

16 June 2021

# ADS and MH Breakout session

The webinar will begin shortly



# House Keeping

- If you are in the wrong break out room, please click leave and select Leave Breakout room and you will be taken back to main event to be reassigned
- Microphones off unless asked to speak or speaking
- For questions, please add these to the chat box, we will come to these at the end, you may be asked to elaborate over the microphone

## In-Meeting Controls

The attendee controls appear at the bottom of your screen. To access the meeting controls, just move your mouse in the Zoom window.



Attendees have access to these features:

### Mute or Unmute:



To mute or unmute your microphone, click the ^ arrow next to the picture of the microphone.

**Please keep your microphone on mute during the presentation**

### Start Video or Stop Video:



To turn your camera on or off, click the ^ arrow next to the picture of the video camera.

**Please keep your video off during the presentation.**

# Agenda

Learning from LeDeR

Core Capability Framework Learning Disability and Autism

National Mental Health education Framework

Education

Agency Support

Q&A

# What is LeDeR?

The LeDeR Programme Started in April 2017 to review the life and death of a person with a learning disability. Everyone with a learning disability aged four and above who dies and every adult (aged 18 and over) with a diagnosis of autism is eligible for a LeDeR review.

People with a learning disability often have poorer physical and mental health than other people and may face barriers to accessing health and care to keep them healthy. Too many people with a learning disability are dying earlier than they should, many from things which could have been treated or prevented.

The learning from deaths of people with a learning disability (LeDeR) programme was set up as a service improvement programme to look at why people are dying and what we can do to change services locally and nationally to improve the health of people with a learning disability and reduce health inequalities. By finding out more about why people died we can understand what needs to be changed to make a difference to people's lives.

Oversight has now moved to NHS instead of Bristol University and there is a national policy which can be found [here](#). This policy aims to set out for the first time for the NHS the core aims and values of the LeDeR programme and the expectations placed on different parts of the health and social care system in delivering the programme from June 2021.

# What is a LeDeR review?

In a LeDeR review someone who is trained to carry out reviews, usually someone who is clinical or has a social work background, looks at the person's life and the circumstances that led up to their death and from the information they have makes recommendations to the local commissioning system about changes that could be made locally to help improve services for other people with a learning disability locally. They look at the GPs records and social care and hospital records (if relevant) and speak to family members about the person who has died to find out more about them and their life experiences

## Reporting the death of a person with a learning disability?

Anyone can notify a death to the LeDeR programme and the more deaths we are aware of the more accurate the information we have will be.

To report a death please use the [online form on the LeDeR website](#)

# LeDeR Core Principles

1. LeDeR is a service **improvement** programme aimed at improving local services for people with a learning disability and autistic people, and reducing premature mortality.
2. We value the **on-going contribution of people with a learning disability and autistic people** and their families to all aspects of our work, and see this as central to the development and delivery of everything we do.
3. LeDeR reviews will be conducted by dedicated reviewers working in **multi-disciplinary teams** with appropriate supervision and administrative support.
4. Reviews will be completed in as timely a way as possible so that where **good practice is identified, or issues identified** these can be shared and addressed as soon as possible.
5. We take a **holistic perspective**, looking at a person's life as well as their death.
6. The key principles of **communication, cooperation and independence** will be upheld when working alongside other investigation or review processes.
7. The programme overall strives to ensure that reviews lead to **reflective learning** which will result in **improved** health and social care service delivery.
8. LeDeR reviews are **not investigations**.

# Outcomes

**We will know that the LeDeR programme is effective when local areas identify:**

- a **reduction in the repetition** of recurrent themes found in LeDeR reviews
- reduced levels of concern and areas for improvement in reviews
- reduced frequency of deaths that were potentially **avoidable** or **amenable** to good quality healthcare.
- evidence of service **improvement actions** as a result of learning from reviews. This can often be quite simple changes put in place by health and social care providers like ensuring proper communication between family members and carers or between carers and hospital staff, making sure that people's care plans are followed, or that postural support is provided or that annual health check health plans are followed.

**We expect the LeDeR programme to deliver:**

- a **positive** experience of the LeDeR process for bereaved families
- decreasing numbers of **preventable** deaths
- greater use of **reasonable adjustments** in health and care services for people with a learning disability and autistic people
- better **outcomes** for people as a result of local service improvement projects
- increased **awareness of the main causes** of death for people with a learning disability and autistic people among health and social care professionals both locally and nationally
- improved **data** about the lives and deaths of autistic people.

