Health Education England

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Contents

This handbook has been written to accompany The Oliver McGowan Mandatory Training on Learning Disability and Autism. Delegates may download and use this to capture local resources. The original content is updated via the elearning for healthcare hub. This is version 1.1.

Introduction

This handbook has been co-produced by Gloucestershire Health and Care NHS Foundation Trust, Inclusion Gloucestershire, Family Partnership Solutions CIC and Gloucestershire County Council. It has been designed to accompany the elearning of the Oliver McGowan Mandatory Training on Learning Disability and Autism.

The team that co-produced this handbook comprised people with a range of lived experiences and these include: learning disability, autism and family, parent and sibling carers. This is in addition to a wide range of professionals working in learning disability and autism services and a range of stakeholders across health, voluntary and social care settings.

The aim of this handbook is to provide a summary of the content covered in the elearning and expand beyond this with some helpful links to resources that may help you in supporting people with a learning disability and autistic people. You can visit the websites and reading material provided by clicking on the in-text links to go directly to the resource and there is a list of the full links in the appendices.

There are sections left blank, which are intended for you to make your own list of local services and resources.

The information provided within this handbook was correct at the time of writing during the COVID-19 pandemic during the year 2020. The reader is advised to always appraise the information for themselves and check for more recent literature where needed according to local policy and guidance.

We hope that what you learn today will be helpful across all aspects of your life. It is likely that you will meet people who have a learning disability, or autistic people, in many different situations. Examples of these life-situations can include within your work role, but also perhaps as work colleagues or in your social or personal life.

A note on language

In relation to the diagnostic terms or labels that are used, the language around this changes over time.

In recent times, the term ‘intellectual disability’, instead of ‘learning disability’ has been used but in some places you will still hear people using both.

Many autistic people prefer the use of identity-first language. Autism is not something that someone suffers from, lives with or carries around with them. It is a part of them, so the term ‘autistic person’ is preferred.

You may hear people talk about Asperger’s syndrome or ‘high functioning’ autism. These diagnoses are not used anymore but some people may still prefer to use them if they find it fits with their experience.

You may also hear people talk about neurodiversity. If your way of seeing the world matches what most people expect, you could be described as ‘neurotypical’. Whereas autistic people or those with other diagnoses, such as attention deficit hyperactivity disorder (ADHD) or dyslexia, might be described as neurodiverse or neurodivergent. This is because they can have a different way of seeing and interacting with the world.

When you are working with people with a learning disability, or autistic people, it is important to find out what language they find most meaningful and what terms they prefer to use, if they use any at all.

You’ll see many quotes throughout from experts by experience who have been involved in developing this training. The context given within the training is information they are happy to have shared and using the terms they prefer for themselves.

All of the quotes and videos are publicly available online or have been provided with consent especially for this training. We hope that this is helpful to you.

Understanding learning disability

What is a learning disability?

It is often not easy to recognise that someone has a learning disability.

These are some of the things you might notice when working with somebody. These signs may indicate that you need to adjust the way you are doing things.

The difficulties which have been identified are not always explainable by a specific condition. Some specific syndromes have particular physical attributes.

The person may have difficulty with:

- remembering basic information, for example date of birth, address, health
- reading/writing (and understanding meaning), completing forms
- explaining symptoms and emotional experiences
- understanding and processing new information
- understanding and telling time; sequencing of events
- understanding and recognising risks
- recognising signage/money/numbers
- planning and organising things for themselves

A learning disability is a lifelong condition that starts before adulthood. A learning disability affects someone across all areas of their life and is characterised by:

- a significantly reduced ability to understand new or complex information and to learn new skills
- a reduced ability to cope independently
- a lasting effect on development

Specific learning difficulties such as dyspraxia, dyslexia and ADHD that affect a subset of skills, are not the same as a learning disability. A learning difficulty does not affect general intelligence, whereas a learning disability is linked to an overall cognitive impairment.

It is important to note that everybody with a learning disability is an individual, with their own identifiable strengths, understood difficulties and unique experiences.

You may hear people talking about different types of learning disability (-ies) which can affect them at differing levels, and these could be mild, moderate, severe or profound. Some people are keen to have these labels, but they are not always helpful because they can sometimes act as barriers to accessing services.

It is important to remember that these levels of difficulty reflect an individual's level of learning disability compared to other people with a learning disability, not the general population. For example, a person having a mild learning disability still means the person will have significant difficulties when compared to someone of average ability and functioning, which will impact on their daily life.

The level of support someone needs depends on the individual and should not be decided by the 'label'. The type of support can range from living independently with someone available in the background to help with bills and appointments, to full care in all areas of their lives. For example, people with what are sometimes called profound and multiple learning disabilities may need someone to physically help them to eat and use the toilet. Whatever the level of learning disability, having a learning disability should not be a barrier to quality of life.

Our co-production team have talked about assessments, diagnosis and labels. Whilst some people said that labels and diagnoses were helpful to gain access to services and get help, others did not feel the same way.

It is important to see the person first regardless of their diagnosis. People do not fit into 'boxes' and you will have heard this theme repeated in the film clips. There are 1.5 million people with a learning disability in the UK – 351,000 are children aged 0-17. A learning disability occurs when the brain is still developing. This can be before, during or soon after birth.

There are different types of learning disability, which can be mild, moderate, severe or profound and in all cases a learning disability is a lifelong condition. The level of support someone needs depends on the individual. For example, someone with a mild learning disability may only need support with things like getting a job.

However, someone with a severe or profound learning disability may need full-time care and support with every aspect of their life – they may also have physical disabilities (Mencap).

A person is identified as having a learning disability and being eligible to receive a service if all three of the following are present:

- significant impairment of intellectual functioning
- significant impairment of adaptive behaviour
- onset before adulthood

1. Intellectual functioning: The person will have significant challenges in general mental ability. This can include reasoning, planning, solving problems, thinking abstractly, comprehending complex ideas, learning quickly and learning from their experiences. Just over 2.4% of people (determined by reference to a normal distribution with the general population) may be expected to have a general level of intellectual functioning commensurate with a diagnosis of a learning disability.

2. Adaptive behaviour: Concerns “the collection of conceptual, social and practical skills that have been learned and are performed by people in their everyday lives”. Examples of each skill include:
    - conceptual skills: language, reading and writing; and money, time and number concepts
    - social skills: interpersonal skills, social responsibility, self-esteem, gullibility, naivety, follows rules/obeys laws, avoids being victimised, and social problem-solving
    - practical skills: activities of daily living (personal care), occupational skills, use of money, safety, health care/transportation, schedules/routines and use of the telephone. Relative to the general population a person with a learning disability has significant difficulties with such activities of daily life

3. Onset before adulthood: This means there should be evidence of the presence of each of the other two criteria before the person attains the age of 18 years.

(The British Psychological Society, 2016)

The team stressed the importance of remembering that:

> "Labels follow you for life and change how you feel about yourself and that assessments should be used to help people to be supported rather than list the things that the person cannot do."

Causes of a learning disability

The causes of a learning disability are often not known but this section includes some of the more common causes that are known about. These include: genetic conditions, difficulties during pregnancy and birth, and early childhood illnesses. The sections below outline some of the conditions associated with each cause.

Genetic conditions

May be an inherited condition or arising from chromosomal abnormalities such as:

- fragile X
- Down's syndrome
- Prader-Willi syndrome
- Rett syndrome
- syndromes without a name

During pregnancy

- maternal illness/infection
- physical trauma, for example incidents such as accidents, domestic abuse
- alcohol use – foetal alcohol syndrome
- uncontrolled diabetes

At birth

- oxygen deprivation
- head trauma
- premature birth
- infection

Childhood (less common)

- metabolic disorders
- infection, examples of this include meningitis
- seizures
- brain injury, examples of this are accidents and abuse
- oxygen deprivation, an example is choking
- neglect, severe deprivation, malnutrition

Profound and multiple learning disability

Profound and multiple learning disability usually refers to someone with a severe learning disability and who also has severe physical disabilities and complex health needs. Someone with profound and multiple learning disability may have severe difficulties seeing, hearing, speaking and moving. They may have complex health and social care needs due to these and/or other conditions.

People with profound and multiple learning disability will need 24/7 support for all aspects of daily living. These include but are not limited to: personal care, mealtime support, attending appointments and engaging in meaningful activity. They have limited movement in lying, sitting, transferring and general mobility, are often hoisted for all transfers, and will need specialist seating to provide appropriate postural support and achieve a functional sitting position. They also usually have other health concerns that require monitoring and review.

These include, but are not limited to:

- dysphagia
- epilepsy
- respiratory issues
- constipation
- pressure care
- postural needs

If a person does not walk and spends the day in a chair and is unable to maintain an upright seated position the force of gravity will encourage a sideways/forward lean. Over time this can lead to joint rotation in places like the hips, which then impact on the ability to sit in a symmetrical position at the pelvis. This can lead to changes in body shape.

A change to posture can cause issues such as scoliosis, which is the curvature of the spine. It can also cause other issues such as hip rotation and/or contractures in related limbs. This is where muscles tighten and range of movement is reduced. This can lead to other health problems such as pressure on internal organs and digestion difficulties. This can cause reduction in any mobility and range of movement, swallowing difficulties, constipation, respiration issues and pressure areas.

Life expectancy

For a person with profound and multiple learning disability, life expectancy is less than the average population. This can be due to the health complications associated with the postural deformities mentioned above that can shorten life.

Epilepsy can also cause significant issues if left undetected, or a late diagnosis of other health problems (if the patient is unable to explain if in pain and where) and will also have an impact on life expectancy.

People with profound and multiple learning disability are more susceptible to infections and illness and the impact this will have on their body can be more severe than in comparison to the general population. When a possible, more serious health issue has been identified sometimes further invasive assessment and subsequent treatment might be needed.

However, the suitability of this will be determined through the best interest process, as sometimes it is felt that further assessment and potential treatment could cause more harm to the person. Alternatively, the possible outcome would not outweigh the risks they would face due to their already identified complicated health status.

Health concerns due to compromised posture

1. Respiratory disease

Respiratory disease is the leading cause of death for people with profound and multiple learning disability. They are more susceptible to respiratory infection; this could be due to:

- compromised swallowing and risk of aspiration
- postural differences (thoracic cage abnormalities) which can limit lung capacity in comparison to someone who does not have a profound and multiple learning disability
- having a compromised breathing system, asthma, etc
- airway obstruction when asleep, loss of tone, etc, meaning that a low level of oxygen is being circulated

2. Pressure areas

Deformities, reduced mobility, inability to independently change position and spending a long time in the same position makes skin breakdown a concern for those with profound and multiple learning disability. The extra pressure disrupts the flow of blood through the skin. Without a blood supply, the affected skin becomes starved of oxygen and nutrients, and begins to break down, leading to an ulcer forming.

Early symptoms of a pressure ulcer include:

- part of the skin becoming discoloured – people with pale skin tend to get red patches, while people with dark skin tend to get purple or blue patches
- discoloured patches not turning white when pressed
- a patch of skin that feels warm, spongy or hard
- pain or itchiness in the affected area

3. General population versus people with profound and multiple learning disability

As people age conditions such as general wear and tear, osteoporosis, arthritis, becoming more susceptible to infection and illness, deterioration of bone density and loss of muscle tone all impact on their level of functioning and quality of life. Contractures are also seen in those with dementia or following a stroke, for example.

A diagnosis of osteoporosis means some people are at greater risk of fractures, and general wear and tear on the spine as we age may result in a need for physiotherapy input or even surgery.

For those with profound and multiple learning disability, these complications are seen earlier in life. Some people with profound and multiple learning disability have these issues throughout their entire life.

4. Energy levels and impact on daily activity

Someone with cerebral palsy may experience ‘burnout’. This is where their functional skills decline earlier than might be expected. However, this is not due to health issues, or typical ageing process, but due to them trying to constantly feel secure in their positioning, voluntary actions or managing their involuntary movements.

Someone with cerebral palsy has to work harder and use a lot more energy than their able-bodied counterpart. Even maintaining a basic sitting position can take a lot of energy and concentration, or even reaching for a utensil to eat with, leaving them exhausted on a daily basis.

There will be varying degrees of increased and decreased muscle tone, involuntary movements (quick and jerky or slow writhing movements) of the limbs, and tremors. For many people with cerebral palsy, the physiological system is constantly active and the potential for full physical relaxation is limited.

As a result of this you might see:

- additional time required to perform previously acquired skills
- difficulty in performing previously acquired skills, for example dressing, washing, transferring and toileting
- increased co-ordination difficulties
- need for longer and more frequent rest periods
- sleep disturbance

Specialist learning disability services

Some regions have community learning disability teams (CLDTs) or other specialist professionals available. Physiotherapists and occupational therapists (OTs) see people with profound and multiple learning disability for a regular postural management review to try to reduce postural deterioration and prevent the impact of some of the above issues for as long as possible.

Physiotherapists will conduct a review of any postural changes by taking measurements of hip and knee flexion and looking at changes in range of movement and then making comparisons with previous assessments. Concluding these examinations, both the physio and OT will review and assess the need for equipment such as specialist seating, supportive shower chairs, sleep systems, and slings, to help the client with profound and multiple learning disability engage with 24-hour postural care.

This will hopefully prevent, but at least reduce, the deterioration in posture by providing some specialist equipment and the right amount of support and comfort during transfers, mealtimes, personal care, day-to-day living and at night.

The clinicians will then provide guidelines and explain how equipment is to be used, the importance of using it correctly, who to contact when it does not meet the client's needs, or when posture or equipment needs to be reviewed.

It is important that the equipment provided is used as prescribed. Any loss or damage to parts needs to be reported as soon as possible so the part can be reviewed or replaced to ensure the person is as well supported and as comfortable as they can be throughout their daily routines.

