PURPLE PLEDGE OF PRINCIPLES FOR ACUTE SECTOR HEALTH SERVICES

HANDBOOK

This handbook is designed to accompany the Purple Principles and Pledges for health professional's training videos, which can be located here:

Purple Principle and Pledges for health professionals

The National Mandatory Learning Disability and Autism Training [Sometimes delivered as Oliver McGowan Training] Provides you with the foundation of understanding – The Purple Principles aims to help you to embed this in your services practice

eQUALITY
for people with learning disabilities

Improving health outcomes for people with learning disabilities

Hertfordshire Services

Purple Star Strategy Team 01438 844 681
purplestarstrategy@hertfordshire.gov.uk
If you have any queries throughout your Purple Star Accreditation or Monitoring Process, please don't hesitate to get in touch with the team on the above number or email address.

Health Professionals can find information on our service and tools at -
www.hertfordshire.gov.uk/LDprofessionals
People with learning disabilities and their carers can also find information about our services and keeping healthy at –
www.hertfordshire.gov.uk/LDMyHealth

Health Liaison Team 01438 845 372
healthliaisonteam.referrals@hertfordshire.gov.uk
The nurses in this team support people with a learning disability in accessing secondary health care. If you refer someone to secondary health and have concerns about how their health needs will be met, then contact this team. Leave a message and they will call back. This service is available Monday-Friday 9am-5pm.

Purple Folder 01438 843 848
purplefolder@hertfordshire.gov.uk
For adults who are registered as having a learning disability, please visit our website for details on our new 2023 version purple folder The Purple Folder | Hertfordshire County Council

Community Learning Disability Nurses
Every GP surgery has been offered the support to enable them to become Purple Star Accredited by meeting the Quality Outcome Framework targets. You can contact the Community Learning Disability Nursing service for any advice or help for a person with learning disabilities by using the email addresses or telephone numbers below.

watfordthreerivers.adt@hertfordshire.gov.uk	01442 454 343
stalbans.adt@hertfordshire.gov.uk	01442 454 300
dacorum.adt@hertfordshire.gov.uk	01442 454 444
hertsmere.adt@hertfordshire.gov.uk	01442 454 242
welwynhatfield.adt@hertfordshire.gov.uk	01438 843 600
northherts.adt@hertfordshire.gov.uk	01438 845 629
Stevenage.adt@hertfordshire.gov.uk	01438 845 529
eastherts.adt@hertfordshire.gov.uk	01438 843 111
Broxbourne.adt@Hertfordshire.gov.uk	01438 843 400
0-25_Central@hertfordshire.gov.uk	01438 845 258

Health and Social Care Service - 0300 123 4042

Monday - Friday 9-5 service

If you feel someone may need some help from a Community Learning Disability Nurse or Social Worker.

This may be due to concerns you have about:

- Family circumstances
- Care Support
- Low level mental health anxiety concerns
- Meeting / managing their health needs
- Or anything else – this is your starting point

Single Point of Access (HPFT) 0300 777 0707

If someone presents with significant mental health issues, then the best starting point is SPA as they can offer intensive support for people with a mental health and learning disability diagnosis

beyond a 9-5 Monday-Friday service

Herts Help 0300 123 4044

HertsHelp - We're here for you
info@hertshelp.net
This is the generic Hertfordshire help service to support people in finding the right service they need. They know what's available, including private and voluntary sectors in all aspects of life.

Learning from Deaths Review Mortality Programme (LeDeR)

To tell LeDeR about the death of someone with a learning disability: **01278 727411**

Report the death of someone with a learning disability (leder.nhs.uk) https://leder.nhs.uk/report

The Purple Star Strategy

The Purple Star brand was developed in 2014 by the Hertfordshire Community Learning Disability Services through the Health Liaison Team [Herts County Council] in partnership with people with a learning disability, people who support them and the University of Hertfordshire Business School.

The Purple Star is a Trademark which is accredited to GP Practices in Hertfordshire who demonstrate the delivery of high quality reasonably adjusted services to adults with learning disabilities, in line with the requirements of the Equality Act 2010.

Like a "kite mark" the presence of a Purple Star at a health service provider indicates that a defined set of standards, as set out in the Purple Star Promise, have been achieved by that health service provider and are consistently being maintained and monitored via an independent steering committee.

A new Layer of Purple Star for ALL health care Providers.

Following the success of the Purple Star Accreditation for GP practices, we wanted to be able to offer similar service improvement enablement to all community, acute and end of life healthcare providers too. People with a learning Disability die an average of around 26 years younger than the rest of the population **(LeDeR 2019)** Delays in diagnosis, due to barriers in communication and capacity to understand their health needs, is a significant issue and we want to be able to support **ALL** health providers to be aware of the role they can play in reducing these risks … and so we have developed the **…**

PURPLE PLEDGE of PRINCIPLES RECOGNITION

The new Mandatory Learning Disability and Autism training will help your team have the core understanding of WHY services need to be adapted. This will help your service establish HOW to make those changes and what services are there to help you in Hertfordshire.

How Does the Purple Pledge of Principles work for your service?

The Purple Star Team have developed training videos in 8 chapters for your services to utilise and create a pledge of practice from.

You can use these videos:

- as bitesize training within staff meetings
- as individual staff members – setting targets in professional development for staff to complete
- in small groups
- As part of induction for new staff

This is a handbook to accompany these videos. In this handbook you will find some of the information from the videos in written format and some forms for your service to keep a record of the pledges made as individuals or as a whole service. These pledges can be both to maintain practice that already enables good health outcomes for your patients with a learning disability or Autism **OR** they can be pledges, no matter how small, on how individuals or the whole service will improve their practice.

These Videos and accompanying handbook will:

1. **Give the knowledge to be able to go away and form your own Pledges /action plan for service changes that will enable better access / breakdown barriers for people with a Learning Disability and Autistic people.**
2. **Provide your service with a toolkit of resources to enable better reasonable adjustments – this is to support your services learning disability or vulnerable adults champion to feel confident in ensuring all staff understand how to meet the health needs of people with a learning disability.**
3. **Provide an understanding of the role of the Learning disability nursing service - (Acute liaison and Community LD teams) and links for making referrals.**
4. **Provide you with food for thought / ideas of pledges the service can make and a provide a form to evidence this.**

   We will also:
5. **Provide ongoing updates and advice, through the Purple Star Team, on new legislation / tools etc that may benefit you in meeting the health needs of people with learning disabilities.**

Receiving the Purple Pledge of Principles Recognition

The certificate of recognition is an acknowledgement of your services engagement with the Purple Principles of Reasonable adjustments and your pledges for maintaining current good practice and making improvements.

Your service will provide us with the following information, and this will be presented to the independent Purple Star Steering Committee to receive Purple Pledge of Principles Recognition of your commitment and dedication to improving / maintaining excellent reasonable adjustments.

1. **Evidence how many of the current workforce have watched the 8 training videos and been involved in the pledges of Practice Changes**

2. **Create a Pledge of Practice changes / action plan / positive current practice you will maintain -** These actions may be tiny changes that an individual practitioner has reflected on and will change in their practice **OR** team/system changes that the whole team will develop and embed within the service. They all need recording on the pledges form.

3. **Notify us of the Internal Governance that will be used to hold you to account for your pledges.** The Pledges will be the responsibility of the organisation to fulfil and will not be monitored by the Health Liaison Team. How well new pledges are embedded into their own processes and their own service governance of this, is totally down to that service and what works within their organisational and line management structure. This could be via their equality and diversity leadership structure, commissioning, or service line management structure.

It is also good to:

Build in a patient / service user feedback process that asks questions that will help evidence the impact of the pledges in practice.

What happens if your feedback indicates you are not doing so well?

We are here to support and not judge!! So, use the Purple Star Team to help you revisit your pledges and help you improve your practice

THE TRAINING VIDEO LINKS

Before we start …. Here is a 4-minute Whiteboard created by Herts Community Trust, to help you truly understand the impact of the reasonable adjustments we can make for people with a learning disability and Autistic People

CC255 Herts Reasonable Adjustments

Please now plan how your service will:

- **Ensure the staff team all watch the videos below [as a team or individually]**
- **Establish Who will keep a record of this**
- **Establish Who will keep a log of the individual and service Pledges**
- **Establish Who will be the overarching body of governance to ensure the pledges are achieved within your organisation**
- **Take responsibility in following this up**

Here are the Video links and you can use the material in the handbook below to accompany each Video

Video 1 - definitions

This is a snippet taken from a training session to help health professionals understand The Difference between Learning Disability, Learning Difficulty and Autism

Video 2 - Making reasonable adjustments

This principle focuses on what the health inequalities are that people with a learning disability and autistic people face and why these happen

Video 3 - Making reasonable adjustment

This principle focuses on the importance of reviewing and adapting your processes to ensure they are accessible from very first contact through to seeing the clinician. The focus is on the Accessible Information Standard 2016 and how to put this into practice.

