

Health & Social Care Training Manual

Learning Disabilities Manual

During this module you will be asked some questions to simply provoke thought and test your current knowledge please have a note pad or supervision workbook to hand to make notes. Your performance will only be measured on the answers you select when completing the knowledge test at the end of the module.

Learning Disability Training Course

Knowledge Manual to deliver level 2 knowledge, understanding of Learning Disabilities and its impact and requirements within Care Homes and Care Environments.

Learning Outcomes:

At the end of this course you will have a better understanding of the following

- What the main causes of learning disabilities are.
- What the key pieces of legislation relating to learning disabilities are.
- What the main barriers are facing people with learning disabilities.
- How to improve communication with individuals with learning disabilities.
- How to promote positive care practices and personalised care when interacting with individuals with learning difficulties.
- Understand what LeDeR is and what it means for individuals with learning difficulties and those working in the care industry.

This training is to cover Tier 1 and 2 of the new requirements.

Section 1 - What can cause a learning disability?

A learning disability occurs when the brain is still developing (before, during or soon after birth). Several things can cause a learning disability.

Before birth things can happen to the central nervous system (the brain and spinal cord) that can cause a learning disability. A child can be born with a learning disability if the mother has an accident or illness while she is pregnant, or if the unborn baby develops certain genes.

Genes are chemicals in our bodies that contain information about us, like how we look.

A person can be born with a learning disability if he or she does not get enough oxygen during childbirth, has trauma to the head, or is born too early. Although modern healthcare has reduced the risk of difficulties occurring during birth, sadly these dangers cannot be eliminated completely. Complications can occur at birth such as when a baby is in the breech (reverse) position. This and other difficulties can delay the time in labour / giving birth, leading to the mother becoming exhausted and the baby becoming physically distressed, increasing the risk of trauma or harm to the baby.

Sometimes the umbilical cord, which carries nutrients to the baby whilst in the womb, can become wrapped around the baby's neck before or during the process of birth; this can result in the baby being starved of oxygen. This is known as Asphyxia and can result in damage to the baby's brain causing learning disabilities.

After birth, a learning disability can be caused by early childhood illnesses, accidents and seizures.

Meningitis and other infections in early years can also contribute to the onset of a learning disability, by causing damage to the brain. This is normally known as Acquired Brain Injury (ABI) as opposed to a learning disability.

Poor diet and lack of stimulation from parents and others can also lead to a failure to meet developmental targets and can contribute to a learning disability.

There are many for whom the cause of their learning disability is never known. According to BILD (British Institute for Learning Disabilities) this is around 50% of people with mild learning disabilities. For people with severe or profound learning disabilities the cause is usually clearer and the proportion for whom the cause is not known falls to 25%.

A learning disability can be diagnosed at anytime. A child may be diagnosed at birth, or differences may be noticed in the child's development during their early years. For some it may be many years before a diagnosis is made, others may never receive a diagnosis at all.

Mild Learning Disabilities

Most people with a learning disability will fall into this category (almost 80%). Many go through life quite independently and may only need help from social services or the NHS in the event of a crisis. They may benefit from additional help to access housing or employment but many will cope well enough without help from social services.

Moderate Learning Disabilities

12% of people with a learning disability are thought to have a moderate level, this means they may need support with everyday tasks such as dealing with their money, paying bills and perhaps with personal hygiene. They may be able to go out independently and have a job, be able to communicate in a limited range of vocabulary.

Severe Learning Disabilities

This is a smaller group of individuals (7%). They are likely to need quite a lot of support with their personal care, in social activities and in communicating with people who they do not know.

Profound Learning Disability

Only 1% of people with a learning disability are considered to fall into this category. They are likely to be very dependent on others for personal care and other essential needs. They might not be able to communicate using words but may be able to do so by signing, electronic communication boards and by using object referencing. Many will have additional health complications or impairments such as epilepsy, a physical disability or sensory impairment.

What is the medical model and social model of disability?

The medical model of disability says people are disabled by their impairments or differences. The medical model looks at what is 'wrong' with the person, not what the person needs. We believe it creates low expectations and leads to people losing independence, choice and control in their lives.

The social model of disability is a way of viewing the world, developed by disabled people.

The model says that people are disabled by barriers in society, not by their impairment or difference. Barriers can be physical, like buildings not having accessible toilets or they can be caused by people's attitudes to difference, like assuming disabled people can't do certain things.

The social model helps us recognise barriers that make life harder for disabled people. Removing these barriers creates equality and offers disabled people more independence, choice and control.

Down's Syndrome and Learning Disability

Down's Syndrome is caused by an extra chromosome in your cells. In the majority of cases, it can't be inherited and occurs by chance at the time of conception. People with Down's Syndrome have an extra copy of chromosome 21, which results in a distinctive appearance as well as a learning disability.

A person with Down's syndrome will have some degree of learning disability, but the level of ability will be different for each individual.

A child with Down's Syndrome might take longer than other children their age to reach certain milestones and to develop certain skills. They may also need ongoing support for different aspects of their life when they become an adult.

As with other conditions associated with learning disability, every person with Down's Syndrome is an individual and, with the right support and opportunities, can lead a happy and fulfilling life.

People with Down's syndrome will typically have some level of learning disability and characteristic physical features.

There are some health problems associated with Down's Syndrome, such as heart problems and difficulties with sight and hearing, but these will not affect everyone with the condition.

Phenylketonuria (PKU) is a rare but potentially serious inherited disorder

Our bodies break down the protein in foods, such as meat and fish, into amino acids, which are the "building blocks" of protein.

These amino acids are then used to make our own proteins. Any amino acids that are not needed are broken down further and removed from the body.

People with PKU cannot break down the amino acid phenylalanine, which then builds up in their blood and brain. This can lead to brain damage.

Diagnosing PKU

At around 5 days old, babies are offered new-born blood spot screening to test for PKU and many other conditions. This involves pricking your baby's heel to collect drops of blood to test.

If PKU is confirmed, treatment will be given straight away to reduce the risk of serious complications. Treatment includes a special diet and regular blood tests. With early diagnosis and the correct treatment, most children with PKU are able to live healthy lives. **About 1 in 10,000 babies born in the UK has PKU.**

Symptoms of PKU

PKU does not usually cause any symptoms if treatment is started early.

Without treatment, PKU can damage the brain and nervous system, which can lead to learning disabilities.

Other symptoms of untreated PKU include:

- Behavioural difficulties such as frequent temper tantrums and episodes of self-harm.
- Fairer skin, hair and eyes than siblings who do not have the condition (phenylalanine is involved in the body's production of melanin, the pigment responsible for skin and hair colour).
- Eczema.
- Repeatably being sick.
- Jerking movements in arms and legs.
- Tremors.
- Epilepsy.
- Musty smell to the breath, skin and urine.

Treating PKU

Diet

The main treatment for PKU is a low-protein diet that completely avoids high-protein foods (such as meat, eggs and dairy products) and controls the intake of many other foods, such as potatoes and cereals.

In addition, people with PKU must take an amino acid supplement to ensure they're getting all the nutrients required for normal growth and good health.

There are also several low-protein versions of common foods (such as flour, rice and pasta) specifically designed for people with PKU and related conditions to incorporate into their diets. Many of these are available on prescription.

If a high phenylalanine level is confirmed, a baby will immediately be started on a low-protein diet and amino acid supplements.

Phenylalanine levels are regularly monitored by collecting blood from a finger prick on to a special card and sending it to a laboratory.