As mentioned above, if postural care needs are not appropriately met, a person may experience the following issues if they are not appropriately cared for:

- pain
- contractures
- spinal deformities
- increased risk of fractures (due to reduced bone density)
- loss of function (for example impact on safe swallowing and normal digestion; actively and safely participate in transfers)
- increased need for surgery
- pressure areas and sores
- decreased respiratory, cardiac and digestive functioning due to possible pressure on internal organs as a consequence of postural deformities
- exhaustion in trying to maintain a position to feel secure

Postural care is used to try to slow down, prevent and reduce the impact that the person's condition will have on their body to keep them well and able to function within their abilities for as long as possible.

People with a profound and multiple learning disability are reviewed regularly as part of the 'postural management care pathway'.

A referral to specialist services should be made through a GP. Please see the services and resources section for more details about the work of a CLDT.

Enter the details of your local learning disability services below.

Resources:

Books

Made Possible: Stories of success by people with learning disabilities – in their own words. Editor: Saba Salman. Publisher: Unbound (28 May 2020). ISBN-13: 9781783528264.

Websites

For 50 years, Bild has protected and supported the rights of people with learning disabilities, seeking to build a more fair and equal society where everyone has the same rights and opportunities. Bild offers:

- workforce development programmes, qualifications, training for family carers
- organisational development and consultancy
- membership for individuals and organisations
- communities of practice, resources and events to inform and support practice
- grant-funded projects to support government initiatives

Mencap supports people with complex needs – including its members, universities, government departments, local authorities, NHS trusts, service providers and mainstream organisations to champion rights, ensure excellent support and continually improve practice. It offers the following support and services:

- workforce development, accreditation and training
- organisational development and consultancy
- grant-funded projects to support government initiatives
- communities of practice, guidance publications and conferences

Foundation for People with Learning Disabilities helps to make things better for people with learning disabilities. Its office is in London, but it works with people all over the United Kingdom and sometimes in other countries too. It works with:

- people with a learning disability
- families
- carers
- local authorities
- service providers

Supporting people with profound and multiple learning disabilities - core and essential service standards. The core and essential service standards are designed to improve the lives and life experiences of people with profound and multiple learning disability.

They provide an informative and practical resource to enable those who commission services for, as well as those who support, children and adults with profound and multiple learning disability. This is to ensure access to consistent high-quality support by any service provider throughout their lives.

The ‘About profound and multiple learning disabilities factsheet’ is downloadable and printable.

You will find answers to questions that we are often asked about Down’s syndrome on the Down’s Syndrome Association webpage. This information will help you to separate the facts from some common misconceptions. If you do not find what you are looking for, please call our helpline and speak to one of our specialist advisors.

You can also learn about the ongoing work of the Down’s Syndrome Association.

MacIntyre was established in 1966 by Kenneth Newton Wright, the parent of a child with a disability, MacIntyre has grown to become a leading national charity that is highly respected and committed to setting standards and increasing choice. It provides learning, support and care for more than 1,200 children, young people and adults who have a learning disability and/or autism at locations across England and Wales.

Check what resources are available in your area, and make some notes below.

Understanding autism

What is autism?

Autism is not a learning disability, but it can also impact learning and dealing with daily life. Instead of affecting cognitive ability across the board, autism specifically concerns social and communication skills, thinking flexibly and sensory perceptions. Emotional and mental health may be affected.

As with learning disabilities, the executive functions of planning and adaptable thinking are likely to be reduced. All of these may impact learning, pace of response and behaviour significantly. Thus, an autistic person may appear to have reduced intellectual abilities, however many possess an average to extremely high intellectual capability.

Autism is a lifelong developmental disability which affects how people communicate and interact with the world. One in 100 people are autistic and there are around 700,000 autistic adults and children in the UK.

Autism is often referred to as a spectrum. Every autistic person has a different combination of traits and sensitivities and is unique. Autism can occur across the full range of intellectual ability. This means some people with autism also have learning disabilities, some have average intelligence with or without specific learning difficulties, and some have high intellectual functioning.

A linear spectrum (Figure 1) represents what most people think the autism spectrum is. People often link this to level of intellectual functioning, referring to ‘high functioning autism’ being at one end and those with associated learning disabilities at the other.

Figure 1: Linear spectrum

Figure 2: Multi-faceted spectrum.

In fact, Figure 2 is a more accurate representation of what the spectrum of autism looks like – it is multi-faceted and spans several areas. People can be at different points on that spectrum for each area. They may experience varying strengths and challenges across different aspects of their lives which can vary from day to day, or even hour to hour. Many call this the ‘spiky profile’ of autism. Therefore the term ‘high functioning autism’ is not used any more as it is misleading and unhelpful. (Alvares, Bebbington et al., 2020)

Autism is often referred to as a hidden disability as it is impossible to tell someone is autistic from looking at them or based on first impressions.

Autistic people have varying and often complex needs. Some autistic people may require 24-hour care and support in many areas of their daily lives, whilst others may have no formal support needs.

Some autistic people have successful careers, own their own houses, are married and have children. Others will fall somewhere in between.

People may experience varying challenges across different aspects of their lives, and therefore need different types or amounts of support in different areas. For example, an autistic person with high intellectual functioning may run their own company but struggle to do their washing independently or remember to shower regularly.

Likewise, an autistic person with a learning disability may receive 24/7 support due to their needs, but they could have a particular interest in washing machines and be able to do laundry independently and know lots about different types of machines.

We cannot assume that someone's intellectual ability or use of language reflects their needs.

Like everyone else, every autistic person is a unique individual with their own strengths and areas of difficulty.

We must consider each individual's experience, the different aspects of their life, and the adjustments they need and how they are met. These notions are at the centre of what we talk about in this training. Furthermore, we shall consider how they can be helpful to all autistic people, if they are tailored to the unique needs of the individual.

Social communication can be challenging for autistic people because of:

- taking things literally and not understanding abstract concepts
- needing extra time to process information or answer questions
- repeating what others say to them (this is called echolalia)

In social interactions autistic people may:

- appear to be insensitive
- seek out time alone when overloaded by other people
- not seek comfort from other people
- appear to behave 'strangely' or in a way thought to be socially inappropriate
- find it hard to form friendships

This does not mean that autistic people do not feel empathy, or are unable to develop friendships, relationships and successful careers. It may be that describing emotions and understanding unwritten social rules is challenging. With the right support in place, all autistic people should be able to live the life they choose.

Prevalence of autism across genders

Three times as many males as females are diagnosed with autism. There are multiple theories about this, including a range of biological and environmental factors which may mean men and boys have a higher prevalence of autism.

However, it is also felt that women and girls may be better at masking or camouflaging their difficulties and that autism traits in girls and women can look quite different. This may mean that autism is under-reported, and therefore under-diagnosed in females.

There is some evidence that rates of autism are higher in gender-diverse people, but the reasons why are unknown (Warrier, Greenberg et al., 2020).

Autism in the Somali community

A series of five evidence-based short films and factsheets about autism for the Somali community have been launched by researchers at the University of Bristol (funded by the National Institute for Health Research (NIHR) and community organisation Autism Independence.

Like other migrant groups, the Somali community has high numbers of children with autism, many of whom are likely to be severely affected. However, there is no Somali word for autism, making it hard to understand and accept.

Autism Independence, led by Nura Aabe, works with over 100 children with autism in Bristol, supporting families from the Somali community and other Black, Asian and minority ethnic backgrounds.

Nura came to Bristol from Somalia at the age of 10 and her oldest son has autism. She is now studying for a PhD at the University of Bristol. Autism Independence works with health, social care and education services to bridge the gap between families' needs and service provision.

Previous research led by the NIHR Applied Research Collaboration West (ARC West) in collaboration with Autism Independence has revealed that cultural stigma surrounding mental health, challenging behaviour and disability means that families in the Somali community often hide their child and don't seek help early. Parents can feel isolated and don't engage with support services for their child.

The new films and factsheets build on the success of 2019's Overcoming Barriers, which tells the stories of some of the Bristol-based Somali families supported by Autism Independence.

The Somali-language version of Overcoming Barriers has been viewed more than 160,000 times on YouTube, while the English-language version reached more than 36,000 views. The new films address some of the issues raised in the hundreds of YouTube comments following the launch of Overcoming Barriers.

You can access these resources below:

- Video - Overcoming Barriers: Autism in the Somali Community (YouTube Video)
- Ted Talk - No More Us and Them - Disrupting Attitudes to Autism

What is not a learning disability or autism?

Often the language used to describe different conditions is confusing, especially learning disability versus learning difficulty, which is not helpful. Although many of the things listed here may affect learning or an aspect of someone's day-to-day life, the impact is unlikely to affect every part of their lives. It is more helpful to consider conditions using the umbrella term of neurodiversity as mentioned earlier, including:

- dyslexia
- attention deficit hyperactivity disorder (ADHD)
- specific learning difficulties, for example reading and writing
- dyspraxia
- brain injury after the age of 18
- degenerative neurological conditions
- mental health problems

It is also worth saying that for some of the conditions listed here there are treatments that can reduce the impact that they have on someone's life, like taking medication to help with the symptoms of ADHD. There are no treatments for either autism or learning disability, and there are many people who feel quite strongly that we should not look for treatments but rather celebrate people's differences.

Resources

- The National Autistic Society is one of the most well-known organisations that advocates for autistic people. Its ‘I Exist’ campaign raised awareness of autistic adults and the support needs that some may have; before this much of the focus had been on autistic children. The Autism Act came into power in 2009 and since then there has been much work going on to promote better understanding.
- The Independence Trust in Gloucestershire ‘My Autism Information Booklet’. It contains vital information about how to support someone with their social and communication needs.
- *The Reason I Jump: One boy’s voice from the silence of autism* – author: Naoki Higashida. Publisher: Sceptre (24 April 2014). ISBN-10: 1444776770 ISBN-13: 978-1444776775

Check what resources are available in your area, and make some notes below.

Transition from childhood to adulthood

Young people and transitions

Typically, when we talk about transition, people think about moving from being a child to an adult and this is going to be the focus of this section. However, it is also important to remember that transitions can be anything that involves a change, such as moving from home to school.

Changing from night-time to daytime, going from one activity to the next, throughout any day we all go through many transitions.

Any transition involves change and the need for us to adjust to the next 'thing' and many people with a learning disability and autistic people can find change difficult.

However, transitions happen all the time and there are a lot of significant changes that take place in the teenage years. These range from the joys of puberty and all of the complexities that brings, to potentially several changes in educational environments. These may become bigger, noisier and much less familiar, with greater expectations of autonomy and organisational skills.

The move from primary school to secondary school can be a particularly big step for autistic children who do not have an associated learning disability. They may not yet be recognised as autistic and if they are performing well academically, they may be expected to cope well with the transition. However, children face many more transitions throughout the day at secondary school. This can range from different classrooms, different teachers to different children in each class. Each of these transitions could be stressful for the child.

We know that the support needs of people with a learning disability and autistic people are likely to be present in childhood and to continue into adulthood.

Although many people think of the distinction between childhood and adulthood being when the individual turns 18, when we think about supporting people through this process we need to be thinking about a much wider timeframe.

The preparation for adulthood should begin to happen as early as possible, and certainly no later than year 9 (when aged 13 or 14 years). For those young people who have an Education, Health and Care Plan (EHCP) the local authority has a duty to ensure that the year 9 annual review meeting consider and discusses what provision is required to assist the child or young person in preparation for adulthood and independent living.

Due to the nature of learning disability and autism, this transition may also take longer, partly because puberty may be later but also because many people remain in educational settings until their early twenties. For individuals with a learning disability, they may stay in the same school or college through to their twenties and so the significant change out of this setting may be delayed.

Meanwhile, for autistic people without a learning disability, they may leave school to go on to college, then possibly university, then into the workplace, so they may have numerous significant changes in this short timeframe.

Preparing for adulthood

Questions to consider include:

- Is the young person registered with a local GP?
- Are they on the learning disability register?
- Are the family aware of the benefits of an annual health check from age 14?
- Is it clear what reasonable adjustments are likely to be needed to support the child's mental or physical health?
- If the young person will need adult health care services, who will plan for the health transition with them?

Resources

Preparing for Adulthood (PfA), funded by the Department for Education, is a partnership bringing together a wide range of expertise and experience of working with young people with special educational needs or disability (SEND) and families, at a local and national level and across government. Its aim is to support young people into adulthood with paid employment, good health, independent living options and friends, relationships and community inclusion.

The National Development Team for Inclusion (NDTi) has a section of tools and resources to support preparing for adulthood.

Check what resources are available in your area, and make some notes below.

Health inequalities

People with a learning disability and autistic people face many health inequalities.

The Learning Disabilities Mortality Review programme (known as LeDeR) was established in May 2015 to review all deaths of people with a learning disability, to learn from those deaths and to put that learning into practice.

LeDeR has found that people with learning disabilities continue to die younger than those without disabilities; in 2019 men with learning disabilities died on average 22 years younger, and women 27 years younger, than people in the general population. The LeDeR project has also found that people with learning disabilities die from avoidable medical causes of death twice as frequently as people in the general population; they are also more likely to die in hospital, as opposed to at home or in a hospice.

A term you may hear is 'diagnostic overshadowing', which means attributing any difficulties or changes in presentation to someone's diagnosis and not considering other factors. This can have devastating consequences – for example, assuming an increase in someone's aggressive behaviour is due to them having a learning disability and not looking any further to consider that they may be in pain.

This can result in potentially missing serious physical health needs. An example of diagnostic overshadowing with a mental health diagnosis might be assuming that someone's lack of appetite is based on physical health issues and not considering that it could be a sign that the person is depressed.

At the extremes, diagnostic overshadowing can result in failure to provide potentially lifesaving treatments based on assumptions that, due to their diagnoses, people do not have a good quality of life even if treated.