Video 4 - TEACH

This principle focuses on reasonable adjustments – In Hertfordshire we break reasonable adjustments into 5 areas and use the acronym TEACH. This principle focuses on the letter T – TIME

Video 5 - TEACH

This principle focuses on reasonable adjustments – In Hertfordshire we break reasonable adjustments into 5 areas and use the acronym TEACH. This principle focuses on the letter E – Environment

Video 6 - TEACH

This principle focuses on reasonable adjustments – In Hertfordshire we break reasonable adjustments into 5 areas and use the acronym TEACH. This principle focuses on the letter A – Attitude

Video 7 - TEACH

This principle focuses on reasonable adjustments – In Hertfordshire we break reasonable adjustments into 5 areas and use the acronym TEACH. This principle focuses on the letter C - Communication and how important it is to always assess the persons capacity to understand the risks of refusal of health investigations or treatment and to make best interest decisions where someone can't understand to avoid delays in diagnosis and treatment

Video 8 - TEACH

This principle focuses on reasonable adjustments – In Hertfordshire we break reasonable adjustments into 5 areas and use the acronym TEACH. This principle focuses on the letter H – Help This section also touches on Safeguarding and how we all must work together to identify potential safeguarding risks

At the end of each principle, you are invited as a team or individual to consider what you have heard and make a pledge for what you will do to improve equitable health outcomes in your area of health practice.

PRINCIPLE 1

What is a learning disability, learning difficulty and Autism?

Please watch this video alongside this section of the handbook: Principle 1

The definition of a Learning Disability is:

- **Impaired Intelligence (IQ below 70)** but IQ is rarely tested
- **Reduced ability to understand new or complex information** and impaired ability to learn new skills
- **Impaired Social Functioning**
- **Reduced ability to cope independently**
- **Started in childhood** Before the age of 18
- **Life long**
- **With lasting effect** on development

A learning disability is a reduced intellectual ability and difficulty with everyday activities. For example, household tasks, socialising or managing money – *which affects someone for their whole life.*

Learning **disability** is often confused with learning **difficulty**. Dyslexia and Dyspraxia are called a "learning difficulty" **NOT** a learning disability because they do not affect a person's intellect or ability to learn, it just makes it more difficult.

Mental health problems can also present as a learning disability but again, a mental health problem does not affect intellect or the ability to learn but may affect the person's ability to absorb information at that time.

These descriptions of a Learning Disability may help:

Mild learning disability

- **Social functioning** – ability to maintain social network independently.
- **Education** – likely to have been educated in mainstream school with recognised additional needs.
- **Dependency** – able to live independently with recognised need for support.
- **Communication** – likely to be verbally communicative.
- **Understanding** – may appear to have more understanding than they do, likely to have difficulty processing new or complex information unless clearly and fully explained in an understandable way.

Example: 'Geoff'

Geoff is 31 years old and lives in his own flat with his girlfriend. He has a part time job at B&Q and is a season ticket holder at the local football club. Geoff is quite chatty and often gives the impression of understanding when he doesn't. Geoff needs support understanding letters and finances. He went to the local comprehensive school and had some support with reading and writing. He left school with no formal qualifications.

Moderate learning disability

- **Social functioning** – likely to need support to maintain social networking.
- **Education** – likely to have been educated in specialist or mainstream education with dedicated support.
- **Dependency** – likely to need support with daily living.
- **Communication** – may or may not have verbal communication therefore reliable communication would need to be facilitated by others who know them well. Likely to benefit from supplementary communication tools such as easy read information, Makaton etc.
- **Understanding** – limited understanding beyond clear and straight forward conversation. Likely to have difficulty processing new or complex information.

Example: 'Charlotte'

Charlotte is 25 years old and has Down's syndrome. She received her primary education in a mainstream school with individual support and transferred to a special school for her secondary education. She lives at home with her parents but would like her own flat. Charlotte attends college three days a week and a local weekly disco for people with learning disabilities, where she meets her boyfriend. Charlotte can be familiar and very tactile with people she does not know well making her extremely vulnerable. She has a few well-rehearsed sentences that give an impression of a higher level of communication than is the case

Severe learning disability

(Including those with profound and multiple learning disability)

- **Social functioning** – likely to be dependent on others to have any social network.
- **Education** – likely to have been educated in specialist education.
- **Dependency** –dependent on others for daily living. They may or may not have a physical disability.
- **Communication** – individualised communication and use of non-verbal techniques including body language and behaviour. Communication is likely be very difficult so consultation with others who know them well is important.
- **Understanding** – very limited or no obvious understanding, with difficulty processing basic information

Example: 'Jenny'

Jenny is16 years old and has both a severe learning disability and some physical disability which means she is unable to walk unaided. She is totally reliant on others to meet her personal care needs. She attends the local special school and will leave when she is 19 years old. She lives with her mother and two younger siblings.

Her social network is through school and short break service. Jenny has no verbal communication and responds best to familiar people. Jenny is more likely to respond to a simple single choice question as she finds it difficult to communicate complex choices or information. When Jenny is in pain or distressed, she usually bites her hands, rocks back and forth and cries.

What causes a learning disability?

A learning Disability can be caused by:

- **An inherited condition** – a condition passed down through the parents
- **Chromosomal differences**– Most syndromes can be identified through DNA analysis of chromosomal differences, for example, Downs Syndrome is caused by an additional part on Chromosome 21.
- **Complications during birth** – reduced oxygen supply during birth can cause brain damage
- **A very premature birth** – the baby may not develop fully
- **Mother's illness during pregnancy –** e.g., Chicken pox in early pregnancy when the foetus may form a pox impacting brain development
- **The mother drinking during pregnancy** – this is called fetal alcohol syndrome
- **A debilitating illness or injury in early childhood** – e.g., a head injury from a car accident, bad fall, or Meningitis
- **Neglect and/or a lack of mental stimulation early in life** – if the brain isn't given the chance to develop or the baby isn't fed properly it can cause brain damage

Some syndromes and conditions have very specific health concerns associated with them…

For example, people with Downs Syndrome have higher risks of issues with eyesight and hearing, heart disease, dysphagia, GOARD, sleep apnea, mental health problems (25-30% suffer with anxiety and depression), early onset dementia (10-22% get it in their 40s), early menopause, osteoporosis, hypothyroidism (15-37%), diabetes type 1 and type 2, obesity (89-95%), skin conditions and cervical spine issues with degenerative changes (70%)

So as a medical professional it is always important to ascertain if they have syndrome specific additional potential comorbidities (this is the presence of two or more diseases or medical conditions in a patient).

Classification of Learning Disability in Primary Care

NHS England

Introduction

People with learning disabilities have a decreased ability to communicate their symptoms, needs and choices and as a result of this they have an increased risk of avoidable morbidity and mortality.

Whilst acknowledging the limitations of 'labels', services can only be 'reasonably adjusted' to achieve better health outcomes for people with learning disabilities and meet the obligations of providers under the law, if we recognise people with Learning Disability and their individual needs as they enter healthcare systems. Furthermore, the planning and commissioning of effective health services to meet the needs of people with learning disabilities can only be achieved if we continually gather detailed data on their health status, experiences of healthcare and their health outcomes. Severity of Learning Disability is well correlated with severity of health needs and poorer health outcomes, making classification of Learning Disability status important.

The vast majority of people with Learning Disability are not known to specialist LD services or local authority social care. As such they may never have had a formal IQ based assessment of the severity of their learning disability. The most comprehensive registers of people with learning disability in any locality will be the ones held by GPs on their clinical record systems. This classification tool is designed as a quick reference guide to assist general clinicians and other care professionals, without specific learning disability expertise, to pragmatically make a decision about the severity of somebody's learning disability when recording their status on their clinical system.

It is not intended that the tool should be used to replace any classification made by specialist services and where this is in place in the patient record this should be used, unless there is concern that it is incorrect.

The definitions used map well to the ICD-10 codes though they are intentionally less detailed to make them easier to use in day to day clinical settings.

At any point in time complex healthcare needs may occur for anyone, whether they have a mild, moderate or severe learning disability therefore the stratification does not include reference to health status. It should be noted that Learning Disability differs from Learning Difficulty. The latter may refer to problems such as Dyslexia, Dyspraxia, ADHD etc. and people with these problems in isolation do not have a learning disability, they have a learning difficulty and as such should not appear on Learning Disability registers.