A dietitian will create a detailed dietary plan for your child that can be revised as your child grows and their needs change. As long as a person with PKU sticks to a low-protein diet throughout childhood, and their phenylalanine levels stay within certain limits, they'll remain well and their natural intelligence will be unaffected.

Aspartame

People with PKU must also avoid food products that contain aspartame, as it's converted into phenylalanine in the body.

Aspartame is a sweetener found in:

- Sugar substitutes such as the artificial sweeteners often used in tea and coffee.
- Diet versions of fizzy drinks.
- Chewing gum.
- Squash and cordial.
- Some alcopops.

All food products that contain aspartame or a related product should be clearly labelled. There are also medicines that contain aspartame, such as some children's cold and flu remedies. It's a legal requirement for any medicine that contains aspartame to state it on the patient information leaflet that comes with the medicine.

Regular blood tests

A child with phenylketonuria will need regular blood tests to measure levels of phenylalanine in their blood and assess how well they're responding to treatment.

Only a drop of blood is needed, and it can be collected at home and sent to the hospital by post.

You may be able to have training so you can do your child's blood tests, or be able to test yourself if you have PKU. This will make testing more convenient.

It's recommended that children who are:

- 6 months of age or younger should have their blood tested once a week
- Between 6 months and 4 years of age should have their blood tested once every 2 weeks.
- Over 4 years of age should have their blood tested once a month.

Someone with PKU will usually need to have regular blood tests throughout their life.

How PKU is inherited?

The genetic cause (mutation) responsible for PKU is passed on by the parents, who are usually carriers and do not have any symptoms of the condition themselves.

The way this mutation is passed on is known as autosomal recessive inheritance. This means a baby needs to receive 2 copies of the mutated gene to develop the condition – 1 from their mother and 1 from their father.

If the baby only receives 1 affected gene, they'll just be a carrier of PKU.

If you're a carrier of the altered gene and you have a baby with a partner who's also a carrier, your baby has:

- a 1 in 4 chance of inheriting the condition.
- a 1 in 2 chance of being a carrier of PKU.
- a 1 in 4 chance of receiving a pair of normal genes.

Adults with PKU

Many adults with PKU find they function best while on a low-protein diet. The current advice is for people with PKU to remain on a low-protein diet for life. Unlike in young children, there is not yet any evidence that high phenylalanine levels cause any permanent brain damage in adults with PKU.

Some adults with PKU may have higher phenylalanine levels because they find it difficult to follow the low-protein diet or have returned to a normal diet. As a result, they may find they do not function as well. For example, they may lose concentration or have a slower reaction time.

These adverse effects can usually be reversed by going back on to a strict diet to bring the phenylalanine levels down again. Anyone who returned to a normal diet should still be supported by their clinicians and have a regular follow-up to monitor their condition for any complications that might arise.

For women with PKU, it's essential that they return to a strict diet if they're considering becoming pregnant, as high phenylalanine levels can harm an unborn child.

PKU and Pregnancy

Women with PKU must take particular care during pregnancy, as high levels of phenylalanine can damage their unborn baby.

Provided that phenylalanine levels are strictly controlled during pregnancy, problems can be avoided and there's no reason why a woman with PKU should not be able to have a normal, healthy baby.

It's recommended that all women with PKU plan their pregnancies carefully. You should aim to follow a strict low-protein diet and monitor your blood twice a week before becoming pregnant.

It's best to try to conceive once phenylalanine levels are within the target range for pregnancy. During pregnancy, you'll be asked to provide blood samples 3 times a week and will be in frequent contact with a dietitian. As soon as your baby is born, phenylalanine control can be relaxed and there's no reason why you cannot breastfeed your baby.

Contact your PKU doctor and dietitian as soon as possible if you become pregnant when your phenylalanine levels are not adequately controlled.

If your phenylalanine levels can be brought under control within the first few weeks of your pregnancy, the risk of damage to your baby should be small. But your pregnancy will need to be monitored very carefully.

PRADER-WILLI SYNDROME (PWS)

Prader-Willi syndrome is a rare genetic condition that causes a wide range of physical symptoms, learning difficulties and behavioural challenges. It's usually noticed shortly after birth.

Symptoms of Prader-Willi syndrome

Typical symptoms of Prader-Willi syndrome include:

- An excessive appetite and overeating, which can easily lead to dangerous weight gain
- Restricted growth (children are much shorter than average).
- Floppiness caused by weak muscles (hypotonia).
- Learning difficulties.
- Lack of sexual development.
- Behavioural challenges, such as emotional outbursts and physical aggression.

Causes of Prader-Willi syndrome

Prader-Willi syndrome is caused by some missing genetic material in a group of genes on chromosome number 15.

This leads to a number of problems and is thought to affect part of the brain called the hypothalamus, which produces hormones and regulates growth and appetite.

This may explain some of the typical features of Prader-Willi syndrome, such as delayed growth and persistent hunger.

The genetic cause happens purely by chance, and boys and girls of all ethnic backgrounds can be affected.

It's extremely rare for parents to have more than 1 child with Prader-Willi syndrome.

Diagnosing Prader-Willi syndrome

Prader-Willi syndrome can usually be confirmed by carrying out genetic testing.

Genetic testing may be recommended if a child has the symptoms of Prader-Willi syndrome. Babies who are very floppy at birth may also be tested.

Managing Prader-Willi syndrome

There's no cure for Prader-Willi syndrome, so treatment aims to manage the symptoms and associated difficulties.

This includes managing the person's excessive appetite and behavioural challenges.

One of the most important parts of caring for someone with Prader-Willi syndrome is to try to maintain a normal weight.

They should have a healthy, balanced diet, avoiding sweet treats and high-calorie items right from the start.

If someone with Prader-Willi syndrome is allowed to eat as much as they want, they'll quickly become dangerously overweight.

Someone with the syndrome can eat much more than other people and still feel hungry.

Limiting food intake can be very challenging. People with Prader-Willi syndrome may become frustrated when they want extra food, and their hunger can make them hide or steal food.

Long-term problems caused by Prader-Willi syndrome

Prader-Willi syndrome itself is not life-threatening. But compulsive eating and weight gain can cause young adults with the syndrome to develop serious obesity-related conditions such as:

- Type 2 diabetes.
- Heart failure.
- Breathing difficulties.

If their diet is well controlled and they do not become overweight, adults can have a good quality of life and probably a normal life expectancy.

Many adults with Prader-Willi syndrome take part in activities such as voluntary or part-time work but it's unlikely they'll be able to live fully independent lives.

What is Fragile X syndrome?

Fragile X is a genetic condition that affects both boys and girls, although boys are often more severely affected. It can cause a range of issues with language, emotions, attention, behaviour and social interaction.

Fragile X and learning disability

Fragile X is the most common inherited cause of learning disability.

Of the people who have Fragile X, nearly all boys will have a learning disability but only a third of girls. The learning disability could be mild, moderate or severe, which will affect the amount of support the person needs day-to-day.

How does Fragile X affect someone?

Someone with Fragile X might have a short attention span, be easily distracted, act impulsively, feel restless, be very active, and have heightened senses, but no two people are the same.

Many people with Fragile X might act in a way that is similar to someone with autism, including avoiding eye contact, feeling anxious in social situations, extreme shyness, enjoying familiar routines and hand flapping or hand biting.

People with Fragile X share some physical features, including a long narrow face with prominent jaw bones and ears. These features are difficult to see in young children, which is why diagnosis can sometimes be delayed.

