

# LeDeR Newsletter

A newsletter brought to you by CWICB – February 2023

**Welcome** to our fourth issue of the NHS Coventry & Warwickshire Integrated Care Board (ICB) LeDeR newsletter.

## What is the LeDeR programme?

***Learning from lives and deaths – people with a learning disability and autistic people (LeDeR).***

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

Established in 2017 and funded by NHS England and NHS Improvement, LeDeR works to:

- *improve care for people with a learning disability and autistic people*
- *reduce health inequalities for people with a learning disability and autistic people*
- *prevent people with a learning disability and autistic people from early deaths*

## LeDeR Reviews:

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

Anybody can make a referral to LeDeR, if they believe that a person that has died had a learning disability (and was aged 4+) or was autistic (and was aged 18+).

This can be done via the following link:

<https://leder.nhs.uk/report>

## Our local LeDeR Team:

Hello! My name is Sophie Meszar. I am new to the NHS Coventry & Warwickshire ICB, starting in October 2022 and I am the new Local Area Contact (LAC) for the LeDeR programme, as of January 2023.



I qualified as a Physiotherapist in 2012 and have spent the last 10 years working frontline, most recently as a Clinical Specialist in Acute Paediatrics.

In my role as LAC I will be responsible for overseeing the reviews, abstracting the learning to be had, and implementing this learning across the system. I am really passionate about making positive change and I look forward to the challenge of putting learning into action, as well as recognising the positive practice to be celebrated.

## LeDeR Governance:

We have a dedicated LeDeR Governance Group which takes place on a monthly basis. Senior health and social care representatives from across Coventry and Warwickshire attend the meeting, consider findings of reviews, and oversee an action plan linked to the learning.

Since 1<sup>st</sup> April 2022 (up until 31<sup>st</sup> December 2022), the Coventry & Warwickshire LeDeR Programme has received:

**52 Notifications.**

42 reviews have been completed (22 Initial and 20 Focused) and 8 were out of scope.

There are currently 29 reviews on the system, with 5 on hold whilst we await the outcome of other investigations.

**Key learning taken from reviews:**

- Lack of referrals to get a person's regular care package reinstated whilst they are admitted to hospital, to provide support for the person
- Poorly completed DNACPR and ReSPECT forms
- Lack of follow-ups following a number of *Did Not Attend*s (DNA) from an individual for various appointments
- Delay to/lack of mental capacity assessments.

**Examples of Positive Practice taken from reviews:**

- ✓ *The GP provides an excellent Learning Disability Annual Health Check service. The GP practice uses role plays to ensure that its patients with a learning disability understand what is involved and why*
- ✓ *In the 18 months that this gentleman lived at the care home, he progressed to using a toilet, having regular baths, eating a balanced diet and engaging with staff and medical professionals. Staff from the Community Learning Disability Team stated that the improvement they noticed in him was "huge". The care home staff also raised money for him to have birthday and Christmas presents and they also used their own money to buy him essential items*
- ✓ *The family was very happy with the support provided by the Acute Liaison service and the Community Learning Disability Team*
- ✓ *Care home staff escalated concerns to health care professionals appropriately and in a timely manner.*

In each edition of this newsletter, we will share information based upon a key theme of our LeDeR learning.

Spotlight on:

### The Mental Capacity Act

In a number of LeDeR reviews we have seen a lack of mental capacity assessments being completed. This has meant that a best interest decision has not been undertaken for the individual. These have been for a range of different decisions including:

- DNACPR (Do not resuscitate)
- ReSPECT forms
- Treatment and care whilst in hospital
- Tenancy agreements.

This has meant that unfortunately some decisions have been made on behalf of an individual without following the correct process.

**The Mental Capacity Act** is an important law for people with a learning disability.

It helps make sure that people who may lack capacity to make decisions on their own get the support they need to make those decisions.

Where they are not able to make their own decision, the Mental Capacity Act says a decision must be made that is in their 'best interests'.

#### **The 5 main principles of the Mental Capacity Act:**

1. Always assume the person is able to make the decision until you have proof they are not
2. Try everything possible to support the person make the decision themselves
3. Do not assume the person does not have capacity to make a decision just because they make a decision that you think is unwise or wrong
4. If you make a decision for someone who cannot make it themselves, the decision must always be in their best interests
5. Any decisions, treatment or care for someone who lacks capacity must always follow the path that is the least restrictive of their basic rights and freedoms.

**The Mental Capacity Act Code of Practice** includes four main points to help someone make a decision:

1. Provide relevant information
2. Communicate in an appropriate way
3. Make the person feel at ease
4. Support the person

The Mental Capacity Act sets out a best interests checklist, which must be followed when making a **best interests decision**:

- |                                   |   |
|-----------------------------------|---|
| -Will the person regain capacity? | -Do not make any assumptions.                   |
| -Involve the person               | -Consider past, present and future wishes       |
| -Consult all relevant people      | -Always pick the very least restrictive option. |
| -Consider all the information     |   |

**Useful links/documents for further information and details on the Mental Capacity Act:**

[The Mental Capacity Act - easy read document](#)

[The Mental Capacity Act - Code of Practice](#)

[The Mental Capacity Act - NHS](#)

## Other News & Information:

**1) The Oliver McGowan Mandatory Training** on Learning Disability and Autism has been co-produced, trialled, independently evaluated and will be co-delivered by trainers with lived experience of learning disability and autism.

In July the Health and Care Act 2022 introduced a requirement that regulated service providers ensure their staff receive training on learning disability and autism which is appropriate to the person's role.

Please visit the links below for further details on how to access this training, along with the powerful story of Oliver McGowan and the subsequent campaign which followed, which led to this training being developed and recently rolled out:

- [The Oliver McGowan Mandatory Training on Learning Disability and Autism](#)
- [Oliver McGowan's Story & Campaign](#)

**2) Coventry and Warwickshire Partnership NHS Trust** have produced a new adult and children **Learning Disability and Autism service brochure**, which you can access here:

- [Learning Disability and Autism service brochure](#)

**3) Reasonable Adjustments** can be simple changes made by a healthcare professional. Making reasonable adjustments can mean removing barriers that people with a learning disability and autistic people face (and people with any type of disability) or providing something extra for someone to enable them to access the healthcare they need.

Please watch the short video via the link below, for more information on Reasonable Adjustments, which is performed by people with lived experience:

- [Making Reasonable Adjustments for people with a Learning Disability and Autistic people](#)

## Useful online links:

[LeDeR - Home](#)

(For more information about the national LeDeR programme)

[Coventry & Warwickshire Partnership NHS Trust - Learning Disability Services](#)

(Overview of services, contact details and LD Annual Health Check resources)

[What are Reasonable Adjustments and why are they important?](#)

## KEY CONTACTS

***For further information about our local LeDeR programme, please feel free to contact:***

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Feedback on the usefulness of this newsletter would be welcomed and appreciated, such as whether you find the content useful, whether you feel that anything in particular is missing, or whether you feel that less or more detail is needed. Please email any feedback to [dougie.philippou@nhs.net](mailto:dougie.philippou@nhs.net)