

HEALTH AND WELL-BEING BOARD
28 SEPTEMBER 2021**Herefordshire and Worcestershire Learning from Lives and Deaths- People with Learning Disability (HW LeDeR) Annual Report 2020/21**

Board Sponsor

Simon Trickett, Chief Executive NHS Herefordshire and Worcestershire CCG/ ICS Lead

Author

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Priorities

Mental health & well-being

Being Active

Reducing harm from Alcohol

Other (specify below)

(Please click below
then on down arrow)

Yes

Yes

Yes

Safeguarding

Impact on Safeguarding Children
If yes please give details

No

Impact on Safeguarding Adults
If yes please give details

No

The HW LeDeR Programme works in alignment with safeguarding processes

Item for Decision, Consideration or Information

Information and assurance

Recommendation

- 1. The Health and Well-being Board is asked to note the HW LeDeR Annual Report for 2020/21, note the intention to develop a LeDeR Strategy during 2021 and agree to receive an annual update on progress against agreed priorities.**

Background

2. People with a Learning Disability continue to be some of the most marginalised individuals within our local communities and experience some of the greatest health inequalities. Data to the end of 2019 (latest available national data) confirms that men with a learning disability die on average 22 years younger than men in the general population and woman die on average 27 years younger. The median age of death is 60 years, the age at which many others may be starting to reflect on and plan for years of happy retirement ahead.

3. LeDeR is a national service improvement programme commissioned by NHS England. The programme was developed following a recommendation of the Confidential Inquiry into the Premature Deaths of People with Learning Disability published in 2013. The programme roll-out was phased across England and commenced in the Midlands during late 2017. The purpose of the programme is to identify and implement learning that will prevent premature death and reduce health inequality for people with a Learning Disability.

4. The programme provides an infrastructure for reviewing the life and death of individuals notified to our system by the national LeDeR web-based platform. Learning, good practice and recommendations are collated from each individual LeDeR Review and analysed into themes to form system priorities for action.

5. The HW LeDeR Annual Report for 2020/21 outlines how as a collaborative partnership we have learnt from the outcomes of reviews, since 2017 and specifically over the last 12 months to April 2021, and how we have started to influence the shaping of services to achieve improvements in outcomes.

6. Key points of learning from 2020/21 data about the lives and deaths of people with a Learning Disability within our Integrated Care System geography

1. 79% of people who died were aged over 50 years- this compares to an England average of 72%. 2% of deaths reported were for those aged 17 years or younger, compared to 7% across England
2. In Worcestershire the median age of death for men improved from 60 years in 2019/20 to 62 years of age in 2020/21.
3. Deaths reported in 2020/21 more closely represented the ethnicity profile of Worcestershire (8% of deaths were for people who represent an Asian, Black or other minority ethnic group). We need to do more to fully understand the ethnicity profile of our Learning Disability population to ensure that we are receiving notifications that reflect the needs of all local people.
4. A greater percentage of people in Worcestershire were able to die in a place other than a hospital bed (less than 40% in 2018/19 to 53% in 20/21). This compares to an average of 41% for LeDeR notifications from across England).
5. As a system we have had a smaller ratio of deaths due to Sudden Death in Epilepsy, sepsis and bowel impaction than the England LeDeR programme average.
6. Deaths linked to cardio-vascular disease have remained fairly static. Analysis of underlying health conditions undertaken this year reflects that all those who had cardio-vascular disease listed in Part 1 of their death certificate also had a high Body Mass Index.
7. The profile of deaths notified during 2020/21 was impacted by COVID-19. Worcestershire reported 9 more deaths during 2020/21 (36 cases) than the average across the previous 2 years. Individuals with COVID-19 listed in Part

1 of their death certificate totalled 8 and were all reported April to June 2020 (one COVID-19 death in wave 2 was reported in 2021/22).

