

Agenda item:

**Scrutiny Review on Improving Access to Primary Health Care for People with PMLD on 5 September 2006**

Report Title: **Scrutiny Review on Improving Access to Primary Health care for People with Profound and Multiple Learning Disabilities – Scope/Terms of Reference**

Report of: **Chair of the Review Panel**

Wards(s) affected: **ALL**

**1. Purpose**

To approve the scope and terms of reference for the Scrutiny Review on Improving Access to Primary Healthcare for People with Profound and Multiple Learning Disabilities (PMLD)

**2. Recommendations**

2.1 That the scope and terms of reference for the review be approved

**Contact Officer:** Robert Mack Principal Scrutiny Support Officer, Tel 0208 489 2921

**3. Executive Summary**

3.1 This report outlines the proposed scope and terms of reference of the scrutiny review for on improving access to primary health care for people with PMLD as well as reporting on the action learning project associated with it.

**4. Reasons for any change in policy or for new policy development (if applicable)**

4.1 N/A

**5. Local Government (Access to Information) Act 1985**

5.1 The background papers relating to this report are:

Health Scrutiny Support Programme – Bidding Guidance for Health Scrutiny  
Action Learning Project Funding – Centre for Public Scrutiny

Treat Me Right; Better Healthcare for People with a Learning Disability – Mencap  
Mencap Briefing on Our Health, Our Care, Our Say  
Valuing People with PMLD – PMLD Network

These can be obtained from Robert Mack – Principal Scrutiny Support Officer on  
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## **6. Background,**

### *Health Scrutiny Action Learning Projects*

- 6.1 The Centre for Public Scrutiny was awarded £2.25 million from the Department of Health in November 2003 to run a three year support programme to assist Councillors with their new powers to scrutinise health. As part of this programme, all local authorities have been invited to bid for funding to undertake “action learning health scrutiny projects”. The purpose of this is to develop innovative projects that not only make recommendations to improve the health of local people but also test and evaluate the health scrutiny process locally and share the lessons from this with other local authorities and health partners. This year, Haringey submitted a successful bid on improving access to primary health care for people with profound and multiple learning disabilities (PMLD) and was one of only nine local authorities nationally to be successful.
- 6.2 The project will have two strands;
- A health scrutiny review led by the Review Panel
  - “Action learning” which will be looking at how the scrutiny review is working and, through this, build a shared understanding of what works and why with the aim of developing and sharing these lessons nationally. This will be led a Project Steering Group comprising of key partners as well as members of the Review Panel.

### *Haringey’s Successful Bid*

- 6.3 Bids had to focus upon priorities identified within the government’s White Paper “Our Health, Our Care, Our Say”. Specific reference is made within this to the needs of people with learning disabilities. The White Paper recognises the fact that they face particular health inequalities. Recent research suggests that 2% of the general population have a learning disability but it is estimated that this will increase to 7% by 2021. In addition, there will be a 37% increase in the number of adults with learning disabilities aged over 60. People with a learning disability;
- Are 58% more likely to die before the age of 50 than the general population. They are three times more likely to die from respiratory disease and have higher rates of gastrointestinal cancer and coronary heart disease.

- Have a higher prevalence of certain medical conditions, such as epilepsy, dementia and schizophrenia.
- Are more likely to follow unhealthy lifestyles such as not having a balanced diet and not taking sufficient exercise
- Are generally poor and live on benefits or a low income.

6.4 The White Paper acknowledges that the NHS has historically not served such people well. Many people with a learning disability have a poor experience of using health services and can find it difficult to access mainstream services;

- Not all healthcare professionals may fully understand their needs. Learning disability organisations report that some doctors believe health problems to be the result of the disability and assume that not much can be done about them. Whilst some medical conditions are known to be associated with having a learning disability, most of these can be treated
- They can experience difficulties in obtaining access to routine screening. For example, they are much less likely to have cervical smear tests (19% compared to 77% of the general population). This can lead to undiagnosed or misdiagnosed conditions.
- There can be problems with treatment in hospital if nurses and doctors do not understand their needs. There have been instances of neglect because they have been unable to tell staff that they are in pain as well as problems around feeding.
- It is possible that people with a learning disability can be subject to discrimination involving value judgements being made about their worth. In the most extreme circumstances, treatment can be denied through the use of “do not resuscitate” notices or the failure to make life saving interventions

6.5 There is currently a lack of information on the use by people with learning disabilities of primary health care facilities. Research by Mencap suggests that many primary practitioners may not be well equipped to address the needs of people with learning disabilities with a high percentage of GPs not having received any formal training to assist them.

## **7. Scope:**

7.1 It is intended that the scrutiny review will focus particularly on the needs of people with profound and multiple learning disabilities (PMLD) that are living at home, who can have particular difficulties in accessing primary health care. Access to good quality primary healthcare is a key factor in enabling them to maintain their independence. The health and welfare of their carers is also crucial to them and the review will also focus on how their health can be improved. Due to the increase in life expectancy of people with profound and multiple learning disabilities that has taken place, there are now more instances of them being cared for by elderly carers and this is therefore an even more pertinent issue.

