## KENT AND MEDWAY JOINT HEALTH AND WELLBEING BOARD

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## LEARNING DISABILITY ANNUAL HEALTH CHECKS

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## **Summary**

This report presents an overview of the health inequalities experienced by local people with learning disabilities. In Kent and Medway, it is known that only a quarter of people with a learning disability are on a GP learning disability register, meaning they miss out on extra support which could improve their health. In addition, only 41.7% and 40.8% of people on the register in Kent and Medway respectively in 2017/18 received a learning disability (LD) health check, which aims to provide holistic support and intervention to improve health outcomes. Work is underway in Kent and Medway to improve uptake. Specific opportunities are available to improve the health and wellbeing of people with learning disabilities in prison and to make use of the summary care record (SCR).

#### 1. Budget and policy framework

- 1.1. LD annual health checks are delivered by general practice through a directly enhanced service (DES) commissioned by the NHS. GP Practices do not have to sign up to delivering the LD health checks. Practices are remunerated for the LD annual health checks they provide. Every person aged 14 and over on a learning disability register, is eligible for this service.
- 1.2. NHS England has set a target for GPs and Clinical Commissioning Groups (CCGs) to increase the access to the LD annual health checks, so that by 2020 75% of people on a GP learning disability register in England should have received a check. The recently published NHS Long Term Plan (2019) has also committed to piloting a specific health check for people with autism.

## 2. Background

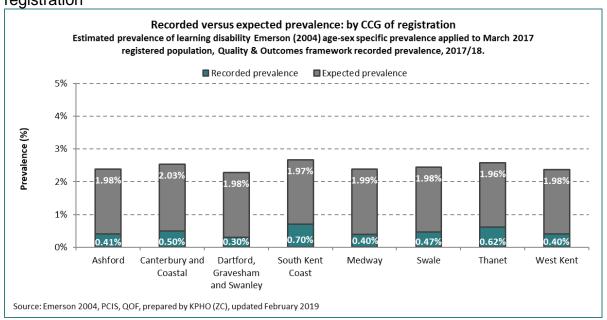
2.1. People with a learning disability have worse physical and mental health than people without learning disabilities. It has been found, on average, that the life expectancy of women with a learning disability is 18 years shorter than women without a learning disability. For men, the difference is 14 years shorter<sup>ii</sup>. In particular, people with a learning disability experience greater levels of multi morbidity, epilepsy and mental health issues. In Kent 18% of persons with learning disabilities have two or more other long term<sup>iii</sup> conditions. There is also evidence of greater inequities in access to care.

#### 3. Advice and analysis

#### 3.1. The learning disability annual health check

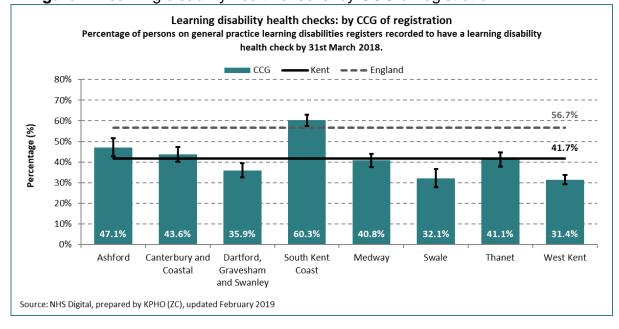
- 3.1.1. The LD annual health check is one tool to help mitigate the health inequalities experienced by people with a learning disability. They have been available since 2008. The LD annual health check is a holistic review of a person's health and wellbeing in its broadest sense, considering any particular diseases, medication, lifestyle and access to preventative healthcare including screening and immunisations. It also helps build a relationship between the practice and the person with a learning disability. Following the LD health check, a health check action plan should be produced.
- 3.1.2. In Kent and Medway, the recorded prevalence of learning disabilities varies by CCG area, ranging from 0.3% in Dartford, Gravesham and Swanley to 0.7% in South Kent Coast. The recorded prevalence is far below the expected prevalence of learning disabilities, resulting in 24,000 people with learning disabilities in Kent alone not being present on a GP register who should be. Figure 1 presents a comparison of expected and recorded prevalence of learning disability by CCG area. This under-recording presents a challenge as it means that in most areas less than a quarter of people with learning disabilities are on a register and therefore eligible for an annual LD health check.
- 3.1.3. Further analysis in Kent has found that older people with learning disabilities are most likely to receive an annual LD health check. A focus on deprivation found that the uptake of LD health checks in 2017/18 was most likely in the most deprived areas.
- 3.1.4. There is evidence that LD health checks have a positive impact on the health of people with learning disabilities, including detecting unmet health needs, taking<sup>iv</sup> a preventative approach to health, increasing referrals to secondary care<sup>v</sup> and reducing preventable emergency admissions. Local analysis for Kent has identified that the rate of non-elective hospital admissions was lower for people with learning disabilities who had received a LD health check. It was also found that for those people with learning disabilities who did have a non-elective admission, the cost of the admission was lower for people who had the LD health check compared to those who had not.