It should also be noted that people with Autistic Spectrum Disorders and severe physical disability such as cerebral palsy should not be presumed to have learning disability as frequently they do not.

Learning Disability Register Inclusion Tool

- This is a checklist for GPs to assist them in identifying a person with a learning disability.
- This is not a diagnostic tool so always apply sound clinical judgement.
- The aim of this tool is to identify people who would benefit from being on the GP practice's Learning Disability register
- Inclusion on the register does not mean that the person will automatically be eligible for specialised learning disability services – that decision is based on needs.

Definition of a learning disability: A significantly reduced ability to understand new or complex information, to learn new skills (Significantly impaired intelligence)
AND A reduced ability to cope independently, (Impaired social / adaptive functioning)
AND Which started before adulthood (onset before aged 18) with a lasting effect on development

*Consider the following for reasons why a person cannot achieve these things at the time of the assessment:
- sensory impairment (hearing or sight impairment), English is not their first language

Questions to consider	yes ✓	no ✗
Did person attend any special schools or were they statemented in mainstream school? Do they have an educational health care plan		
Is there a diagnosis of a learning disability/mental handicap in any notes? IQ under 70 (please refer to read code list of definite and potential diagnosis of a learning disability)		
Is the person known to the Learning Disability Service?		
Is the person under the care of a consultant psychiatrist for learning disabilities?		
Has anyone ever told the person that they have a learning disability?		
Did the person achieve qualifications at school?(GCSE at low grades could indicate LD but high grade GCSE, A Levels or university education then LD is not likely		
How does the person function in society? Does the person need support with activities of daily living? Tell me what you do during the day. Does this indicate that they require support to undertake daily living activities?		
Does the person need help to read i.e. appointment letters or other official letters?		
Does the person have problems with simple numerical calculations? (i.e. "If I gave you £5 to buy milk. Milk costs £1.50 – how much change would you have left?)		

Does the person need assistance with transport? (unable to get around independently?)		

Leeds and York Partnership NHS
NHS Foundation Trust

Does person have difficulty with:		
Communicating needs	yes	no
Writing	yes	no
Self-Care	yes	no
Living independently	yes	no
Interpreting social cues	yes	no
Controlling their behaviour	yes	no
Co-ordinating movement	yes	no
Learning new skills	yes	no
Understanding new or complex information	yes	no
Do they have a sensory impairment?	yes	no
Is English their first language?	yes	no
Several 'yes' answers could indicate the presence of a Learning Disability*		

Factors which MAY indicate No learning disability	Factors that MAY indicate a learning disability
• Normal development until other factors impact (before 18). • Diagnosis of ADHD, dyslexia, dyspraxia or Asperger's • Successfully attended a mainstream education facility without support. • Gained qualifications (GCSE and/or A 'Levels) • Able to function socially without support • Independently manage their financial commitments • Able to drive a car. • Contact with mental health services • Recorded IQ above 70 • Communication difficulties due to English as a second language	• Record of delayed development/difficulties with social functioning & daily living before the age of 18. • Requires significant assistance to undertake activities of daily living (eating & drinking, attending to personal hygiene, wears appropriate clothing) and/or with social/ community adaptation (e.g. Social problem solving/reasoning). NB need for assistance may be subtle. • Presence of all three criteria for LD i.e. Impairment of intellectual functioning/social adaptive functioning and age of onset. • Range of information presenting a picture of difficulties in a number of areas of function, not explainable by another 'label' • Contact with specialist Learning Disability consultant. • Attendance at specialist education facility for people with intellectual delay

What is Autism?

Autism is not a learning disability. The person may have full intellectual ability but struggle with understanding societies typical communication cues and styles. Some Autistic people do have an underlying learning disability as well.

Please watch this video on Autism, as this patient group equally need support to overcome health inequalities https://www.nhs.uk/conditions/autism/what-is-autism/

Autism symptoms and behaviours

Individuals with autism may present a range of symptoms, such as:

- **Reduced eye contact**
- **Differences in body language**
- **Lack of facial expressions**
- **Not engaging in imaginative play**
- **Repeating gestures or sounds**
- **Closely focused interests**
- **Indifference to temperature extremes**

These are just a few examples of the symptoms an individual with autism may experience. Any individual could have some, all, or none of these symptoms. Keep in mind that having these symptoms does not necessarily mean a person has autism. Only a qualified medical professional can diagnose autism spectrum disorder.

Most importantly, an individual with autism is first and foremost an individual. Learning about the symptoms can help you start to understand the behaviours and challenges related to autism, but that's not the same as getting to know the individual. Each person with autism has their own strengths, likes, dislikes, interests, challenges, and skills, just like you do.

Comorbidities with autism

When a person has more than two or more disorders, these conditions are known as comorbidities. Several comorbidities are common in people with autism, these include:

Anxiety
Depression
Epilepsy
Gastrointestinal and immune function disorders
Metabolic disorders
Sleep disorders

Identifying comorbidities can sometimes be a challenge because their symptoms may be mimicked or masked by autism symptoms. However, diagnosing and identifying these conditions can help avoid complications and improve the quality of life for individuals with autism.

Don’t Assume!

Don’t assume, based on appearance or behaviour,

that someone does or does not have a learning disability!

Rosie Jones – comedian

Stephen Hawking – Physicist, cosmologist and author

Time to talk and make a Pledge

What are your previous experiences and apprehensions of LD?

Did You know the difference before today?

Could you Pledge to read the scenarios to feel more confident in recognising a LD?

Could you Pledge to watch the autism video?

NOTES:

Please transfer your Pledges to the team's pledge Document at the end of this handbook

PRINCIPLE 2

Why are there health inequalities?

Recap of Mandatory training with additional examples to help you reflect on the impact of your practices

Please watch this video alongside this section of the handbook

Principle 2

People with Learning Disabilities are dying considerably younger than the general population.

Learning Disability Mortality Review (LeDeR 2019) found that people with Learning Disabilities are dying on average **26 years *younger*** than the general population. 23 years for men, and 29 years for women.

The Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) (2013). The inquiry looked at the deaths of 247 People with Learning Disabilities. The findings showed that nearly **50% of deaths were *avoidable*** compared to 24% in the rest of the population.

What are the barriers to getting the same health outcomes as any other patient would get?

Communication – if you are unable to tell someone you are in pain you might display behaviour that is misunderstood with nobody realising it relates to a health issue. This can lead to a delay in diagnosis that could be the difference between living and dying avoidably.

Health Screening – there is a low attendance rate for health screening among the learning disability population. This may be due to not understanding the importance of going, or family and carers not seeing it as critical, so avoiding it as it would be too challenging. Limited ability to weigh up the risk of not attending versus the dislike of going through the screening, means people may not get screened without understanding the risks this involves. (**Mental Capacity**)

Accessibility – access to buildings could be difficult if you have anxiety about going to health settings/new places due to sensory overload. Accessibility can also be impacted by practical things, such as not having someone to support at appointments or not wanting to pay for transport. This, again, may mean the person is 'making a decision' not to access health without being able to weigh up the risk of this decision.

Diagnostic overshadowing – this is when symptoms are attributed to the persons learning disability for example, if an individual has incontinence – this may be put down to their learning disability rather than another health cause. Or if the individual is being unresponsive, a doctor may assume that this is their 'normal' because they have a learning disability and not realising this is a severe decline from their baseline.

Treatment options – surgery involving complicated rehabilitation might not be offered if there are concerns the person might not comply with the essential rehabilitation plan. For example, if after surgery they need to be non-weight bearing, but are getting up and down, putting themselves at greater risk.

Signs and Symptoms – health problems might be accompanied by unusual signs and symptoms, for example someone with a severe learning disability might demonstrate discomfort by self-injuring or hitting out. The person may not show any signs of pain and not be able to vocalise the changes / pain they are experiencing.

Understanding their own health needs – health promotion materials might not be accessible to people with Learning Disabilities or explained in a way they understand, so people accept refusal even though they don't have capacity to understand the risks of that refusal.

