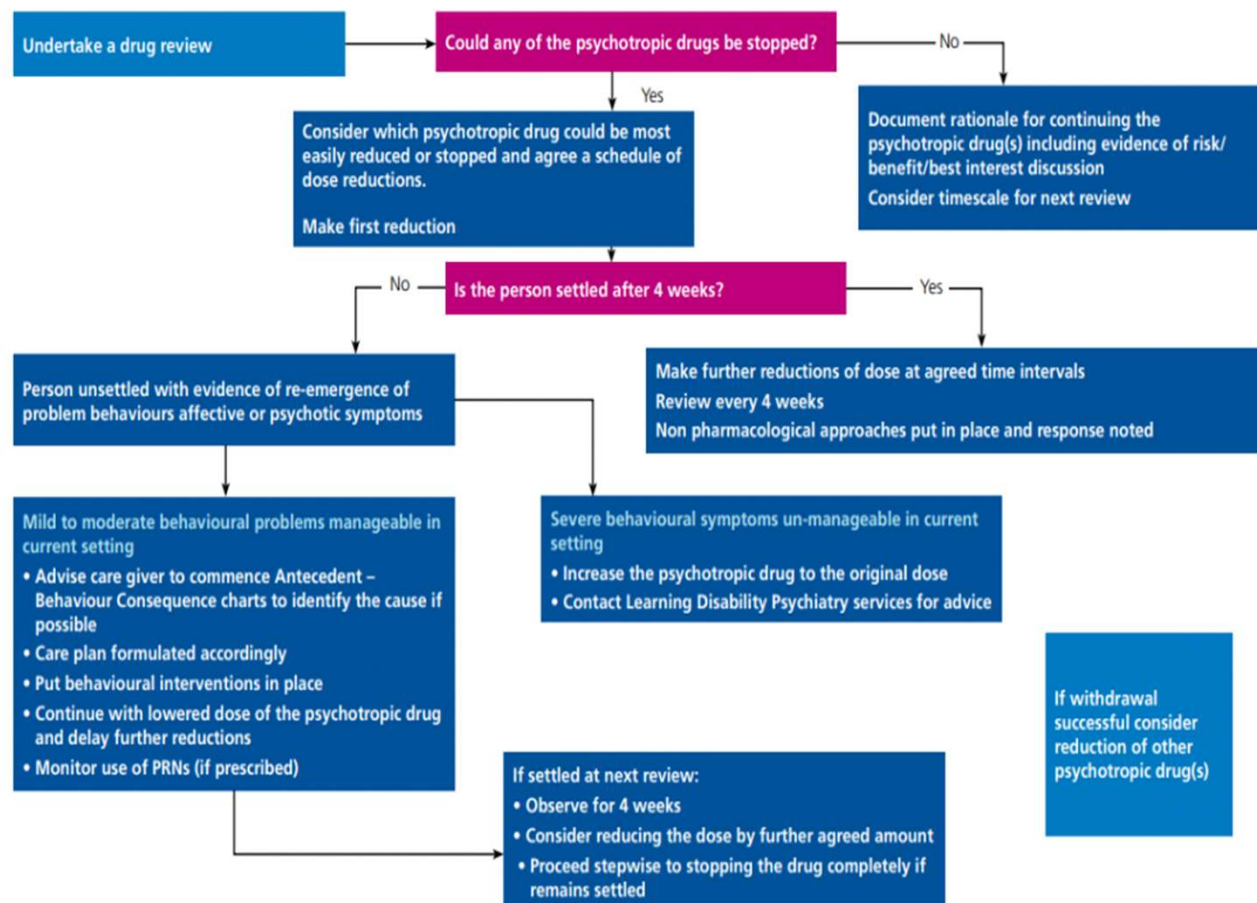
- There is evidence that the person with a learning disability, autism or both has gained significant benefit from the use of the psychotropic drug(s) and recent attempts to withdraw the drug(s) has resulted in a deterioration.
- The nature of the behaviours experienced prior to prescribing psychotropic drug(s) was so severe that withdrawal is considered clinically inappropriate by the carers and others.

# Prescribing psychotropic drugs



# STOMP

## Algorithm for the review, reduction or stopping of psychotropic drugs in people with a learning disability, autism or both



# Risk, legislation and safeguarding

Clinicians have a responsibility to:

- Be aware of the importance of addressing inequalities for people with a learning disability.
- Be aware of the key legislation, policy and guidelines relating to people with a learning Disability and ASD, including one's own responsibilities under the Mental Capacity Act 2005, the Equality Act 2010, the Care Act 2014, Human Rights Act and the Accessible Information Standard.
- Be aware of how individuals and organisations should work together to prevent abuse and neglect and to ensure the safety and wellbeing people with a learning disability or ASD.