Figure 1: Recorded versus expected prevalence of learning disabilities: by CCG of registration



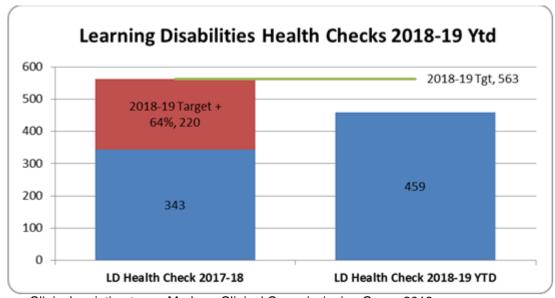
- 3.1.5. The Learning Disabilities Mortality Review (LeDeR Programme) Annual report<sup>vi</sup> cites that more than a third of deaths in people with learning disabilities were potentially amenable to health care interventions. LeDeR is providing evidence in action that the restriction to good quality healthcare is directly restricting people's right to life as people with learning disabilities die younger. Delivery of good quality LD annual health checks in Primary Care are one way that equality of access to good healthcare can be achieved.
- 3.1.6. In Kent the coverage of the learning disability annual health checks is 41.7%, the figure is similar in Medway at 40.8%. This is lower than the England average of 56.7%. Figure 2 presents the variation in coverage of the LD health check, uptake ranges from 31.4% in West Kent to 60.3% in South Kent Coast CCG.

Figure 2: Learning disability health checks: by CCG of registration



3.1.7. The Clinical Variation (CV) Team at Medway Clinical Commissioning Group have been working with General Practice (GP) managers to identify learning disability patients that have not completed a health check within the past twelve months. This has resulted in a total of 459 LD health checks being completed for the period April 2018 to March 2019. This is an increase of 116 health checks (34%) compared to the total number of checks completed in 2017-18. The CV team will continue to work with GP managers during 2019-20 to further increase LD health check uptake, which is currently 40%, to 49% which will bring Medway in line with National uptake. Figure 3 shows the comparative number of LD health checks for 2017/18 and 2018/19.

Figure 3: Learning disability health checks 2018-19 Year to date



Source: Clinical variation team, Medway Clinical Commissioning Group 2019

3.1.8. Further analysis has been undertaken to look at the uptake of health services designed to prevent ill health. Table 1 presents the summary data. The uptake of the seasonal flu immunisation and colorectal screening is similar for those people registered with a learning disability compared to the general population. However, far fewer eligible women with a learning disability are accessing cervical and breast screening services than the general population, in Kent there is a 41.9% gap in uptake for cervical screening, in Medway the figure is 43.7%.

Intervention	England, Kent, Medway-General Population	England LD	Kent LD	Medway LD	CCG Range
Seasonal Flu Immunisation	48.9%, 45.0%, 45.5%	44.7%	42.1%	34.4%	32.3% DGS to 49.4% South Kent Coast
Cervical Screening	71.4%, 74.4%, 73.4%	31.2%	32.5%	29.7%	29.7% Medway to 37.9% Canterbury and Coastal
Breast Screening	74.9%,76.9%, 76.2%	52.5%	47.2%	29.8%	29.1% South Kent Coast To 65.1% Swale
Colorectal Screening	59.0%, 60.6%, 56.9%	77.8%	69.0%	56.5%	53.2% South Kent Coast To 91.7% Thanet

- 3.1.9. Across Kent and Medway, a programme is being planned by NHS England to increase the uptake of cervical screening in eligible women with a learning disability. This will build on initiatives developed in other parts of the country to ensure that people with learning disabilities are supported and receive information in the appropriate way, to make an informed decision about having screening, undergoing the screening itself and receiving the results.
- 3.1.10. In Kent, the Learning Disability Nursing Team have been working to increase the uptake of breast screening. The GP link nurses identify those women with a learning disability in the practices being targeted by the next round of screening. The women are offered support and information in an accessible format.