# National Themes

**Respiratory** conditions remain the most significant causes of premature mortality for people with a learning disability where deaths have been reviewed as part of the LeDeR programme.

**Constipation is easily preventable and treatable.**

It is unacceptable that, of the deaths reviewed as part of the LeDeR programme in 2018, 12 people died from constipation.

**Epilepsy People with a learning disability are much more likely than the general population to have epilepsy:**

About 1 in 3 people (32%) who have a mild to moderate learning disability also have epilepsy. The more severe the learning disability, the more likely that the person will also have epilepsy.

**Sepsis is a life-threatening reaction to an infection.** It happens when your immune system overreacts to an infection and starts to damage your body's own tissues and organs. Sepsis is sometimes called septicaemia or blood poisoning.

**Do not attempt cardiopulmonary resuscitation**

Whilst there are situations where do not attempt cardiopulmonary resuscitation (DNACPR) directions may be appropriate, the 2018 report raised concerns about instances in which a learning disability was cited as the reason for making a DNACPR order.

**Cancer.** The rate of deaths from cancer for people with a learning disability (13% for men and 15% for women with a learning disability in 2019) are half that for the general population but the 2018 report showed that, for the deaths reviewed as part of the programme, gaps in services and support for accessing cancer screening may have contributed to the death of 7%

# Hertfordshire Themes

## Commissioning

There have been some cases where people have been moved from a LD home to a mainstream home as care needs have changed. E.g. they have developed dementia. However the learning disability suddenly just doesn't disappear, they still need specialist support and it is becoming more apparent that this is not being addressed correctly.

## Cancer screening

Review of 110 deaths from June 2019 to Dec 2020

22 due to cancer (20%)

Often people with LD are not supported to attend appointments., due to no reasonable adjustments being made

## Avoiding Hospital Admissions

Encouraging monitoring of physical health and base line abilities. There has always been push back from care staff are they are not regarded as professional members of staff. However during Covid, care staff have embraced the pulse oximeter and monitoring temperatures and taking blood pressures. They are seeing the benefit to their residents with this, the momentum just needs to be kept going as the pandemic eases

# Hertfordshire Themes

## **Diagnostic overshadowing - when things get missed!**

When all that is seen is the learning disability and people don't look at the reasons for a change. A non verbal person with a sore throat may not be able to communicate that they are feeling ill. When offered food its pushed/thrown away. This is put down to negative behaviour etc.....unpicking a reason is often missed and this can lead to significant health issues as times such as missing earl signs of cancer.

## **End of Life Care**

Training needed for support staff and other professionals that have input into the lives of people with LD. EOL is often left until too late, this has been greatly highlighted by the pandemic. Planning is either not done or left until a person is too unwell to have any input or understanding of what is going on.

EOL planning ideally needs to be discussed when a person is still well and their health hasn't started to decline. The planning should be done in ways so that the person has their wishes followed

People then need to be aware of where that plan is and they know to follow it. We have reviewed a number of cases where people have repeated admissions to hospital, when all the person really wanted was to die peacefully at their home. But the records weren't available or agreed etc

Dignity in death is something that lacks, for people with learning disabilities

# Hertfordshire Themes

## Communication, information and care co-ordination

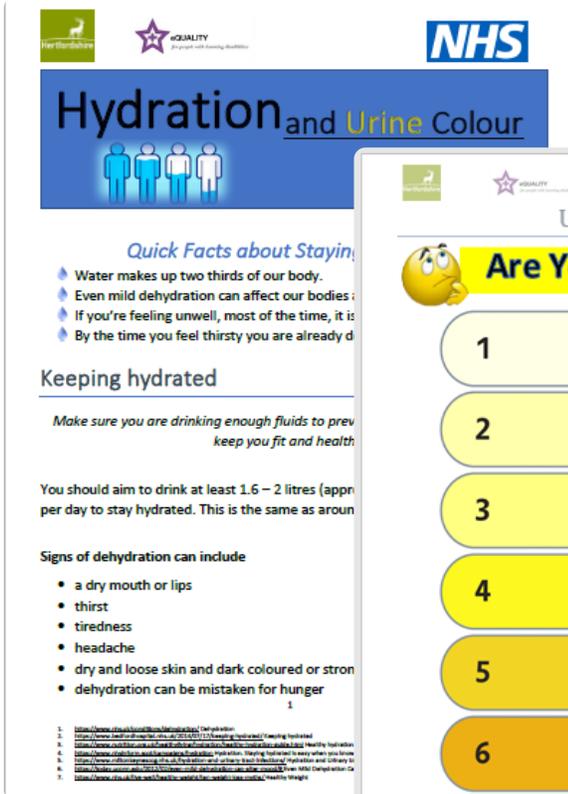
There is often a lack of good communication between services, especially when a person doesn't have a family member to advocate for them and to chase issues up for them. Some people would really benefit from having a care co-ordinator/keyworker/champion that oversees their lives to make sure they receive the support needed. Services do not always have conversations with each other when needed, do not see the bigger picture and call for multi disciplinary help.