People with Learning Disabilities may have additional health conditions

These are some of the conditions that generally people with learning disability have high risk of either suffering or dying from:

- **Cancer** – there is a higher rate of death due to delays in diagnosis because people with learning disabilities are less likely to voice their symptoms early enough, some people have a higher pain threshold, and some people are reluctant to accept treatment.
- **Coronary heart disease** – second highest cause of death - at around 18% - may be due to condition, but also exercise, diet and lifestyle.
- **Dental issues/oral hygiene –** due to diet and how they are supported. Poor dental care also leads to throat cancers and heart disease.
- **Diabetes** – this is linked to obesity, due to poor lifestyle choices.
- **Epilepsy** – there is a higher chance of having epilepsy where a brain has an injury or damage, and uncontrolled seizures may cause further damage to the brain.
- **Gastro-intestinal problems –** double the rate of gastro-intestinal cancers such as oesophageal, stomach and gallbladder.
- **Mental health problems**
- **Obesity –** very high rate of obesity in people with learning disabilities
- **Respiratory disease** - Highest cause of death at nearly 50% (compared to 15% in general population)
- **Sensory impairments –** 60% of people with learning disabilities need glasses and 40% are hearing impaired
- **Swallowing/feeding problems -** The swallow reflex is really complicated and when it goes wrong this can cause aspirational pneumonia (where food or liquid goes into the lungs and they get an infection) Look out for signs of the swallow reflex changing, such as keeping food in the mouth for a long time and not swallowing, dribbling, or coughing when eating and drinking, they may need a swallow assessment.
- **Constipation –** in 2019 there were 12 deaths from constipation on the LeDeR report of people with learning disabilities. Know your **Bristol stool chart** to be able to spot changes.

  Bristol stool chart explained

MEET SIMON

Simon lives in a residential care provision in Hertfordshire. He likes trains and cars. He is non-verbal and communicates his happiness by jumping up and down and clapping. When he is unhappy or unwell, he becomes lethargic and won't get out of bed.

One day, Simon's behaviour dramatically changed. He started biting his hand, he was jumping about but squealing in a way that indicated he wasn't happy. If staff approached him, he hit out. He was biting his arm and started throwing furniture.

The care team called the doctors surgery to request a home visit. They said they wanted to rule out stomach pain as he was hitting his stomach too and had not opened his bowels for a week.

The GP came out but could not get into the room with Simon due to his aggressive behaviour towards him. The GP prescribed a sedative and said he would return the next day to examine again.

Simon's behaviour escalated even with sedation.

That day a learning disability nurse visited the home on a separate matter relating to a different resident. She heard the screaming and asked what was happening. When the staff told her what had happened the nurse asked about Simon, what is Simons usual way of behaving? What do you think he could be communicating with this change in behaviour?

The staff then said how Simon is always calm. They said that the only time he had ever been this aggressive before was when he was in excruciating pain and had a total bowel blockage having eaten socks. When asked if they had told the doctor this, they said that they had said they thought he might be blocked but had not given that full picture because 'they didn't want to tell the doctor his job and the doctor hadn't asked…'

When the doctor was called again, with this additional information he was able to weigh up the risk of delaying physical examination by 24hrs and decided that it was in fact in Simons best interest to be taken straight to hospital.

Simon was in theatre that night. He had a total blockage with socks and the surgeon felt he would not have survived until the next day.

Time to talk and make a Pledge

Think about the service you offer:

Imagine a patient who has no understanding of their health condition and what you are needing to do to help them? What are likely to be the fears and barriers and what can you do to help overcome these?

What aspects will they find challenging?

The next 6 principles will help you develop your ability to overcome these – can you now pledge to watch and complete these in a specific time frame?

Please transfer your Pledges to the team's pledge Document at the end of this handbook

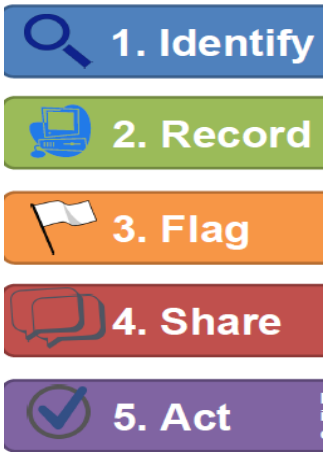
NOTES:

PRINCIPLE 3

Adapting your service

Please watch this video alongside this section of the handbook: Principle 3

Accessible Information Standard 2016



It is a legal requirement for all health and social care providers to identify, meet and share the information and communication needs of people who use their service.

For people with a learning disability - The Accessible Information Standard requirement means all health and social care providers need to:

IDENTIFY – Ask all patients/service users how they like to be communicated with. Consider if this would affect how information is sent to them for example, do they prefer phone calls?

RECORD – Make sure you tell the patient and get **agreement** from them that this information will be recorded on your system, and on their Summary Care Record Additional Information. The patient (or family/carer) must agree to the exact wording used for this record.

FLAG – This information MUST be flagged on your system and on the Summary Care Record Additional Information so ALL professionals KNOW how to communicate with this person and can access this information easily and instantly.

SHARE – Whenever referring this person to other professionals or liaising with other professionals you MUST notify them of the persons preferred method of communication, using the agreed wording.

ACT – Make sure that you always follow the communication method requested and recorded.

Accessible Information Standard

CIPOLD (2013) found that a large contributing factor to the health inequalities faced by people with learning disabilities is delays or failings to attend health appointments due to not receiving information in an accessible format that the person could understand. By adhering to the Accessible Information Standard, this ensures that professionals are reducing this risk factor for people with learning disabilities.

The Reasonable Adjustment Digital Flag 2024

This extends the AIS as it is the new Nationally Accessible Record that will indicate where a person needs Reasonable Adjustments, including communication needs, and will have the option to include

- **Details of their significant impairment**
- **Key Adjustments that should be considered**
- **Underlying conditions**

ALL organisations under Health and Social Care, by April 2024 were required to prepare for the new digital flag by ensuring they have processes in place on their own systems that:

- **Identify**
- **Record**
- **Flag**
- **Share**
- **Meet**
- **Review**

The reasonable adjustments and communication needs of the people known to their service who have a learning disability and / or are Autistic.

Watch this video; Gavin Says- Check you know the best way to contact someone.

In the video, Gavin explains how if he used to receive a letter asking him to come for an appointment, he would just put them in the bin. This is because, firstly, he didn't always understand the letter and secondly, if it looked a bit scary, he didn't like the idea of going, so he would bin them and not tell anyone he had received them. He would have gone down as a Did Not Attend and not had his treatment, so knowing a bit about the person before communication is vital…

Think about your website – do you have easy links to information for your learning disability patients? Remember – if you get it right for people with a learning disability, you get it right for everyone… Everyone likes bitesize simple information.

Think about your appointment process – Does it work for people with a learning disability who may not have someone to help them? How complicated is the press 1, press 2, process? Do you have a designated line that bypasses that process for the patients who would find the appointment process a barrier to getting healthcare?

Think about the initial contact- Add a sentence to your letters or emails in an easy-read format, say 'call us if you want to know more' and make sure the person who takes the calls has the skills to communicate effectively. If making a phone call, ask the person if they have a disability, learning disability or anything else that would mean they need some extra help, this could be the difference between them attending or not attending. Also, try to keep your tone of voice calm and friendly, as a brisk or hurried conversation can be misinterpreted as you are annoyed with them.

Watch this video; Gavin Says- Your tone on the phone can make a difference.

Gavin explained to us that when he makes a call to someone to book an appointment, if that person sounds very rushed and tries to get Gavin off the phone quickly, he interprets that as the person being cross with him and this then puts him off going to the appointment.

Time to talk and make a Pledge

What changes can you make at entry point?

Can you add a line to your letters to say 'This is very important and it is about your health. Call if you need help- understanding'

Can you refer anyone with a Learning disability OR people you think MAY have a learning disability, to the acute liaison nurses?

Can you change DNA's to WNB's [Was Not Brought] the same as children's services so that they person is followed up to check they understood and made an informed decision not to accept the health intervention.

Can you refer to Safeguarding if they have support / carers who have failed to bring them on 2 occasions?

Can you Make sure you understand their AIS and reasonable adjustments before

Please transfer your Pledges to the team's pledge Document at the end of this handbook

NOTES:

PRINCIPLE 4

Time

Please watch this video alongside this section of the handbook: Principle 4

Under the **Equality Act 2010**, every health provider has a duty to make reasonable adjustments to bridge the health inequalities. In Hertfordshire, the Learning Disability Health Liaison Team developed the acronym **TEACH** to help you consider all the different ways in which you may need to make reasonable adjustments.

Reasonable adjustments need to be made at **ALL** stages of health care delivery from the person being able to make an appointment through to clinicians referring on.

Think T.E.A.C.H

Time
Does the person find it hard going to health appointments at a certain time of day? Does the person need extra time for them to feel relaxed so that they can accept treatment? Does the person need extra time to explain things?

Environment
Would the person be more likely to be relaxed and accept health treatment if they are in a place they know well? Does the person hate noises, busy spaces or new places? What can be done to make this easier?