How is Fragile X diagnosed?

Fragile X can be diagnosed with a blood test. It cannot be diagnosed through physical features or behaviour. Because it is a genetic condition, it is possible to test individuals to find out if they are a 'carrier' of the gene and could pass it on to their children. Diagnosis before the child is born is also possible.

What is Cerebral Palsy?

Cerebral Palsy is a physical condition that affects movement, posture and co-ordination.

It is usually diagnosed at birth or in early childhood.

Cerebral Palsy and learning disability

Cerebral palsy is not a learning disability, but some people with Cerebral Palsy might have a learning disability.

What causes Cerebral Palsy?

Cerebral Palsy is usually caused by an injury to the brain before, during, or shortly after birth, such as a lack of oxygen or illness.

How does cerebral palsy affect someone?

Each individual with cerebral palsy will be affected differently, and it can vary from mild to severe.

For some people, Cerebral Palsy will affect them physically, making muscle movements more difficult. Others may also be affected by seizures, epilepsy or difficulties with speech and language.

Getting support

Although there is no cure for Cerebral Palsy, physiotherapy can help to improve posture and muscle control.

An early diagnosis can also help to ensure someone with a learning disability or problems with speech and language receives the professional support they need early in their development.

What is Autism?

Like a learning disability, Autism is a lifelong condition. Autism is sometimes referred to as a spectrum, or Autism Spectrum Disorder (ASD).

Autism is **not** a learning disability, but around half of autistic people may also have a learning disability.

Autism is a condition that has many facets which will vary from each individual. This means that one solution or action will not suit everyone. All care and support needs to be designed with the specific individual in mind. For the carer it is important to get to know the individual that they are working with and speak to family and other support services to find out any relevant information.

ASD

Autism is often referred to as ASD or Autism Spectrum Disorder.

There are three common features of Autism, which might affect the way a person:

- Interacts with others in a social situation.
- Can communicate with others.
- Experiences the world around them.

What is Asperger's syndrome?

People with Asperger's syndrome see, hear and feel the world differently to other people.

People with Asperger's syndrome will not usually have a learning disability, however they may experience challenges such as specific learning difficulties, anxiety or other conditions.

What is Pathological Demand Avoidance (PDA)?

Pathological Demand Avoidance (PDA) is a form of autism which may also affect the way a person communicates and relates to other people.

People with PDA may experience challenges such as specific learning difficulties, but their central difficulty is that they are driven to avoid everyday demands and expectations to an extreme extent. This avoidance is rooted in an anxiety-based need to be in control.

Signs of Autism

The signs of Autism will be different for everyone, and affect different people in different ways in different environments (they are dimensional), but you might notice some of the following if your child has Autism:

- Difficulty interpreting verbal and non-verbal language
- Difficulty 'reading' other people and expressing their own emotions
- Sensory sensitivity and highly focussed interests
- Repetitive behaviour and routines
- Behaviour that challenges, such as episodes of frustration or in some cases violent behaviour

Diagnosing Autism

Diagnosis can be a very emotional time, and getting help from family, friends and professionals is really important to help you through the process.

Many people have mixed feelings about the process of diagnosis, and everyone's experiences will be different.

It's also important to remember that, although there is no 'cure', getting a diagnosis can be the first step towards making sure the individual will get the support they need to make the most out of life.

When do you notice the signs of autism?

While you might notice some of the signs of Autism in the first few years of the person's life, it may only be when they are at school, or even when they are an adult, that a diagnosis is made.

Sometimes an Autism diagnosis is delayed because health professionals want to be certain before they make a diagnosis. In other cases, a delayed diagnosis might be because the signs of Autism go undetected, especially if they present in a more subtle way (often the case with girls/women, and those with a PDA profile).

More boys than girls are diagnosed with Autism, and there is an ongoing debate about whether this is for genetic reasons or because the process of diagnosis tends to pick up autistic traits more common in boys, and the possibility that this is leaving some girls undiagnosed.

Autistic Diagnosis

If you think an individual has autism, you should talk to your GP or health visitor about your concerns. You can also ask to be referred to another relevant healthcare professional. This could be a psychologist or psychiatrist or, if the individual is young, a paediatrician or Child Development Centre (CDC).

If the individual is at school, you could speak to their teacher or to the school's special educational needs coordinator (SENCO) for advice and how to get the right support. Any other professionals working with the individual, for example a speech and language therapist or educational psychologist, may also be a good source of advice.

Keeping Note

It's a good idea to keep a diary of your child's behaviour and habits which you can show to any professionals you meet. Write down when it happened, what they were doing, the environment they were in at the time and anything notable that happened just before the event took place.

Finding help and support

Each autistic person is different, and the impact their condition has on their life will depend on many factors. These will include the severity of their condition, any additional diagnoses, such as a learning disability or a mental health problem, and whether they display any challenging behaviours.

While some autistic people will need very little extra support, others will need more specialist, even 24 hour, help. Each autistic person is also an individual in their own right, and will have their own likes, dislikes and characteristics just like everyone else, which will also affect the kind of support they want and need. Support and coping strategies need to be tailored to each individual.

Section 2 – Key pieces of legislation

The Mental Capacity Act 2005

The Mental Capacity Act 2005



The Mental Capacity Act says no one should assume a person cannot make decisions for themselves.



It says people should have support to make their own decisions about their lives.



For example, health care staff in hospital should give people information about their treatment in a way they can understand.



The Mental Capacity Act says people are allowed to make **unwise** decisions.



There might be times when a person cannot make some decisions for themselves. This is called **lacking capacity**.



Someone might **lack capacity** if they have a learning disability, dementia or a physical health problem, for example.



If someone **lacks capacity**, other people have a duty to make the decision for them in the person's **best interests**.



The person should still be involved as much as possible in making the decision and the decision must be the **less restrictive** option.

5 Principles of the Mental Capacity Act

1. Everyone is assumed to have capacity to make decisions unless it can be established that they lack capacity.
2. A person should not be treated as unable to make a decision unless all practical steps to help them to do so have been taken without success.
3. A person is not to be treated as unable to make a decision merely because they make what others might regard as an eccentric or unwise decision.
4. Any decision made on behalf of someone who lacks capacity must be made in their best interests.
5. Before the decision is made, it must be considered whether the outcome can be effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

Equality Act 2010



The Equality Act 2010

 The Equality Act says all people should be treated equally in places like schools and hospitals.

 It protects people from **discrimination**.

 **Discrimination** is when someone is treated unfairly because of their race, disability, sexuality, or something else about their identity.

 It says changes should be made for disabled people to make sure they are treated equally.

 For example, doctors could offer a disabled person a double appointment if they have a learning disability.

 This is called giving people **reasonable adjustments**.

Accessible Information Standard 2015

The Accessible Information Standard 2015



The Accessible Information Standard says that people who have a disability must get information about their health care and social care in a way they can understand.



It says that people working in health care and social care must ask what support you need to understand information.



For example, you might want Easy Read letters or you might want to be contacted by telephone.



These are called **reasonable adjustments**.



The **reasonable adjustments** you need must be recorded clearly somewhere so other staff know what support you need.

Human Rights Act 1998 **The Human Rights Act** is the UK law that exists to ensure that everyone's rights are respected and protected here at home.



