



**Leicester, Leicestershire
and Rutland**
Integrated Care Board

LeDeR

High Impact Actions

2024 - 2025

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A proud partner in the:



**Leicester, Leicestershire
and Rutland**
Health and Wellbeing Partnership

What are the High Impact Actions?

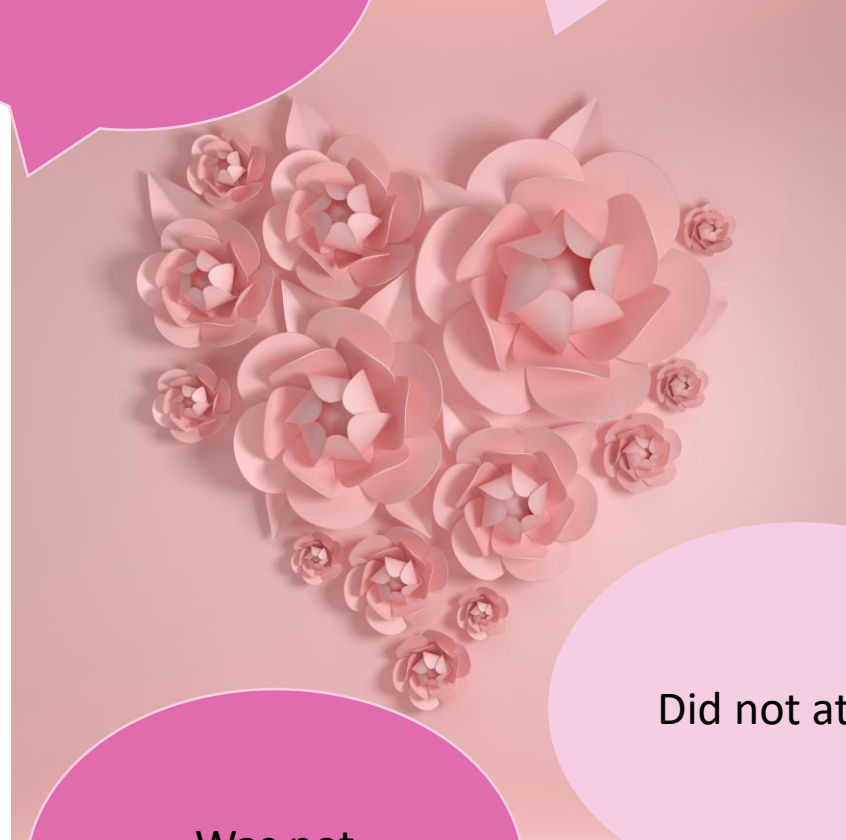
1. **Reduce avoidable mortality** in the 3 clinical priority areas for **Learning Disability and Autism**
 - o **Cancer, Respiratory and CVD.**
2. **Focus on co-morbidities associated with premature death and DNACPR/RESPECT**
3. Assure and Sustain Performance:
 - o LeDeR review completion within 6-month KPI
4. Improve the quality of LeDeR reviews and actions from learning
 - o Facilitate peer review opportunities
5. Improve access and understanding of **importance of LeDeR reviews**
 - o Communicating more with stakeholders encouraging referrals to LeDeR to better understand the experience of LeDeR for families and relevant others particularly **minority ethnic groups** and autistic people
6. Improve accuracy of **Learning Disability Registers** & Increase the quality and **uptake of AHC**
 - o To support continued improvements in data accuracy for thematic analysis
 - o Improve the quality of AHC's

Saira

- Female
- Rett Syndrome
- Profound Learning Disability
- 42yrs
- Cause of death:
 - 1a) Cervical cancer
 - ✗ No cervical screening.
 - ✗ No mental capacity act assessment.
 - ✗ Delays in pain and symptom control.
 - ✗ Stage 4 cancer diagnosis.
 - ✗ No involvement of LD Specialist support

Reasonable adjustments

Would not tolerate



Was not brought

Did not attend

1. Reasonable Adjustments

1. Make reasonable adjustments to improve access to care:

Each partnership and collaborative to establish reporting processes to evidence that:

- A. The Reasonable Adjustment Digital Flag is fully implemented in their pathway and staff are accessing the RADF e-learning resource.
- B. Improvement plans are in place across services to improve access through reasonable adjustment.
- C. Inequality of access to care in their services for the LDA population is reducing.



2. Preventing Avoidable Deaths

2. Intervene earlier to prevent premature death from cardiovascular and respiratory conditions.

Respiratory is the leading cause of death in people with a LD in LLR, nationally it is CVD for both the general population and people with a LD.

A. PCNs to implement improvement plans with the support of the LDA Collaborative to improve access to local early intervention and prevention offers for the LDA population and reduce premature deaths from cardiovascular and respiratory conditions, and cancer.

