Joint Strategic Needs Assessment Coventry 2015

Consultation on Priority Issues

Central England Law Centre’s Response

Central England Law Centre

1. Coventry Law Centre is the trading name in Coventry for Central England Law Centre Ltd. We have offices in Coventry and Birmingham and we target our services to reach those who are most vulnerable – by which we mean people who are excluded, for example, either by poverty or disability or long term illness, or homelessness, or immigration status.

We hold Legal Aid contracts in Community Care and therefore have significant experience of representing people affected by disability or long term illness.

Premature deaths of people with learning disabilities.

2. The issue on which we wish to focus is the prevention of avoidable premature deaths of people with learning disabilities.

The evidence

3. It is well-established that people with learning disabilities have poorer health than their peers “in part because they have more difficulty in identifying important symptoms and getting access to appropriate care”.

There is clear evidence that average life expectancy is significantly lower and that there are a significant number of premature avoidable deaths.

4. Between 2010 and 2013 the ‘Confidential Inquiry into premature deaths of people with learning disabilities’ (CIPOLD) investigated the events leading to all known deaths of people with disabilities (aged 4 years and older) over a 2-year period in 5 Primary Care Trust areas in South-West England. The Executive Summary to their final report records the following findings:

“The median age of death for people with learning disabilities (65 years for men; 63 years for women) was significantly less than for the UK population of 78 years for men and 83 years for women. Thus men with learning disabilities died, on average, 13 years sooner than men in the general population, and women with learning disabilities died 20 years sooner than women in the general population. Overall, 22% were under the age of 50 when they died.” (Page 2) [Emphasis added.]

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2 “There is consistent evidence that people with learning disabilities (LD) in England die much earlier than the rest of the population and that a large proportion of these deaths are preventable” NHS England, Reducing premature mortality in people with Learning Disabilities http://www.england.nhs.uk/wp-content/uploads/2014/09/info-ld-interventions.pdf
“Of the 238 deaths of people with learning disabilities for which agreement was reached by the Overview Panel, 42% were assessed as being premature.” (Page 3) [Emphasis added.

Preventing premature deaths - reasonable adjustments

5. CIPOLD found that there were two major causal factors contributing to these avoidable deaths (1) the failure to make prompt diagnoses and (2) the failure to provide effective treatments promptly, if at all. They concluded:

“The quality and effectiveness of health and social care given to people with learning disabilities has been shown to be deficient in a number of ways. Despite numerous previous investigations and reports, many professionals are either not aware of, or do not include in their usual practice, approaches that adapt services to meet the needs of people with learning disabilities. The CIPOLD study has shown the continuing need to identify people with learning disabilities in healthcare settings, and to record, implement and audit the provision of ‘reasonable adjustments’ to avoid their serious disadvantage.”(Page 5.) [Emphasis added.]

Annual health checks

6. In 2014, NHS England published guidance “Reducing premature mortality in people with Learning Disabilities: Effective interventions and reasonable adjustments”. It identifies annual health checks for people with learning disabilities as the most “far reaching” adjustment to primary care services because they are “effective at detecting unmet health needs and triggering further health investigations and treatment”.

7. The learning disability annual health check scheme was introduced in 2008, with GPs receiving additional payments for this work. The scheme has been continued year on year, the details (including the requirements of the health check to be undertaken) being set out in the General Medical Services Contract Guidance.

8. Since 2010, Public Health England has produced an annual report on the progress being made implementing the health check scheme. The most recent report, “The Uptake of Learning Disability Health Checks 2013 to 2014”, looks at coverage (i.e. the percentage of the number of people with learning disabilities on the GP registers who received an annual health check) and the extent of GP practice participation.

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4 Publications Gateway Ref No 02142
5 http://www.nhsemployers.org/~/media/Employers/Documents/Primary%20care%20contracts/GMS/GMS%20guidance%202010-present/2015-16/201516%20GMS%20Guidance.pdf
9. Annex 1 to the report provides CCG level data. The report found that, for Coventry and Rugby CCG, only 39% of eligible people with learning disabilities on the participating GPs registers received an annual health check. Furthermore, only 52% of the CCG’s GP practices participated in the scheme.

