



Agenda item:

[No.]

Overview & Scrutiny

On 1st December 2008

Report Title: **Access to Healthcare for Adults with Profound and Multiple Disabilities**

Report of

Mun Thong Phung

Director of Adult, Culture and Community Services

Signed:

PR
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Ward(s) affected: **All**

Report for: **Non-Key Decision**

1. Purpose of the report

1.1. To provide members with an update on action following the Scrutiny Review "Healthy and Equal" - improving the health of people with profound and multiple learning disabilities. This report was agreed in June 2007.

2. Introduction by Cabinet Member (if necessary)

2.1. I endorse the comments in this report and welcome the progress made against the key recommendations.

3. State link(s) with the Council Plan Priorities and actions and/or strategies:

3.1. Background and links to Council Priorities

Evidence suggests that people with learning disabilities have an increased incidence of a wide range of physical and mental health conditions. In particular those people with profound and multiple disabilities face higher health inequalities than other people with learning disabilities and the general population.

The review and subsequent action plan have and will continue to contribute to the council's priorities of:

- 3 – Encouraging lifetime wellbeing at home, work, play and learning
- 4 – Promoting independent living while supporting adults and children when needed.

3.2. Use of Resources and Value for Money

It is generally felt that adults with learning disabilities particularly those with profound and multiple disabilities will require less resources to meet their needs when support is targeted early and is aimed to improve their overall health. For example, if access to learning and leisure is provided many people will maintain good mental health reducing the need for additional resources and perhaps admission to specialist units. However, as there is no 'hard' data or evidence to support this view. Ergo, caution needs to be exercised when considering this viewpoint.

Both locally, pan London wide and indeed nationally there is significant pressure to contain the social care spend on learning disability services largely as a result of the high prices in residential and non residential care commissioning costs. Further work across London is currently taking place to work on more effective 'market management' with the aim of more effective control of the independent sector.

3.3. National Focus

In July 2008 the government's independent enquiry into access to healthcare for people with learning disabilities produced its report – "Healthcare for all"

This report followed the MENCAP report "Death by indifference" which raised concerns about how a number of adults with learning disabilities had died in hospitals as a result of poor practice and neglect. Two scrutiny reviews were considered by the report team as an example of good practice and officers from the Learning Disabilities Partnership and Scrutiny Service gave evidence to the review/inquiry.

4. Recommendations

- 4.1. That members note the action taken since agreement of action plan, including the review of the Personal Medical Service (PMS) contact, improved development of Health Action Planning and the appointment of a Nurse Consultant and subsequent review of specialist nursing in the local Learning Disability Partnership.

5. Reason for recommendations

N/A.

6. Other options considered

- 6.1 As this report is asking members to note progress to date and further action required, it has not been necessary to consider any further options.

7. Summary

7.1 Background to Review

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

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

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

a. The General Health of People with Learning Disabilities

People with learning disabilities have much poorer health than the general population. Research has shown that:

- 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 in learning disabilities from cancer in the UK is currently higher than the general population (26% learning disabilities vs. 11.7% - 17.5% general population);
- Women with learning disabilities are more likely to undergo cervical smear tests than the general population (24% vs. 82%; 19% vs. 77%). There is a similar situation for breast cancer examinations;
- People with a Learning Disability 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; and
- Prevalence rates for schizophrenia in people with learning disabilities are approximately three times greater than the general population.

b. Conclusions of the Review:

The review found evidence to support the following:

- 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; and
- The needs of carers in how they are able to support somebody is often not taken into consideration

c. Summary of action taken

i. Health Action Plans and Review's of service (Recommendation 2)

The format used to review the services provided to adults with learning disabilities has recently been revised and includes a specific section to monitor progress on Health Action Plans.

ii. Specialist Nursing

In July 08, a specialist nurse consultant was appointed by the Learning Disability Partnership and her first task was to undertake a review of specialist Learning Disability nursing across community and in-patient services. The post-holder is also seconded one day per week to the Department of Health to act as lead for the implementation of the National Learning Disability Nursing Strategy.