Right to life
(Article 2)



Right not to be tortured or treated in an inhuman or degrading way
(Article 3)



Right to be free from slavery or forced labour
(Article 4)



Right to liberty
(Article 5)



Right to a fair trial
(Article 6)



Right not to be punished for something which wasn't against the law when you did it
(Article 7)



Right to respect for private and family life, home and correspondence
(Article 8)



Right to freedom of thought, conscience and religion
(Article 9)



Right to freedom of expression
(Article 10)



Right to freedom of assembly and association
(Article 11)



Right to marry and found a family
(Article 12)



Right not to be discriminated against in relation to any of the human rights listed here
(Article 14)



Right to peaceful enjoyment of possessions
(Article 1, Protocol 1)



Right to education
(Article 2, Protocol 1)



Right to free elections
(Article 3, Protocol 1)



Abolition of the death penalty
(Article 1, Protocol 13)

What are Human Rights?

Human rights are the rights we are all entitled to simply by virtue of being human. These rights ensure that we are all treated with dignity, respect and without discrimination. Human rights are based on values such as fairness, respect, equality and dignity but they are more than just nice ideas, they are protected in law.

The European Convention on Human Rights and the Human Rights Act set out a rule book for how governments must treat individuals.

Where do Human Rights come from?

After the horrors of World War II, it was recognised that whilst democracy is a partial check on power, it is not enough. The world community came together to agree on the Universal Declaration of Human Rights (UDHR). The UDHR set minimum standards that protect everyone. A way of ensuring that never again can an elected government decide who matters and who does not. This is the foundation for all human rights law.

What is our Human Rights Act?

The Human Rights Act 1998 was passed with cross-party support by parliament; it does not belong to any one political party. Our Human Rights Act takes 16 of the fundamental human rights in the **European Convention on Human Rights** and pulls them down into our law here at home.

Deprivation of Liberty Standards

Added to the Mental Capacity Act and came into effect in 2009. They allow some restrictions to be made on a person's liberty but only if it is in the best interest of an individual who lacks the capacity to make that decision for themselves.

Liberty Protection Safeguards

This should have been in place in April 2022 but there has been a delay. This is to replace DOLS.

What's the difference between DoLS and LPS? DoLS applies to a specific institution (such as a care home or hospital) and cannot be transferred. LPS will apply to the 'arrangements' for the person's care, so can consider a wider range of settings a person accesses providing a more comprehensive consideration of their lives.

People with a learning disability experience more physical and mental health problems than the general population, and they often find it is more difficult when accessing health care. They are also less likely to engage in health improvement or any health promotion initiative. Barriers to good health can, for people with learning disabilities include identifying their own health needs, struggling to explain health related problems and problems in attending hospital or GP appointments.

A lack of appropriate health promotion materials, health problems may also be misattributed to the learning disability. Unfortunately, many individuals with a learning disability suffer from these difficulties accessing healthcare.

This can be resolved by a responsible carer who implements the following practices

- Phoning the surgery to book an appointment on behalf of the individual.
- Request a house call if the individual struggles with a busy / noisy environment.
- Support the individual during the appointment if they have communication difficulties.
- Request any information that can be provided in an easy read format.

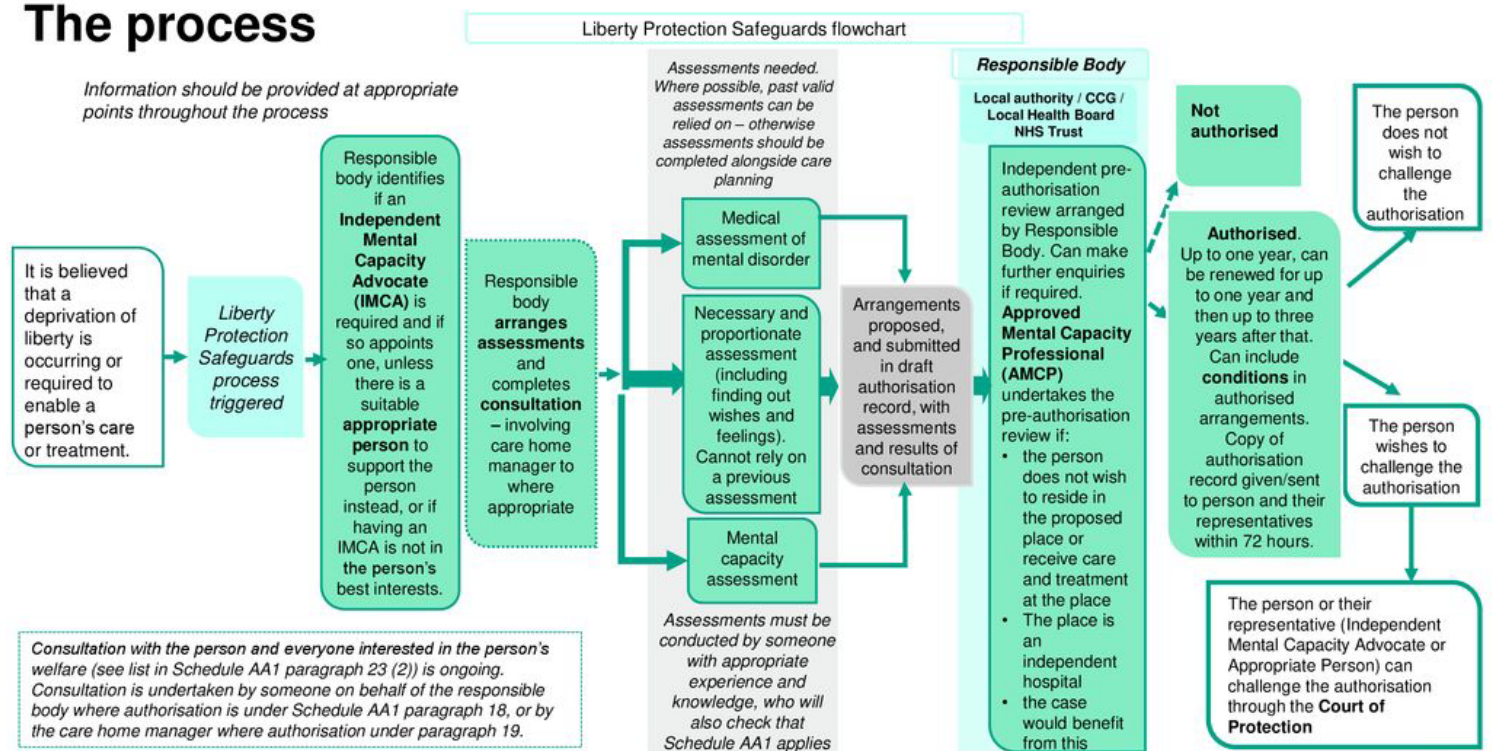
The Oliver McGowan mandatory training in learning disability and Autism was passed into law in July 2022 and included within the Health Care Act 2022. This includes legislation supported by the Government to legislate for mandatory training across the health and social care sectors.

Oliver had mild autism, epilepsy and learning difficulties after contracting meningitis at three weeks old. The aim is to gain a better understanding of how to ensure that individuals with a learning disability and/or autism can receive safe, effective and dignified care and those who provide the care have all the relevant knowledge, skills and behaviours to do so.

There is a core capabilities framework for supporting people with a learning disability and a new framework for supporting autistic people.

These frameworks identify the different levels of skills and knowledge that staff in the care sector must have to support individuals with a learning disability and / or Autism.

The process



Core Capabilities Framework for Supporting People with a Learning Disability

Introduction and Background

Since the original 'Learning Disabilities Core Skills Education and Training Framework' was published, the learning disability workforce has been the focus of much attention, not least as a result of the national Transforming Care Programme which aims to improve health and care services so that everyone can live in the community, with the right support, and close to home. The Learning Disabilities Mortality Review (LeDeR) Programme has also highlighted the persistence of preventable health inequalities and that people with a learning disability die, on average, 15-20 years sooner than people without a learning disability.

