

Staffordshire Health and Wellbeing Board - 04 March 2021

Safeguarding Adults with Learning Disabilities

Recommendations

The Board is asked to:

- a. Note the evidence of health inequalities for adults with Learning Disabilities dying from COVID-19;
- b. The HWB is asked to consider the findings with a view to initiating activity to understand the causes of the disproportionality and actions to tackle the determinants.

Background - Care Act 2014 considerations for Safeguarding Adult Board (SAB) and Health and Wellbeing Board (HWB)

- 1. Safeguarding Adult Boards (SABs) became statutory under the Care Act 2014 which states that the main objective of a SAB is to assure itself that local safeguarding arrangements and partners act to help and protect adults in its area who:
 - a. Have needs for care and support
 - b. Are experiencing or at risk of abuse and neglect; and
 - c. As a result of those care and support needs are unable to protect themselves from either the risk of, or the experience of abuse and neglect.
- Every SAB must send a copy of its annual report to the Chair of the HWB. It is expected that the HWB will fully consider the contents of the report and how they can improve their contributions to both safeguarding throughout their own work and to the joint work of the SAB.
- 3. The SAB is interested in a range of matters that contribute to the prevention of abuse and neglect of adults with care and support needs and should have an overview of how this is taking place in its area and how this work ties in with the HWB.
- 4. The HWB and the SAB have a mutual interest in ensuring that there is a clear prevention programme to improve health and wellbeing and reduce ill health, in line with the Health and Wellbeing strategy, as well as ensuring a commitment from all partners to the prevention programme and assuring its implementation.

Safeguarding of Adults with Learning Disabilities

- 5. This report draws together the growing evidence of the disproportionate impact of COVID-19 on adults with learning disabilities.
- 6. In June 2020 the <u>Care Quality Commission published national data showing the</u> number of deaths of adults with a learning disability receiving care during



<u>coronavirus</u>. The data shows that between 10 April and 15 May there were 134% more deaths than in the same period last year

- 7. From 10 April to 15 May, the Care Quality Commission received notifications of the deaths of 386 people with learning disabilities from providers delivering specialist services, 134% up on the 165 recorded in the previous year. Most of this difference is covered by the 206 deaths attributed to suspected or confirmed COVID-19.
- 8. The figures also showed that people with learning disabilities were dying from COVID-19 at a much younger age than the wider population. While 89% of people to have died from suspected COVID-19 up to May 22 this year were aged 65 or over, deaths from the disease were highest among people with learning disabilities aged 55-64, who accounted for a third of COVID deaths in the CQC figures. This reflects the 20-year life expectancy gap faced by people with learning disabilities in the UK.
- 9. In September 2020 a report by the Learning Disabilities Mortality Review Programme (LeDeR), which reviewed the circumstances leading to death for a sample of 206 adults with learning disabilities, 79% of whom died from COVID-19 from 2 March to 9 June 2020 found that people with learning disabilities have faced "discriminatory practices" through the pandemic, with data suggesting they died from COVID at six times the rate of the general population during the first wave.
- 10. Of those who died from COVID-19, 82% had a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision. While reviewers felt that the majority of these (72%) were correctly completed and followed, several noted that frailty or learning disabilities were, inappropriately, given as a rationale for a DNACPR decision. Also, several reviewers noted that the decision-making process for DNACPR decisions had not adhered to the Mental Capacity Act (MCA), with no references to capacity assessments having been carried out in a number of cases.
- 11. In November 2020 a report from Public Health England, found that based on cases referred to LeDeR and after adjusting for differences in age and sex, and likely underreporting people with learning disabilities died from COVID at 6.3 times the rate of the general population, from 21 March to 5 June. Both the LeDeR and PHE reports showed that people with learning disabilities were dying from COVID at a much younger age than the general population, reflecting many previous reports showing premature mortality among the group. Those with learning disabilities aged 18-34 were 30 times more likely to die from the virus than the general population in that age bracket, while the age band with the largest number of deaths for people with learning disabilities was 55 to 64 years compared with over 75 for the general population.
- 12. The SAB has recently discussed the findings of the national research with a view to seeking clarification on the situation for adults with Learning Disabilities in Staffordshire. The local findings have some similarities with the published reports prompting a range of questions including - What should be done in relation to the findings? By whom?



- 13. The HWB is asked to consider the findings with a view to initiating activity to understand the causes of the disproportionality and actions to tackle the determinants.
- 14. It is likely that as a society we will be adapting life with COVID-19 for some years to come which adds to the importance of developing an effective response to health inequalities.

List of Background Documents/Appendices:

Appendix 1 - CQC Learning Disability deaths data published June 2020

<u>Appendix 2 - Deaths of people with Learning Disabilities from COVID-19 published by</u> University of Bristol September 2020

<u>Appendix 3 - PHE Report – Deaths of people identified as having died with COVID-19</u> in England in Spring of 2020 published November 2020

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