Information is often not passed on from one service to another so that assessment are accurate.

Purple folders are a great tool, but they aren't always up to date or accurate or even filled in at all. .... Its all little things that need to be got right that can then have a huge positive impact on a person life.

## Case example - Keith

Service user independently used the toilet. Carers supported Keith to learn that if his wee was ever colours 7 or 8 he must tell the staff. Keith came out the toilet one day and showed the carers his wee was colour 8. After investigation he was diagnosed with cancer of the bladder and started treatment. Without the carers supporting him to know about the colours of wee this would never have been picked up.



**Hydration and Urine Colour**

*Quick Facts about Staying Hydrated*

- Water makes up two thirds of our body.
- Even mild dehydration can affect our bodies.
- If you're feeling unwell, most of the time, it is because you are dehydrated.
- By the time you feel thirsty you are already dehydrated.

**Keeping hydrated**

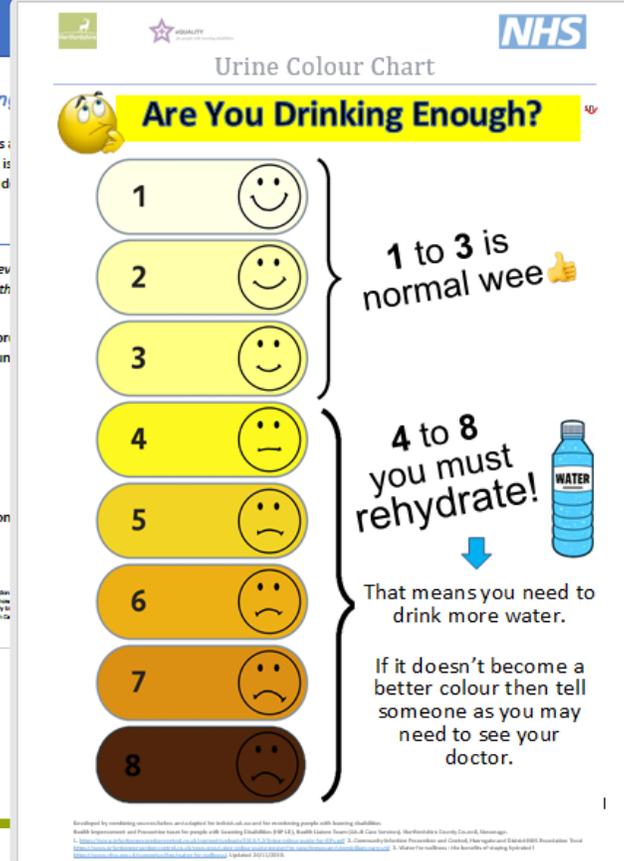
*Make sure you are drinking enough fluids to prevent dehydration and keep you fit and healthy.*

You should aim to drink at least 1.6 – 2 litres (approx) per day to stay hydrated. This is the same as around 8 glasses of water.

**Signs of dehydration can include**

- a dry mouth or lips
- thirst
- tiredness
- headache
- dry and loose skin and dark coloured or strong smelling urine
- dehydration can be mistaken for hunger

1. NHS.uk, 2. NHS.uk, 3. NHS.uk, 4. NHS.uk, 5. NHS.uk, 6. NHS.uk, 7. NHS.uk, 8. NHS.uk



**Urine Colour Chart**

**Are You Drinking Enough?**

1	
2	
3	
4	
5	
6	
7	
8	

**1 to 3 is normal wee** 👍

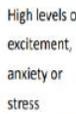
**4 to 8 you must rehydrate!** 🚰

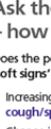
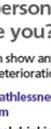
That means you need to drink more water.

If it doesn't become a better colour then tell someone as you may need to see your doctor.