Attitude
If the person is anxious what can be done to help them relax so that they are more likely to get the same treatment as someone else?

Communication
How should people talk to the person? Are there things that they hate people saying or doing? Does the person have a have favourite subject that they like to chat about that helps them feel relaxed? Are there things the person likes to show people to help them settle? Does the person need things written down or drawn to help them understand better?

Help
Does the person have a Purple Folder/Preparing for Adulthood Purple Health Pages or Purple Card that shows what reasonable adjustments they need and what they usually look, communicate and behave like, so the Doctors can recognise signs of changes?

TIME

Take time to find out the needs of the person and gather good background information, share this information with other health professional's

Take time to go back to the referrer if they have not shown up for an appointment, to see if there is anything else you could do to help them attend

Take time to make sure they have made an informed decision not to attend the appointment and that they fully understood the implications of not attending

Watch this video; Gavin Says- Think about time of day

Gavin tells us about his friend who could not deviate from his structured day without it causing him distress, he would allocate himself 2 hours a day which he called his 'free time' and could only tolerate appointments or extra things in his day within this allocated free time.

Try to offer different **times** of the day for appointments

Take time to explain about medications or procedures and make sure the person has understood, maybe ask them to repeat back to you what they need to do.

Time to talk and make a Pledge

Can you make more time to gather background information on your patients?

Can you give extra time for appointments where needed?

Can you offer different times of the day for appointments for people who need them?

Please transfer your Pledges to the team's pledge Document at the end of this handbook

NOTES:

PRINCIPLE 5

Environment

Please watch this video alongside this section of the handbook: Principle 5

The environment is not just the building, it is the people around you, images on the walls or screens, smells, things around you and noises. Some people struggle with sensory overload of a clinical environment…

Sensory Overload of the environment

Sensory overload is very common in people with a learning disability and autistic people.

Just being able to climb in their shoes and imagine what YOUR environment may feel like for them will help YOU to know how to help them.

Remember that they MAY not be able to filter out things that aren't relevant to them.

- ***ALL** noises may sound excessively loud – they may be sounds so familiar to you that you don't hear them, like the beep of the appointment machine or the growl of the blood pressure machine.*
- ***ALL** images on the wall may be leaping out at them,*
- ***ALL** equipment and furniture MAY be alarming if its unfamiliar to them,*
- ***ALL** smells will impact their stress levels, especially unfamiliar smells*

Imagine ….

You have been zapped into the sky and dropped in a room on another planet … imagine how you would be trying to instantly take in everything around you and assess the risk and fear… how would you feel?

Your heart is racing, your eyes are darting around, you are shaking, you start to cry, something totally unfamiliar approaches you … you jump, you scream. They move to touch you … You hit out and run but there is nowhere to go … you start knocking things over in your desperate plea to find a safe place…

This is Fight or Flight mode …. If someone's behaviour is challenging … they are probably in fight or flight mode - what are they communicating and what can you do to answer that communication and help them feel in that safe place?

You could…

- Seek the guidance of those that know the person well to see what they think will help.
- Mirror their actions of reassurance
- Ensure your body language, tone and facial expressions are giving an aura of kindness, caring, and understanding … not fear, frustration and wanting them to go…
- Take time to allow them to come out of fight or flight mode and feel secure in your company
- Remember … it's not behaviour … its communication

When someone struggles with your environment,

it's time to think outside the box-here are some examples:

- A man is always seen in the car outside, this is where he feels safe and will allow first level of investigations to happen. If further things are needed then a best interest decision can be made as to how to progress, but without this stage everything would remain undiagnosed.

- A man who hates waiting rooms and noise wears his headphones and waits in the car, he then goes straight into the room when it's his time.

- A lady who brings her dog because she is only calm when her dog is with her. A member of staff waits with her dog outside when she is called in to the appointment.

- A lady who likes the waiting room as she likes to look at the fish… but hates it when its noisy, must have appointments very early when it is quiet and has a chair facing the fish tank ready… she will then relax and engage.

- Another gentleman loves to 'high-five' everyone, when he enters a clinical setting, if everyone 'high-fives' him he will accept treatment, if they don't, he refuses treatment.

Watch this video; Gavin Says-Think about whether a change in environment with help

If the person with learning disabilities is struggling to accept the help offered a change of environment could make the difference between them accepting or rejecting healthcare.

Time to talk and make a Pledge

What can you do as individuals or a service to adapt your physical environment?

Hide equipment that isn't needed?

Have a less busy wall?

Provide a quiet space?

Have the option for people to wait outside?

Gain the skills and confidence when someone is anxious, to bring them out of flight or fight mode?

Make sure you contact the acute liaison nurses if additional support is needed to get the same health outcomes as anyone else would have?

Please transfer your Pledges to the team's pledge Document at the end of this handbook

NOTES:

PRINCIPLE 6

Attitude

Please watch this video alongside this section of the handbook: Principle 6

This isn't just about treating everyone with dignity and respect but is also about valuing everyone's life equally. If a person isn't accepting medical treatment or examinations, then the medical practitioner needs to be considering their mental capacity to understand **WHY** the treatment/investigation is being recommended and the possible **RISKS** of not having it.

It's having the attitude to find solutions to the obstacles that the persons learning disability puts in the way of them receiving an equitable health service. If they don't have capacity to understand, weigh up the risks of their refusal then a best interest decision must be made, ensuring every step possible has been taken to meet their health needs.

Watch this video; Gavin Says-make sure you explain WHY the person needs the healthcare

It is not about being kind and using the 'Aww bless' attitude, when he had his fear of needles, often he was told 'ok, don't worry about it then' and did not proceed with the treatment.

After one nurse took the time to explain to Gavin why it was so important, in a way he understood, his first thought was 'didn't all the other people care about my health then?' and 'did they want me to die?'. He describes this as 'Killing with Kindness'.

Gavin also has difficulty maintaining a healthy weight and people would often offer biscuits and sweet treats to him, trying to be nice and kind, but once he learned about the dangers of being obese, he realised this was not the best thing for them to do and they should have been talking to him about the risks of being overweight instead.

A Harry Potter Reasonable Adjustment

A man with a learning disability who refuses all medical interventions has found a way of accepting them through his love of Harry Potter.

With most medical decisions he does not have the capacity to fully understand the risks of his decision to refuse treatment and so Best Interest Decisions must be made.

He recently reached a point that his refusal to have his toenails cut was impacting his ability to wear shoes and walk.

The GP was weighing up whether it was in his best interest to have a general anaesthetic as his behaviours meant he would not accept any podiatry support whilst awake.

The risk of infection and inability to mobilise was a tough decision to weigh up against the risk of anaesthetic.

Then, one of our learning disability nurses discovered his passion for Harry Potter and started to think outside the box.

With good communication, a bit of creativity, a bit of wizardry attire, a couple of wands and an open-minded podiatrist, they were able to set up his Hogwarts podiatry within his flat and all assumed different Harry Potter characters. It took time, but they worked their 'magic' without any need for risky anaesthetic.

A great example of least restrictive approaches to best interest decision making.

So … when someone asks you to talk about Dogs to help a person remain calm or asks you to see them in the car instead of the consulting room, think of Harry Potter and stick on whatever the metaphorical wizard hat is, that is required to get equitable health outcomes for YOUR patient.

Time to talk and make a Pledge

What can you do as a service to ensure your attitude is a solution finding one, that enables someone with a learning disability or autism to get the same health outcomes as anyone else?

Please transfer your Pledges to the team's pledge Document at the end of this handbook

NOTES:

PRINCIPLE 7

Communication

Please watch this video alongside this section of the handbook: Principle 7

There are no golden rules on how to communicate, as it is different for everyone, but being able to put yourself in the shoes of the person, being empathetic and reading their communication style is a good place to start.

Communication is using accessible information to enable understanding, for example, easy read leaflets, pictures, symbols, or sign language and using the Purple Folder to both read back and record. The purple Folder will enable health professionals to understand the person's baseline and assess changes in their health that they may not be able to verbalise.

(See page 38 for information about the purple folder)

Only a small percentage of communication is verbal, it is mostly body language. If you don't give off an aura of safety, warmth, and friendliness, then the person is unlikely to accept any physical examinations from you.

On the next two pages are ten top tips on how to communicate effectively with someone who has a learning disability.

10 tips for Health Professionals for communicating with people with a Learning Disability (LD)

1 Talk to the person first (not their family/support worker)

- Get their attention – and give them yours. Try not to look at notes or your computer screen while you are talking to them
- Be at the person's level, make sure they can see your hands and face clearly, as they will use gestures or facial expression to help them understand.