The Care Quality Commission (CQC) is currently conducting a national review into the use of Do Not Resuscitate orders during COVID-19 because concerns have been raised about improper use based on someone's diagnosis. Some of the most common concerns found during LeDeR reviews relate to:

- delays in the diagnosis and treatment of illness
- poor care co-ordination and communication between agencies
- omissions in care or the provision of substandard care
- poor application of the Mental Capacity Act
- lack of timely referral to specialists, including learning disability services and neurologists

GPs hold a register of all the people with learning disabilities registered with their surgery and should invite everyone on that register to have an annual health check every year. It is therefore important to encourage people to sign up to the Learning Disabilities Register.

Within the NHS Long Term Plan there is an increased focus on the needs of autistic people and their families, starting with autistic children with the most complex needs. An annual health check similar to that already offered to people with learning disabilities will be developed and piloted for autistic people.

Health inequalities faced by people with a learning disability and autistic people with or without learning disabilities are also being tackled through increased access to other health promotion initiatives.

Examples of this include:

- flu vaccinations
- COVID-19 vaccinations
- good health screening, such as regular checks for breast or prostate cancer

For a long time, people with learning disabilities and autistic people with or without learning disabilities have been vulnerable to being given too much or inappropriate medication, and their medication is not always reviewed as well or as often as it could be. Stopping over medication of people with a learning disability, autism or both (known as STOMP) and supporting treatment and appropriate medication in paediatrics (known as STAMP) continue to be key priorities.

On 23 March 2021, NHS England and NHS Improvement (now NHS England) published “Learning from Lives and Deaths – People with a Learning Disability and Autistic People”. This is the new LeDeR policy, and the name has changed to reflect the inclusion of autism.

This means that from 2021, the deaths of all autistic people will also be reviewed. Learning from these reviews will be used to better inform services of how they can work together to reduce health inequalities (for autistic people, as well as people with a learning disability).

The findings from the independent review of the LeDeR process following Oliver McGowan’s death have also informed many of the recommendations in this new policy. This includes greater governance around the review process and more support for those carrying out the actual reviews.

Annual health checks

People with a learning disability often have poorer physical and mental health than people without a learning disability, but this does not need to be the case. People should be offered a free, annual health check from the age of 14 years to help them stay well by talking about their health and finding any problems early, so that they can get the right care.

Most surgeries send out a pre-health check questionnaire to gather useful information. After gaining this information, at the annual health check the GP or a nurse will do a physical check-up and talk about any medication the person is taking.

The person will be asked about things that are more common for people who have a learning disability such as epilepsy, constipation or problems with swallowing. The GP or nurse will check any existing health problems and will also ask if family or carers are getting the support they need. The individual should be given a health action plan after their annual health check, and this will help them and people who are supporting them to keep them healthy.

The benefits of having an annual health check include:

- it is an opportunity to get to know the GP better
- it is also an opportunity for the GP to meet with family carers to check on them too
- for children, having regular annual health checks with their own GP can help to make sure that things go well when they move to adult services

At present, autistic people without a learning disability are not offered annual health checks, but evidence suggests that they are also at risk of poorer physical and mental health outcomes. Again, the NHS Long Term Plan is committed to developing a check for autistic people who do not have learning disabilities too.

People with a learning disability and autistic people are both less likely to be invited to checks or screenings and, if invited, are less likely to be supported to attend routine health screening such as cervical or prostrate screening. It is important that these things are made more accessible and that people are encouraged to attend with the appropriate support and reasonable adjustments in place. The same is true for vaccinations.

Many people with a learning disability and autistic people need support to live a healthy life, especially in areas such as nutrition, hydration and weight management.

Recent LeDeR reviews continue to find that people with a learning disability have died due to constipation, which is not acceptable.

We know that some people with a learning disability and autistic people may have slightly different baseline presentations. Therefore, it is important that health professionals know what is normal for the individual and what to look for in terms of signs that they are not well.

For some people, additional aids or equipment may be needed to help them stay well and maintain their independence, such as physical aids for accessing the community and tools to make tasks easier around the home. The transition to adulthood can be a particularly good time to think about any equipment needs as people develop greater independence. Some people may be looking to move away from the family home, and equipment may support them to manage independently in areas where their parents may have previously helped them.

Social prescribing can also play an important role as part of a holistic approach to improve wellbeing and give people more control over their lives. A social prescriber link worker helps the person to think about what is important to them, and then connects them to relevant community groups or resources, to improve their quality of life. GPs, other services and the individual themselves can refer to their local social prescribers.

The social model of disability

Many argue that the reason people experience these inequalities is because they are disabled by barriers in society, not by their impairment or difference.

Some examples include:

- physical barriers like buildings having no ramp, lift or accessible toilet, but also less obvious things like using strip lighting, which many people with sensory processing sensitivities find difficult

- procedural issues such as strict ‘two missed appointments and you’re discharged’ type policies, which can disadvantage people who find planning and organising their time difficult; this could also include wider policy and staff training issues

- attitudes to difference, which might include people assuming that autistic people or people with a learning disability cannot work, or can only take on menial tasks

- information and communication, for example sending letters with complex language that someone with a learning disability might struggle to understand, or using phrases that autistic people might not understand due to a tendency to interpret things literally

- lack of opportunities, for example, if someone wants to work it can be difficult due to limits on what they can do because of the impact on their benefits – many autistic people earn an average or above-average salary, but many people with a learning disability may struggle to get paid enough to come off their benefits and are therefore limited in how many hours they are allowed to work

- a lack of positive representations of autistic people and people with a learning disability within society so young people are not witness to positive role models and may feel like they have little to aspire to

To find out more information on the social model of disability, read Inclusion London's social model of disability webpage.

Sharpe et al. (2019), in the context of addressing health inequalities in general practice, said that autistic people are often 'hidden' from existing health and social care services. This is important because autistic people with or without a learning disability are at higher risk of experiencing physical and mental health issues.

Around 30% of autistic adults have comorbid learning disability, physical, and mental health conditions. While those with comorbid learning disabilities are more susceptible to physical health issues, those without a learning disability are at higher risk of mental health problems.

Autistic adults without a learning disability die 12 years earlier when compared to the general population so it is important that those working in health and social care are aware of these hidden vulnerabilities.

Sadly, research shows that autistic people are at greater risk of suicide when compared with the general population, particularly autistic females and autistic people without a learning disability; with suicide being among the top three causes of premature mortality for the latter (Hirvikoski et al. 2016).

Many of the triggers for suicide can be the same for autistic people as for the general population. Autistic people are more likely to experience bullying, social isolation and loneliness, and difficulty accessing support. In addition to comorbid mental health conditions, they might have difficulties understanding, communicating and managing their own feelings.

Our experts explained that it is very hard to communicate feelings and to find words, and that sometimes people dismiss their feelings which makes this worse.

This highlights the importance of making sure that autistic people get the right support regarding their mental health, social difficulties and understanding their diagnosis. Support may also be needed to access the things that make life meaningful for the individual, for example interests, work and relationships.

Physical health and emergency decisions

The RESTORE2 mini is a useful tool for non-registered care staff and family carers to use to help assess a person's 'unique wellness' and to monitor for signs of physical deterioration.

RESTORE2 stands for **R**ecognise, **E**arly **S**oft **S**igns, **T**ake **O**bservations, **R**espond and **E**scalate.

Please find some resources below to help with assessing and managing physical health and making decisions in emergency situations:

Resources

- ReSPECT | Resuscitation Council UK
- Training and resources for care providers including RESTORE2
- West of England Academic Health Science Network (weahsn.net)
- NEWS | National Early Warning Score - eLearning Programme (ocbmedia.com)
- National Early Warning Score (NEWS) 2 | RCP London
- Video – Soft (early) signs of being unwell

Check what resources are available in your area, and make some notes below.

Communication

This section contains information about communication. Some of this is specific to supporting autistic people, some to supporting people with a learning disability, but often, what helps one person can also help another.

Here are some key points:

- being unable to express yourself/participate is frustrating and disempowering
- it can be difficult to work at someone else's pace
- there are many communication methods we can use besides speech
- shared communication systems are important for successful interaction
- where there are communication difficulties, some of the details/nuance lost
- the same information can be interpreted differently by different people
- assumptions/expectations can lead to us missing or misinterpreting information
- how successful communication is, is likely to vary across contexts/conditions
- there are ways to improve communication – knowing the person, being face to face, knowing what systems of communication you both use
- choice and control is important
- uncertainty and dismissive responses are unhelpful

Poor communication

Poor communication can:

- impact concentration, frustration, difficulty moving on
- cause the potential for distress, which may be expressed in other ways such as through behaviour
- lead to disengagement and withdrawal, learned helplessness
- over the long term, impact on mental health, wellbeing, self-esteem – interactions and (dismissive) comments that may seem minimal to one person could have a significant impact on others, particularly if they repeatedly have these experiences in their daily lives

Communication differences

Common areas of difficulty:

- attention and listening
- processing speed
- (working) memory
- understanding
- lack of vocabulary to express range of needs, ideas or emotions
- ability to construct a sentence
- fluency of speech, an example of this is stammering
- articulation
- social skills

Up to 90% of people with a learning disability have communication difficulties, with around half having significant difficulties in both expressing themselves and understanding what others say.

We need to be able to pay attention and maintain focus to listen. A person's ability to do this can be affected by how they are feeling in the moment and what is going on around them.

Some people find it difficult to understand spoken and written language, especially if a lot of words are used. Some people may not understand jokes or know the meaning of well-known phrases such as 'piece of cake'.

Difficulties processing information may be related to a delay in understanding what is heard, known as auditory processing. Some people may have impaired processing, meaning that maybe only one word in three is actually heard.

Our working memory allows us to hold information and then store it in our brain. If the working memory is impaired, people can't store information in their brain for next time.

> 50–90% of people with a learning disability have communication difficulties (RCSLT, 2010)

There is often a mismatch between people's expressive ability and their understanding. This can go both ways and some people can express more than they can understand and vice versa. Some people struggle to express themselves due to difficulties with articulation, which may be due to physical factors like muscle tone affecting lips and tongue movement, while some people choose not to use spoken language.

Differences in communication for autistic people

Differences in social communication and social interaction across multiple contexts are also common for autistic people:

- absence of or limited speech; highly articulate speech
- echolalia
- literal interpretation of words and phrases
- facial expressions
- eye contact
- body language
- speech intonation
- understanding the non-verbal rules of social communication
- repetition, rituals and sensory use of language or sounds
- masking or camouflaging and associated effort/fatigue

The differences in communication skills and styles are often more subtle for autistic people but, as we have said throughout the course, this can vary a lot between people, and for the same person, depending on the type of day they are experiencing.

It is important to remember that we should never judge someone's ability based purely on their use of spoken language. Many autistic people are highly articulate but even these people may find it difficult to express themselves when stressed. On the other hand, someone may not communicate using spoken language, but may have a good understanding of what is being said to them and what is going on around them.

Echolalia is the repetition of words or sounds; the person may be repeating phrases they have heard before, or the last word that you said. Echolalia can also be linked to sensory preferences as some people will repetitively repeat the same word or sounds because of the pleasurable sensory feedback they receive from doing so.

Many autistic people are known to make literal interpretations of language and may find understanding metaphors and similar phrases difficult.

One of our family carers [Rosie] explained that her brother took the bedtime saying ‘sweet dreams’ as an encouragement to think about sweeties at bedtime. Whilst this sounds like quite a pleasant experience, some autistic people report feeling distressed by visual images conjured up by metaphors such as ‘wears his heart on his sleeve’ or ‘open a can of worms’.

> “My brother thought that ‘sweet dreams’ meant he should think about the sweet shop at bedtime – we didn’t realise this or think about what we were saying until he was about 40 and started saying ‘lemon sherbets and swirls’ in response!”

Some of the non-verbal elements of communication are also often different for autistic people.

Many people are aware of differences in eye contact and are confused when someone who is known to be autistic appears to maintain good eye contact. Whilst it is not true that all autistic people dislike eye contact, it is an issue for many. However, some will have learnt ways of coping with this or masking it. It is important when working with autistic people, especially children, that we do not insist on them looking at us when we speak to them, as many can find this distressing.

Many autistic people work very hard to follow the unwritten rules of social communication; they may watch other people for cues on how to do it and then use learnt techniques to help mask the difficulties they experience. This is exhausting and many people report feeling extreme fatigue after prolonged social interactions.

Over time this masking, along with sensory overload, can contribute to what many autistic people call ‘autistic fatigue or burnout’, which can cause exhaustion along with increased meltdowns and sensory sensitivity, physical pain, and sometimes physically shutting down including the loss of speech.

> “People not understanding us or not supporting us with our communication needs can put us at risk in many ways and it can have a significant impact on our wellbeing.”

> "I'm a vocal person, but when I'm overwhelmed, I can't talk, and I'm trying to get my phone out so my widget programme can tell people what I am trying to say, but they don't want to listen to the assistive technology, they want me to be neurotypical."

This quote is from one of the experts by experience involved in co-producing this training and illustrates the importance of understanding her unique expressive abilities and how this can change over time.

The four areas of support include:

Letting people know what is going to happen	Helping someone to express themselves	Helping someone understand what you're saying	Getting to know someone better
Verbal Calendar, diary Apps Written or visual timetables Now/next board Storyboards Objects of reference Multisensory cues Routine, grouping Own behaviour/ non-verbal cues	Verbal Writing Gesture/sign Voice output communication aids (VOCAs) Talking mats Picture Exchange Communication System (PECS) Communication book Choice boards Attend to behaviour/ non-verbal cues Virtual communication	Simplify language Signing Gesture Easy-read information Social Stories Pictures Writing Demonstration/ action Written materials Reading lists Being consistent in our behaviour and non-verbal cues	Asking questions Consistency Taking time to build relationships Previous notes Communication passports Communication dictionaries Intensive Interaction Hospital passport Life stories Familiar carers/ supporters Using interests

Any of these strategies could potentially be helpful; however, this depends on the person's unique needs and abilities, the context, and how they best receive information or express themselves. Some of these things, like putting a note on the calendar or always keeping our keys in the same place, are things that we might all do at times. Some of them are specific tools designed to aid the communication of those who find it difficult.