A review of nursing has been completed and includes revised responsibilities for staff including (Recommendation 17):

- A specific person to liaise with GP's and acute services on admission (Recommendation 3);
- An information pack for GP's due to be launched in early 2009 (Recommendations 5, 4 and 15); and
- Support to improve access to improved screening particularly for inpatient units (Recommendation 6).

iii. Relationships with GP's (Recommendation's 1, 5, 12,13 and 16)

The review noted that for many people their local GP was their main contact with the NHS, following the review the TPCT has recently reviewed its contracting arrangements with GP's to implement a local enhanced service for adults with learning disabilities. This will include funding to provide an incentive to take this up and additional support provided by specialist staff in the Learning Disabilities Partnership. Specifically this will include health checks for all local people with learning disabilities, flexibility in length and time for consultations and better links with treatment of longer term conditions e.g. diabetes.

The review also noted that many of the buildings that were used by GP's did not have full access for people with disabilities. At present contracts between

the TPCT and GP's require all buildings to be fit for purpose and all GP practices as businesses must comply with the Disability Discrimination Act¹.

iv. Access to Aids and Adaptations (Recommendation 7)

The review highlighted that many people with profound and multiple needs did not have access to aids and adaptations. A subsequent review has shown that this often occurs as a result of a lack of clarity about the role of the Council's Adaptation Service and specialist OT's in the Learning Disabilities Partnership. A protocol has been agreed to agree respective responsibilities.

v. Services for Carers (Recommendation's 8, 9, 10 and 14)

The review was particularly concerned about how caring for someone with profound and multiple disabilities often had a significant impact on the health and wellbeing of the carer. The focus of carers' events this year to celebrate carer's week was to improve access to benefits and a number of specific events took place to assist carers to improve benefit take-up. In addition the local Learning Disabilities Partnership has provided funding for carers to have a break in addition, to over 50 people who use planned respite. Our target for providing services to carers is 11% and we are presently achieving 22.4%. The forthcoming review of advocacy services will include a review of advocacy for carers.

vi. Services for Young people (Recommendation 11)

The review highlighted the need for enhanced services for children. The council has signed up to the "Every Disabled Child Matters" campaign; this includes enhanced provision for respite and better planning for transition to adult services.

vii. Community Dental Service (Recommendation 18)

At the time of the review a number of posts in the Community Dental Service were frozen, this made access to specialist dental treatment quite difficult. These posts have now been unfrozen and permanent recruitment is taking place as covered by temporary staff.

viii. Health Action Planning (Recommendation 2)

The review felt that it was essential that the provision of Health Action Plans was available to as many people as possible. Following this an audit took place across the borough to find out what had been happening locally. To date 26% of service users have a health action plan. In addition, over a 120 staff have attended facilitator and awareness training and work is on-going with children services to ensure that all children with disabilities that are moving to adult services have a health action plan. Targets are set and are reported through the normal performance management systems.

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<http://www.dh.gov.uk/en/AdvanceSearchResult/index.htm?searchTerms=disability+discrimination+act>

d. Further action required

Many of the actions required from the review were not just the responsibility of the local authority but our partners in the Teaching Primary Care Trust. Many of these actions required detailed work across complex partnership arrangements and the subsequent review and revision of contracts with local GP's and the work has taken longer than previously anticipated. For example, the revised contracts for GP's which will include an enhanced service for people with learning disabilities will be in place in April 2009.

Since the appointment of the nurse consultant in our local Learning Disability Partnership a great deal of work has been completed in relation to reviewing the service. Initial work has included clarification of responsibilities for nursing the subsequent review of job descriptions and recruitment to posts. A local action plan has been agreed to continue to develop this work particularly in relation to contact with GP's, Primary Care and Mental Health and acute services.

8. Chief Financial Officer Comments

N/A.

9. Head of Legal Services Comments

N/A.

10. Head of Procurement Comments

N/A.

11. Equalities & Community Cohesion Comments

N/A.

12. Consultation

- a. Regular reports on progress against the action plan have been discussed at the Learning Disabilities Partnership Board.

13. Service Financial Comments

- a. All changes within the Learning Disability Partnership have been achieved within existing revenue budget limits.

14. Use of Appendices/Tables and Photographs

- a. No appendices have been used with this report

15. Local Government (Access to Information) Act 1985

- a. **Healthy and Equal** – Improving the health of people with profound and multiple disabilities. A Review by the Overview and Scrutiny Committee
Healthcare for All – Report of the Government Inquiry into access to healthcare for people with learning disabilities.
- b. Copies of all documents are available from the report Gary Jefferson on 0208-489-1688 or gary.jefferson@haringey.gov.uk.