## 3.2. LD Annual Health Reviews and the NHS Plan

- 3.2.1. In addressing health inequalities for people with learning disabilities the new NHS Plan (2019) has outlined a number of actions that all health and social care economies will need to address<sup>vii</sup>. Amongst these actions is the requirement to:
  - "Increase the uptake of annual health checks in primary care by patients with a learning disability to 75%, and the piloting of health checks for patients with autism a significant proportion of whom will also have a learning disability"
- 3.2.2. Work is currently underway across Kent and Medway to drive up the number of individuals who take up LD annual health reviews (paragraph 3.1.6). Initial findings are that this approach is increasing numbers, however there is a risk that if this initiative is confined to one local area that

improvements in the uptake of annual health reviews will not be seen across the patch.

#### 3.3. **Summary Care Records**

- 3.3.1. Summary Care Records (SCR) are an electronic record of important patient information, created from GP medical records. They can be seen and used by authorised staff in other areas of the health and care system involved in the patient's direct care. SCRs can be accessed through the NHS Spine web portal and as such can provide at a minimum important information in relation to current medication, allergies and patient demographic details. The patient can also choose to include additional important information such as long term conditions or significant medical history.
- 3.3.2. For individuals with learning disabilities and their carers this tool that can be utilised to provide significant information at a time of distress like an A&E visit when remembering all the details may prove challenging. It also ensures that clinical staff can provide safer care that is not delayed as the relevant information is at hand. Often the LD annual health check facilitates the development or refresh of a SCR and as such highlights the importance of the completion of LD annual health checks.

## 3.4. LD Annual Health Reviews and the Criminal Justice System

- 3.4.1. The House of Commons Health and Social Care Select Committee Report Prison Health (2018) identifies that prisoners with learning disabilities form a significant part of the prison population Report authors identified that prison can give an opportunity to identify those with a learning disability that may have previously gone undiagnosed. As such prison health services needed to be adequately equipped to undertake assessment, diagnosis and provide support for people with learning disabilities.
- 3.4.2. In addition, the report recommends that a memorandum of understanding exists with each local authority to address the provision of social care. In this way it is felt that health inequalities amongst people with learning disabilities in the criminal justice system can be systematically addressed.
- 3.4.3. The provision of the LD annual health check sits at the heart of addressing health inequalities for people with learning disabilities (LD). In 2015, 'Equal Access, Equal Care; Guidance for Prison Healthcare Staff treating Patients with Learning Disabilities' was published, outlining the changes and standards for prison healthcare settings to ensure prison healthcare services are on par with services delivered to people with LD in the community<sup>ix</sup> The guidance states that "the mental health team will also work with the primary care team in the development of learning disability registers that will enable an LD annual health check and health action plan to be completed".
- 3.4.4. In carrying out the services the Provider procured by health commissioners and prison governors is "exercising public functions" and as such must pay due regard to the Public Sector Equality Duty under section 149(1) of the Equality Act 2010 to deliver the Services accordingly. In addition, 'parity of esteem' is the principle by which mental health must be given equal priority to physical health. It was enshrined in law by the Health and Social Care

Act 2012 and as such applies to everyone who has a learning disability and a mental health condition<sup>xi</sup>.

- 3.4.5. "The Transforming Care Model Service Specifications: Supporting implementation of the service model" document states that "community support is reliant on interdependencies across the local geography to ensure that needs of the population as a whole are met, either by providing the intervention directly or by supporting colleagues to provide interventions as needed"xii. These interdependencies include links with mainstream services in the community, which can support the various needs that the person has.
- 3.4.6. It is within this policy context that challenges exist across Kent and Medway in ensuring that people with LD, including those within the criminal justice system or who have been released from prison, have access to annual LD health reviews and the development of health action plans. Although the Model Service Specification gives direction as to what provision should look like these directions are not prescriptive and direct readers towards the provision of localised services based on assessed need. With 7 prisons and 1 secure training centre within the Kent and Medway boundaries this is an issue that requires further consideration and discussion, particularly for those who are released into the local community.

#### 3.5. Challenge

- 3.5.1. Members of the Kent and Medway Joint Health and Wellbeing Board are asked to discuss and give their views on how partner organisations can support in the following areas:
  - Increasing the uptake of LD annual health checks
  - Increasing the use of summary care records for people with learning disabilities.
  - How it can be ensured that people with LD including those within the criminal justice system or who have been released from prison have access to LD annual health reviews and the development of health action plans.
  - To increase the registration of people with learning disabilities.
  - To increase the uptake of preventative interventions by people with learning disabilities.

