

Agenda item: [No.]

Cabinet On 19 June 2007

Report Title: Response to the Scrutiny Review of Improving the Health of People with Profound and Multiple Learning Disabilities

Report of: Director of Adult, Culture and Community Services

Wards(s) affected: All Report for: Non Key

1. Purpose

1.1 To respond to the recommendations of the recent scrutiny review

2. Introduction by Cabinet Member

- 2.1 As Executive Member for Social services and Health I welcome the publication of this scrutiny report.
- 2.2 There is clear evidence to show that Adults with learning disabilities (LD), particularly those with profound and complex needs face terrific inequality in accessing many aspects of health care. An action plan has been developed jointly with the Teaching Primary Care Trust (TPCT) to ensure that the recommendations can be implemented in a planned way.

3. Recommendations

- 3.1 That members welcome the recommendations of the scrutiny review
- 3.2 That members agree the action plan as set out in Appendix A

Report Authorised by: Mun Thong Phung, Director of Adult, Culture and Community Services

Contact Officer: Gary Jefferson, Head of Service, Learning Disabilities Partnership. gary.jefferson@haringey.gov.uk, 020 8489 1383

4. Director of Finance Comments

4.1 The Director of Finance has been consulted and there are no specific financial implications arising from this report. The financial implications arising from implementing the action plan will need to be fully identified and reported through financial management processes of the council.

5. Head of Legal Services Comments

5.1 There are no legal implications in the consideration of this report and action plan.

6. Local Government (Access to Information) Act 1985

- 6.1 Report to Scrutiny Committee Improving the health of people with profound and multiple learning disabilities
- 6.2 [Also list reasons for *exemption or confidentiality (if applicable)]

7. Strategic Implications

- 7.1 Adults with learning disabilities (LD) including those with Profound and Multiple Learning Disabilities (PMLD) and people with milder forms of disabilities face clear health inequalities.
- 7.2 Many of the recommendations contained in the report are clearly the responsibility of the local specialist Learning Disabilities Partnership. However for change to take place other non specialist services will need to ensure that that they respond in a positive way to what is proposed.
- 7.3 The report also highlights the needs of carers in their role in ensuring that the person that they care for remains healthy. Many of these people also have poor health themselves which at times affect their ability to care.
- 7.4 The scrutiny review made 21 recommendations and the initial responses to these are outline in Appendix A

8. Financial Implications

8.1 There are no financial implications in the delivery of the recommendations of this review. All change can be achieved from available resources.

9. Legal Implications

9.1 There are no legal implications contained in this report.

10. Equalities Implications

- 10.1 People with PMLD are amongst some of the most disadvantage members of our community.
- 10.2 Within the local population of people with a learning disability there is a higher proportion from certain African/Caribbean and Asian communities than the wider population. For example, there is a higher prevalence of autism amongst the males from African/Caribbean community.
- 10.3 In addition there is a higher prevalence of learning disability in the east of the borough than the west.

11. Consultation

11.1 The review panel included members from the local patient and public Involvement Group, voluntary organisations and staff both from the NHS and local authority.

The National Development Team for Learning Disabilities undertook a detailed consultation with a group of carers of people with a PMLD. This included individual and group interviews together with the keeping of a diary about experiences of accessing health care.

In addition, the review and recommendations have been discussed at the Learning Disabilities Partnership Board, Carers Forum, and Service Users Forum.

All consultations were positive and many people appreciated that their individual experiences were taken into consideration by the review.

12. Background

12.1 The scrutiny review of health services for people with profound and multiple learning disabilities started in May 2006 and was completed in February 2007.

- A health scrutiny review by a panel of members and key stakeholders
- "Action Learning" which looked at how the review worked and the lessons for similar reviews

A vast amount of research was undertaken and the National Development Team for Learning Disabilities undertook a detailed consultation exercise with a sample of eight carers.

12.2 People with learning disabilities have much poorer health than the general population and services have traditionally failed to ensure the health needs of people with learning disability are met

Research has shown that:

The review had two strands:

- People with learning disabilities, particularly people with Down's Syndrome have an increased risk of early death to the general population
- The incidence of deaths from cancer in the UK is currently higher than the general population (26% vs. 11.7% 17.5%)
- Women with learning disabilities are less likely to undergo cervical smear tests than the general population (19% vs. 77%). There is a similar situation for breast cancer examinations.
- People with a LD are affected by Coronary Heart Disease at higher levels than other members of the community.
- Respiratory disease is the leading cause of death for people with learning disabilities (46% - 52% compared to 15% - 17%)
- Health screening when undertaken reveals high levels of unmet physical and mental health needs
- People with learning disabilities are between 8.5 and 200 times more likely to have visual impairment in comparison to the general population
- Prevalence rates for schizophrenia in people with learning disabilities are approximately three times greater than the general population.

12.3 This review concluded that:

- People with learning disability are seen as a low priority in many services.
- Many healthcare staff do not understand much about the differing needs of people with a disability.
- Staff rarely consult or involve families and carers.
- Many people do not get appropriate treatment that would help them as staff are unsure about how people can give their consent.
- Access to complaints are often ineffectual
- People are seen as often only needing help in relation to their learning disability and not wider health needs.
- The needs of carers in how they are able to support somebody is often not taken into consideration

13. Conclusion

- 13.1 The scrutiny review was both wide ranging and timely and has focussed on key issues relating to the health of local residents with learning disabilities
- 13.2 The approach of the review in involving and taking evidence from the local groups and carers is to be welcomed.
- 13.3 We are confident that if the recommendations of this review are implemented many of the barriers that exist to prevent equal access to healthcare for people with PMLD will be reduced.

14. Use of Appendices / Tables / Photographs

Appendix A – Action Plan