10. On both measures the CCG fell below the overall national figures. Nationally, 71% of practices were registered to participate in this period and 44% of those eligible and registered received a check.

11. Not only did the CCG fall below the national figures for both measures, but also below the level of coverage and participation achieved by neighbouring CCGs. The overall coverage achieved in the relevant NHS regional team area (Arden Herefordshire and Worcestershire) was 53.7% and practice participation, was 69.3%.

12. The report conclude that the national figures raised “important questions for clinical audit and service planning locally.” [Emphasis added.] (Page 24.)

13. We have undertaken an initial exploration of the implementation of annual health checks in Coventry, and possible causes of the deficiencies in coverage, with Grapevine, an organisation with considerable experience and acknowledged expertise in working with people with learning disabilities.

14. Grapevine’s experience is consistent with the statistical evidence and suggests that the low uptake is not primarily the result of informed and capacitated decisions to decline the offer of a health check. To the contrary, the evidence is that those who are intended to benefit from the checks are unaware of them and do not have the support they need to access them.

15. A Grapevine project worker, working with young people with learning disabilities, reported that she had never heard of any of the young people with whom she works being offered such a check, and, in particular, commented that she was not aware of any of the young women having been offered a smear test, an issue which should, of course, be picked up in an annual check.

16. The Grapevine staff reported that they have seen no evidence of incorporation of annual check-ups in the Education, Health and Care Plans or other standard paperwork.

17. A senior member of staff of the organisation told her story of her son’s experience. He had never been invited for such a check and it was only when she received an email from the Downs Syndrome Association providing information about the scheme that she was able to support her son to request and attend a check with his GP. The practice was registered to provide annual checks but, on the face of it, did not take steps to ensure that the potential beneficiaries were aware of their entitlement or to support them to access the scheme.

18. Concerns were also expressed that adequate health education is not provided, in any systematic way, for people with learning disabilities which, if provided, would facilitate their
understanding of the importance of maintain their health, their entitlement to annual check-ups and how to access appropriate health services.

**Other reasonable adjustments**

19. Annual health checks are only one of the reasonable adjustments that health bodies should make to ensure access to appropriate health services. A list of other “commonly recommended systemic reasonable adjustments” in both primary care and acute health care settings is set out in Annex 1 to NHS England’s guidance on reducing premature mortality:

- Clear identification of people with learning disabilities
- Patient-held records for those with multiple health conditions
- Named healthcare coordinator for people with complex or multiple health needs
- Accessible information for people with learning disabilities and their carers
- Accessible processes to make appointments
- Longer appointment times and planned appointments at beginning/end of day to reduce waiting time within health care setting
- Working in partnership with families and paid carers providing information, inclusion in decision-making, adjusted visiting hours and facilities for overnight stays.
- Proactive access to learning disability liaison specialist staff to remove barriers and facilitate access
- Clear health action plan following annual health check
- Risk assessment and reasonable adjustment action plan when entering acute care
- Advocacy from people with learning disabilities
- Annual audits of scale type and effectiveness of reasonable adjustments
- Training for all staff to promote effective reasonable adjustments

20. As we understand it, there is little information about the implementation of such reasonable adjustments locally. We were interested to learn from Grapevine that they have been requested by the Council to undertake an audit of reasonable adjustments made by GPs in the provision of primary care. This is to be welcomed. However, we understand that they have experienced some difficulties securing access to local practices for this purpose.

21. We were also concerned to learn that the regular training on reasonable adjustments, to which Grapevine, contributed ceased two years ago.

**The JSNA : Coventry City Council’s Consultation**

22. The joint strategic needs assessment (JSNA) currently being undertaken will of course inform the next Joint Health and Wellbeing Strategy (JHWS) for Coventry. The consultation document identifies a number of potential priority issues which will (subject to the outcome of this consultation) inform the drafting of the new strategy. One of the 24 listed potential priority issues is health inequalities. However, within this overall category the only inequality
identified is that between affluent and deprived areas of the city. The consultation material notes that the difference for men is 11.2 years and 8.6 for women. We are concerned that there is no reference to the inequalities in life expectancy experienced by people with learning disabilities (found in the CIPOLD investigation to have been 13 years for men and 20 years for women).

