

HEALTH AND ADULT SOCIAL CARE SELECT COMMITTEE – 20th NOVEMBER 2008.

REPORT OF THE DIRECTOR OF ADULT COMMUNITY AND HOUSING SERVICES

HEALTH CARE FOR ALL - REPORT OF THE INDEPENDENT INQUIRY INTO ACCESS TO HEALTHCARE FOR PEOPLE WITH LEARNING DISABILITIES

PURPOSE OF REPORT

1. To advise Select Committee of the recommendations contained in Sir Jonathan Michael's report into access to health care for people with learning disabilities.
2. To comment on the PCT's action plan for local implementation

BACKGROUND

3. This report has been published following an inquiry chaired by Sir Jonathan Michael in response to a report from Mencap entitled 'Death by Indifference', which described the experiences of six people who died whilst under NHS care.
4. **The report highlights the following evidence of concerns:**
5. People with learning disabilities find it much harder than other people to access assessment and treatment for general health problems that have nothing directly to do with their disability.
6. There is insufficient attention given to making reasonable adjustments to support the delivery of equal treatment, as required by the Disability Discrimination Act. Adjustments are not always made to allow for communication problems, difficulty in understanding, or the anxieties and preferences of individuals concerning their treatment.
7. Parents and carers of adults and children with learning disabilities often find their opinions and assessments ignored by healthcare professionals, even though they usually have the best information about, and understanding of, the people they support. Their complaints are not heard; they are expected to do too much of the care that should be provided by the health system and are often required to provide care beyond their personal resources.
8. Health service staff, particularly those working in general healthcare, have very limited knowledge about learning disability. They are unfamiliar with the

legislative framework, and commonly fail to understand that a right to equal treatment does not mean treatment should be the same. The health needs, communication problems, and cognitive impairment characteristic of learning disability in particular are poorly understood. Staff are not familiar with what help they should provide or from whom to get expert advice.

9. Partnership working and communication (between different agencies providing care, between services for different age groups, and across NHS primary, secondary and tertiary boundaries) is poor in relation to services for adults with learning disabilities.

10. Although there are examples of good practice, which the report highlights, witnesses described some appalling examples of discrimination, abuse and neglect across the range of health services.

11. The Inquiry investigated the reasons underlying these serious problems in health care for people with a learning disability, and found the following:

12. People with learning disabilities are not visible or identifiable to health services, and hence the quality of their care is impossible to assess. Data and information on this sub-set of the population and their journeys through the general healthcare system is largely lacking and what exists is inadequately co-ordinated or understood.

13. Lack of awareness of the health needs of people with learning disabilities is striking in primary care and this is particularly important since primary care is the single point of access to health promotion and ill health prevention, as well as most health care and treatment.

14. The health needs of people with learning disabilities do not appear to represent a priority for the NHS. Although the Operating Framework for the NHS in England for 2008/9 refers to the need to ensure that appropriate care is provided, the detailed guidance 'Vital Signs' gives this area only Level 3 priority. This means that it is a matter for local not national decision and is not subject to the same rigorous performance management as a national priority.

15. Compliance with the legislative framework covering disability discrimination and mental capacity is not effectively monitored nor performance managed in primary, community, secondary or specialist care services.

16. Healthcare inspectors do not focus specifically on the quality of health services provided for people with learning disability, so they slip through the regulatory net.

17. Despite examples of good practice across the country, the lack of knowledge and information means that timely, appropriate and 'reasonable adjustments' as defined by the disability legislation are not easy to make, even when services are keen to adapt their approach for people with learning disabilities.

18. Training and education about learning disability provided to undergraduates and postgraduate clinical staff, in primary care and in hospital services across the NHS is very limited.

19. Together with the ignorance and fear that is often provoked in the absence of training, these factors reinforce negative attitudes and values towards people with learning disabilities and their carers and contribute significantly to a failure to deliver equal treatment, or to treat people with dignity or respect.

20. The following advisory framework is already in place:

21. New arrangements to monitor compliance by the Commission for Equality and Human Rights.

22. Reform of the General Medical Services (GMS) contract so that general medical practitioners (GPs) can earn points through the Quality and Outcome Framework by establishing a register of their patients over eighteen years old with a learning disability.

23. A primary care service framework for managing the health of people with learning disabilities from Primary Care Contracting.

24. A requirement in the Operating Framework for 2008/9 for all PCTs to develop local action to improve services, including general health services for people with learning disabilities.

25. A focus on health issues in 'Valuing People' and support for local services from the Valuing People Support Team and a series of regional events to promote the primary care framework and support services to develop Local Enhanced Schemes.

26. A range of guidance on health checks, health facilitation, health action planning, the role of community learning disabilities teams (CLDTs), and how to develop Disability Equality Schemes.

27. The Health Care Commission, Mental Health Act Commission and CSCI have recently carried out a Joint Review of Learning Disability Commissioning in by the Council and PCT in Dudley. This programme of reviews has been initiated by the Michael report and other national inquiries and reports which have been critical of health care and social care for people with a learning disability. The report of the Joint Review will be presented to Select Committee in January or March 2009.

28. The Michael report finds that good practice is patchy, but some commissioners and providers have taken steps to improve healthcare for people with learning disabilities as follows:

29. Improved primary care services in Westminster, South Birmingham, Surrey and other parts of the country where Local Enhanced Services Schemes have been, or are being developed.

30. Effective liaison between acute general and specialised services and health facilitation in South Staffordshire and Shropshire Healthcare NHS Foundation Trust, and Humber Mental Health Teaching NHS Trust.

31. Patient records systems in Gloucestershire Partnership Trust, Oldham PCT and Sheffield Teaching Hospital Foundation NHS Trust that signal special needs using a traffic lights scheme.

32. A high quality of teaching for medical students at St. George's University of London with a direct contribution from people with learning disabilities.
33. Local scrutiny of access to health care for people with learning disabilities by Haringey local authority's Overview and Scrutiny Committee.
34. **The Inquiry's recommendations are set out in Appendix 1, together with an action plan for local implementation.** This plan has been approved by the PCT Board and implementation of the plan will be subject of further consultation with the Learning Disability Partnership Board

FINANCE

35. The only significant financial implication for the Council would be further investment in the development of the Special Needs Register to enable the baseline information it contains to be validated and its accuracy and use expanded.

LAW

36. The relevant legislation includes the Human Rights Act, the Disability Discrimination Act 2005, the Mental Capacity Act 2005, and the Care Standards Act 2000.

EQUALITY

37. The recommendations in the action plan for Health Care for All are consistent with the Equal Opportunities policy of the Council.

RECOMMENDATION

38. Health and Adult Care Social Care Select Committee is asked to consider and comment on this report.



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