8. LeDeR Rapid Reviews undertaken as part of the LeDeR process enabled us to identify learning that shaped our planning during and following wave 1 of the pandemic and helped us protect more people in wave 2. This included the coordination of COVID-19 testing across Learning Disability care settings ahead of the national offer (to support the identification of asymptomatic cases and reduce outbreaks) and endorsement to offer COVID vaccinations for people with a Learning Disability living in a care setting alongside older people in care settings in JCVI 1.
9. The percentage of cases notified to HW LeDeR with an underlying health condition of epilepsy, cardio-vascular disease, a mental health diagnosis, constipation, dysphagia or for having 3 or more long term health conditions were slightly greater for Worcestershire than the LeDeR England average. We need to do more to understand the profile of health need across the whole of our Learning Disability population to help shape next steps. An updated Joint Strategic Needs Assessment for Learning Disability in 2021 will help us to do this.

7. What we achieved during 2020/21

1. Learning and recommendations extracted from completed reviews are themed to help our LeDeR Learning into Action Group determine key priorities. A workstream (Priority Action Group) is developed for each key priority area.
2. The COVID-19 pandemic resulted in some aspects of workstream activity being paused to enable a focus on emerging areas of significant need.
3. Actions taken (detailed within the Annual Report on pages 34-36) supported the following outcomes:
 - 84.9% uptake of Annual Health Checks achieved by HW Primary Care Networks
 - a coproduced resource pack to support Primary Care Networks to sustain high completion rates and high levels of quality of Annual Health Checks <https://herefordshireandworcestershireccg.nhs.uk/our-work/learning-disabilites-and-autism/annual-health-checks>
 - an increase of 14-25 year olds on GP Learning Disability Registers
 - 88% uptake of COVID-19 vaccination for people with a Learning Disability by the end of March with further increases to exceed 90% into April 2021.
4. Learning extracted from COVID 19 related Rapid Reviews also increased confidence that national media reports of the discriminatory application of Do Not Resuscitate decisions for people with a learning disability were not widespread within our system.

Next steps

8. A new national LeDeR Policy was published in March 2021. Implementation of the Policy is required during 2021/22 and includes revised governance and workforce

arrangements and a broadening of the scope to include all adults with a diagnosis of Autism. A 3 minute video on the revised LeDeR Programme can be viewed here <https://www.youtube.com/watch?v=v2b9ZU-4tRM>

9. The LeDeR Policy 2021 requires that we develop a 3 year LeDeR Strategy. Learning from LeDeR has informed the Learning Disability and Autism 3 Year Plan approved by the Learning Disability Partnership Board and ICS Learning Disability and Autism Programme Board in April 2021.

10. Our priorities for supporting people to develop longer, healthier and happier lives will form the basis of our LeDeR Strategy and are outlined below and in table 6 on page 38 of the Annual Report:

- Emotional well-being and good mental health
- Choice and shared decision making for periods of acute ill-health or toward end of life
- Recognising and responding to health need through Annual Health Checks
- Maximising protection from respiratory conditions
- Good bowel health
- Preventing health needs associated with obesity

11. All priorities are underpinned by the following enabling principles:

- people with lived experience remain at the heart of the LeDeR programme
- Meaningful inclusion and choice informs better health outcomes and decisions (including mental capacity assessment and best interest decisions)
- our system workforce need to be equipped to recognise and respond to the personalised adjustments that enable access and equity
- collaborative working and information sharing achieve great things

Legal, Financial and HR Implications

12. Implications of the new LeDeR Policy will be determined during 2021

Privacy Impact Assessment

13. Not applicable

Equality and Diversity Implications

14. The Learning Disability and Autism work programme aims to reduce discrimination and advance equality of opportunity and outcomes for and with people with a learning Disability or Autism. All commissioning decisions that are informed by the outcomes of the LeDeR programme will be subject to a full Equality Impact Assessment.

Contact Points

County Council Contact Points

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Specific Contact Points for this report

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Supporting Information

Appendix 1- Herefordshire and Worcestershire Learning from Lives and Deaths-
People with Learning Disability (HW LeDeR) Annual Report 2020/21