23. The JSNA must of course assess current and future health and social care needs and when preparing the assessment regard must be had to guidance issued by the Secretary of State for Health\(^7\). The current guidance\(^8\) says that health and wellbeing boards will need to consider “how needs may be harder to meet for... vulnerable groups who experience inequalities such as people who find it difficult to access services” (page 8). The evidence clearly demonstrates that this should include people with learning disabilities. The Public Health England report “Joint Strategic Needs Assessments 2014: How well do they address the needs of people with learning disabilities?”\(^9\) makes a number of recommendations for what it describes as “essential” elements for a JSNA, the first of which is that “all JSNAs should contain a section on people with learning disabilities that includes enough information to inform future planning of services and supports”.

24. Section 116 of the Local Government and Public Involvement in Health Act 2007 requires health and well-being boards to have regard to the NHS Mandate when preparing their JHWS. The current Mandate 2015-16\(^10\) includes, as one of its priorities, the prevention of premature deaths. Progress is to be measured by reference to the NHS Outcomes Framework which includes reducing premature death in people with a learning disability, specifically the excess under-60 mortality rate in adults with a learning disability. (See page 9 NHS Mandate.) As noted above, NHS England has issued specific guidance on how to achieve this. The JHWS is, of course, informed by the JNSA. If the latter is silent on this issue, it is likely that the JHWS will also fail to address it, which would be inconsistent with the Mandate’s identified priorities.

Conclusion

25. The issue of premature deaths amongst people with learning disabilities should be included as one of the Coventry JSNA priority issues. Sufficient information should be gathered and included to enable a detailed strategy for reducing premature deaths to be incorporated into the JHWB Strategy 2016.

26. There are a number of aspects of the issue, for example:

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\(^7\) Section 116 Local Government and Public Involvement Health Act 2007
\(^8\) Statutory Guidance on Joint Strategic Needs Assessments and Joint Health and Well Being Strategies” Department of Health 26 March 2013
\(^9\) https://www.improvinghealthandlives.org.uk/publications/1240/Joint_Strategic_Needs_Assessments_2014_How_well_do_they_address_the_needs_of_people_with_learning_disabilities?
• Why are so few local practices participating in the learning disability health check scheme and what can be done to improve participation?

• What steps need to be taken to improve take up? For example, steps need to be taken to ensure that GP practices contact those entitled to a check-up with accessible information about the scheme, how to make an appointment and the support available to attend.

• The reintroduction of regular training on reasonable adjustments for GPs should be considered.

• How could those who are entitled to a check-up be best supported to access the scheme? Investment is needed to improve health education so that it is adequate to help those with learning disabilities understand the importance of looking after their health and how to access their health system including making an appointment.

• What steps could be taken to ensure that those who support people with a learning disability are aware of the annual health check-up scheme and those with professional responsibility to provide care and support do so to ensure that appointments are made and kept? For example, the standard paperwork for (1) adult and children social care assessments and care plans (2) Education Health and Care plans (3) transition assessments and (4) safeguarding should all include a section dealing with annual health checks up to ensure the issue is covered in any relevant assessment and that the support needed by the individual to make and keep the appointment is in place.

27. An audit of reasonable adjustments would, of course, provide valuable information to inform strategic planning. It would be helpful if the assessment could explore the current difficulties experienced by Grapevine in completing this work. In our view, a parallel audit should also be undertaken of NHS Trusts.

28. People with learning disabilities are dying prematurely. This has been known for many years, but the issue was not addressed in Coventry’s 2012 JHWS and, as is clear from the evidence detailed above, effective action is now urgently needed. That action will not be taken unless the issue is prioritised in the JSNA and sufficient information and analysis is provided to ensure that an effective strategy is developed and implemented.

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