It is important that we take responsibility for adapting our own communication to be most meaningful to the individual, as well as supporting the individual with their own methods of communicating.

Tips for good communication

- choose your environment (consider sensory needs)
- one person communicating at a time
- introduce yourself and who you are
- always put the person first, even if they cannot communicate verbally or appear disengaged
- give the person your full and direct attention: head up, eye level, visible
- check you have their attention (do not force eye contact)
- use the individual's preferred communication method/aids
- speak clearly and at an appropriate pace
- make sure your tone and body language match your message
- allow processing time
- check back for shared understanding
- be aware of tone and approach matching communication without 'talking down'
- receptive and expressive abilities may differ, and change based on context
- echolalia and acquiescence
- 'listen' – words, communication methods, tone, body language, behaviour, emotional response
- start open ended and provide support as needed
- use clear, unambiguous language appropriate to level of understanding; be mindful of how you ask questions ("can you..." may get a yes/no answer and not result in the desired action)
- avoid jargon, abbreviations, 'figures of speech', sarcasm, metaphors

- do not give too much information at once
- provide regular summaries
- consider gesture, writing, drawing demonstrations if it helps the person
- pitch written materials at the right level – this can include plain English, easy-read or academic references for people who like to read about/research their options
- match visual resources to symbolic understanding – these can be photos, symbols
- be prepared to repeat, reword, explain, or give examples as needed
- be mindful of time order, pronouns/names – for some people, when they say 'you' they are actually talking about themselves
- be aware of the impact of distress, feeling unwell, being overwhelmed
- involve support if present
- always tailor your communication to the person and what works best for them

Ask Listen Do

Ask Listen Do is a project to improve services for children, young people and adults with a learning disability, autism or both, their families and carers. It is led by partners across health, social care and education, working with people and families. Ask Listen Do is about making it easier for people to give feedback, raise a concern or complain about their health care, social care or education. This improves lives, the services people receive, and it helps to keep people safe.

The project is about changing how things are done so people have their voices heard and have better experiences of services. Public sector organisations have a legal duty to do this under the Equality Act.

Visit NHS England's Ask Listen Do webpage for links to booklets for people, families and organisations. There are also links to a film for people and families, and a staff training film for organisations. You can use them and this leaflet in your meetings.

You may also find the Making Ask Listen Do work for you report helpful.

The principles are simple:

Ask people about their experiences and get their feedback; ask them and their carers for their opinions and views regarding their treatment and care.

Listen carefully to what is being said and maintain an understanding of the individual's thoughts, feelings and condition.

Do act respectfully, empathetically and take the person's views and feelings seriously. Consider the person, their views, condition and the context of the situation before beginning on working with them to find aids, solutions and improving their day-to-day living. Keep the person at the centre of every decision made.

The Triangle of Care is a scheme initially developed by the Carers Trust for mental health services. It is a complementary model to Ask Listen Do and highlights the importance of working together with people and their family carers in all settings.

In order to provide the best care for individuals and promote wellbeing, we must consider and bring together the three points of the triangle – the individual (who might also be referred to as the service user, client or patient), their family carers, and professionals (including paid carers). We have co-designed this course to hold all three perspectives in mind as we move through the material.

Resources

For family and parent carers

It is also important to think about what it is like for siblings growing up alongside an autistic sibling, or one with a learning disability.

Having an autistic sibling or a sibling with a learning disability may mean that the other young people in the family grow up with different home experiences to their friends; this does not necessarily mean negative experiences, simply different.

Relationships with their siblings may be different to the relationships they see their friends have with theirs, and they may end up taking on some informal caring responsibilities. It is likely that their sibling might need more time, input and attention from their parents and family to meet their needs, which may mean other young people in the family have to adjust around this. For some siblings this may mean that they might need access to their own support to understand and explore the impact on them.

However, while having an autistic sibling or a sibling with a learning disability may present challenges, there are many examples of young people who grow up to be passionate advocates for their siblings and others with similar difficulties. Some talk about how growing up with their sibling has given them skills like patience, tolerance and empathy, and encouraged them to pay attention to everything that someone is trying to communicate.

Sibs

Sibs exists to support people who grow up with or have grown up with a disabled brother or sister. It is the only UK charity representing the needs of over half a million young siblings and over one and a half million adult siblings.

Kinship

Kinship is the leading kinship care charity in England and Wales.

> “We are here for all kinship carers – the grandparents and siblings, the aunts, uncles, and family friends who step up to raise children when their parents aren’t able to.”

In order to provide the best care for individuals and promote wellbeing, we must consider and bring together the three points of the triangle – the individual (who might also be referred to as the service user, client or patient), their family carers, and professionals (including paid carers). We have co-designed this course to hold all three perspectives in mind as we move through the material.

GP carers register

If the GP’s surgery has a carers register, the carer can ask to be added. If the GP knows someone is a carer, they can keep an eye on their health and they will have someone to speak to in confidence about how they are feeling.

They can also advise on local organisations and carers services that may benefit the family now and in the future.

Triangle of Care leaflets and resources

The original Triangle of Care guide was launched in July 2010 by The Princess Royal Trust for Carers (now Carers Trust) and the National Mental Health Development Unit to highlight the need for better involvement of carers and families in the care planning and treatment of people with mental ill health.

The Triangle of Care was developed to address the clear evidence from carers that they need to be listened to and consulted more closely.

Leaflets and posters can be downloaded and used locally as there is space for contact details and an organisation’s logo to promote the national messages of the Triangle of Care project.

Services which are implementing the Triangle of Care and are considering how to measure outcomes from implementation may benefit from the outcomes briefing. This has been developed in consultation with all services that are currently working on the Triangle of Care in mental health.

Ask Listen Do – communicating with someone who has a learning disability

Ask

- always communicate with the person first, even if you're not sure that they are able to understand you
- ask what someone's preferred methods of communication are
- ask if there is a communication passport, hospital passport, care plan, or any other document that the person/their support has that you could see, to help you understand the person's needs and how best to support them
- begin with open questions; if people struggle then provide more support and move to yes/no questions if needed (you may need to repeat or rephrase things)
- ask – what would you like to happen? how would you like to be supported? what is the best way I can help you?
- ask if there is anyone else it would be helpful to talk to
- always consider the person's capacity to make decisions about sharing information with others: only share information or talk to other people with the individual's consent or (if they lack capacity) where it is in their best interests
- if someone is struggling, do not ask "what is wrong with you?" but instead "what has happened to you?"

Listen

- **listen to all ways somebody might communicate their thoughts, feelings and preferences; this includes body language, tone, behaviour, and any other method they use to communicate**
- **do not jump in when someone is taking time to think; allow time and listen carefully to the person's views and choices – people need more processing time; be patient and persevere**
- **listen to the person's own language and understanding; use their words and style to communicate with them, where it is helpful**
- **in listening, check that the individual has understood what you have said; get them to summarise in their own words**
- **avoid making judgements or assumptions, which can be barriers to good listening**
- **consider involving an advocate if the individual needs support in order for their voice to be heard**

Do

- **empower people; support them to have choice and control in their own life; make sure you keep the person at the centre**
- **encourage people to ask questions and to tell you if they do not understand something**
- **never talk about the person as if they were not there**
- **treat the person in an age-appropriate way, respecting their roles and experiences**
- **be respectful, and take time to find out about the person's preferences and cultural needs**
- **do not assume that because the person has a learning disability that they do not understand, but make sure that things are explained in more simple language**
- **this means avoiding jargon, phrases of speech and long complex sentences; break things down into chunks/smaller steps**
- **make use of existing reports and care plans that help you understand someone's areas of strength and needs, and how best to adapt your approach**
- **think holistically about the individual and their life; consider their broader needs, such as good supportive relationships, meaningful occupation, the right environment, and meeting their mental and physical health needs, and the impact these may have**
- **promote independence and skills development in a way that is meaningful and accessible for the individual**

Ask Listen Do – communicating with an autistic person

Ask

- ask what the person’s preferred methods of communication are
- ask about someone’s sensory needs, for example asking the following questions: “is this a good place for us to have a conversation?” or “is there anything here that is distracting or overwhelming for you that we could change?”
- ask the person how they would like to be supported each time – because of the ‘spiky profile’ of autism things may change across meetings; we should not underestimate people’s skills and abilities, or conversely expect people to perform well in all areas
- if someone is becoming overwhelmed, calmly ask them (or someone supporting them) if they are ok, but bear in mind they will need more time to respond than you might expect
- ask if there is a support plan or any other document that the person/their support has that you could use, to understand the person’s needs and how to support them best
- ask if there is anyone else it would be helpful to talk to
- always consider the person’s capacity to make decisions about sharing information with others, and only share information or talk to other people with the individual’s consent or where it is in their best interests (if they lack capacity); if someone temporarily lacks capacity (perhaps if they are overwhelmed), then wait until they regain capacity if you can

Listen

- **listen to the person's own language – how do they describe their difficulties and identity? do they refer to themselves as 'an autistic person' or 'a person with autism'? if you are unsure, ask, and use identity-first language by default as the generally preferred option ('autistic person')**
- **listen out for signs that the person may be displaying echolalia (repeating what you/others have said); this may mean you are not getting a true response**
- **listen out for any other response tendencies – for example agreeing with everything you have said, or choosing the last/most recent option you have given them every time; if in doubt, ask the same questions differently to check the response**
- **as well as listening, notice and observe people's non-verbal expressions, emotions and behaviours**
- **if you are not sure of the meaning of someone's expressions, ask them or someone that knows them well; remember, the same gesture or behaviour can have different meanings across different times and contexts, and this will be unique to each person**
- **support someone who is overwhelmed to express this in any way that is helpful to them**

Do

- be respectful, and take time to find out about the person’s preferences and cultural needs
- remember that everyone is different; the same person may function differently across areas and at different times
- remember that someone’s language ability or functioning/skills in one area is not necessarily a reflection of their needs; take your lead from the person themselves, and if in doubt ask them what they need in that moment
- remember that someone may be masking/camouflaging in front of you in order to meet societal expectations; this means you may not be seeing the full picture of their difficulties
- do not assume that the presence of ‘usual’ social etiquette in autistic people means they have enjoyed or fully comprehended the aspects of a social situation they may have been masking/copying/learnt behaviours
- social interactions may be very tiring for the person; consider whether they would benefit from shorter conversations/appointments and what time and space they might need afterwards to rest and recover – do not put too many demands on them immediately after
- understand that ‘shutdowns’, ‘burnout’ and ‘meltdowns’ can lead to losses of ability and motivation, often across multiple areas and sometimes lasting for months
- look for signs that someone is becoming overwhelmed or shutting down and ask what you can do to help; try to create a quiet, safe space as best you can; ask other people to move along, turn off loud music and turn down bright lights – whatever might reduce the information overload
- if someone is having a meltdown or shutting down, ensure they are physically safe; they are unlikely to be able to recognise and manage risks at that time
- support people at their own pace and time
- do not discount autism in women or girls just because they appear very sociable
- consistent, predictable routines and structure are very important and a change can be distressing; anticipate and plan for changes so the person is prepared
- provide consistency and routine where you can – an example of this is to see them on the same time/day or in the same room; consider the use of assistive technology and simplifying communication

Books Beyond Words

Books Beyond Words elearning is an award-winning series of wordless picture stories covering topics including physical and mental health, lifestyle and relationships, abuse and trauma, grief and bereavement, employment, and criminal justice.

Each story is co-created with and for people who find pictures easier to understand than words. This includes people with learning disabilities and/or autism, people with cognitive or communication difficulties, such as dementia, people who have difficulty with reading, including some deaf people, and people who do not use the language of the country where they are living.

Check what resources are available in your area, and make some notes below.

Reasonable adjustments

Reasonable adjustments are changes that have been made to a service so that people with any disability can use them like anyone else.

Health and public services have a legal duty to make reasonable adjustments (Equality Act 2010) in order to:

- eliminate discrimination
- promote equality of opportunities
- take account of a person’s disability, even where this means treating them more favourably

Whilst we all strive to meet people’s preferences, where autistic people and people with a learning disability are concerned, we all have a legal duty to find out what is necessary to make our service more accessible.

We need to make sure that we are making the right reasonable adjustments for everyone we work with so that everyone has fair access to support, as in the second box, but ideally, we should always be striving to break down the barriers altogether, to stop disabling people.

In the first image, it is assumed that everybody will benefit from the same supports. They are being treated equally.

In the second image, individuals are given different supports to make it possible for them to have equal access to the game. They are being treated equitably.

In the third image, all three can see the game without any supports or accommodations because the cause of the inequity was addressed. The systemic barrier has been removed.

Source: Interaction Institute for Social Change | Artist: Angus Maguire.

Sensory processing

Did you know that there are many sensory systems? These are the main seven that are widely recognised:

- sight (visual)
- hearing (auditory)
- taste (gustatory)
- smell (olfactory)
- touch (tactile)
- proprioception (using our muscles to understand where our body is in space)
- vestibular (the sense of how the body moves against gravity)

And more recently researchers have introduced the notion of an eighth sense – that of interoception, which is our ability to understand our internal feelings such as those created by the body. For example, messages about how fast your heart is beating or if you need the toilet.

There are even more sensory systems that are being considered, which relate to specific experiences such as temperature and pain.

Learning how to process sensory-based information as it is received can be challenging for all of us at times, but more challenging for an autistic child or a child with a learning disability. We must filter out what things are important and what things to ignore. For instance, if we hear our name being called, we respond to this, even though there may be other sounds in the room that could distract us. Some children have difficulty with this filtering process.