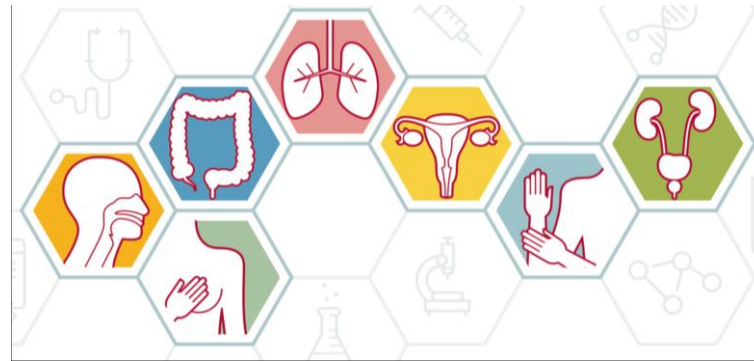
B. The ICB to add an LDA domain developed with the LDA Clinical Lead GP to the Primary Care Quality Assurance Tool used by 85% of practices.



3. Improve cancer screening and earlier diagnosis

3. Improve cancer screening and earlier diagnosis of cancer.

A. The ICB to agree an improvement plan to increase access to cancer screening for people with a learning disability and autistic people in readiness for transfer of the commissioning responsibility for screening from NHSE.



4. Immunisations and vaccinations

4. Improve uptake of immunisation and vaccination

A. The ICB to agree an improvement plan to increase access to immunisations and vaccinations for people with a learning disability and autistic people in readiness for transfer of the commissioning responsibility from NHSE.



5. Quality Assurance

5. Introduce quality assurance processes to stimulate, co-ordinate and monitor improvements in all partnerships/collaboratives and primary care (cross referenced to proposals 1 & 2).

A. The ICB Quality team and LDA Collaborative to co- design with partnership and collaborative clinical leads a single quality indicator and supporting plan to be adopted and reported against by all partnerships and collaboratives.

B. PCNs to agree with the ICB and LDA Collaborative LDA quality indicators and local improvement plans in response to the learning from LeDeR.

C. Scheduled review in July 2025.



Top ten actions you can take to improve the lives and prevent the premature deaths of people with a learning disability and autistic people (aged 18 and over)



1

Inform us when an autistic person or a person with learning disabilities dies. You can do this online at <https://leder.nhs.uk/report>



2

Accurate recording of ethnicity is essential and should be a priority. Please ensure to report the deaths of those from the city and from diverse ethnic backgrounds.



3

Mental Capacity Act assessments really do make a difference - review your practices to ensure compliance and share your experiences.



4

Don't estimate weight - please measure, using appropriate equipment, and record accurately. List of scale locations: <https://urlis.net/i4pw0fy2>



5

Some people have behaviours that challenge which will also change as they grow older. Please put plans of care in place early to support people's behavioural and healthcare needs for life.



6

Have meaningful conversations about end-of-life in advance to ensure people are able to take an active part in discussions about their care.



7

Screening inequities exist, and every effort should be made to improve uptake. Speak to your Primary Care Liaison Nurse for support - lpt.pclin@nhs.net



8

Stop prescribing psychotropic medications unless they are necessary. For STOMP/STAMP enquiries please contact: lpt.ldstomp@nhs.net or lpt.camhs-stomp.stamp@nhs.net



9

Aspiration pneumonia happens as a consequence of a precipitating event. Early identification of risk factors and ongoing management saves lives.



10

Blood tests may sometimes need to be done differently. Do not delay in using reasonable adjustments. Refer to specialist learning disability services if needed -



Use the following link to report to the LeDeR programme:
<https://leder.nhs.uk/report>





Two Important Statements from LeDeR

1. There remains a systemic culture of acceptance with the misuse of the **Mental Capacity Act (2005)** for People with a Learning Disability and Autistic people. LLR LeDeR urges our local system to act now and enforce the MCA and ensure it becomes intrinsic to our everyday care and support to people with a LD and Autistic people.
2. Secondly, people with a Learning Disability are at increased risk of communication and **pain** being misinterpreted or missed altogether and it is essential to safeguard this. There are communication tools/passports and a DISDAT (Disability distress assessment tool) that are readily available for people with a LD. Care providers, particularly those who are either not specialist in the field of LD or who do not know the person well and other services involved in their care must ensure that the communication needs and of upmost importance how pain is communicated by the person are known and prioritised. A priority must be with regard to those individuals who are moved away from their care setting into nursing care providers due to end of life care needs.

What is the ask to the Health and Well Being Board?

- Given that the life expectancy of people with a learning disability is 20yrs younger than the general population in LLR.
- How does the board ensure and that the needs of people with a learning disability and autistic people in LLR are included in every paper, presentation, pathway and service that is delivered?
- Key High Impact Areas:
 - Respiratory (leading cause of death)
 - Cardiovascular (national leading cause of death)
 - Cancer

It is not about a different service, but how we include people in the services we already have.



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