2 Speak clearly and use easy everyday words and sentences

- Don't make language complicated or use medical jargon or abbreviations.
- You may have to use the person's own vocabulary for body parts or procedures and go at the pace they set. Look in their **Purple Folder** for any communication tips

3 Take time

- Give the person time to listen to and process what you say, as people with LD need longer processing time.
- Many people with LD have other needs that may impact on their communication, for example physical disabilities, sensory impairments, epilepsy, pain, or side-effects of medications.

4 Use visual cues to support understanding

- Use all support available to you to back up what you are explaining. This could mean pointing to items, showing objects, photos, or pictures, or using internet videos as examples. www.easyhealth.org.uk also contains some useful easy read resources you can download or use.
- Seek advice from your Learning Disability Link nurse if communication is a barrier to their understanding and accepting treatment.

5 Give information a bit at a time

- Use short sentences – Give one or two pieces of information at a time.
- Break large pieces of information into smaller chunks and give time for people to listen and understand.

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Hertfordshire

6 Get to know how the person chooses to communicate

- If you know a person has communication needs, try and find out **before** your appointment how to support them. Make sure this is flagged on your systems to help other health professionals who may see them. [requirement under the Accessible Information Standard]
- If they use an alternative method of communication, they will probably carry something that can help you (such as a My Purple Folder), or may be accompanied by a someone who can help.

7 Do not ask too many questions

- Questions are hard as they require listening, processing, planning and responses from the person. If you ask lots of yes/no questions, they may answer you but may not have understand what you said so give false information
- Try to ask open ended questions, or encourage the person to tell you what they need to in their own way.

8 Check the person has understood you

- Do not ask 'do you understand?' as people may respond 'yes' but this may not necessarily be accurate.
- Ask them to tell you what you have said so you can gauge their understanding and reiterate the parts they miss.
- Summaries the information and try to provide it to them in an accessible format.

9 Make sure the environment is communication friendly

- Ensure the room you are in is free from preventable distractions / anxiety provokers and adapt wherever possible e.g. noisy clock, noisy waiting room, flickering light or computer screen, medical equipment that isn't relevant to their appointment. Remember someone with an LD may not be able to use previous experiences to filter out what is not relevant, so may become unnecessarily panicked about things that don't relate to their health appointment.

10 Ask for help- there is no substitute for knowing a person well

- Check that **you** have understood fully and Don't pretend you can understand if you really don't!

Communication

Complete your background research

Don't forget, if you have done your background research you should have all the core knowledge about that person. For example, one gentleman absolutely hated the phrase 'young man' and if he was greeted with this on arrival, he would become very agitated, and it would disrupt the service you are trying to provide him. Some things you just need to know about a person and no two people are the same.

Getting help to communicate

Remember to involve the carer, support worker, family member or friend… whoever has come along to support the person, because they are the ones who know them best, they will be able to tell if they are communicating well and understanding everything that is being said.

You need to open that door of communication *'You are an expert in Simon… please tell me, what is he usually like? What do you think he may be communicating/ may be wrong with him?'*

As someone working within a health setting… from first call through to clinician you ARE the SCARIEST people on the planet.

People are apprehensive about 'opening up' to you unless asked.

Diagnosis when there are communication barriers is all about finding the pieces of the diagnostic jigsaw puzzle … you need the help of the people who know the person well to make sure you get enough pieces to build an accurate picture.

Time to talk and make a Pledge

What can you do as individuals or a service to improve your communication skills and confidence to ensure they don't have an impact on equitable health outcomes?

Please transfer your Pledges to the team's pledge Document at the end of this handbook

NOTES:

PRINCIPLE 8

Help

Please watch this video alongside this section of the handbook: Principle 8

Getting help means listening to others (carers, parents, people who support the person in society and partners) **THEY** are the experts in the person and may have essential information to help you build the jigsaw puzzle of diagnosis and ways of enabling the person to accept health interventions that they otherwise wouldn't. They will also be the ones who can identify early signs of changes from baseline and reduce the risk of delays in diagnosis.

Health Outcomes is Teamwork, so whenever anyone with a learning disability enters your department embrace the expertise of the people that know the person well….

If some is being admitted, make sure you complete a shared care agreement which clearly identifies who will deliver what… make sure that this focuses holistically on the persons physical, emotional, and clinical needs and is a shared plan that will enable the best support and health outcomes for the person. Remember it's the small things that make all the difference… who will remind them to drink and check they stay hydrated? Who will look for the signs that they need the toilet and remind them where it is?

Also, **HELP** is about seeking help or advice from specialist services when you have concerns or are unable to find solutions to meeting the persons health needs (for example a community Learning Disability Nurse or Social Worker).

Mental Capacity and Best Interest

The **Mental Capacity Act 2005** sets out the law around supporting people with learning disabilities to make decisions. The CIPOLD report found that poor adherence to the Mental Capacity Act led to premature deaths of people with Learning Disabilities. It is vital that everyone involved in providing healthcare to people with a learning disability understands and follows the Mental Capacity Act.

In This Section we try to help embed an understanding of how Mental Capacity and Best Interest is something you do every day – if you decide NOT to do something for someone who doesn't have capacity to understand what is needed, you have, in effect, made a Best interest decision … so we want to help you to truly understand this law in everyday practice.

ACID Test

Always think…

If someone without a learning disability came to me with the same ailment/illness/treatment/need, what would I be doing and in what timeframe?

If that is not achievable because of barriers due to their learning disability, THEN you need to assess their Capacity to understand what is needed and the risk of not doing it.

Then, if they are NOT able to make an informed decision with their refusal – you need to clinically act in the BEST INTEREST using LEAST RESTRICTIVE approaches to get EQUITABLE health outcomes

Five Principles of MCA:

1. **Never Assume!** Just because someone has a diagnosis of a learning disability does not mean that they lack capacity on every decision.

Simplify the bare minimum information you would expect ANY patient to understand and explain it in those terms.

You MUST assess for each situation and cannot make a blanket statement that someone with a learning disability does not have capacity. The person's capacity to understand may be altering with each medical decision, and at different points in their life.

2. **Informed Decisions:** You must make practical steps to support someone with a learning disability to understand and make an informed decision. Remember the C in TEACH. If there is minimal risk of delaying treatment and it is felt, with time, they may be able to understand and

accept treatment, then give the people who support the EXACT simplified information that you would expect them to understand to be deemed to have capacity.

THINK CURB

- **Communicate** – Tell them why you think the investigation/treatment is a good idea and what the risk is if you don't do it. Get the people who support them to help if necessary. Can the person communicate that they have understood this back to you?
- **Understand** – Check they understand what you have said and again use their person who supports them to help.
- **Retain** – This would be via for example, them telling you back what will happen and why in their own words. Not just parroting or saying 'yes'.
- **Balance the decision** - Weigh up the information and choice they have made. This would mean they would need to show that they understand the possible consequences of refusing.

If the person Does NOT have Capacity, it is a MEDICAL best interest decision. Next of Kin and Carers CANNOT consent or refuse consent on behalf of the patient UNLESS they have lasting power of attorney for their health and wellbeing.

3. **Unwise Decisions:** People with Learning Disabilities have the right to make unwise decisions. So, if they can demonstrate that they understand the risk of their decision this is their choice. You can ask people who support them to keep discussing and encouraging them to change their mind, but you cannot make a best interest decision if THEY have capacity in this medical decision.

"I know that the smear test can help make sure I never get cancer there, but I would rather risk dying of cancer than have a smear test'"

4. **Best Interests:** If a person with a Learning Disability has been found to lack capacity about a decision, then a best interests decision needs to be made.

- If it is a small decision with negligible health risks you can make this there and then with the carer (for example, carrying out a physical examination, taking bloods, flu jab, completing annual health check)
- Bigger decisions with bigger health risks need a multi-disciplinary decision

You do this every day! – you weigh up what is the right course of action for the patient, and you tell them. When they don't understand, you weigh up, with the people who support the person, how achievable that course of action is and what would need to be done to achieve this successfully… **Remember the H in Help. The people in their life are the experts in the person … you are the experts in health … this is Teamwork**.