The launch of the NHS Long Term Plan (2019) has provided additional focus on action the NHS will take to strengthen its contribution to prevention and health inequalities, including mechanisms to ensure that people with a learning disability and/or autism get better support.

Developing the workforce to meet these aims requires a review of roles and associated education and training.

What is the purpose of the framework?

This framework describes what is required for supporting people with a learning disability in a range of settings, from those who need a general awareness of learning disability, to the skills, knowledge and behaviours required of those who are experts and lead services for people with a learning disability. The framework is relevant to all people with a learning disability, including children, young people and adults and comprises 25 capabilities grouped into 5 Domains. Within the capabilities, there are 3 tiers, each for a particular 'target audience':

Domains	Tiers
A. Understanding learning disability	Tier 1 Those that require general awareness of people with a learning disability and the support they need. Tier 2 Health and social care staff and others with responsibility for providing care and support for a person or people with a learning disability, but who would seek support from others for complex management or complex decision-making. Tier 3 Health, social care and other professionals with a high degree of autonomy, able to provide care in complex situations and/or may also lead services for people with a learning disability.
B. Health and wellbeing	
C. Personalised care and support	
D. Risk, legislation and safeguarding	
E. Leadership and management, education and research	

Use of the framework can support all aspects of workforce development including enabling individuals and organisations to:

- Identify key capabilities required for a job role, team or service.
- Plan the content of education and training
- Commission education and training
- Support training needs analysis and the assessment of capabilities.

Who is the framework for?

The framework should be of particular value to:

- Managers in organisations / individual employers.
- Service commissioners.
- Education and training providers.

The framework also enables workers and teams to be clear about the requirements of their roles (and/or training needs) and can be used by people with a learning disability, friends and carers to better understand the capabilities they can expect from those providing services.

How was the framework developed?

This is an update of the original 'Learning Disabilities Core Skills Education and Training Framework' previously published in 2016. This updated framework was jointly commissioned by Health Education England and NHS England (Learning Disability Programme). Project delivery was led by Skills for Health. The framework review and development was guided by a steering group representing key stakeholders, including British Institute of Learning Disabilities, Care England, Health Education England, Mencap, NHS England, Skills for Care, Skills for Health and VODG (Voluntary Organisations Disability Group).

What is the impact of the framework?

People with a learning disability have a right to access good quality healthcare. People with a learning disability generally have more health problems than other people and a higher risk of premature death. Health and social care staff need the capabilities to support and encourage people with a learning disability to optimise their physical and mental health.

They need to promote and implement reasonable adjustments, remove barriers to access and enable the health needs of people with a learning disability to be met.

This updated framework provides additional emphasis on:

- Health promotion and raising awareness of health conditions.
- Reasonable adjustments, addressing health inequalities and avoiding premature Mortality.

The purpose of this framework is to support development and planning of the current and future workforce, to inform the design of curricula and the delivery of education and training programmes – working in partnership with people with a learning disability.

The aim is for this framework to become the standard against which service and workforce quality will be measured.

Section 3 - Communication

People with learning disabilities are more likely than non-disabled people to have difficulty in communicating their ideas and needs. For some, the use of accessible, straightforward language will be sufficient to help, for others it is often helpful to use words alongside pictures or symbols to help a good level of understanding.

- Always give the individual specific information and ensure that they understand what is happening and why.
- Use the individual's name at the start of any communication so that they know you are talking to them.
- Many individuals with a learning disability may not be able to 'read' the social cues we use all the time and misunderstand the social comments

E.g., I'll be with you in a second. Ok its been a second now, I just need to do this, I won't be long.

By misunderstanding these social cues can cause them to get distressed and possibly result in challenging behaviours.

- If you are not sure if someone has understood you, rather than asking them if they have understood (as they will quite often say yes when they have not). You can say 'I'm not sure that I explained that very well, what did you understand from what I was saying? This takes the focus off of their ability to process what is being said.
- Avoid using jargon.
- Listen to what they have to say. It lowers confidence and self-esteem if they feel they are being ignored.
- Break communication into smaller chunks.
- Involve family members or carers in the communication if this will have a positive impact.
- Give individuals time to listen, understand and to respond.
- Try to speak face to face rather than on the telephone.
- Using language appropriate to age and ability.
- Recognise non-verbal communication and checking understanding. Look for changes in expression – are they making or avoiding eye contact. Changes in demeanour – are they tense / on edge or relaxed and at ease. Type of movements – sudden movement or a reaction and repetitive movements.
- Try rephrasing the question in a simplified form and make sure that you give adequate time to listen, understand and respond.
- Can anyone else help with communication (for example a family member , support worker, advocate etc).
- Hospital passports can be a good way of helping healthcare professionals know the support and communication needs of a person with a learning disability.
- Making communication accessible for all. This can be simple things such as not using jargon and speaking clearly, or more complex things like using communication aids such as picture cards. Do not be patronising but do check understanding.

- Remember that everyone with a Learning Disability has a voice and that voice counts.
- In a group situation support everybody to have a voice.
- Use Makaton / pictures if this is the preferred method of communication.
- Information to be in easy read format / large print or pictures.

Communication Barriers

- People with a learning disability were told that they may not receive life-saving treatment.
- Some hospitals failed to provide adequate care while government guidance on visiting resulted in the removal of critical support.
- There was a reduction in access to learning disability nurses and some acute learning disability nurses were redeployed to other units.
- Inappropriate discharge from hospital meaning many people left hospital too quickly with some emergency readmissions following soon afterwards.
- Remote consultations (e.g. over the phone or video call) were not suitable for many people with a learning disability.
- Many of us take for granted the fact that we are able to work a job. It is something which is easy to overlook the significance of, especially if you have never experienced discrimination of adversity in the workplace before. For people with learning difficulties, discrimination is something that many have sadly experienced by the time they reach employment age.
- While we have made great strides as a society in reducing or removing as many of the barriers that prevent people with learning difficulties from fully participating in society, there is still some way to go. For example, employers are much less likely to hire, or even consider hiring, applicants who suffer from learning difficulties.
- Only one in 10 people with learning disabilities are in employment – but at least 65 per cent have said they would like a job. It's a shocking statistic. According to Mencap, more people with learning disabilities are excluded from the job market than any other disabled group. The problem starts at school age – only one in three go on to take part in further education or training.
- This is a terrible state of affairs; especially when you consider what we know about the connection between job satisfaction and overall satisfaction with our lives. Jobs are more than just something that we must do to generate money. Jobs are where we meet new people and form new relationships. Performing well at our jobs also gives us a reason to feel more positive about ourselves and our futures.
- Perhaps most importantly of all, having a job means having a degree of security. A constant and reliable income stream provides some level of guarantee that an individual will be able to feed, house, and heat themselves. Some of those with learning difficulties will be entitled to some level of social security, but these payments won't equate to a full-time wage.
- Even in the wider world, there's little hope of integration with so-called 'normal' society. Those with learning difficulties face routine discrimination, which is worse if their disability is a visible one. Part of the problem lies in the fact that many of the most common learning difficulties are poorly understood. For example, plenty of people have heard of dyslexia but, other than those with direct experience of the

condition, exactly what it entails on a day to day basis can be a little bit more of a mystery.