### *Patient and Public Participation*

- 7.2 The views of people with PMLD and their carers about their care should play an important role in determining the kind of services that they receive but they are not always sought. In addition there are particular challenges in consulting effectively with them due to the nature of the disabilities in question. The external funding that has been obtained for this review will enable some specific research and consultation to be undertaken that would otherwise not have been possible.
- 7.3 Part of the of the funding that has been provided is intended for the commissioning of a consultation exercise in order to find out what people with PMLD and their carers think about primary health care services in Haringey and how they think that health professionals could work better with them to improve their health. The purpose of this is to give the Panel some perspective of the challenges faced by people with PMLD and their carers as well as their ideas on how primary care services could be made more responsive to their needs.
- 7.4 The bid stated that the review would commission the following consultation:
- In-depth consultation with a sample group of 10 people with profound and multiple learning disabilities on their views of health services and how they feel that their health needs could better be addressed. This will be undertaken by a researcher with additional specialist assistance in communication.
  - A health diary of 6 people with profound and multiple disabilities which records their contact with health services over a period of six months. This will be done by a researcher working together with carers. It will provide a snapshot of the patient experience from a user perspective that will hopefully illustrate to the review panel of the challenges that can be faced by service users and carers.
  - The setting up of a focus group of carers to obtain their views.
- 7.5 The undertaking of this consultation will require specialist skills. In order not to delay the project unduly, external support for this part of the project has already been sought so that the organisation chosen is in a position to start by the beginning of September. This action has been taken in consultation with the Chair. In addition, it is proposed that other patient and public participation will be undertaken such as consultation with relevant voluntary sector organisations and community groups and the relevant Patient and Public Involvement Forum.

### *Terms of Reference*

- 7.6 The following terms of reference for the review are proposed;

"To work with stakeholders, partners and the local community to develop and undertake a health scrutiny review on improving the access to primary healthcare of people with profound and multiple learning disabilities and their

carers within Haringey that aims to make recommendations to the Council and its partners on;

- Prevention of ill health
- Enhancing the quality of the patient experience
- Cross service approaches to service delivery
- Health promotion"

7.7 The scrutiny review will look strategically at the issues in question and focus on:

- Tackling health inequalities
- Cross cutting themes and "whole system" approaches
- Patient and public engagement
- Local service development

7.8 Whilst the number of people with PMLD is relatively small, their needs are high and therefore any improvement in services can result in a commensurate level of benefit to them and their carers. In addition, many of the issues affecting people with PMLD will be the same as those affecting the comparatively larger numbers of people with less profound learning difficulties.

## **8. Action Learning**

8.1 It is a requirement of funding for action learning to be an integral part of the project and a Project Steering Group has been set up to lead on this aspect. They will be assisted by Gladius Kulothungan, a senior lecturer at the University of East London, who has been appointed to act as a facilitator and undertake an evaluation of the project. He undertook a very similar piece of work last year for Tower Hamlets on their successful Action Learning Project bid.

8.2 The Project Steering Group will meet periodically throughout the scrutiny review to discuss issues and challenges arising and to reflect on progress. The aim of this is to gain a better understanding of what works and why. This will feed into an evaluation that will observe and monitor the project to provide an objective analysis of processes, partnership arrangements and engagement with local decision-makers and the community, including service users and their carers. This will be done through a mixture of participant observation, interviews with key players and reference to relevant documentation such as project plans.

8.3 The evaluation will monitor the key stepping stones in the review, collaborating with the Project Steering Group to identify their expectations and then reviewing how they were met and reasons for outcomes either exceeding expectations or falling short. Particular attention will be paid to the experience of partners, stakeholders and service users who will come into contact with the review. Working in this way, a series of short reports will be produced to provide an ongoing commentary and inform the progress of the project (formative evaluation). These will provide an opportunity to incorporate learning into subsequent stages and feed into a final report. There will also be a subsequent evaluation of the uptake and effectiveness of the recommendations, including feedback to service users and relevant community organisations.

- 8.4 The evaluation will aim to look closely at whether the scrutiny review has had a lasting impact and, in particular;
- If it achieved its objectives
  - Its effects on partnership working and particularly the development of the health scrutiny function
  - Whether it raises the profile of learning disability issues and whether they remain on the political agenda
- 8.5 The learning obtained through this process will be used to help develop both health scrutiny and scrutiny generally within Haringey. In addition, they will be shared nationally with other health scrutineers and as part of the 3 year evaluation of health scrutiny being undertaken by the University of Manchester on behalf of the Department of Health.
- 8.6 A workshop for all of the successful bidders for Health Scrutiny Action Learning Project funding was held at the University of Manchester on 18 July and was attended by the Chair and the lead project officer. The helped to provide a greater level of clarity on the action learning element of the review. An account of this is attached for information as Appendix A. In addition, a baseline report has had to be produced for the University of Manchester as part of the evaluation process. This is attached as Appendix B.