Because of differences in processing sensory information people can easily become confused or overwhelmed. In response to this people may:

- feel tired and stressed and need ‘recovery’ or rest times
- strive to control their environment, to maintain predictability, or they may follow a rigid routine in order to cope
- self-stimulate to cut off sensations from outside, for example by rocking or flapping their hands
- respond automatically to sensation in an illogical or inconsistent way because fight or flight responses are exaggerated

- not notice or respond to pain or extreme temperature in the way that we might expect
- self-harm when seeking sensation or trying to overwhelm unpleasant sensory experiences

Some people with sensory processing differences can appear clumsy, which is often linked to spatial awareness. The child may bang into things accidentally and they may also appear to be quite heavy-handed. These factors can result in regular bruising or minor injuries. It is important to respond sensitively and to work to gain a better understanding of where these bruises or injuries are coming from. In addition, we also need to remember that all professionals have a duty to consider safeguarding issues if a child is presenting frequent bruises or other signs of injury.

We therefore need to think about reasonable adjustments that might help people with sensory sensitivities. Helping people to understand their own sensory preferences and triggers can help. If people know what they find stressful and also what they find soothing or calming, they can plan their days in a way that provides balance and gives time for recovery after any potential sensory overload.

The National Autistic Society 'Can you make it to the end?' video shows how it can feel for someone who is overloaded, and how some people can think that this reaction is 'naughty' behaviour.

Reasonable Adjustment Flag

To make sure that reasonable adjustments are made when someone accesses health services, NHS England want to put a note on health records to tell staff that extra support may be needed.

This will be known as the Reasonable Adjustment Flag and will be attached to the NHS Spine record, which means that all parts of the NHS will be able to access it.

The Reasonable Adjustment Flag provides an immediate visible alert; it is a prompt for key adjustments and can signpost to further information.

The flag could tell NHS staff:

- about someone's condition and how it affects them
- what help and support they need to use health services

People can decide if they want a flag and what they want their flag to say.

The flag will only be viewed by staff providing care and, ideally, they will see it before they meet the person so that they can put things in place from the start. Anyone who needs reasonable adjustments can have a flag added to their record, which includes (but is not limited to) autistic people and people with a learning disability.

This video explains how to create and manage flags.

Health/hospital passports

Another useful tool is the My Health Passport, or hospital passport, which can be used by people with a learning disability and autistic people.

There are both easy-read and plain English versions available locally. The passport contains useful information about the person's health and medication. It also provides staff with really helpful information about how the person likes to be treated, what support they need and what is important to them.

Sharing this with staff in health settings, and especially if the person needs to stay in hospital, can help to promote a better understanding of the individual's needs and encourage the use of reasonable adjustments.

Resources

Mencap has produced some helpful resources to use: Health Guides: Hospital Passports, Summary Care Records And Flu Jabs | Mencap

NAS has produced a downloadable PDF passport with guidance for autistic people.

NHS online also provides a support resource if you are going into hospital.

As a reminder, there are lots of key tools and resources out there that capture the reasonable adjustments an individual might need.

Make sure you use them as appropriate to your role – you might be the person who knows the individual well, and is capturing key information about them in support plans and hospital passports to make sure others make the adjustments they need.

You could be a professional meeting someone for the first time, so ask them and any supporters they bring with them, whether they have any of these documents or tools in place and if you can see them to help you better understand the individual’s needs.

Make use of the growing number of schemes that are out there which provide or facilitate reasonable adjustments in different settings, such as quiet shopping hours and the sunflower lanyards to show that someone may be exempt from wearing a face mask or may struggle to understand social distancing. And remember – the most important source of information about an individual is the person themselves, and those that know them best!

For information about making reasonable adjustments, visit:

- Reasonable Adjustments for PWLD easy read final.doc (southwest.nhs.uk)
- NHS England » Reasonable adjustments
- Reasonable Adjustments poster – csp.org.uk

Person-centred planning tools and resources

The Foundation for People with a Learning Disability page links to four key questions to ask when planning, and links to some additional resources:

- Person-centred planning (PCP) | Foundation for People with Learning Disabilities

Helen Sanderson Associates is one organisation that helps with:

- Bespoke organisational support
- Training courses
- Online learning
- Organisational change support
- One-to-one support
- Graphic recording
- Management development programmes
- Training accredited trainers
- Books
- Printing and publishing

Check what resources are available in your area, and make some notes below.

Understanding your responsibilities under the law

We have a legal responsibility to provide support and reasonable adjustments to meet the needs of autistic people and people with a learning disability under:

- Human Rights Act (1998)
- Equality Act (2010)
- Care Act (2014)
- Safeguarding Autism Act (2009)
- Mental Capacity Act (2005) and Amendment (2019)
- Accessible Information Standards
- The United Nations Convention on the Rights of Persons with Disabilities

We know that autistic people and people with a learning disability are at increased risk of being subjected to excessive restrictive practices and abuse, as sadly shown on programmes such as Panorama in recent years.

It is therefore really important that everyone is up to date with their safeguarding training and knows the signs to look out for, including risks associated with organisational abuse, as well as knowing how to escalate concerns within your local organisations.

Mental capacity

When we think about decision making and risks as young people move towards adulthood, we must also think about capacity and who gets to make decisions about the young person’s life.

Parental responsibility and the power to make decisions for a child is not a constant right, it diminishes as the child gets older. This can become a particular issue for those young people who do not have the mental capacity to make a specific decision.

We must always assume that someone has the capacity to make a decision for themselves unless we have carried out an assessment specific to that decision, at that time. We must provide people with enough information, in a format accessible to them, to support them in making a decision.

We must remember that if the person is assessed as having the capacity to make the decision, it is their right to make an unwise decision; most of us do this at times.

If the person is found not to have the capacity to make the decision for themselves, a best interest process should be followed to ensure that the right people are involved in making the decision for them.

In any best interest process the option of a less restrictive pathway or process must always be considered:

- Are they able to understand the information relevant to the decision?
- Are they able to retain that information?
- Are they able to use or weigh that information as a process of making the decision?
- Are they able to communicate their decision (by whatever means)?

Assessing capacity

We assess capacity to make a specific decision, at that particular time.

Step 1:

Is there impairment of, or a disturbance in the functioning of, the mind or brain? (MCA s2(1); Code of Practice 4.3).

Step 2:

A person's capacity to make a decision should be assessed at the time of making that decision. Those of us who have had a COVID-19 vaccine were probably asked about our understanding of the vaccine, the potential benefits and side effects and whether we were happy to proceed.

The vaccinator was assessing our understanding of the process and ensuring that we gave our consent for the vaccination. This was probably a fairly straightforward exercise for most of us. If people appear to find decisions like these difficult, the two-stage process of assessing capacity should be followed.

In order for the Mental Capacity Act to apply, there must first be evidence of impairment, or a disturbance in the functioning of, the mind or brain. Recent changes to the Mental Health Act have reviewed the inclusion of both autistic people and people with a learning disability in this category with regards to being detained under the Mental Health Act but both conditions may still be considered as part of a Mental Capacity Act assessment.

When assessing someone’s capacity to make a decision we must assess the person’s ability to understand, retain and weigh up the information they have been given, and they must also be able to communicate their decision. In doing so we should ensure that we have made every attempt to support communication and understanding. This may mean meeting with the person more than once and being aware of their usual communication style and how this may change over time.

In terms of how we make things accessible, again thinking about the COVID-19 vaccine, many easy-read documents were produced, as well as films and accessible frequently asked question websites; guidance was also produced for families, care providers and primary care practitioners to support them in assessing and recording capacity to consent to the vaccine.

Acting in the person’s best interests

If someone is deemed not to have capacity, a nominated decision maker will be responsible for making a decision in their best interests. The decision maker is the person providing the care or treatment if it goes ahead; for example, if the decision was about a change in accommodation, social care would be the decision maker.

The decision maker must still gain the individual’s views and involve them in the process as far as possible, as well as consulting the people in the individual’s life and the relevant professionals. It is likely that not everyone will agree with the decision or have the same ideas about what is best for the person, so it is important that the decision maker gathers a range of views so they can balance what is in the person’s best interests overall.

Remember, we can only make a best interests decision if the person has been shown to lack capacity around that decision.

The decision maker must consider:

1. whether the person is likely to regain capacity – if so, can the decision be delayed until then
2. how it may be possible to involve the incapacitated person in the decision making and improve their ability to participate as much as possible
3. as far as is practicable, the person's past and present feelings and wishes, beliefs and values that may have a bearing on the decision if they were making it
4. the views of others considered to have an appropriate role in determining what is in the best interests of the person; this includes someone nominated by the person, someone engaged in caring for them, someone holding a lasting power of attorney granted by the person

Key points

- do not assume capacity based on a diagnosis of learning disability or autism
- we must notice and challenge our own and others' assumptions about capacity
- people with a diagnosis might be subject to overly cautious or more restrictive decision making and increased scrutiny; how might we respond to the same situation for a neurotypical/non-disabled individual?
- the network around a person may need support to understand the capacity process, and who is responsible for making different decisions
- the information and support needed to reach a decision will vary
- capacity is time and decision specific; complex situations may involve multiple decisions, and someone may have capacity for some or all of them
- consider who needs to be involved in capacity and best interest decisions
- capacity and best interest processes can feel intrusive and involve sensitive issues; people may need additional support to process and manage the impact

Resources

Easy-read legislation resources:

- ISL036 14 Mental Health Act Review Consultation (publishing.service.gov.uk)
- ISL087 14 Healthy Weight Questionnaire EasyRead (publishing.service.gov.uk)
- Giving adults with autism and their families the best care and support: Easyread (publishing.service.gov.uk)
- MCA Bill Easy Read (publishing.service.gov.uk)
- Easy-read.pdf (publishing.service.gov.uk) – equalities act
- access-info-stndrd-er-upd-jul16.pdf (england.nhs.uk) A Guide to the Human Rights Act: A booklet for people with learning disabillities (equalityhumanrights.com)
- The Human Rights Act | Equality and Human Rights Commission (equalityhumanrights.com)

Check what resources are available in your area, and make some notes below

Safeguarding and crime

Safeguarding means protecting a citizen's health, wellbeing and human rights; enabling them to live free from harm, abuse and neglect. It is an integral part of providing high-quality health care. Safeguarding children, young people and adults is a collective responsibility.

Those most in need of protection include:

- children and young people
- adults at risk, such as those receiving care in their own home, people with physical, sensory and mental impairments, and those with learning disabilities

It is important to make sure that you are up to date with your safeguarding training and are aware of how to raise a safeguarding concern in your organisation.

Some people may experience name-calling and bullying because of their disability. This can be known as 'hate crime'.

This what is hate? video resource produced by West Yorkshire Police covers hate crime and incidents, our rights and characteristics protected under criminal and civil law.

Hate_crime-easy-read-leaflet-1.pdf (pcdn.co) What to do if something bad happens to you

Mate crime is an aspect of hate crime, not separate from it. However, anecdotal evidence shows that many people with a learning disability are befriended, and then exploited, by others. Often, they do not see it happening to them until it is too late. If they do not have good family/social networks to support them the risks are greater.

> All staff, whether they work in a hospital, a care home, in general practice, or in providing community care, and whether they are employed by a public sector, private, or not-for-profit organisation, have a responsibility to safeguard children and adults at risk of abuse or neglect. (NHS England)

Check what resources are available in your area, and make some notes below.

Understanding distress, mental health and wellbeing

> "'Challenging behaviour' says as much about the quality of support a person is receiving as it does about the person." Jim Mansell CBE

The better we can understand this, the more likely we are to be able to support the individual well. Before we consider labelling anything as 'challenging' we need to see past the behaviour and consider the cause, and what the person may be trying to communicate to you.

Viewing actions as a communication or expression of pleasure or distress is a much more helpful response than seeing them as a 'challenge', which becomes de-humanising and the person, not the behaviour, ends up being labelled. When this happens, our reaction to someone's expression of distress or enjoyment may become more disabling than the behaviour itself.

The term 'challenging behaviour' is controversial and unhelpful, and 'behaviours of distress' is preferred as this recognises something behind a behaviour, rather than labelling.

Can you think of a recent example where you might have behaved in a way that someone around you might have considered 'challenging'?

You did these things and nothing changed. If a person with a learning disability or an autistic person does these things, they may be labelled as 'challenging', and labels like that can stick.

It is also important to remember that some autistic people and people with a learning disability can come into contact with the police and criminal justice system because of their behaviour.

Research shows that autistic people are less likely to commit offences than non-autistic people, but if they do, this is most likely to be a function of an autistic trait. There are however a number of things that need to be considered if an autistic individual does have contact with the police. For example, understanding capacity in terms of their ability to see things from a different perspective and to understand the impact of their behaviour on others. Both autistic people and people with a learning disability can be susceptible to being taken advantage of and they may not realise that something they have done is against the law.

People with a learning disability and autistic people are at increased risk of mental heath difficulties but these issues are often not recognised, and even if they are, they are more likely to be seen as a problem in the person, rather than an understandable response to things happening around them.

We know that many people have had bad things happen in their lives and this affects how they cope. Sometimes it can be more helpful to ask “What has happened to you?” instead of “What is wrong with you?” if you are trying to understand someone’s mental health difficulties.

Talking therapies can help some people with their mental health. Sometimes helping people to understand themselves better can make a big difference so talking with them about what works for them, and what doesn’t, can be good. The five ways to wellbeing programme is a good starting point.

What are the five ways?

Connect

There is strong evidence that indicates that feeling close to, and valued by, other people is a fundamental human need and one that contributes to functioning well in the world.

It is clear that social relationships are critical for promoting wellbeing and for acting as a buffer against mental ill health for people of all ages.

With this in mind, try to do something different today and make a connection.This can be achieved in many different ways and examples include the following:

- talk to someone instead of sending an email
- speak to someone new
- ask how someone’s weekend was and really listen when they tell you
- put five minutes aside to find out how someone really is
- give a colleague a lift to work or share the journey home with them

Be active

Regular physical activity is associated with lower rates of depression and anxiety across all age groups.