Developed by working in partnership with people with learning disabilities. Health Improvement and Prevention team for people with Learning Disabilities (HPIPLD), Health Improvement and Prevention, Hertfordshire County Council, Stevenage. 1. NHS.uk, 2. NHS.uk, 3. NHS.uk, 4. NHS.uk, 5. NHS.uk, 6. NHS.uk, 7. NHS.uk, 8. NHS.uk

### Spot the 'soft sign' exercise

Constipation       High levels of excitement, anxiety or stress 

Feeling very poorly or like something is really wrong    Being sleepier than normal   Finding it hard to breathe                



Health Education England

The Oliver McGowan Mandatory Training in  
Learning Disability and Autism  
– Oliver's Story

# Core Capability Framework

## Framework for Supporting Autistic People

[Click here to download the framework](#)

[Click here to download the Easy Read version](#)

[Click here to download a summary briefing paper](#)

The framework comprises of 19 capabilities grouped into 5 domains:

Domain A. Understanding autism

Domain B. Personalised support

Domain C. Physical and mental health

Domain D. Risk, legislation and safeguarding

Domain E. Leadership and management, education and research

## Framework for Supporting people with a Learning Disability

[Click here to download the framework](#)

[Click here to download a summary briefing paper](#)

The framework comprises of 25 capabilities grouped into 5 domains:

Domain A. Understanding learning disability

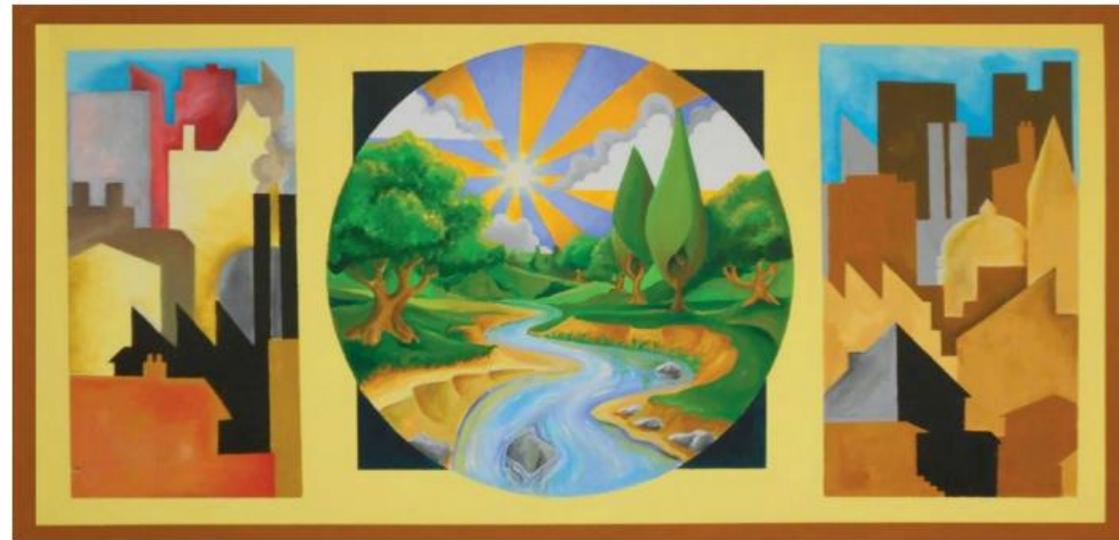
Domain B. Health and wellbeing

Domain C. Personalised care and support

Domain D. Risk, legislation and safeguarding

Domain E. Leadership and management, education and research

# Mental Health Education Framework



Click [here](#) to view

The boxes below are each hyperlinked to their relevant subject summary and outcomes to allow you to quickly view specific subject material. Please note that the greyed boxes are subjects out of scope and as such no outcomes have been recorded in this PowerPoint.

Subject 1: Mental Health Awareness	Subject 2: Establishing positive relationships with individuals who have mental health problems	Subject 3: Promoting general health and well-being for individuals with a mental health problem	Subject 4: Promoting mental health and preventing mental illness	Subject 5: Self-harm and suicide: understanding and prevention	Subject 6: Enabling a recovery focused approach to mental health
Subject 7: Coaching conversations in supporting recovery in mental health	Subject 8: Families, carers and friends as partners in promoting positive mental health	Subject 9: Supporting children and young people with mental health problems	Subject 10: Supporting children, young people and adults with a learning disability and a mental health problem	Subject 11: Mental health identification and assessment	Subject 12: Biopsychosocial formulation in mental health
Subject 13: Appropriate and effective use of medication in mental health care	Subject 14: Using technology to promote positive mental health and deliver effective support	Subject 15: Equality, diversity and inclusion in mental health	Subject 16: Law, ethics and safeguarding in the context of mental health	Subject 17: Research and evidence-based practice in mental health	Subject 18: Leadership in transforming mental health services