- Learning difficulties lie on a spectrum, they can be relatively minor and have minimal impact on an individual's day to day life. However, even in the more severe cases, there is no reason that many of those facing learning difficulties should not be able to find a job if they want one.
- Stereotyping, stigma, and discrimination are challenges people with disability face every day. Much of the disabled community faces exclusion from parts of society other people take for granted.
- Disability exclusion has stemmed from the belief that having a disability makes you 'less than.' In recent years, the disabled community has also been silenced by the popularised positivity movement that believes 'the only disability is a bad attitude.' Although on a surface level this statement sounds encouraging, both attitudes have the underlying message that it is up to the disabled community to change if they want to be part of society.

Removing barriers in society

The social model of disability states that there are six different types of barriers people with disability face. Barrier removal requires expertise, collaboration, advocacy and legal backing.

Everyone can play a part in educating themselves about these barriers and learn how to create new pathways to ensure our society is as accessible and inclusive as possible.

Attitudinal barriers

Attitudinal barriers are created by individuals who can only see the impairment and not the person with a disability. At its worst believing in the stigma attached to disability can result in bullying, isolation and even violence.

On the flip side of this, people can be incredibly patronising using people with disability as 'inspirational porn.' Although this belief has no malicious intent, people with disability do not exist to make others feel good. Being condescending can cause just as much damage as being purposefully hurtful.

Stella Young spoke about the effects different attitudes have on the disabled community in her 2014 TED Talk, "I'm not your inspiration, thank you very much."

"I want to live in a world where we don't have such low expectations of disabled people that we are congratulated for getting out of bed and remembering our own names in the morning. I want to live in a world where we value genuine achievement for disabled people," said Stella.

This barrier is the underlying issue of all the other barriers. People may be unaware of their negative attitudes which is why it is important to make a conscious effort to unlearn these stereotypes. Everyone is deserving of the same respect and rights no matter their disability.

Physical barriers

Physical barriers refer to environments that are inaccessible due to the way they were designed.

Examples include buildings with no wheelchair access, ineffective lighting that creates poor visibility for people with low vision, sidewalks that are too narrow for walking aids or doorknobs that are difficult to grasp for people with arthritis.

There is already a lot of change being made in this space, like the introduction of wheelchair-accessible beach mats and low sensory quiet hours at grocery stores. However, there is always more to be done. Architects, designers, builders, and town planners need to put accessibility first to ensure everyone can enjoy society, rather than a select few.

Systemic barriers

Systemic barriers are the laws, policies, practices, or strategies designed by the government or organisations that discriminate against people with disabilities.

The systemic barriers often stop people from living their day-to-day life. Someone in a wheelchair may struggle to get places if their local train station does not have a ramp or someone with sensory processing issues may struggle to complete work if they are denied a reasonable adjustment of using noise-cancelling headphones. Peter who is on the autism spectrum has found his productivity at work has increased since using noise-cancelling headphones.

Unfortunately, discriminatory laws and policies are often only changed after immense pressure from advocacy groups. Alastair McEwin AM is the Commissioner for the disability royal commission and strongly believes that removing systemic barriers is key to achieving inclusion.

“My drive for the work I do is, quite simply, to ensure that in the future, no disabled person has to experience discrimination or barriers to mainstream society in the same way I have experienced discrimination and barriers as a deaf person,”

Communication barriers

Communication barriers affect people who have disabilities that impact their hearing, speaking, reading, writing, or understanding. Communication is intertwined with everything we do. We need communication to work, build relationships and seek support. Just because someone does not communicate in the same way you do does not mean they should be left out of the conversation. Breaking down communication barriers can be very simple. Speech pathologist Dr Joanne Steel put it clearly when suggesting ways to improve communication.

“Regardless of their speech abilities or cognitive skills, everyone has the right to communicate. So treat them the same as you would any other person, talk directly to them, and ask them questions,”

Other ways we can improve communication include hiring an Auslan interpreter at speaking events, including braille or electronic versions of menus at restaurants, and writing important information in simple, plain English.

Technological and digital barriers

Technology has many benefits for people with disability. It has helped to break down some of the barriers on this list. Thanks to technology people with disability have been able to access education, work remotely and improve communication and community connection. However, there are still some major accessibility barriers that come with technology.

For technology to benefit people with disability, web accessibility tools need to be utilised by everyone. For example, the alternative text or photo description tool is useless if the author has not written one. **Ebony who is visually impaired uses ZoomText that magnifies her two screens and can read to her if her eyes become tired.**

Breaking down barriers as an employer

There are many different ways employers can break down barriers for people with disability. One of the most impactful ways is to hire someone with disability. Not only does employing someone with a disability help the person become a contributing member of society but it can also have major benefits for the business.

Section 4 – How to Promote Positive Care Practices

Ensure that the individual with learning disabilities and/or autism have been registered onto the GP/NHS learning disability register.

Find out about any health conditions.

Understand pain triggers and find out how the individual communicates that they are in pain.

Ensure that they attend (where needed) dentist / optician/ chiropodist / podiatrist/ audiologist as part of their annual health check. Ensure that they are supported to prepare for these and work with the individual.

Support with annual flu/covid vaccination.

Support them to attend a cancer screening program where they have been invited to attend (Cervical/ bowel/ breast / prostate).

Do you need to make any reasonable adjustments to help them attend

- Should they have the first appointment as the clinic will be quieter
- Will they need a longer appointment to help with understanding any treatment.
- Can they sit in a quiet area away from the main clinic area if noise or people are a trigger.
- Will they need information in easy read format.
- Ask or a hospital passport to be made.

Remember that poor health leads to a poorer and shorter life.

If yes to any of the above ensure that this information is documented within their personal plan of care and that this information is passed onto the health care sector that they are attending.

What is Personalised Care?

Personalisation means thinking about care and support services in an entirely different way. This means starting with the person as an individual with strengths, preferences and aspirations and putting them at the centre of the process of identifying their needs and making choices about how and when they are supported to live their lives. It requires a significant transformation of NHS and other publicly provided services so that all systems, processes, staff and services are geared up to put people first.

The traditional service-led approach has often meant that people have not received the right help at the right time and have been unable to shape the kind of support they need. Personalisation is about giving people much more choice and control over their lives in all health and social care settings and is far wider than simply giving personal budgets. Personalisation means addressing the needs and aspirations of whole communities to ensure everyone has access to the right information, advice and advocacy to make good decisions about the support they need.

It means ensuring that people have a wider choice in how their needs are met and are able to access universal services such as health, social care, transport, leisure and education, housing, and opportunities for employment, regardless of age or disability.

Personalised care is one of the five major, practical changes to the NHS that will take place over the next five years, as set out the recently published Long Term Plan. Working closely with partners, the NHS will roll out personalised care to reach 2.5 million people by 2023/24 and then aim to double that again within a decade.

Personalised care means people have choice and control over the way their care is planned and delivered. It is based on 'what matters' to them and their individual strengths and needs.

This happens within a system that makes the most of the expertise, capacity and potential of people, families and communities in delivering better outcomes and experiences.

Personalised care represents a new relationship between people, professionals and the health and care system. It provides a positive shift in power and decision making that enables people to have a voice, to be heard and be connected to each other and their communities.

This approach learns from the experience of social care in embedding personalised care in everyday practice, which has enabled people to take control over the funding for their care. It also builds on pockets of progress made in health.