Exercise is essential for slowing age-related cognitive decline and for promoting well-being.

But it doesn’t need to be particularly intense for you to feel good – slower-paced activities, such as walking, can have the benefit of encouraging social interactions as well as providing some level of exercise.

Today, why not get physical? Here are a few ideas:

- take the stairs not the lift
- go for a walk at lunchtime
- walk into work – perhaps with a colleague – so you can ‘connect’ as well
- get off the bus one stop earlier than usual and walk the final part of your journey to work
- organise a work sporting activity

- have a kick-about in a local park
- do some ‘easy exercise’, like stretching, before you leave for work in the morning
- walk to someone’s desk instead of calling or emailing

Take notice

Reminding yourself to ‘take notice’ can strengthen and broaden awareness.

Studies have shown that being aware of what is taking place in the present directly enhances your wellbeing and savouring ‘the moment’ can help to reaffirm your life priorities.

Heightened awareness also enhances your self-understanding and allows you to make positive choices based on your own values and motivations.

Take some time to enjoy the moment and the environment around you. Here are a few ideas:

- get a plant for your workspace
- have a ‘clear the clutter’ day
- take notice of how your colleagues are feeling or acting
- take a different route on your journey to or from work
- visit a new place for lunch

Learn

Continued learning through life enhances self-esteem and encourages social interaction and a more active life.

Anecdotal evidence suggests that the opportunity to engage in work or educational activities particularly helps to lift older people out of depression.

The practice of setting goals, which is related to adult learning in particular, has been strongly associated with higher levels of wellbeing.

Why not learn something new today? Here are a few more ideas:

- find out something about your colleagues
- sign up for a class
- read the news or a book
- set up a book club
- do a crossword or sudoku
- research something you've always wondered about
- learn a new word

Give

Participation in social and community life has attracted a lot of attention in the field of wellbeing research.

Individuals who report a greater interest in helping others are more likely to rate themselves as happy.

Research into actions for promoting happiness has shown that committing an act of kindness once a week over a six-week period is associated with an increase in wellbeing.

In some areas there is a lack of support for autistic people especially, and sometimes the people providing support may not feel confident in working with a person with a learning disability or an autistic person. Hopefully, this training will help but people can also ask for advice from specialist services.

It is important that we find out the best way to ask the person questions. For some people, a question like “How are you?” can be difficult to answer because it is too broad. However, one of our autistic experts likes all of his support staff to ask him how he is when they arrive on shift, because then he knows that they know what sort of day he is having.

So, remember that there is no ‘one way’ of doing things that works for everyone. What works for one person may be a source of stress for another and could trigger a meltdown on a difficult day; remember, tailor everything to the individual.

Below are Ask Listen Do top tips to support people with a learning disability and autistic people:

ASK	LISTEN	DO
How are you? What has happened to you? Has anything changed? What do you think? What do you want? Do you have the right support? How is your quality of life? Do you have choice and control over your own life? What works well for you? Do you have meaningful occupation? Do you have friends? Who else should we talk to? Don’t avoid the ‘taboos’	To every part of my communication To my history To my family and care team To my goals and wishes Listen out for things that have changed Notice my physical health Ask for help if you don’t understand Find an advocate to support me	Tailor to the individual Support me to understand my own strengths and needs Support me to understand my triggers and things that help Help me to support those around me to understand my needs and preferences Support me to reach my goals Encourage me to look after myself too Involve me in all decisions Be creative Help me understand what support is available Keep an open mind

Check what resources are available in your area, and make some notes below.

Older age and end of life

Old age can have both hopeful and difficult connotations for people but how might some of these be the same or different for autistic people and people with a learning disability?

For example, many of us might look forward to retirement as a time of rest and of freedom, but what if you have never worked? Or what about for the autistic person who does work? and whose job has provided much needed structure and routine for the last 40 years, which is now being lost?

There are also specific considerations for people with particular conditions, such as people with Down's syndrome who are much more likely to develop memory problems and dementia and at an earlier age, meaning they may be struggling with these things before even reaching old age.

In addition, how might some of these things interact with someone's existing difficulties? For example, a person who is very hypersensitive to touch who now must be physically supported with their personal care may find this incredibly aversive. Someone who is very hyposensitive and requires lots of sensory stimulation may find moving to a sedate nursing home difficult.

As with anything, we must think about the individual in context and how ageing may affect them specifically, rather than making generalised assumptions.

Learning disability and dementia

Due to the advances in medical care, life expectancy for those with a learning disability has increased over the last 30 years. However, they are now more likely to live to an age where they may develop dementia.

The onset of dementia in those with a learning disability seems to develop at a younger age than the general population and it is not entirely clear why this is the case. It could be due to genetic factors, or possible brain damage that might be associated with the learning disability, as well as the level of functioning of someone with a learning disability being lower than that of someone from the general population to start with.

People with a Down's syndrome diagnosis are at greater risk of developing early onset dementia, with more than two-thirds developing this before the age of 60. This is thought to be related to the extra copy of chromosome 21 associated with a Down's syndrome diagnosis.

> “One of the genes on chromosome 21 codes for the Amyloid Precursor Protein (APP), which is chopped up inside the brain to make the protein, amyloid.
>
> A build-up of amyloid in the brain is one of the hallmark features of Alzheimer’s, and while it’s still unclear exactly how amyloid contributes to the disease, it’s the focus of much research into new treatments.
>
> It’s thought that because people with Down’s syndrome get an extra dose of APP, they can develop an excess of amyloid in the brain. This appears to make them much more likely to develop Alzheimer’s than someone without Down’s syndrome and at an earlier age.”
>
> Alzheimer’s Research UK (2022)

Unfortunately, the learning disability and Down’s syndrome population are sometimes not given the correct diagnosis in relation to dementia, or diagnosis is late, or there may seem to be a rapid deterioration following diagnosis.

Reasons for this could be as follows:

- people with a learning disability or Down’s syndrome are more likely to have other physical health concerns that are not well managed for various reasons (communication, comprehension, support available, assessment procedures, etc) which might also explain which difficulties or behaviour presentations are the focus for assessment and treatment

- people with a learning disability or Down’s syndrome do not usually have the same routines, roles and responsibilities as people without a learning disability. This means it can be harder to notice a change in their memory or abilities. Some examples of difficulties that a person with a learning disability may face include losing car keys, leaving the gas on whilst cooking, forgetting appointments.

- a loss of skills might not be noticed because people with a learning disability or Down’s syndrome are likely to live in a more supported setting (family, carers, paid support workers, or residential care providers) where most tasks are completed on their behalf (whether they could do them or not), appointments are arranged and sorted for them, and the running of the house is managed by others, and they might access the community with help

- any change in mood and behaviour could be attributed to other reasons and this is particularly true if the person is unable to articulate how they feel and why they are presenting this way. This is open to others' interpretation and reasons for these changes can include change in staff, change in residents and pain. Other reasons can include that sometimes they are thought to be 'looking for attention', or upset by others' behaviour or a new environment

Common symptoms of dementia for a person with Down's syndrome (broadly similar to general population):

- loss of interest in current activities
- short-term memory loss
- withdrawal of spontaneous communication
- loss of amenability/sociability
- increase in wandering
- repetitive actions
- loss of road sense
- confusion between time of day, routines
- sleep disturbances
- change in mood – emotional, tearful, etc.
- behaviour changes (disinhibited, 'odd' behaviour seen, out of character)

It can be difficult to identify when presentation could just be a part of the person's learning disability and inability to communicate as needed. Alternatively, this might be indicative of a physical health problem that needs to be addressed and ruled out or dealt with first.

Standard tests and assessments are generally not suitable for people with a learning disability.

People need to initially consider the level of the person's learning disability and if the potential dementia symptom is a change to how they are usually present. Additionally, we need to ask ourselves the following questions to find out more information:

- Have they stopped doing something they used to be able to do?
- Has their personality changed?
- Do they seem more confused about what they are doing and when?
- Do they need more prompting or do they need more additional physical assistance during personal care and other similar situations?

This part of the assessment can be tricky at times as people move care settings, or move away from living with family to a care setting and that background history might be lost.

A person may live in a residential setting and all activities of daily living (ADL) tasks may just be done for them as part of the placement. If a person is not regularly doing tasks then a loss of skills that could indicate an issue with memory may go undetected.

The following changes in behaviour in Down's syndrome could indicate dementia:

- changes in behaviour/personality (can precede clinical picture of dementia by some years)
- small changes in person's routine and usual ADLs
- seizure onset for the first time

By the time dementia is diagnosed in someone with learning disability or Down's syndrome it might be quite advanced and then deterioration can be quite rapid in comparison to the general population.

The general population would notice these difficulties and communicate these to health professionals and get the right assessment and treatment implemented. Someone with a learning disability and Down's syndrome would not be able to notice these difficulties and is reliant on carers, support staff, close friends and family members to spot the signs.

Changes in personality, behaviour, memory and other related behaviours we have explored, could be indicative of physical health problems. These behaviours include sensory impairment, urinary tract infection, depression, anxiety, poor sleep, thyroid problems and side effects of medication. So, this also needs to be considered as a reason for changes, as well as a possible onset of dementia due to risk of this in the learning disability and Down's syndrome population.

If dementia is suspected in a person with learning disability or Down's syndrome, then the carer or support staff need to discuss concerns with the GP who can refer to the community learning disability team (CLDT) for further assessment. If the CLDT is already working with the person, please call them to raise concerns.

The role of community learning disabilities services in assessment of dementia in people with Down's syndrome and learning disabilities

In some areas where community learning disability services also provide specialist services for older people, there are assessment pathways to support this work. This pathway includes the following steps:

- the learning disabilities memory assessment pathway (LDMAP) highlights the process to be followed to assess people with learning disability or Down's syndrome
- people with a learning disability are initially offered baseline assessments when concerns are raised. However, those with a diagnosis of Down's syndrome are offered a baseline assessment when they turn 30, or when they are known to the service, regardless of any concerns. This enables health professionals to get a good understanding of their general level of functioning, communication and physical and mental health status
- the baselines are completed by an occupational therapist, who would conduct a functional assessment such as an assessment of motor and process skills, a nurse, who would conduct a physical and mental health assessment, and a speech and language therapist, who would conduct a comprehension/communication assessment
- people with Down's syndrome are then regularly reviewed as part of the LDMAP for the rest of their lives, with the frequency of every year or at least once every two years
- if no concerns are raised, then three skills can be identified for staff to be mindful of and to note any changes to these identified skills over the next couple of years prior to the next review – for example life situations such as personal care and domestic tasks. Changes that could be noted include increased prompting to engage in a task, prompting required at various steps during completion of the task or someone no longer able to complete a task that previously they completed independently
- if any change is noted in the three skills or if there are other areas of concern before the next scheduled review, then care providers are encouraged to contact the CLDT to arrange further assessment
- if concerns are raised about a person's changes seen in skills, memory or mood, for a person with a learning disability, but who does not have a Down's syndrome diagnosis, they will also be offered the baseline assessments. However, they will only remain on the LDMAP for as long as is clinically indicated; they are not routinely reviewed for the rest of their lives
- following the initial baselines, a screening tool is then used for review and if concerns are raised from this, then a full assessment from an OT, nurse and speech and language therapist can take place again and be compared with the baselines

- the three skills can also be reviewed at this point and if the assessments highlight possible dementia concerns, then the person is referred to psychiatry for diagnosis
- blood tests, physical health review and possibly a scan might be requested at this point to rule out other health issues and to look for physical evidence that could indicate dementia
- other possible causes for the new presentation are also considered
- a psychiatrist then would formally diagnose dementia based on the thorough assessment process

Supporting families

Suggesting to parents that their adult child is going to be assessed for dementia can be an emotive subject. Many do not want to think about their son/daughter ‘ageing’ before them, so the approach needs to be carefully considered. LDMAP leaflets are provided about the process and the person, and their parents/carers are informed that initially you are taking baselines for future comparison if a concern is raised. Sensitivity and a thorough explanation of what you are doing and why is needed.

Following diagnosis of dementia:

- the person is removed from the LDMAP (this is for assessment only)
- psychiatry may prescribe medication
- nurses will monitor the medication and the impact it has on the person
- three skills are identified for ongoing review by nurses
- the CLDT supports the client as and when needed following diagnosis
- an OT might be needed to support/advise around safe transfers, environmental recommendations, equipment needs and other related notions of support
- a speech and language therapist might be needed to complete eating and drinking guidelines to ensure a safe swallow; they can also provide communication advice as and when needed
- a physiotherapist might be needed to help the person maintain mobility for as long as possible, and to assess and provide appropriate exercises
- psychology might be involved re: behavioural changes and supporting staff to manage this
- referral to social care might be needed – support/funding for other placements, increase in care, etc to ensure the person receives the appropriate level of care and support they need as the dementia progresses

External resources

- www.downs-syndrome.org.uk
- www.alzheimers.org.uk
- www.alzheimersresearchuk.org

Growing old with a learning disability (GOLD)

Research done with people with a learning disability tells us that they are more vulnerable to the negative impacts of ageing.

Health problems and poor treatment means that people need more support to stay well for longer; they are also more likely to feel lonely and isolated with smaller social networks. As a result of this, they are likely to have lower self-esteem and confidence due to being treated differently all their lives.

We need to think about and plan for the future because big changes later in life can be very difficult. For example, the loss of parents can be very upsetting, especially if the person has always lived with them. Planning in advance can include thinking about how the wider family, such as siblings, can start supporting the person earlier on so they are already involved before the parents die.

People in our training team who have siblings with difficulties have told us how they worry about getting them the right support when their parents have died.

So, what about autistic people?