# 4. Risk management

Risk	Description	Action to avoid or mitigate risk	Risk rating
No increase in annual health reviews	Annual health reviews amongst people with learning disabilities in Medway do not increase and as such deaths from avoidable causes continue	Continue to support GP practices to increase the number of people with learning disabilities on their LD registers  Continue to support GP practices to increase the number of annual health reviews for people with learning disabilities  Deliver a targeted social media campaign in Medway to increase the knowledge and awareness of annual health reviews amongst people with learning disabilities and their carers	C2
No increase in the production of summary care records for people with learning disabilities	Clinical teams' access to up to date and relevant clinical information particularly at times of urgency or distress remains limited and impacts negatively on their ability to assess, diagnose and treat people with learning disabilities appropriately. This continues to lead to deaths from avoidable causes	As above  Deliver a social media campaign in Medway to increase the knowledge and awareness of the purpose of summary care records amongst people with learning disabilities and clinical professionals across the board	C2
No links are made with prison health services to support the delivery and uptake of annual health reviews for prisoners and as such deaths from avoidable causes continue	Access and uptake of LD annual health checks for prisoners is unknown and as such the individual and wider societal benefits derived from the annual health checks is unrealised	Risk is that mainstream services in the community continue to have limited contact with prison health services and as such the health and welfare of the learning disability prison population continues to be unknown and as such unsupported by mainstream services.  Agreement needs to be gained across health and social care that work needs to be undertaken with prison services to support the delivery and uptake of annual health checks.	C2

# 5. Financial implications

5.1 There are no financial implications arising directly from this report.

## 6. Legal implications

- 6.1 The Kent and Medway Joint Health and Wellbeing Board has been established as an advisory joint sub-committee of the Kent Health and Wellbeing Board and the Medway Health and Wellbeing Board under Section 198(c) of the Health and Social Care Act 2012
- 6.2 The Joint Board operates to encourage persons who arrange for the provision of any health or social care services in the area to work in an integrated manner and for the purpose of advising on the development of the Sustainability and Transformation Partnership. In accordance with the terms of reference of the Kent and Medway Joint Health and Wellbeing Board, the Joint Board may consider and seek to influence the work of the STP focusing on prevention, local care and wellbeing across Kent and Medway.
- 6.3 The Joint Board is advisory and may make recommendations to the Kent and Medway Health and Wellbeing Boards.

#### 7. Recommendation

7.1 Members of the Kent and Medway Joint Health and Wellbeing Board are asked to support with raising the profile and increasing the uptake of LD annual health checks.

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#### **Appendices**

There are no appendices

## **Background papers**

<sup>&</sup>lt;sup>1</sup> NHS England (2019) The NHS Long Term Plan Available at: https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan.pdf. Accessed [2 April 2019]

ii NHS Digital (2019) Health and Care of People with Learning Disabilities, Experimental Statistics: 2017 to 2018 [PAS]. Available at: <a href="https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/experimental-statistics-2017-to-2018">https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/experimental-statistics-2017-to-2018</a>. Accessed [20 March 2019]

Heslop et al (2013) Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) Available at: <a href="https://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf">https://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf</a>. Accessed [20 March 2019]

iv Robertson, J, Hatton, C, Emerson, E & Baines, S (2014), 'The impact of health checks for people with intellectual disabilities: an updated systematic review of evidence' Research in Developmental Disabilities, vol. 35, no. 10, pp. 2450-2462. Available at: https://doi.org/10.1016/j.ridd.2014.06.007 Accessed [20.03.2019].

<sup>&</sup>lt;sup>v</sup> Buszewicz M, Welch C, Horsfall L, Nazareth I, Osborn D at el. (2014) Assessment of an incentivised scheme to provide annual health checks in primary care for adults with intellectual disability: a longitudinal cohort study. The Lancet Psychiatry; 1(7): 522-530 Available at: <a href="http://dx.doi.org/10.1016/S2215-0366(14)00079-0">http://dx.doi.org/10.1016/S2215-0366(14)00079-0</a>. Accessed [20 March 2019]

vihttps://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/739560/government-response-to-leder-programme-2nd-annual-report.pdf [Accessed 26 April 2019]

vii https://www.england.nhs.uk/long-term-plan/

viii https://www.parliament.uk/business/committees/committees-a-z/commons-select/health-and-social-care-committee/inquiries/parliament-2017/prison-healthcare-inquiry-17-19/

https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/08/equal-access-equal-care-guidance-patients-ld.pdf

xhttps://www.legislation.gov.uk/ukpga/2010/15/contents

xi http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted

xii https://www.england.nhs.uk/publication/transforming-care-service-model-specification-january-2017/