Critically, personalised care takes a *whole-system* approach, integrating services around the person including health, social care, public health and wider services. It provides an all-age approach from maternity and childhood right through to end of life, encompassing both mental and physical health and recognises the role and voice of carers. It recognises the contribution of communities and the voluntary and community sector to support people and build resilience.

Personalised Care:

- Improves people's health and wellbeing, joins up care in local communities, reduces pressure on stretched NHS services and helps the health and care system to be more efficient.
- Helps people with multiple physical and mental health conditions make decisions about managing their health, so they can live the life they want to live, based on what matters to them, as well as the evidence-based, good quality information from the health and care professionals who support them.
- Recognises that, for many people, their needs arise from circumstances beyond the purely medical, and will support them to connect to the care and support options available in their communities.
- Brings six different parts of the health system together based on growing evidence base of what has worked in shared decision making, personalised care and support planning, enabling choice, social prescribing and community based support and personal health budgets and integrated personal budgets.

Personalised care and the NHS Long Term Plan

Personalised care is one of the five major, practical changes to the NHS that will take place over the next five years, as set out the recently published [NHS Long term Plan](#). This follows a decade of evidence-based research working with patients and community groups and included the following key changes:

- Rolling out the NHS Comprehensive model of Personalised Care, so that 2.5 million people can have choice and control over support for their mental and physical health.
- Ensuring up to 200,000 people benefit from a personal health budget by 2023/24, so they can control their own care, improve their life experiences and achieve better value for money.
- Putting in place over 1,000 social prescribing link workers by the end of 2020/21, rising further by 2023/24, with the aim that over 900,000 people are connected to wider community services that can help improve health and well-being.
- Rolling out training to help staff identify and support people in the last year of their life, to jointly develop a personalised and proactive care plan which reduces avoidable hospital admissions and more people able to die in a place of their choosing.

My NHS Hospital Passport

This is my Hospital Passport

For people coming into hospital.

My name is:



Completed by:

Date:

If I have to go to hospital this book must go with me.
This Passport belongs to me. Please return it when I am discharged.

Nursing and medical staff please look at my passport before you do any interventions with me.













Things **you must** know about me

Things that are **important** to me

My **likes** and **dislikes**

Things you must know about me

Name:	<input style="width: 90%;" type="text"/>	         
I like to be called:	<input style="width: 90%;" type="text"/>	
Date of birth:	<input style="width: 90%;" type="text"/>	
Address:	<input style="width: 90%;" type="text"/>	
Telephone number:	<input style="width: 90%;" type="text"/>	

Family contact person:

Contact details:

Main carer:

Contact details:

My Doctor:

Contact details:

I have a Deprivation of Liberty Safeguard (DOLS) in place:
 Yes No

I have a Court of Protection Order in place:
 Yes No

I have a Lasting Power of Attorney for Welfare (LPA):
 Finance Welfare

Other people important in keeping me safe or well:

Name	Role / Profession	Tel. number
<input style="width: 90%;" type="text"/>	<input style="width: 90%;" type="text"/>	<input style="width: 90%;" type="text"/>

Consent - please take into account the five principles of the Mental Capacity Act (2005)

Things you must know about me

Religion:

and religious needs:



How I communicate:

What language I speak:



What to do if I am anxious and how you can help me cope:



Allergies:



How to take my blood, blood pressure, give injections etc:



Medication:

How I take medication (crushed tablets, injections, syrup):



Known Medical Conditions:

Any risks from choking or seizures or other:



Things that are important to me

How to communicate with me:

How I will communicate with you:



How to tell if I am in pain:



Problems with my sight and hearing:



How I keep safe (bed rails, support with challenging behaviour):



Smoking (how many, use of patches):

Smoking is not allowed in the hospital, near the door or in the car park.

You can have help, please ask or call Oxfordshire Smoking Advice Service 0845 40 80 300.



Things that are important to me

How I eat (risk of choking, help with eating, PEG feeds):



How I drink (small amounts, thickened fluids):



Moving around (posture in bed, type of seat, walking aids):



Personal care (dressing, washing, cutting nails):



How I use the toilet (continence aids, help to get to the toilet):



Sleeping (sleep pattern, routine):



My likes and dislikes

Likes: For example - what makes me happy, things I like to do i.e. watching TV, reading, music, routines.

Dislikes: For example - don't shout, food I don't like, physical touch.

My Likes:




Things I don't like:





My NHS Hospital Passport

My carer

How my carer will help me when I am in Hospital:



My carer's needs:

Extra information

Any plans I have for end of life care:

Contact information

For further support or any questions about the Hospital Passport please contact:

Learning Disability Liaison Nurses | 01865 234565

Or contact your local Learning Disability Team:

North Learning Disability Team
Samuelson House, Tramway Road, Banbury OX16 5AU
Telephone: (01865) 903500

Oxford Learning Disability Team
2nd Floor, Knights Court, 2 Between Towns Road, Oxford, OX4 3LX
Telephone: (01865) 904555

South Learning Disability Team
Abbey House, Abbey Close, Abingdon, OX14 3JD
Telephone: (01865) 903100

This Hospital passport is based on original work by Gloucester Partnership NHS Trust and the South West London Hospital Access to Acute Group.

Thank you to the Southern Health NHS Foundation Trust, Oxfordshire Learning Disability Partnership Board, Oxford University Hospitals NHS Trust and Oxford Health NHS Foundation Trust who have collaborated in the re-design of this Hospital Passport.

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N2Y images - <https://www.n2y.com/>

My Care Passport

This is me

My Care Passport

It should be kept with me and brought with me into any care setting, including hospital.

Click here to add your photo from your computer

My name is:

I like to be known as:

Please return my passport to me when I go home.

This is essential reading for all staff working with me. It gives important information about me. This passport should be kept visible and used when you talk to me or think about me.

Things you must know to keep me safe

Things that are important to me

My likes and dislikes

This passport is a pdf file that can be typed into, saved and updated using Adobe Acrobat Reader. Go to: www.surreyhealthaction.org to download it free of charge. You could also print it off and write on it.

More basic information about me

This passport needs to be updated if my needs change.

Where I currently live:
For example - supported living or my family home.

Hours of support I get each day:

Who to contact for more information about me:
Please say name, role and contact phone number.

Other key professionals involved in my care:
Please say name, role and contact phone number.

Key person / people to liaise with about my admission and discharge:

This passport was filled in by:

Date:

Things you must know about me

1. Adverse drug reactions, allergies or intolerances.

Please give details including what my reactions would be.

2. Communication - How well I use and understand speech

Other ways I communicate - signing, pictures or other languages? How I show how I feel. How I communicate yes and no.

3. Food and drink - Food allergies / intolerances and help choosing

Do I need help filling in menus? How I make food and drink choices. See also the likes and dislikes section.

4. Eating and drinking - What help I need

Does my food need to be cut up or liquidised? Do I use dentures to eat? Do I use special equipment?

If there is a risk I may choke please give details of my management plan and seating & posture.

5. Pain - How I show I'm in pain and how to support me

6. Other medical conditions - Such as diabetes, epilepsy, asthma and depression

See separate medication list.


7. How I take medication - One tablet at a time, on a spoon or via a syringe

Do I need help to make sure I have swallowed?


My Care Passport

8. How to support me with medical interventions

Things like taking my temperature, blood pressure, blood test and having injections.



9. How I usually am - for example do I sleep a lot, am I usually very quiet?




10. How do I react to strange places?




11. Keeping me safe - Do I wander? Could I fall out of bed? Do I fall?


Please consider environmental risks.