Unfortunately, there is not much research yet about the experience of older age for autistic people. However, we know that many of the underlying factors that make people with a learning disability more vulnerable are also commonly experienced by autistic people.

This makes it seem reasonable to expect that autistic people may also experience similar difficulties and needs in older age. Autistic people are likely to struggle with social interactions, relationships and, as mentioned earlier, those without a learning disability are less likely to receive formal support. This can result in them being more likely to be socially excluded, and potentially less likely to engage with health services.

A previous study found that autistic people who died prematurely were more likely to have poorer social and living skills. This highlights the importance of appropriate support to help people develop these skills.

Specific concerns

There are also some specific things to think about for people with a learning disability and autistic people in older age.

Some people may only just be getting a diagnosis at this age. For example, if someone with a learning disability has always lived with and been supported by their parents, the extent of their difficulties might only come to light when their parents can no longer care for them. Or an autistic person who has worked in the same job their entire life with the same co-workers, environment and routine may only seek a diagnosis when that familiarity falls away.

Those who are not very physically mobile are more prone to pressure sores and a loss of skin integrity due to being in similar positions for long periods. This can particularly be the case for those who are less active, so might be something we see more of people with long COVID. This can also be a risk for autistic people who engage in repetitive behaviours on the same spot, such as rocking back and forth repeatedly on one side.

We’ve already mentioned particular risks of dementia, and we need to consider how this may present differently. For many of us, an early sign could be something as simple as misplacing our keys, or forgetting to bring the shopping in from the car; but what if you do not have your own front door key? Or do not put your own shopping away?

For many health concerns in older age, pain can be a key indicator. But we need to remember that autistic people and people with a learning disability may experience or communicate pain differently. We also need to consider how changing sensory abilities interact with someone’s sensory needs. For example, someone may have a sensory aversion to bright lights, but declining vision may mean they need bright lights to be able to see clearly.

There are also risks associated with long-term medication use, which prescribers should always bear in mind when recommending any medication.

Things to remember or consider

One particular concern to be aware of for the current cohort of older people, particularly those with a learning disability, is that many of them may have been in services during the days of long-stay institutions.

Additionally, our understanding of good care has developed significantly in their lifetime. This means they may have had some difficult and potentially abusive experiences of care in the past. With this knowledge, it is important to build trust and ensure a sense of safety, particularly if needing to provide increasingly ‘hands on’ care as their needs change.

When thinking about age-related change, we must always compare to what is considered normal for the individual. We cannot always rely on the standard signs of deterioration or difficulty and, as always, we must see the individual in each context. If someone has just moved into a new environment after a lifetime of living with their parents, they may present with a significant deterioration in skills which may lead you to be concerned about dementia. However, we must consider the significance of the change they have been through.

The number of regular health screenings for all of us increases with age, and it is important that we continue to support people to access these with the appropriate reasonable adjustments. As health complexities increase with age, so too can the number of medications given, but the principles of STOMP (stopping over medication of people with a learning disability, autism or both) continue to apply throughout the lifespan.

When someone is reaching the end of their life or facing a significant illness, there are always challenges in considering when to pursue active treatment and when to focus on making someone comfortable. However, we must always make sure that these decisions are not being made purely on the basis of someone being autistic or having a learning disability. It is important to speak up and challenge any decisions that you are concerned about.

Bereavement and loss

As we age, we are more likely to experience increased loss and bereavement in a number of ways, some of which we’ve touched on earlier, like loss of roles, mobility and independence. However, people with a learning disability and autistic people are already likely to have experienced many losses throughout their lives.

Just as parents and families may experience chronic sorrow for the loss of the experiences they expected to have with their child, so too might someone with a learning disability or an autistic person experience sorrow for the life and experiences that they expected to have. This may have increased having seen their peers go on to have those experiences which have not been made possible for them.

Those in care environments may have experienced several placement moves; those receiving care and support may have lost many members of staff over the years. There also may have been losses of services as care packages have changed and services like day centres have shut.

They may have struggled to maintain employment and had losses there; many of these changes may been beyond their control or choice.

People may have suffered greater losses of social connections like relationships and friendships and, sadly, we know that those who are parents are more likely to have had their children removed from their care.

People with associated physical health needs, or those that have not received the appropriate support to stay well, may have experienced premature loss of health and mobility. Similarly, if people have built up friendships with other autistic people and people with learning disabilities. It is likely that many of their friends may have health complexities and have struggled to receive appropriate care, so sadly we know it’s likely that some of them may have died at an earlier age.

These repeated loss experiences can compound one another, as when another loss occurs, this can reactivate, or bring back up, previous losses, even those that appeared to have been resolved, and the sense of loss and grief can become overwhelming.

Double taboo of death and disability

So how good are we at talking about this?

As a culture, we’re not good at talking about death and many people feel uncomfortable talking about disability. This means that death isn’t talked about openly.

People with disabilities often get left out of conversations and important events, such as planning for the end of life, being able to say goodbye to people before they die and going to their funerals. Sometimes people don’t notice when an autistic person or person with a learning disability is grieving.

This could be because it looks different to what people expect or because any change in them gets written off as ‘behaviour’. Sometimes, normal grieving gets seen as a problem because people do not feel confident to support the person through it.

All of this means that people often don’t get the support they need.

Living and dying well

This section contains resources to help with end of life and advanced decisions.

So how do we get things right?

Well, it's simple really – we follow the same principles of Ask, Listen and Do!

Ask

Firstly, we need to have conversations with people and their loved ones, and ideally, we need to do this in advance.

It's important we help people plan for changes that are likely to occur later in their lives, for example the loss of their parents, and what this might mean for their future care.

Episodes of illness can be unpredictable and good care is much more likely if we plan ahead. ReSPECT, which stands for Recommended Summary Plan for Emergency Care and Treatment, is a universally recognised approach to planning for care in an emergency, with an associated form for recording guidance.

The process can be associated with care planning for those with advanced illnesses, but it also has a role for highlighting how to approach care for those who may have additional challenges. For example, some autistic people and people with a learning disability may struggle with a hospital environment. So, options for assessment and care in the home through 'hospital at home' services can be explored as a more appropriate first step.

If a hospital admission is then needed, this could potentially happen in a more controlled fashion with some of the assessments already started. The ReSPECT process helps to enable the right care and discussions about options before an emergency happens, at which point there may not be time to fully explore the options and meaningfully involve the person, or they may lose the capacity to make the decisions at that point.

Listen

We must really listen in these conversations, not just to words but to other forms of communication. If people are using unique language or ideas that we don't understand, we need to unpick those with them to make sure we are understanding them and their wishes correctly. This is to ensure that we have supported the person to understand what is going on.

As we've said, people with a learning disability and autistic people may respond differently, or perhaps not seem to respond at all, to difficult discussions and losses. It is important not to judge or dismiss their experiences, just because they may present differently to how you might expect.

On the other hand, they may seem to have emotional reactions that you consider to be extreme relative to the situation. However, the meaning of a loss or difficulty is unique to the individual and we should support them with how they are experiencing it, not our judgements about it.

We should also avoid assumptions and judgements when speaking with the person's network – some people have shared experiences of others saying they must be 'relieved' at no longer having to care for a loved one with a disability when they had died. Whilst in reality the family was absolutely devastated by the loss of someone they loved.

Do

So what things can we do, alongside having these conversations and really listening to them?

Recommendations

1. Use the resources and tools that are available; make sure the appropriate care planning and information is captured, regularly reviewed, kept updated. This is to ensure they can be used to recognise when someone's health is changing, for example the RESTORE2 model explained on page 33, and to get things in place to ensure they receive the care they need, through the hospital/health passport and Reasonable Adjustment Flag.
2. Find out what your organisations or services care pathways are for end-of-life care and have the conversations you need to in advance, so people's voices and wishes can be heard and respected.
3. When the time comes, support the person and their network to look after each other and to say goodbye in the way that is meaningful to them.
4. If somebody you're working with does die, ensure that LeDeR is notified, so that the death can be reviewed and help us continue to learn how we can better care for people and prevent avoidable deaths. Remember, LeDeR now reviews the deaths of any autistic person, as well as people with a learning disability.

Here are some of the things the Gloucestershire co-production team experts had to say, about looking to the future and having difficult conversations.

> “Talking about the future is hard. We need to be able to talk and get support to feel OK. The unknown is not good for people but daunting to face. We need to empower people (and staff) to ask for support before the thing has happened so that you can prepare and plan.”
>
> “They’re trying to protect you from the grief but you are going to feel it anyway, so they should support you to get ready for it.”

We should also discuss with people in advance about their wishes for their remaining life, and potentially arrangements after they have died. This is a time where it is particularly important to consider someone’s cultural and spiritual beliefs, to ensure they are fully respected and acted upon as the person reaches the end of their life. Remember, loss, end of life and grief have different meanings, rituals and associated emotions across cultures. While some may see death as a sad time, others may see it as a chance to celebrate the life lived, and others may consider it as one step on a longer, spiritual journey.

All of the guidance we’ve already shared about good communication of course applies here, and is even more important for such sensitive discussions. Think about how best to have these conversations at a time and place where the person can have the privacy and consideration they deserve, and with all the appropriate supports in place to enable them to meaningfully engage.

And as these are discussions people can feel uncomfortable having, we can be particularly prone to using unhelpful euphemisms and figures of speech, instead of saying what we really mean.

ReSPECT

ReSPECT stands for Recommended Summary Plan for Emergency Care and Treatment.

This means it is a short plan about what should happen if a person needs health care or treatment in an emergency.

Easy-read guides for ReSPECT:

- G-Care – learning disability and Annual Health Checks (AHCs) (glos.nhs.uk)
- G-Care – learning disability and Coronavirus (COVID-19) (glos.nhs.uk)
- G-Care – learning disability and Daily Living (glos.nhs.uk)
- G-Care – learning disability and Physical Health (glos.nhs.uk)
- Gloucestershire Health and Care NHS Foundation Trust – Easy Read Health Information

Useful documents on this weblink include:

A Pre-Health Check Questionnaire	**My Health Passport in Easy Read**	**The Hospital Communication Book**

This handbook has been written to accompany The Oliver McGowan Mandatory Training on Learning Disability and Autism. Delegates may download and use this to capture local resources. The original content is updated via the elearning for healthcare hub. This is version 1.1.

- Gloucestershire Health and Care NHS Foundation Trust – A to Z of Easy Read Health Resources – Locally and Nationally
- Supercharged Me | Get your Health Check!
- Coronavirus (COVID-19) Resource Hub – Inclusion Gloucestershire
- Inclusion Gloucestershire – Training and Development
- Inclusion Gloucestershire – LeDeR

Check what resources are available in your area, and make some notes below.

Services and resources

Learning disability services

Learning disability services offer services to people with learning disabilities and mental health needs who require specialist assessment and treatment. They are committed to promoting wellbeing and supporting service users, families and carers. They will often work alongside other specialist teams and services to support them to make appropriate reasonable adjustments in order to enable people with a learning disability to access their services and benefit from their expertise. They are organised in a variety of ways nationally and some regions have community learning disability teams (CLDTs).

CLDTs provide specialist health care services for people with learning disabilities to enable and support them to participate in daily activities and increase or maintain levels of independence. They work closely with GPs, education, housing, hospitals, families, community adult, care directorate, children's services, day centres, mental health services, advocacy and respite services and voluntary services.

CLDTs often consist of:

- community nurses who provide specialist advice, support, education and training to help improve the physical and mental wellbeing of people with a learning disability
- physiotherapists who assess and advise on exercises and activities that can help people remain as comfortable and mobile as possible
- psychiatrists who offer a specialist health care service for people with a learning disability and related mental illness
- psychologists who work to promote and enhance the emotional wellbeing and quality of life of people with learning disabilities
- occupational therapists who support with self-care activities, improving ability to access local facilities, functioning in the workplace or college and the development of hobbies and interests
- speech and language therapists who support any adult who needs help with their communication and /or eating and drinking and who has a diagnosis of a learning disability – they also support their transition from children to adult services

Some NHS Trusts provide other specialist teams within learning disability services such as:

- intensive health outreach teams who provide a specialist service for people with learning disabilities and other vulnerable adults with associated health problems and learning disabilities who require intensive assessment
- intensive support service for individuals with learning disabilities who have behaviours that can be described as challenging, and/or mental health needs that cannot be met in mainstream services
- these services help prevent any unnecessary admissions and move people back home from out of county, which could include inpatient services, educational services or residential care
- specialist inpatient service for individuals with a diagnosis of learning disabilities, with behaviours that can be described as challenging and/or mental health needs that require specialist input within a hospital setting. This service is designed for people to access for a short period while a specialist assessment is carried out and treatment plans put in place to allow the person to return to community living, either in their previous accommodation or new accommodation
- health facilitation teams offer support to people with learning disabilities, their carers, support staff and other health professionals. They can provide accessible health information and advice on accessing health services and staying healthy so that everyone can access the same help and support as the general population

Adverse childhood experiences

The Adverse Childhood Experiences Study (ACE Study) is a research study conducted by the US health maintenance organization Kaiser Permanente and the Centers for Disease Control and Prevention that was originally published in the American Journal of Preventive Medicine.

Participants were recruited to the study between 1995 and 1997 and have since been in long-term follow-up for health outcomes. The study has demonstrated an association of ACE with health and social problems across the lifespan (Felitti et al., 1998).

This has shifted policy makers and mental health practitioners towards increasing, trauma-informed and resilience-building practices in health and social care. UK collaborations are sometimes called 'Action on ACEs'.

Watch this ACEs video produced by Public Health Wales to show the impact ACEs can have on two generations of one family.

Children's services

The learning disability team for children is sometimes part of children and young people's mental health services. The team may consist of specialist clinicians offering different types of intervention tailored to meet the needs of young people and their families.

Teams usually run on a locality basis and run clinics from special schools. Teams provide support to children and young people under 18 who have a moderate to severe learning or development disability, attend a special school and are registered with a GP. They also support other professionals working with children who have a learning disability.