*The Health Professional can take into consideration the next of Kin's and carers views **BUT** the carer and Next of Kin **CANNOT** make the decision. It is a medical decision as to what is in the best interest of the patient. It is **ONLY** when someone holds **lasting power of attorney for health and welfare** that someone else can make the decision for the person.*

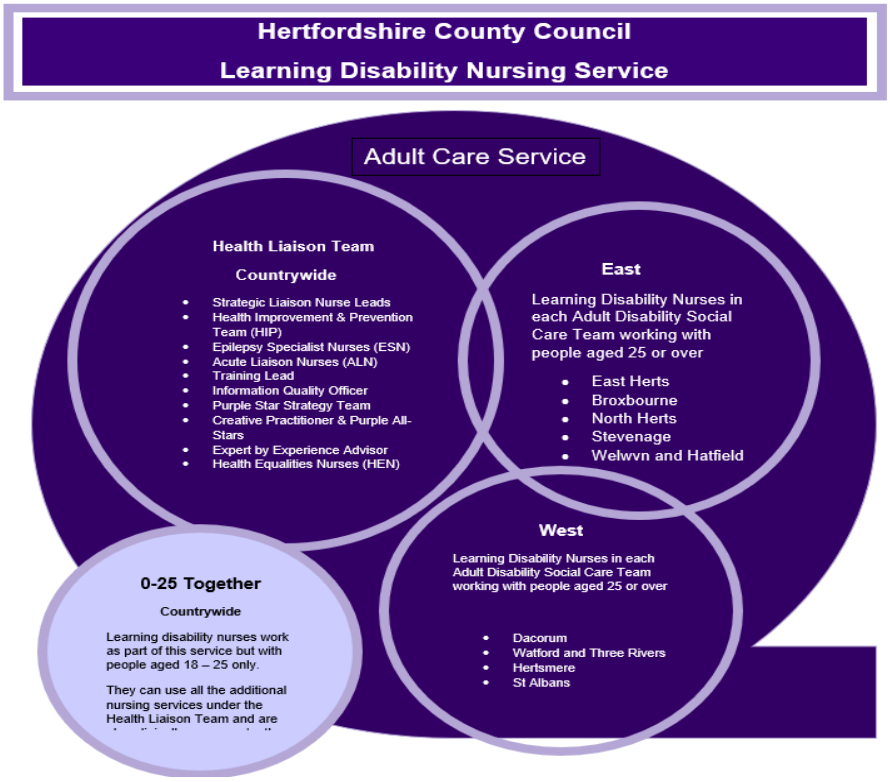
5. **Less Restrictive:** Where possible, always use the less restrictive option.

Example: Someone with a learning disability who is needle phobic and requires a blood test in their best interests. Covert approaches and Distraction techniques should be weighed up as these would be less restrictive than a general anaesthetic. If the only approach adds risk itself, then you must weigh up whether the risk of the approach is greater than the risk of not proceeding

If you need HELP from the Learning Disability Nursing Service then Here is an outline of the nursing service we offer

Within Learning Disability Nursing in Adult Social Care – we also have a number of specialisms – but again, we all work very closely together so can pass to our approriate nursing colleagues

To make a referral to the Adult Care nursing service – you need to complete the nursing referral form referral form



Purple Folder

The purple folder is a health passport that is offered to adults with learning disabilities living in Hertfordshire. Please click on the link below or visit our website for more detail.

Good use of the Purple Folder can reduce the risk of delays in Diagnosis due to communication barriers or reluctance to accept investigations or treatment. It should be used by ALL health services in Herts when a patient attends an appointment with one. If someone with a learning disability says they do not have one, all health services should encourage them to get one. [The Purple Folder | Hertfordshire County Council]

The Purple Folder provides health professionals with a holistic overview of the person's health and their baseline abilities, recent history of other health professional's involvement to help build a diagnostic picture, the reasonable adjustments that need to be made, communication needs of the person to ensure they understand and can make informed choices as well as to ensure you, as health professionals, know whether they are communicating pain or ill health *(for example, one lady screams and bites her hand and this indicates she is excited and happy. Another lady screams and bites her hand and this indicates she is in excruciating pain)* the level of support the person needs to enable them to successfully access healthcare services and the support level they would need with personal care, eating and drinking should they be admitted to hospital.

It is a tool that can support you, as a health professional, to confidently communicate and work with an individual in the most appropriate manner for them. It is a requirement under the **Equality Act** to make reasonable adjustments and a requirement under the **Accessible Information Standard** to use a person's preferred means of communication. The purple folder is deemed to be a health document and therefore, if the information is within the Purple Folder and a health service does not utilise it, they could be questioned over their compliance with these two legislations. The Purple Folder is there to help.

To order a purple folder, please direct the person with a learning disability (over the age of 18) to email purplefolder@hertfordshire.gov.uk

What should you do when someone brings their Purple Folder to your service?

1. If there are any barriers to you being able to give them the same healthcare you would anyone else, check the reasonable adjustments section and communication section to see if there are things you can try that their carer hasn't told you.
2. If you discover something that helps the person e.g., if I talk about dogs he calms and then he trusts me and engages with healthcare, then make sure this is added to the reasonable adjustment's sections so others in the future can use this top tip too.
3. If you are unsure whether they are in pain or of the severity of their illness, read the 'how I behave when I am well / unwell' pages to see if they are likely to be non-verbally

communicating more extreme symptoms than you can establish. Also, check the baseline measurements that are recorded in the folder to see how far off baseline they are

4. If the person has come without support, then complete one of the blank pages called 'The Health Plan after Todays appointment' and write in clear and simple language.
5. After an Annual Health Check, make sure the Health Check action plan is stored in the annual health check section and you have record on the annual health check record page. If the baseline measurements page hasn't been updated, then add any that have been taken at the annual heath check and remind the person the annual update of the purple folder is due at annual health check time
6. Always write a brief summary in the health appointment record

The Health Appointment Record

This should be written on by ALL the health professionals who see the person. It only needs a brief outline of the appointment and actions. This will help gain an overview of all health interventions the person may be currently receiving to aid diagnostic decisions. The records should be kept in chronological order to make this easier for you.

An example of good use of this was a gentleman who started having falls, he became unsteady on his feet, disengaged, slept more, uninterested in the TV and his books. The GP did NOT look at the appointment record pages and went down the pathway of neurological and possible dementia. The neurologist DID look at the record and identified a sudden onset of these changes in February. When they looked at the records, it was identified he had seen an optician in February and been given a new prescription for glasses… this prescription was completely wrong. All the symptoms related to not being able to see. This would have been identified and resolved a lot earlier had the GP read the records.

Getting a NEW 2023 Version of the purple folder

Whether someone has never had a Purple Folder or have an old version [Old versions will say MY purple Folder … new ones say Purple Folder] they are all entitled to a new Version.

All pages are available on the website here www.hertfordshire.gov.uk/purplefolder for the person to complete electronically online and print and add to their folder. To receive folder and inserts they can contact us on 01438 845372 or email purplefolder@hertfordshire.gov.uk

If you think the person does not have a support network to help them complete the Purple Folder, then please let us know and we will support them. We will ask you the key Reasonable Adjustments and Communication approaches that you have established with the person to ensure these are in their folder.

We have also created purple cards that can be stored in a person's wallet and contain the core information on reasonable adjustments, communication needs and help with health. These are a useful addition [not replacement] to the purple folder for people who are more independent and may be out without their purple folder. Do you have patients who would benefit from this? purplefolder@hertfordshire.gov.uk

Me on My Best Day

We have a campaign to encourage all people with a learning disability to film a 20 second video showing what they look, behave, and communicate like when they are well. This is to help health professionals understand how far off their baseline they are. Can you ask your patients to make sure they have one of these on their phone?

This video Me on my best day is a great one for sharing and letting people know it is a good idea to record a video of them on their best day, so health professionals can see any changes in behaviour.

Purple Wrist bands or Dots

Make sure you offer the wrist Band [East Herts] and add the Purple Dot [West Herts] to ensure everyone is aware that this patient will need additional reasonable adjustments to get equitable health outcomes

The Purple All Stars

As part of the Community Learning Disability Service in Hertfordshire, the Health Liaison Team employs a Creative Practitioner. Our Creative Practitioner uses creative arts to communicate and teach key health messages to people with a learning disability and the people that support them. The people in this group form The Purple All Stars. They are supported by the Creative Practitioner to perform and share health messages through plays, song, and dance. Click here The purple all stars to view all of videos performed by our Purple All Stars!

YouTube channel (Please subscribe!!!) community learning disability nursing service

End Of Life Planning

Again, you will need the expertise of the people who know them best to help ensure they have the best end of life possible.

Do they have in their Purple Folder, the list of things they would want and people they would want to see?

Can you ensure this is acted on? It may be a particular blanket or music or source of comfort. It may be a particular friend who they share a home with they would want to visit them?

Make sure you link with the Acute Liasion Nurses so they can link with Social Care, the Community Learning Disability Nurses, the GP and Palliative care.

DNA CPR's and ReSPECT Documents

If you have any involvement in making Resuscitation decisions, then please make sure they have been correctly put in place.