## **9. Overarching Aims/Objectives:**

- 9.1 The following are proposed;
- Developing well informed debate between health scrutineers and service commissioners and providers on the needs of people with profound and multiple learning disabilities within the local community
  - Addressing issues of discrimination
  - Generating a better local understanding of learning disability issues, particularly amongst Members of the Council, the community and media
  - Developing relations between Overview and Scrutiny and local learning disability advocates
  - Contributing to strategic policy for the development of improved services for people with a learning disability, particularly those that address their primary healthcare needs and seek to enhance well being.
  - Assist in the development of a responsive and effective health scrutiny function within the Borough that can provide a link between the community and health services and contribute to local health and social care policy development.

- Develop well informed debate between health scrutineers and service commissioners and providers on the needs of people with profound and multiple learning disabilities within the local community

## **10. Membership;**

### *Scrutiny Review Panel:*

Councillors Emma Jones (Chair), Susan Oatway, Monica Whyte and Richard Wilson.

### *Project Steering Group:*

Members of the Scrutiny Review Panel

Gary Jefferson – Head of Learning Disabilities Service

Chris Eastwood – Head of Occupational Therapy, Haringey Learning Disabilities Partnership

Helen Warner – Haringey PCT PPI Forum

Stanley Hui – HAVCO

Gerry Taylor – Acting Director of Public Health, Haringey TPCT

Rob Mack – Health Scrutiny Lead, Overview and Scrutiny

## **11. Co-options:**

The Review Panel may wish to co-opt additional person(s) to the Panel to assist. The Project Steering Group is recommending that a person with a learning disability be appointed to the review Panel in order that they may have a first hand perspective on the issues that face people with a learning disability in accessing primary health care. The person appointed would be assisted by a facilitator. Such a position would, under the terms of the Local Government Act, have to be on a non-voting basis.

## **12. Proposed Timescale:**

- Stage 1; Defining the scope and strategic context (June – July 2006)
- Stage 2; Consultation with service users and carers (September – October 2006)
- Stage 3; Evidence from service providers (November - December 2006)
- Stage 4; Consolidation of evidence and drafting of conclusions and recommendations (January 2007)

## **13. Key Stakeholders:**

*Council Services;*

Social Services

Children's Services  
Housing Service  
Supporting People

*Partners*

Haringey Teaching Primary Trust  
Barnet, Enfield and Haringey Mental Health Trust

*Voluntary Sector*

Mencap  
The Markfield Project  
HAIL

*Users/Advocacy Groups*

PPI Forum for Haringey Teaching Primary Care Trust

*Key Officers/Partners*

Gerry Taylor - Acting Director of Health Improvement, Haringey Primary Care Trust  
Deborah Cohen - Deputy Chief Executive/Director of Haringey Health Services, Barnet, Enfield and Haringey Mental Health Trust  
Kathy Hostettler – Interim Assistant Director Adults Services  
Gary Jefferson – Head of Service, Learning Disabilities

*The Executive*

Councillor Bob Harris – Executive Member for Health and Social Services

**14. Provisional Evidence Sessions:**

Meeting One: Setting the Scene – 3 October

*Aim:* To gain an understanding of the key issues in respect of the topic to be provided by officers from the Learning Disability Partnership and including:

- How the partnership works
- Definition of PMLD
- Health issues and how they affect people with LD
- Role of primary health care

*Background Information:* Briefing paper from the Learning Disabilities Partnership covering the above issues.

*Possible Witnesses;* Head of Learning Disability Partnership

Meeting Two - 31 October



*Aim:* To obtain the views of voluntary sector organisations and advocates.

*Possible Witnesses;* MENCAP, the Markfield Project, Haringey Association for Independent Living, PPI Forum for Haringey Primary Care Trust

Meeting Three; w.c. 20 November

*Aim:* To receive feedback on the results of the detailed consultation commissioned for the review.

*Background Information:* Briefing paper from researcher outlining results

*Possible Witnesses:* Provider of consultation/research for review.

Meeting Four – 11 December:

*Aim:* To obtain the views of a cross section of the PCT in relation to role of primary care local GPs

*Background Information:*

*Possible Witnesses:* Local GPs, Haringey PCT

Meeting Five: Conclusions and recommendations – 18 January

*Aim:* Sift evidence gathered and make recommendations for improvements.

*Background Information:* Issues paper summing up the evidence received to date as well as highlighting key issues

The panel will have to complete its work by January 2007 in order to fit in with the required timescale.

**15. Visits:**

As an alternative to holding formal meetings, the review panel may wish to visit people or organisations that they wish to receive evidence from.

**16. Key Documentary Evidence:**

The Steering Group may wish to identify any relevant documentary evidence that would be useful for the review panel to refer to.

**17. Publicity:**

- 17.1 The review will provide an opportunity to raise the profile of both learning disabilities issues and health scrutiny locally. Agreement has already been reached with MENCAP Campaigns for them to assist in publicising the outcomes

of the review. The Steering Group may also wish to consider other ways in which the projects could be publicised.