# Hertfordshire

---

## **Safeguarding Adults Board**

Training | Offer June 2021

# Mental Health Awareness

- This session will provide an overview of a range of mental health conditions (from the more common anxiety to less common psychosis) including their prevalence, signs and symptoms, causes and how they can affect people. The aim of the course is to help participants recognise the impact that ill mental health can have on individuals. The course will support participants to consider how they can protect their own mental health and wellbeing and that of others. Participants will be made aware of the importance of challenging stereotypes, myths and stigma surrounding mental health and championing inclusion.
- **For bookings please visit our booking website**

# Mental Health Awareness

Date	Availability
1 July 2021 9:30-12:30pm	Places available
14 July 2021 1:30-4:30pm	Places available
21 July 2021 9:30-12:30pm	Places available
26 July 2021 1:30-4:30pm	Places available
15 Sept 2021 9:30-12:20pm	Places available

# Mental Health and Hoarding

- This session will provide a general introduction to the complex topic of hoarding behaviours and hoarding disorder. Delegates will gain knowledge and range of skills to motivate and support individuals that hoard with greater insight into how hoarding presents itself. There will be a focus on managing some of the more practical challenges of supporting individuals who hoard and how to approach this.
- **For bookings please visit our [booking website](#)**

# Mental Health and Hoarding

Date	Availability
8 July 2021 9:30-12:30pm	Places available
19 July 2021 1:30-4:30pm	Places available
22 July 2021 1:30-4:30pm	Places available
8 Sept 2021 9:30-12:30pm	Places available
16 Sept 2021 1:30-4:30pm	Places available

# New Education Programs Starting 2021

## Posture Friends

Culture, enabling and independence, communication, anatomy and physiology, posture and positioning, therapeutic handling and respiratory care.

## Mental Health

Awareness, positive relationships, promoting and prevention, self-harm and suicide, recovery, coaching, medication, technology, laws, ethics and safeguarding.

# Agency Charter of Excellence

Service to support the  
emergency staffing needs of all  
care providers in Hertfordshire

<https://www.hcpa.info/ace/>



[About](#) ▾[Training & Events](#) ▾[Academy](#)[Recruitment](#) ▾[Contact](#) ▾[Members Zone](#)

# Services



Here at HCPA, we offer members a host of fully-funded, low-cost or discounted services to support all areas of your care organisation, either through us directly or via our network of trusted partners.

## I'm looking for support with...

[Agency Charter of Excellence](#)[EU Transition](#)[Insurance](#)[Quality Audits & Mock Inspections](#)[Business Savings & Investments](#)[Executive Coaching](#)[Jigsaw Team Building](#)[Safeguarding Support](#)



The Agency Charter of Excellence Mark is recognition for all staff recruitment agencies who offer care Staff to Adult care provider in Hertfordshire

ACE Mark holders have demonstrated that they:

- Have strong policies and processes in place
- Actively monitor quality and maintain robust quality standards, especially during COVID-19
- Engage & retain good, well-trained candidates or new workers

[If you are a provider wishing to use one of the ACE Mark holders - click here](#)

[If you are a recruitment agency and wish to be an ACE Mark holder – click here](#)

**Type of service offered:**

- All
  Administration
  Care staff
  Cleaners
  Cooks
  Drivers
  Maintenance
  Managers
  Nurses
  Seniors

**Hertfordshire areas covered:**

- All
  East Hertfordshire
  North Hertfordshire
  Three Rivers
  Welwyn Hatfield
  Broxbourne
  Dacorum
  Hertsmere
  Stevenage
  Watford
  St. Albans

Search

**Company****Type of services offered****Areas in Hertfordshire covered**

+

+



247 Lifeline Ltd

Administration, Care staff, Cleaners, Cooks, Managers, Nurses, Seniors

East Hertfordshire, North Hertfordshire, Three Rivers, Welwyn Hatfield, Broxbourne, Dacorum, Hertsmere, Stevenage, Watford, St. Albans

+



ACH Healthcare Ltd

Care staff, Nurses

East Hertfordshire, North Hertfordshire, Welwyn Hatfield, Broxbourne, Stevenage

+



Care4You Direct Limited

Care staff, Cleaners, Drivers, Nurses, Seniors

East Hertfordshire, North Hertfordshire, Three Rivers, Welwyn Hatfield, Broxbourne, Dacorum, Hertsmere, Stevenage, Watford, St. Albans



**HCPA Agency Charter of Excellence Mark**

[businessdevelopment@hcpa.co.uk](mailto:businessdevelopment@hcpa.co.uk)

# Q & A