The Safeguarding Board released a step by step guide to help 'people who support someone' and health professionals ensure these are correctly completed.

A step-by-step guide to putting a do not attempt cardiopulmonary resuscitation order in place (hertfordshire.gov.uk)

SINCE Hertfordshire have adopted the ReSPECT tool it has been noted that these have scope for being completed in a way that can appear that the clinician is making a value-based judgement rather than a clinical judgement. So please check the wording and that the person has been enabled to be as involved as much as possible.

Here is a **Link to a Guide** Hertfordshire and West Essex ICB ReSPECT and some examples – but also feel free to contact us for advice around Purple Star Recognition on purplestarstrategy@hertfordshire.gov.uk

It is essential that the person is given the opportunity to understand this medical decision too…

Here is an easyread tool you can use to explain CPR.

What if my heart stops? easy read.

Conversations when a person is unwell.

Abbreviations: **DNACPR or DNAR or DNR** - Do Not Attempt Cardio-pulmonary Resuscitation

MCA - Mental Capacity Act **LPA** - Lasting Power of Attorney

IMCA - Independent Mental Capacity Advocate

Safeguarding

Safeguarding means protecting people's health, wellbeing and human rights and enabling them to live free from harm, abuse, and neglect. It is fundamental to high-quality health and social care. The main areas of abuse are:

- Physical
- Sexual
- Financial
- Psychological/emotional
- Neglect and acts of omission
- Discriminatory
- Organisational abuse
- Neglect and poor practice
- Self-neglect
- Domestic Abuse
- Modern Slavery

Report anything that may potentially be deemed abuse at any level.

Even if it is just an uncomfortable feeling you have, still report it so it can be investigated.

Never put yourself in a position where you could regret not mentioning something.

Link to safeguarding portal:

Report a concern about an adult - Hertfordshire County Council

The murder of Steven Hoskin

What happened?

Steven Hoskin lived alone in St Austell; he had a learning disability placing him at risk of abuse. Steven was 39 years old and was subjected to “harrowing” abuse ending in his death in St Austell, Cornwall on 6 July 2006. He was forced to swallow a lethal dose of paracetamol, hauled around his bedsit by a dog collar and burned with cigarettes. Darren Stewart, 29, and Sarah Bullock, 16, were convicted of Hoskin’s murder. They had made Steven walk to a viaduct and forced him to climb over the edge leaving him holding on for his life. Bullock then made Hoskin fall 30 metres to his death by kicking his face and standing on his hands.

A serious case review and an internal management review, highlighted failings to share information between numerous agencies.

He had been placed in a bedsit by adult social care in April 2005 and he was allocated two hours of help each week, but he chose to cancel the service in August and by September the council closed his case. The serious case review found that Steven Hoskin then “lost all control of his own life” when Stewart and his girlfriend moved in and began to abuse him.

Steven’s decision to end contact with adult social care “was not investigated or explored”, the review found.

Prior to his death, Steven had contacted different agencies over 40 times, including the police and health and social care agencies to indicate he felt he was in danger, but no report was vocalised by him well enough to be fully acted on. None of these reports were ‘joined up’ to be able to unpick the degree of risk Steven was in.

Actions for improvement

Following the SCR, the following improvements and actions have been taken to improve adult safeguarding practice:

- Improved systems of information sharing and reporting, encouraging a rapid response.
- Development of police and ambulance systems to indicate when there are repeat calls from the same people. This enables information to be shared between relevant agencies to develop appropriate, comprehensive responses.
- Increased awareness of agencies to be more responsive to signs of suspected abuse where the adult is at risk because of a pre-existing condition. In Steven's case this was his learning disability.

EVEN IF IT'S A SMALL CONCERN – REMEMBER!

EVERY TINY BIT OF INFORMATION YOU SUPPLY MAY BE A SIGNIFICANT PIECE TO A BIGGER PICTURE!

Here is a video outlining the case study of Steven Hoskin's murder and what has changed since. It highlights when a safeguarding response is required and what problems persist:

Have we learned the lessons from Steven Hoskin's murder?

PRINCIPLE 8

Help

Time to talk and make a Pledge

What can you do as individuals or a service to improve ensure you use the HELP needed to overcome the barriers of limited capacity and achieve equitable health outcomes?

Can you improve you use of the Purple Folder or Purple Card?

Do you ask for the Me on my Best day Videos?

Do you have a Learning Disability Champion to help staff ensure all elements of HELP are covered?

Please transfer your Pledges to the team's pledge Document at the end of this handbook

NOTES:

RECORD OF PLEDGES IN PRACTICE Training Completed

TO RECEIVE PURPLE PLEDGE OF PRACTICE RECOGNITION THE FOLLOWING DOCUMENTS CAN BE SUBMITTED TO THE PURPLE STAR TEAM PurpleStarStrategy@hertfordshire.gov.uk

We *(name of service)* under the organisation of *(Name of Trust/organisation/company)* pledge to the purple principles of enabling equitable health outcomes for patients with a learning disability and/or Autistic people.

The named people in the team taking responsibility for this are:

……

Please detail the process you will use for governance for overseeing the pledges are achieved
(Include: who the governance lies with and when/how it will be reviewed within your organisation)

Total number of staff within the service seeking Recognition;	

Principle number/date completed. Each Principle's "Time to Talk" must be signed off and relevant Pledges added to the following Record of Pledges document									
Name/Role of person	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**"Time to talk" signed off by;**

RECORD OF PLEDGES FROM INDIVIDUALS/SERVICE

Service / Teams Pledge Document

(Review date should be decided by relevant senior member of staff according to when this Pledge can reasonably be achieved, and the Outcome recorded)

Date	Name (s) of people making the pledge	Pledge of improvement or current good practice that will be maintained	Date of review for pledges of improvement	Outcome/update

Date	Name (s) of people making the pledge	Pledge of improvement or current good practice that will be maintained	Date of review for pledges of improvement	Outcome/update

Monitoring Process for Purple Pledges Recognition by HCC Purple Star Steering Group

- The department should identify a Named Person who is in a Senior position whose role it is to check the Principles have been completed and pledges made by each individual team member.
- The department are asked to utilise the hospital feedback mechanisms such as Ask, Listen, Do to seek feedback from people with a learning disability using the service.
- The department are asked to display a poster that gives information on how people can give feedback directly to the Purple Star Strategy Team.
- Any positive or negative feedback that is received by the Purple Star Strategy Team or Acute Liaison Nurses will be feedback to the Named Person as above. Your response to this feedback will then be shared with the Purple Star Strategy Steering Group. If they feel this brings into question any of the principles within the Recognition they may freeze this until further pledges have been completed and considered.

Useful Websites and Telephone Numbers

Information for people with learning disabilities – www.hertfordshire.gov.uk/LDMyHealth

Information for professionals – www.hertfordshire.gov.uk/LDProfessionals

Help in the Community

Advocacy services – www.pohwer.net/	0300 456 2370
Carers in Herts -www.carersinherts.org.uk/	01992 586969
Herts Help - www.hertshelp.net/	0300 123 4044
Health Watch - www.healthwatch.co.uk/	0300 068 3000

Safeguarding Adults -
http://www.hertfordshire.gov.uk/services/healthsoc/supportforadults/worriedabout/vulnadult/HSAB/

http://www.scie.org.uk/publications/elearning/adultsafeguarding/

Hertfordshire County Council - http://www.hertfordshire.gov.uk/ 0300 123 4042

Hertfordshire Partnership Foundation Trust - www.hpft.nhs.uk/

NHS Patient advice and Liaison service - www.hertfordshire.nhs.uk/.../pals.html

Mencap - www.mencap.org.uk/ 0808 808 1111

Easy Read/Signs and symbols

Easy read health resources - www.easyhealth.org.uk/

Makaton - www.makaton.org/

Photo Symbols – www.photosymbols-cloud.com/

Resources/Useful websites

Mental Capacity Act - https://www.gov.uk/government/collections/mental-capacity-act-making-decisions A brief guide to the Mental Capacity Act (2005): Implications for people with learning disabilities. Available from British Institute of Learning Disabilities www.bild.org.uk (£10.00) or as a free download at www.scie.org.uk/publications/mca/files/bild-mca.pdf

Mental Capacity consent pathway and Best Interest Decision pathway are available here http://www.rcgp.org.uk/learningdisabilities

https://www.gov.uk/government/publications/reference-guide-to-consent-for-examination-or-treatment-second-edition DoH reference guide to consent to examination and treatment

https://www.gov.uk/government/collections/mental-capacity-act-making-decisions Mental capacity Act 2005