

Update on learning using a case study

LeDeR helps us learn about the lives and deaths of people with a Learning Disability or Autistic Adults. LeDeR wants to reduce the unfair differences in healthcare that can be prevented.

Merlin

Merlin lived at home with his mother and younger sister. He liked going swimming with his mother and sister every week.

Merlin enjoyed support sessions with his support workers every week. He attended a youth club which he loved. Merlin had help in finding transport that could meet his needs so he could attend a music workshop.

Merlin had a mild learning disability and Erythropoietic Protoporphyrria (EPP). EPP is a rare condition that causes extreme sensitivity to sunlight and bright lights. Merlin's skin would burn and blister if he was out in daylight for a long time. His mother had to make sure that lights at home were not bright and their windows were shaded, so his skin was protected.

When Merlin became an adult, his mother felt that everything was left for her to sort out and that there were not many services for people with a learning disability.

When Merlin became an adult, his mother felt that the level of support to coordinate services was much less than when he was a child. She felt that she had to take on more responsibility for arranging Merlin's care, which she said she found difficult.

She also felt that the number of services that were available to support him and other people with a learning disability was much less than when he was a child.

Merlin had regular health checks and monitoring of his condition. Reasonable adjustments were in place. He had appointments at the end of the day, and someone always went with him. However, his mother felt that the annual health checks were basic.

Merlin had support from Community Learning Disability Team (CLDT) to help manage his weight and was given the option to exercise.

About his death:

In early November 2024, Merlin became unwell and was taken to hospital by ambulance.

It was found that Merlin had suffered a bleed on the brain (a stroke). Merlin went into intensive care where doctors said that he would sadly not recover. Days before Merlin had a stroke, he had headaches, and his mother tried to get a GP appointment however she was unable to.

He was looked after in Intensive Care, and a Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) was put in place.

Merlin sadly passed away in the same month.

Good Practice

- Use of pre-health check questionnaire and health action plans
- Good use of reasonable adjustments
- Support from a mental health professional for self-advocacy and confidence building
- Weight management support
- Support finding transport to meet his needs and do things he enjoyed.

Learning

- Help raise awareness of EPP
- Better transition support for people and parents when moving from child services to adult services
- Better access to urgent GP support for people with rare conditions
- Continue work with GP surgeries to make sure Annual Health Checks are detailed and useful.

We would like to thank the families who have kindly given us permission to share the stories of their loved ones to help improve services. The name of this person has been changed to protect their identity.

Learning Disability Annual Health Check Toolkit

Gloucestershire Integrated Care Board (ICB) have developed a Learning Disability Annual Health Check clinical toolkit. This toolkit aims to help health professionals to complete the best quality Annual Health Checks across Gloucestershire.

The toolkit has information around making reasonable adjustments, links to training and support materials and printable health check documents.

View the toolkit here: <http://bit.ly/4mfluqJ>



Numbers to Date (August 2025)

95%



Complete

401 reviews
done since
2017

Out of a total of 421.

LeDeR now reviews the deaths of autistic adults (without a learning disability)

Reviews of autistic people over the age of 18 has been part of the LeDeR process since January 2022. However, Gloucestershire LeDeR are yet to be told about the death of anyone who had autism (without a learning disability).

We can only do a review if LeDeR is told about someone's death. The reviews help improve services and reduce health inequalities. You can tell LeDeR about a death through their website: <https://leder.nhs.uk/report>

Please Note: The notifier will need the person's NHS number.

For more information on LeDeR or to report a death to the programme please visit this website: <https://www.leder.nhs.uk/>

To view the national LeDeR policy in full please follow this link: <https://www.england.nhs.uk/wp-content/uploads/2021/03/B0428-LeDeR-policy-2021.pdf>

To view the national LeDeR policy in easy read please follow this link: <https://www.england.nhs.uk/wp-content/uploads/2021/03/LeDeR-Policy-2021-Easy-Read.pdf>

If you have any feedback on this newsletter, please contact Harriet

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