

LLR LeDeR Programme: Take home fact sheet 2024

LeDeR - Learning from the lives and deaths of people with a learning disability and autistic people



Deaths notified to the LLR LeDeR programme

A total of 94 deaths of people with a LD and Autistic people were notified to the LLR LeDeR Programme from 1st April 2023 – 31st March 2024. Of those people:

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- 11 were adults with a learning disability and autism
 - 60 were adults with a learning disability
 - 22 people were out of scope
 - 1 person was autistic

Age at death

66 years

was the median age at death for those who passed away and their deaths notified to LeDeR in 2023/24. This has increased from 62 years last year.

Leading cause of death

- 1.Respiratory (remains the leading cause of death)
- 2.Cardiac
- 3.Cancer and neurological.



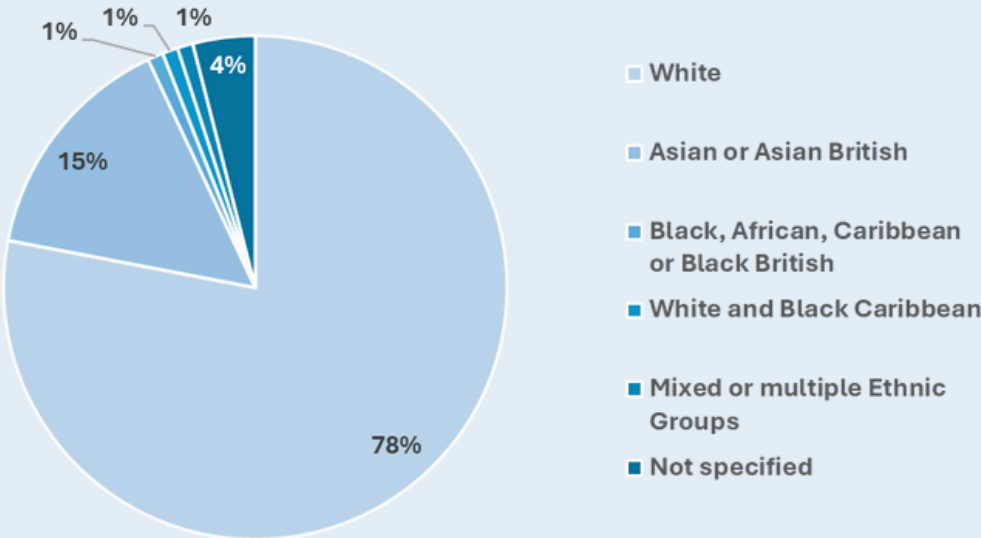
Important statements from LeDeR

- 1.The system in LLR continues to be unsuccessful in the correct use of the Mental Capacity Act (2005) for people with a learning disability and autistic people. LLR LeDeR urges our local system to take action that will improve this.
- 2. People with a learning disability are at increased risk of communication of pain being misinterpreted or missed altogether and it is important to safeguard this.



Ethnicity

The ethnicity of the people of whose deaths were reported were:



The median age of death was 65 years for those from a diverse ethnic background.

Top areas of learning

- Person centred care
- Deteriorating patient
- Care planning

Person centred care reaching the top area of learning for LLR LeDeR is an outstanding achievement and one to be celebrated. There has been an increased focus on improving the care of the deteriorating patient which is still high on the agenda for the coming year.

Positive practice



LLR LeDeR has seen a reduction in the prescribing of psychotropic medication without a STOMP/STAMP review. This is very positive and reflects the hard work of our GP and Psychiatry colleagues and the STOMP/STAMP workstream.



LLR LeDeR has seen a improvements in the number of people who had a positive behaviour support (PBS) plan (81%) where behaviours that challenge were present than those who did not have a PBS plan (19%). This is very positive and shows the hard work from the PBS team and LD Services.

Learning disability annual health checks

over 80% of annual health checks completed in the past year

Significant improvement in uptake of across LLR now moving focus towards quality.

Improving reporting for autistic people

This year there were only two deaths of autistic people completed in the LLR LeDeR Programme and both individuals were male.

This concerning problem is shared nationally. The notifications of deaths of autistic people is a priority and LLR LeDeR have set a quality improvement project on increasing the notifications of the deaths of autistic people.

Intersectionality

Intersectionality continues to be promoted in the LeDeR governance panels and reviews. LeDeR is striving to increase in the learning into action in this area. There are no focused reviews due to being open to the criminal justice system as an offender in five years previous. Most focused reviews are carried out due to diverse ethnicity. There was one death reviewed due to the person being sectioned under the mental health act in the five years' previous.

Thematic analysis

There were four areas of focus for LLR LeDeR during 2023 – 24, which were:

- Concerns around the deteriorating patient and/or concerns around end-of-life care – local priority focused review area
- Leading a Safe Programme – Deaths of those living in care homes
- Weight
- Mental Capacity Act

Venepuncture

LPT LD service has been successful with a grant to run a pilot scheme consisting of a LD Phlebotomy team to offer blood taking to those individuals with a LD unable to use generic phlebotomy services. This will help to improve disease detection and prevention and reduce morbidity and mortality. This is an exciting venture that the team have not seen replicated in other areas of the country.

Screening

Barriers to screening remain for people with a LD and autistic people. In 2023-24 for those eligible for cervical screening, only 9% of people attended - less than last year. The LD PCLN team have worked with one Primary Care Network in LLR who have proposed to run an enhanced service for LD specialist cervical screening clinics into 2023-24.

Vaccinations

77%

of people had their flu jab in LLR

This is an increase of 7% on the previous year.

Covid vaccine

This year there have been no deaths from COVID-19. Most people have had either three or four COVID vaccines, with no-one reporting to have had zero vaccines although there is a group of people this information is unknown.

View the Top Ten Learning into Action points: <https://rb.gy/815lva>

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