They can provide assessment, intervention and support with:

- behavioural difficulties
- sleep problems
- mental health
- risk management
- puberty and sexuality issues
- epilepsy awareness and monitoring
- medication
- health promotion

How to care for children with complex needs

If your child has been diagnosed with an illness, disability or sensory impairment and needs a lot of additional support on a daily basis, they're described as having 'complex needs'. A child might have complex needs from birth, or after an illness or injury. The social care and support guide contains information and support for family and carers.

Transition from childhood to adulthood

Preparing for Adulthood (PfA) – funded by the Department for Education, is a partnership bringing together a wide range of expertise and experience of working with young people with special educational needs or disability (SEND) and families, at a local and national level and across government. Its aim is to support young people into adulthood with paid employment, good health, independent living options and friends, relationships and community inclusion.

Austism spectrum condition (ASC) services

ASC services offer assessment and diagnosis to those aged over 18 who do not currently have a diagnosis of ASC. An assessment may typically take place over two appointments lasting approximately three hours each.

If a diagnosis is given, the person may be offered a six-session course which will help them to understand autism, and give them coping strategies for daily living. They may also have occupational therapists who can offer sensory sessions and additional coping strategies.

If you feel you or someone who you support may have an ASC, please visit your GP in the first instance.

Autism.org has an Autism Services Directory which helps autistic people, their families and the professionals who work with them to find local and national services.Types of services it includes are residential, supported living and respite, employment support, diagnostic, schools and nurseries, social groups and leisure activities, solicitors and advocacy organisations.

Check what services are offered in your area, and make some notes below.

Coronavirus resources

Please find some adapted and easy-read resources below:

- Supporting individuals with face coverings and other COVID-19 related challenges aims to to help individuals to feel more comfortable with new ways of living, such as wearing face coverings while out. The main part of this framework focuses on desensitisation techniques to support someone to get used to face coverings, and a short section on desensitisation for swab testing.
- The pulse-oximeter easy-read guide aims to help people to use a pulse oximeter to check that they're okay.
- The coping with coronavirus resource provides free picture stories and illustrated guides to support people with learning disabilities and autism through the coronavirus pandemic. It includes:
    - protecting ourselves
    - beating the virus
    - testing for coronavirus
    - mental health, end of life and bereavement resources
    - secure settings resources
- The Lenny and Lily children's stories for recovery provide useful resources to help children make sense of their experiences during the COVID-19 pandemic, communicate their feelings and prepare for more change as they go back to the classroom. As the stories are told in pictures alone, it is not necessary for children to be able to read words to enjoy them. They are appropriate for pupils in both mainstream and special education settings. Supporting text at the end of each story gives teaching staff and parents guidance on how to use the stories with children.
- Mencap developed easy-read guides to help invidiuals stay safe and well during COVID-19.
- A detailed information pack around COVID-19 vaccines for people with complex needs who will require additional support to have their vaccine, especially where a best interests decision is likely to be needed.
- A collection of easy-read resources to support people with swabbing, vaccines and annual health checks has also been made available by Gloucestershire Care.

Websites and books about sensory processing

Websites:

- Sensory Direct – weighted therapy products
- Fledglings – toys, clothing and sensory products for disabled children
- Sensory Toy Warehouse
- Special Needs Toys

Literature:

- The Out of Sync Child – Carol Stock and M.A. Kranowitz, 2005 (ISBN 0399531653)
- The Out of Sync Child Has Fun – Carol Stock and M.A. Kranowitz, 2006 (ISBN 0399532719)
- Raising a Sensory Smart Child – Lindsey Biel and Nancy Peske, 2009 (ISBN 0143115340)
- Understanding your Child's Sensory Signals: A practical daily use handbook for parents and teachers – Angie Voss, 2011 (ISBN 1466263539)
- The Sensory Team Handbook – Nancy Mucklow, 2009 (ISBN 098114392X)
- No Longer a Secret – Doreit S. Bialer, 2012 (ISBN 1935567292)
- Can't Eat: Won't Eat – Brenda Legge, 2008 (ISBN 1853029742)
- Too Loud, Too Bright, Too Fast, Too Tight – Sharon Heller, 2003 (ISBN 0060932929)
- Learning to Feel Good and Stay Cool – Judith M. Glasser and Kathleen Nadeau, 2014 (ISBN 1433813432)

Check what services are offered in your area, and make some notes below.

Appendix 1

Resources and links

1. Mencap – Learning disability explained. Our no-nonsense information and resources will help you get to grips with learning disability. https://www.mencap.org.uk/learning-disability-explained
2. British Institute for Learning Disabilities website: https://www.bild.org.uk/
3. Person-centred planning: https://www.learningdisabilities.org.uk/learning-disabilities/a-to-z/p/person-centred-planning-pcp
4. Factsheet about profound and multiple learning disabilities: https://www.mencap.org.uk/sites/default/files/2016-11/PMLD%20factsheet%20about%20profound%20and%20multiple%20learning%20disabilities.pdf
5. Supporting people with profound and multiple learning disabilities core & essential service standards: https://www.pmldlink.org.uk/wp-content/uploads/2017/11/Standards-PMLD-h-web.pdf
6. Down's Syndrome Association: https://www.downs-syndrome.org.uk/
7. MacIntyre, providing support for children, young people and adults who have a learning disability and/or autism at locations across England and Wales: https://www.macintyrecharity.org/
8. Made Possible: Stories of success by people with learning disabilities – in their own words: https://books.google.co.uk/books?hl=en&lr=&id=cWbMDwAAQBAJ&oi=fnd&pg=PT10&dq=Stories+of+success+by+people+with+learning+disabilities+&ots=-ue7Ma5xt3&sig=zrOa_ZmxhPaYobEGD-RRX-akOqk&redir_esc=y#v=onepage&q&f=false
9. Alvares GA, Bebbington K, Cleary D, Evans K, Glasson EJ, Maybery MT, Pillar S, Uljarević M, Varcin K, Wray J, Whitehouse AJ. The misnomer of 'high functioning autism': Intelligence is an imprecise predictor of functional abilities at diagnosis. *Autism*. 2020 Jan;24(1): 221-232. doi: 10.1177/1362361319852831. Epub 2019 Jun 19. PMID: 31215791. https://journals.sagepub.com/doi/10.1177/1362361319852831?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%20%200pubmed
10. Overcoming Barriers: Autism in the Somali Community (English version): https://youtu.be/Osr8qFLy3CM
11. No More Us and Them – Disrupting Attitudes to Autism: https://www.ted.com/talks/nura_aabe_no_more_us_and_them_disrupting_attitudes_to_autism

12. My autism information booklet: https://www.independencetrust.co.uk/sites/default/files/fileman/IT/MY_AUTISM_INFORMATION_BOOKLET.pdf
13. The Reason I Jump: One boy's voice from the silence of autism. Author: Naoki Higashida. Sceptre (24 April 2014). ISBN-10: 1444776770 ISBN-13: 978-1444776775
14. LeDeR – Learning from lives and deaths: https://leder.nhs.uk/
15. Annual health checks – Learning disabilities: https://www.nhs.uk/conditions/learning-disabilities/annual-health-checks/
16. ReSPECT: https://www.resus.org.uk/respect
17. Training and resources for care providers including RESTORE2: https://www.weahsn.net/our-work/transforming-services-and-systems/keeping-people-safe-during-and-after-covid-19/training-resources-for-care-homes/
18. Standardising the assessment of acute-illness severity in the NHS elearning programme: https://news.ocbmedia.com/
19. National Early Warning Score (NEWS) 2: https://www.rcplondon.ac.uk/projects/outputs/national-early-warning-score-news-2
20. Soft signs of being unwell: https://www.youtube.com/watch?v=JYafrPgAUL4
21. Visual timetables: https://bcuhb.nhs.wales/services/hospital-services/neurodevelopmental/documents/visual-timetable/
22. Objects of reference: https://www.sense.org.uk/information-and-advice/communication/objects-of-reference/
23. Voice output communication aids: https://link.springer.com/referenceworkentry/10.1007/978-1-4419-1698-3_1713
24. What is PECS® https://pecs-unitedkingdom.com/pecs/
25. Communication passports: https://www.communicationmatters.org.uk/what-is-aac/types-of-aac/communication-passports/
26. Intensive Interaction: https://www.intensiveinteraction.org/
27. Ask Listen Do: www.england.nhs.uk/asklistendo
28. Ask Listen Do: Making conversations count in health, social care and education: https://www.england.nhs.uk/wp-content/uploads/2019/07/ask-listen-do-v2.pdf
29. Triangle of Care posters and leaflets: https://carers.org/resources/all-resources/70-triangle-of-care-posters-and-leaflets
30. Books Beyond Words: https://booksbeyondwords.co.uk/elearning
31. Can you make it to the end? Sensory overload video: https://www.youtube.com/watch?v=aPknwW8mPAM

32. Reasonable Adjustment Flag: https://digital.nhs.uk/services/reasonable-adjustment-flag
33. Creating a Reasonable Adjustment Flag on the NHS Spine: https://youtu.be/dX-IwYXXEwE
34. Getting help with your health: https://www.mencap.org.uk/advice-and-support/health/health-guides#%3A~%3Atext%3DA%20hospital%20passport%20provides%20important%20information%20about%20a%2Cimportant%20when%20they%20are%20first%20admitted%20to%20hospital
35. My Health Passport: https://www.autism.org.uk/advice-and-guidance/topics/physical-health/my-health-passport
36. Reasonable adjustments for people with learning disabilities (easy read): http://www.apictureofhealth.southwest.nhs.uk/wp-content/uploads/reasonable-adjustments/Reasonable-Adjustments-for-people-with-learning-disabilities.pdf
37. Reasonable adjustments to reduce health inequalities: https://www.england.nhs.uk/learning-disabilities/improving-health/reasonable-adjustments/?fbclid=IwAR0ZmV8Q6K0JMFU1kKJzV6DXk8qDPPBb6mpTth5Dp6hGa0gN1iednYCjHI0
38. University of Bristol on LeDeR: http://www.bristol.ac.uk/sps/leder/
39. Talking Mats: https://www.talkingmats.com/
40. Mencap Help in Hospital: https://www.mencap.org.uk/advice-and-support/health-coronavirus/health-guides
41. Sibs: https://www.sibs.org.uk/
42. Kinship: https://kinship.org.uk/
43. Carers Trust Triangle of Care leaflets: https://carers.org/resources/all-resources/70-triangle-of-care-posters-and-leaflets
44. Helen Sanderson Association: http://helensandersonassociates.co.uk/
45. Inclusion Gloucestershire LeDeR: https://www.inclusiongloucestershire.co.uk/engagement/leder/
46. Adverse Childhood Experience video: https://vimeo.com/189604325
47. Public Health Wales Adverse Childhood Experience: https://phw.nhs.wales/services-and-teams/ace-aware-wales/
48. Mencap: Coronavirus help to stay safe and well: https://www.mencap.org.uk/advice-and-support/coronavirus-covid-19/coronavirus-help-stay-safe-and-well
49. Reasonable adjustments poster: https://acppld.csp.org.uk/system/files/documents/2020-02/learning_disability_a3_poster.pdf

50. Helen Sanderson Associates: http://www.helensandersonassociates.co.uk/what-we-do/bespoke-organisational-support/
51. Helen Sanderson Associates: Training Courses: http://www.helensandersonassociates.co.uk/what-we-do/training-courses/
52. The Care Act (easy read): https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/365345/Making_Sure_the_Care_Act_Works_EASY_READ.pdf
53. Autism Strategy (easy read): https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/375430/Autism_Strategy_Easy_Read.pdf
54. Autism statutory guidance (easy read): https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/417935/Autism_statutory_guidance_easyread.pdf
55. Mental capacity (easy read): https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/775143/mental-capacity-amendment-bill-easy-read.pdf
56. The Equality Act (easy read): https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/85039/easy-read.pdf
57. Making health and social care information accessible: https://www.england.nhs.uk/wp-content/uploads/2016/07/access-info-stndrd-er-upd-jul16.pdf
58. The Human Rights Act: https://www.equalityhumanrights.com/en/human-rights/human-rights-act
59. Hate crime: https://www.unitedresponse.org.uk/resource/what-is-hate/?_cldee=cm96ei5tY2RvbmFsZEBnaGMubmhzLnVr&recipientid=contact-dfa95394b6ccea1180e1005056877cb9-49d12515f84145d2901a3ae07e6d4a10&esid=da4841a4-7491-eb11-b1ac-000d3a870018
60. What to do if something bad happens to you (easy read): https://s33156.pcdn.co/wp-content/uploads/hate_crime-easy-read-leaflet-1.pdf
61. Mate crime: https://arcuk.org.uk/safetynet/files/2012/08/RCC-Mate-crime-PCJA.pdf
62. Alzheimer’s Research UK: http://www.alzheimersresearchuk.org/
63. Alzheimer’s Society: www.alzheimers.org.uk
64. ReSPECT – Recommended Summary Plan for Emergency Care & Treatment: https://g-care.glos.nhs.uk/pathway/917/resource/7
65. Learning disability and annual health checks (AHCs): https://g-care.glos.nhs.uk/pathway/998/resource/11

66. Learning disability and coronavirus (COVID-19): https://g-care.glos.nhs.uk/pathway/1024/resource/11
67. Learning disability and daily living: https://g-care.glos.nhs.uk/pathway/1014/resource/11
68. Learning disability and physical health: https://g-care.glos.nhs.uk/pathway/1008/resource/11
69. Key documents and resources: https://www.ghc.nhs.uk/other-areas/learning-disabilities/key-documents-resources/
70. A–Z of Easy Read Health Resources: https://www.ghc.nhs.uk/files/Easy%20Read%20Resources%20Locally%20and%20Nationlly0.pdf
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Appendix 2

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