

**Greater Manchester LeDeR (Learning Disability and Autism)**  
**Annual 2022/2023 Report**

Report of the Associate Director of Nursing, Quality & Safeguarding

## 1. INTRODUCTION AND PURPOSE OF REPORT

Learning from lives and deaths- people with a learning disability and autistic people (LeDeR) is an NHS England (NHSE) service improvement programme.

LeDeR's purpose is to improve the quality of health and social care for people with a learning disability and/or autism and autistic people. LeDeR requires a review of the care received after the death of an adult over 18 years with a learning disability and/or autism, to identify what is working well and what still needs to change. Actions to grow good practice and achieve improvements where needed are agreed.

GM have recently produced the first combined LeDeR annual report as an Integrated Care Board (ICB) for 2022/23. This allowed for wider and more detailed thematic analysis on which to base initiatives and outcomes. The aim remains for people with a learning disability and autistic people across GM to experience good health and good care, and no longer experience health inequalities or die from preventable causes.

### 1. Health Inequalities

Evidence indicates that people with a learning disabilities and autism have poorer health than people without a learning disability and have differences in health status. The health inequalities faced by people with learning disabilities start early in life, and often result from the barriers they face accessing timely, appropriate and effective health care.

The GM report highlights significant health inequalities faced by people with a learning disability and or autism. The median age of death was 62 years with a disparity of 20 years and 25 years for males and females respectively in comparison to the general population.

There were significant associated health conditions noted which included diabetes, epilepsy, hypertension and complex mental health problems with inconsistent care pathways. People with a learning disability are at an increased risk of being overweight or obese compared to the general population and this was evident in at least 26 instances where this information was available.

Respiratory conditions accounted for the most recorded causes of death within GM at 35.9% of the completed reviews. Of these cases, 38.9% were due to aspirational pneumonia with 49.1% due to community or hospital acquired pneumonia. Flu and COVID19 vaccinations uptake remain lower in those with a learning disability than the general population. Circulatory conditions accounted for the second highest cause of death at 15.2%. This included conditions such as Myocardial Infarction (Heart Attack) and Cerebral Vascular Accidents (Stroke) for which is known both hypertension and obesity are significant risk factors.

## 2. Quality of Care

Although there were many initiatives associated with positive practice from the completed reviews, implementation was not universal. Initiatives have been introduced nationally to improve outcomes for people with a learning disability, including annual health checks, health action plans and hospital passports. These initiatives are supported by legislation such as the Mental Capacity Act (MCA) and Best Interests (BI), but there was evidence that these are still being inconsistently applied.

The most recurring themes from completed reviews:

- Inconsistent delivery and follow up of preventative screening and immunisations (Flu, COVID19 and Pneumonia).
- Inconsistent use of health action plans. Not having a health action plan diminishes the likelihood of health improvement in the person.
- Inconsistent use of reasonable adjustments to allow an individual to access health care. This relates to primary, community and inpatient care.
- Management of long-term health conditions was inconsistent.; this especially relates to dysphagia, diabetes, hypertension, epilepsy, weight management and constipation.
- Inconsistent coordination of care when a person was under multiple hospital services.
- Inconsistent discharge planning process from hospital to community.

## 2. CONCLUSIONS AND RECOMMENDATIONS

The findings and key recommendations from the report will form part of the Greater Manchester learning disability and autism physical health strategy for 2023-2025. This will be overseen by the GM Learning Disability and Autism Good Health Group in collaboration with localities.

- A focus on early intervention and prevention, which recognises the impact of intersectionality, including how people will be supported to access structured medication reviews, screening and immunisation.
- Support the delivery of the annual health check and health action plans and enabling improved access for people from a minority ethnic background and other vulnerable groups. Prioritise those individuals who have not had an annual health check in 22/23.
- To ensure reasonable adjustments needs of people are being identified, shared and anticipated.
- To introduce quality and audit cycle to ensure both quality and completeness of annual health checks.
- Scope out dysphagia pathways considering the new clinical guidance from the British Thoracic Society.
- Ensure care providers have up to date knowledge on the management of conditions such as epilepsy, diabetes, healthy weight, and constipation and are aware of the importance of maintaining up to date epilepsy care plans.
- Ensure the quality (completeness, validity, and accuracy) of ethnicity coding for people with a learning disability. All NHS care providers should routinely

and accurately collect ethnicity data relating to people with a learning disability.

- Complete the healthy weight scoping across GM and work collaboratively with partners to ensure mainstream services are accessible for people with a learning disability.
- Raise the profile of the MCA and BI within primary and secondary and social care providers.
- Work with our partners to increase healthcare workers confidence and competence in using the MCA/BI.
- Work with primary care to scope out and develop prevention of adult not brought- Learning Disability and or Autistic People. This is aimed at adults without capacity and primary care appointments.
- To continually learn and deliver change as a result of LeDeR.

2.1 The Health and Wellbeing Board are asked to:

- Ensure there is a robust local system governance (representing both health and local government and including people with lived experience) responsible for overseeing the delivery of the recommendations from the GM LeDeR annual report locally. There will need to be a relationship that allows information to flow between the GM Learning Disability and Autism Good Health Group and the locality in relation to the associated priorities.
- Ensure there is appropriate representation from each of the localities on the GM Learning Disability and Autism Good Health group that can report back on locality progress.

## BACKGROUND PAPERS

Attached in email

Anyone wishing to inspect the above background papers or requiring further information should contact Jemma Billing on telephone number Tel: 07775005603 or alternatively email [J.billing1@nhs.net](mailto:J.billing1@nhs.net)