# Clinicians responsibilities

- Understand that autistic people have a right to be supported to make their own decisions and must be given all practicable help before anyone concludes that they cannot make a decision.
- Be aware of how views and attitudes of others can impact on the lives of autistic people and their families and carers, such as through social isolation, bullying and social misunderstandings.
- Be aware of disability hate crime, hate crime and bullying and how to report such incidents.
- Know how to raise a Safeguarding Concern and whom to contact for information and advice on Mental Capacity Act or Equality issues.

# Management, education and research

Clinicians should be able to:

- Understand the features of effective team performance within care and support for autistic people, including consistency and clear communication of information.
- Advocate for and practice co-production with people with learning disabilities and ASD, their families, and carers.
- Support a positive culture and shared vision within the team.
- Support individual team members to work towards agreed objectives in care and support for people with ASD, ensuring that these objectives are consistent with promoting the wellbeing and quality of life of autistic people.
- Describe strategies and tools that could be adopted to reduce staff stress levels, to build resilience and to maintain the wellbeing of staff within the team.
- Know the appropriate type and level of resources required to deliver safe and effective services in care and support for autistic people.

Short video:  
Working with  
people with  
autism

[https://youtu.be/68qSnG\\_MaoQ](https://youtu.be/68qSnG_MaoQ)

# Help and advice: healthcare workers

- Your local community learning disability service or team will prove to be an invaluable source of information, support, and advice about your patients with learning disabilities and ASD.
- This team may incorporate specialist assessment, support, and intervention services, delivered by psychologists, psychiatrists, behavioural analysts, nurses, social care staff, speech and language therapists, educational staff, occupational therapists, physiotherapists, physicians, paediatricians, and pharmacists.
- Other people who may offer help and advice (depending on your question or issues) are your local safeguarding lead, mental health services, clinical geneticists, and neurologists.

# Help and advice: patients and carers

The following charities have a wide range of advice and support on offer for patients and carers:

- Mencap <https://www.mencap.org.uk/>
- Mind [Mind support and information](#)
- Learning Disability England <https://www.learningdisabilityengland.org.uk/>
- Change <https://www.changepeople.org/>
- National Autistic Society <https://www.autism.org.uk/>

We also provide additional e-learning courses on consent, mental capacity act, safeguarding adults and children, and working in a person-centred way.

# Summary

This course covered:

- The definition of learning disability.
- The definition of autism spectrum disorder.
- Why an awareness of learning disability and autism spectrum disorder is important.
- Why this is important in primary care.
- What range of conditions are covered by the term learning disability.
- What issues you may encounter in primary care when dealing with people with learning disabilities or autism spectrum disorder.
- How to make reasonable adjustments to help a person with learning disabilities or autism.
- Where to signpost people and carers for help and support.
- Where to look for further help and advice.

# References and Resources

## References and Resources

- NICE CKS Learning Disabilities <https://cks.nice.org.uk/learning-disabilities#!evidence>
- NHS England Liaison and Diversion Manager and Practitioner Resources Learning Disability <https://www.england.nhs.uk/commissioning/health-just/liaison-and-diversion/resources/>
- NHS England Transforming Care for People with Learning Disabilities <https://www.england.nhs.uk/learning-disabilities/care/#:~:text=TCPs%20are%20made%20up%20of,local%20plans%20for%20the%20programme.>
- NHS Improvement The learning disability improvement standards for NHS trusts <https://www.england.nhs.uk/learning-disabilities/about/resources/the-learning-disability-improvement-standards-for-nhs-trusts/>
- Health Education England Learning Disability <https://www.hee.nhs.uk/our-work/learning-disability>
- Mental Capacity Act 2005 <https://www.legislation.gov.uk/ukpga/2005/9/contents>
- Mental Capacity Act Code of Practice <https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice>

# References and Resources

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- Equality Act 2010 [https://www.legislation.gov.uk/ukpga/2010/15/content\\_s](https://www.legislation.gov.uk/ukpga/2010/15/content_s)
- Skills for Health Supporting autistic people and/or people with a learning disability <https://www.skillsforhealth.org.uk/info-hub/learning-disability-and-autism-frameworks-2019/>
- NICE CKS Autism in children <https://cks.nice.org.uk/topics/autism-in-children/>
- National Autistic Taskforce <https://nationalautistictaskforce.org.uk/>
- NICE Autism spectrum disorder in under 19s: support and management <https://www.nice.org.uk/guidance/CG170>
- NICE Learning disabilities and behaviour that challenges: service design and delivery <https://www.nice.org.uk/guidance/ng93>
- NHS England and NHS Improvement Stopping over medication of people with a learning disability, autism or both (STOMP) <https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/>



## CONTACT INFO



+44 207 692 8709



admin@belmatt.co.uk  
info@belmatt.co.uk



[www.belmatt.co.uk](http://www.belmatt.co.uk)



Suite 570, 405 Kings Road  
Chelsea  
SW10 0BB