

# LeDeR Newsletter

A newsletter brought to you by CWICB – April 2023

**Welcome** to our fifth issue of the Coventry & Warwickshire Integrated Care Board 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>

## 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.

## LeDeR Team News:

Amy Williams became our new Senior LeDeR Reviewer at the beginning of March 2023, in place of Jennifer Burgin who is now on maternity leave.

We congratulate Amy on securing this role and we wish Jennifer all the best in her time away from work with her new family.

Since 1<sup>st</sup> April 2022 (up until 31<sup>st</sup> March 2023) the Coventry & Warwickshire LeDeR Programme has received:

### **73 Notifications.**

57 reviews have been completed (36 Initial and 21 Focussed) and 9 were out of scope.

There are currently 31 reviews on the system, with 6 on hold whilst we await the outcome of other investigations.

### Key learning taken from reviews:

- There is a need for more learning disability awareness training for primary and secondary care staff.
- Awareness needs to be raised on the importance of advocacy for people with a learning disability, including how this can be accessed by/for people.
- A focus is required on the quality of the learning disability annual health checks that take place.
- It has been identified that pneumonia is the largest cause of death and therefore work is required to focus on this.

### Examples of positive practice taken from reviews:

- ✓ The care home manager spoke very highly of the care provided by the GP practice; they were said to have been responsive to requests, carried out home visits and made reasonable adjustments on multiple occasions.
- ✓ The family spoke highly of the care received in the Intensive Care Unit. There was good communication and the staff were caring.
- ✓ The staff and manager from the care home were great advocates for the person, escalating any concerns to healthcare professionals in a timely manner.
- ✓ There was excellent communication between the care home, the GP practice and the person's family.

### Other News & Information:

#### Learning Disability Annual Health Checks

The Learning Disability Annual Health Check (AHC) programme has continued to see an improvement in the uptake of these health checks over recent years, with our end of year 2022/23 target of 72% set to be exceeded.

Whilst the official data for March 2023 has yet to be published (at the time of creating this newsletter), we are on course to achieve around the 80% mark for AHC delivery, i.e. 80% of people aged 14 yrs. or over on practices' LD registers received an AHC in Coventry & Warwickshire (not taking into account people who declined an AHC or did not attend their appointment).

Subsequently, approx. 95% of the people who received an AHC also received a completed Health Action Plan, which whilst being a high percentage and not inclusive of people who declined a Health Action Plan, we want this to be as close to 100% as possible in 2023/24.

This progress is extremely positive and great to see, particularly as in 2019/20 the AHC uptake in our region was approx. 40%, which saw us as one of the lowest performing regions in the country in that year.

Most importantly however, is that this increase in uptake means that more people with a learning disability are now accessing their health check, which can be of great importance to them and can allow detection of any potential health problems earlier on.

Our focus in 2023/24 is on the quality and consistency of the AHCs being delivered, along with looking at how to engage 'hard to reach' people who have never received an AHC (or not for several years), reducing the number of DNAs and looking at cancer and other types of screening that is offered to people and the uptake of it.

#### LeDeR Focus Group

In April we met with the Grapevine team for our quarterly LeDeR Focus Group, with the focus this time being on Cancer Screening.

There were six Experts by Experience in attendance, three with a learning disability and three who were autistic and the group had a very interesting, engaging and productive session on bowel, breast and cervical screening, discussing what people already know/don't know about them, what barriers there are to accessing screening (and possible solutions to them) and we also looked at available easy-read materials on these types of screening together.

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

**Spotlight on:**  
**Cancer Screening**

Data available from NHS Digital/England suggests that people with a learning disability and autistic people are less likely to receive screening for bowel, cervical and breast cancer, compared to people without these diagnoses.

This difference is smallest for bowel screening and greatest for cervical screening.

People with a learning disability and autistic people can find it difficult to access screening and make an informed choice about being screened. This can be because of:

- practical barriers, including mobility issues and difficulty using appointment systems
- a lack of understanding of instructions, e.g. for the bowel cancer screening kit
- a lack of family or carers to support attendance at screenings
- stress and anxiety about screening
- a lack of knowledge about screening
- communication barriers
- a lack of knowledge among health professionals of the needs of people with a learning disability or autistic people
- a lack of awareness among screening staff about [reasonable adjustments](#), accessible information and other resources to support people with a learning disability and autistic people.

People with a learning disability and autistic people can benefit from:

- being able to access information in easy read format
- healthcare professionals taking time to ensure that they understand what is happening and the choices they can make.

Public Health England produced a [suite of easy guides](#) to help explain screening tests to people with a learning disability and autistic people.

In addition, local providers of bowel, breast and cervical screening services can also direct people who cannot read or do not like written words to the [Beyond Words cancer screening picture stories](#). These resources, which can be downloaded and printed out from the charity's website, include suggested storylines for family members, carers or health professionals to refer to.

Please watch these [3 short video clips of service users with a learning disability talking about screening](#) for a powerful reminder of the importance of focusing on inequalities and reducing barriers to screening.

**Additional online links:**

[Population Screening Timeline - Videos & Reading Materials](#)

[Promoting access to cancer screenings \(for care providers\)](#)  
(scroll down to the *Cancer Screening* section)

[Bowel Screening - Easy read Invitation & Guide](#)

[Breast Screening - Easy read Invitation](#)  
[Breast Screening - Easy read Guide](#)

[Cervical Screening - Easy read Invitation](#)  
[Cervical Screening - Easy read Guide](#)

### **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:**

Sophie Meszar – LeDeR Local Area Contact: [sophie.meszar2@nhs.net](mailto:sophie.meszar2@nhs.net)

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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)**