12. Things that may worry or upset me - How I may show this.




13. How to support me if I'm anxious or upset - Also see the likes and dislikes section.




14. Behaviours I have that may be challenging or cause risk

What you can do to support me with my behaviours - things that help me relax.




15. My sight - Any problems I have, aids I use like glasses or magnifying glass.

Can I clean my glasses myself?



16. My hearing - Any problems I have, aids I use like a hearing aid?


Can I put my hearing aid in myself? Do I know how to turn it on?



17. Other vital information - Such as advance care decision.

If I have a 'Lasting Power of Attorney' please specify whether it covers 'Health and Welfare' and/or 'Finance and Property'. Please also say if I have an 'End of Life Care Plan'.


Please also say who holds these documents and how to contact them.




Things that are important to me

Important people Family, friends & staff who support me.	Level of support I need when well Who needs to stay and how often.
	

How I use the toilet when I am well -e.g. continence aids and getting to the toilet.




Personal care - support I need with things like dressing, washing and teeth cleaning.




Moving around - for example posture in bed, walking aids and wheelchair.


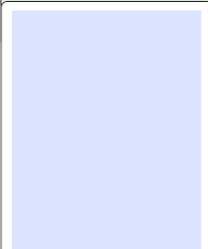
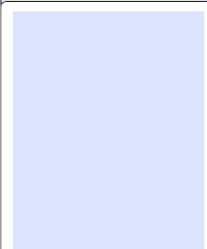
Do I need help with moving around?



Sleeping - my sleep pattern / routine / time of waking.



My likes and dislikes

Things I like Could include: Music, TV, foods, activities and how I relax.		Things I don't like Could include: Things that worry me, foods, activities and ways I don't like being treated.
		

My history - What is important that you know about my life (past and present)

Please also use this space for any further information.



We would be delighted to receive your feedback on this document.
Please go to www.surveymonkey.com/s/NGK1MG7 and complete our short feedback form. We will use the information to review and update the document in the future. Thank you.

Based on a previous 'Hospital Passport' this version is designed to be used for all people within a variety of care settings. The content was developed together by Surrey and Borders Partnership NHS Foundation Trust, Acute Liaison, Specialist Therapies and Older Adults services, Royal Surrey County Hospital and the Surrey Alzheimer's Association.
This passport was designed by The Clear Communication People Ltd using our Easy Pica Imagebank.
Email: mia@clearcommunicationpeople.co.uk for more information.

Section 5 - LeDeR

About LeDeR

LeDeR is a service improvement programme for people with a learning disability and autistic people.

Established in 2017 and funded by NHS England and NHS Improvement, it's the first of its kind. LeDeR works to:

- Improve care for people with a learning disability and autistic people.
- Reduce health inequalities for people with a learning disability and autistic people.
- Prevent people with a learning disability and autistic people from early deaths.

LeDeR reviews

A LeDeR review looks at key episodes of health and social care the person received that may have been relevant to their overall health outcomes. We look for areas that need improvement and areas of good practice. We use these examples of good practice to share across the country. This helps reduce inequalities in care for people with a learning disability and autistic people. It reduces the number of people dying sooner than they should.

So far, over 9000 reviews have been completed. From these reviews it has been found out information and learning on the best way to carry out these reviews. The data and evidence to make a real difference to health and social care services across the country.

How LeDeR fits with existing local and national reviews of deaths

There are several different review processes for people who die. For example:

- Child death review.
- Safeguarding adults' review.
- Review of deaths of people in hospitals.

If this is the case, we will work together to try to avoid unnecessary duplication. Reviewers will make it clear to families where and how the LeDeR process links with other reviews or investigations.

The LeDeR process

Anyone can tell us when someone four years old or over with a learning disability dies or autistic people we will include people aged eighteen years or over.

The reviewer will contact a:

- Health care professional.
- General Practice (GP).
- Family member.
- Care provider.

Once we have the details of someone's death, we start the review process, which we will complete in six months. Sometimes it will not be possible to complete the review in 6 months because there might be other processes going on like a coroner's inquest or another investigation. A LeDeR review waits until all these have happened first.

We know that some family members might not be ready to talk with us straight away. A reviewer or member of our team will perform an initial review which includes:

- Speaking to the family member or someone close to the person who died. This allows us to build up a picture of their life and the type of person they were. This will also help the reviewer understand more about the person. The reviewer might also speak to someone they lived with or a carer who they were close to.
- A detailed conversation with the GP or a review of the persons GP records.
- A conversation with at least one other person involved in the care of the person who died.

After this, the reviewer uses their judgement to decide if a focused review needs to happen. A focused review will usually happen if:

- The reviewer finds areas of concern or things they think we can learn from.
- The person is from a Black, Asian or minority ethnic background.
- The person was autistic with no learning disability.
- The person had been under mental health or criminal justice restrictions at the time of death or 5 years previously.

A family member can always ask us to complete a focused review. A conversation will take place between the family and the reviewer about the expected outcome of a LeDeR review.

What happens next?

A focused review will look in more detail at the person's life. The review will also involve more people with different jobs.

The reviewer will send the completed review to the local governance group or panel with the areas of learning, good practice and concern. The group or panel will decide on actions to take, who will take these actions and the help they need to reduce health inequalities and stop people dying too young.

Roles and responsibilities, Who does what in LeDeR?

Local integrated care systems (ICSs) are responsible for carrying out the LeDeR review. Before 2021, it was the clinical commissioning groups (CCGs) responsibility.

Local integrated care systems (ICSs) responsibilities:

- Help to improve the quality of services for people with a learning disability and autistic people.
- Reduce health inequalities.
- Reduce people with a learning disability and autistic people dying earlier than the general public. This is also called premature mortality.

Because of the new policy, some of the roles and responsibilities in LeDeR have changed. Below is an outline of the key roles and changes.

National LeDeR team

NHS England and NHS Improvement are employers of the national LeDeR team.

The National LeDeR team responsibilities:

- Helps to support CCGs and ICSs to complete LeDeR reviews.
- Use the information to change and improve the way they provide services in their area.
- Help systems to learn from one another about learning and good practice.
- Make sure that there is an academic partner to support the programme.
- Commission a web platform to help reviewers complete reviews.

Regional Coordinators

We have 7 NHS England and NHS Improvement learning disability and autism teams across the country. A regional coordinator is part of each team and provides oversight for LeDeR.

Regional Coordinators Responsibilities:

- Provide operational support for local area contacts (LACs) and reviewer teams.
- Support the LAC with any unresolved local issues.

Local Area Contact (LAC)

From 2021, the LAC role will sit in the ICS. There is now greater independence between the review team and the LAC.

The LACs responsibilities:

- Acts as the contact person for the regional coordinator.
- Works with the review team.
- Promotes LeDeR at a local level across health and social care.

Reviewer teams

Review teams include reviewers and senior reviewers.

The review teams' responsibilities:

- Carry out LeDeR reviews in a professional, compassionate, and caring way.
- Treat bereaved family members and loved ones with respect, compassion and courtesy.
- Share their findings with the local governance group or panel.

The LeDeR is to help with key episodes in Health and Social Care at Health checks/ Flu or Covid vaccinations. Cancer screening. Lifestyle . This is to make improvements and to share good practice. This in turn will increase the annual health checks and an increase in the uptake of flu/covid vaccinations. Hospital records can be improved and conditions flagged so that reasonable adjustments can be made.

LINKS

www.mencap.org.uk/treatmewell

www.legislation.gov.uk

www.olivermcgowan.org

www.autism.org.uk