Councillors: *Dogus, Jones (Chair), Oatway and Wilson

* Member present

Also present: Mr. G. Sapiets (NDT), Ms. D Burkens and Ms. H. Warner (Haringey PCT

PPI Forum), Ms. G. Taylor (Haringey PCT) and Mr. G Jefferson

(Haringey Learning Disabilities Partnership.

LC21. APOLOGIES FOR ABSENCE

An apology for absence was received from Councillor Monica Whyte.

LC22. URGENT BUSINESS

None.

LC23. DECLARATIONS OF INTEREST

None.

LC24. MINUTES

It was agreed that the minutes of the meeting of the meeting of 31 October be agreed.

LC25. ACTION LEARNING

The Panel noted that one of the requirements for the funding that had been obtained for the project was that it fed back on what had been learnt about health scrutiny through a process called "Action Learning". This could best be described as learning through doing. Members and stakeholders present were invited to contribute their reflections on the progress of the scrutiny review to date in order to assist in this process. The following points were made:

- There was some confusion concerning the terminology being used. It was not always clear whether evidence referred to people with a Learning Disability (LD) or Profound and Multiple Disability (PMLD). It was noted that PMLD referred to a more severe level of disability then LD. This might be an additional physical disability as well as communication difficulties. People with PMLD could, however, communicate but this might not be by speech.
- Previous scrutiny reviews had sometimes made what appeared to be an excessive number of recommendations which could dilute their effectiveness. In addition, progress in implementing recommendations was not always clear to people from outside of the Council and especially those who had participated. This could lead to the perception that the review had been ineffectual.
- George Sapiets from NDT, who had been commissioned to undertake in depth consultation with people with PMLD and their family carers as part of the review, stated that the selection of participants had worked well. There was a good cross section of people who appeared to be representative of the local

community. NDT felt that it was very commendable that this work was taking place as it was not an area where much work had been done.

The Panel noted that all primary care trusts had recently been written to by the Department of Health on their provision for people with LD in the light of incidents that had taken place in Cornwall. They were being asked to audit their provision. The review would assist in this process and its recommendations would be integrated into the response to the audit.

The Panel discussed the arrangements for the next meeting which was scheduled to provide an opportunity for local primary care practitioners to air their views on how services could be improved. It was agreed that, in addition to GPs, efforts would be made to involve dental services in the discussion. In addition, it was agreed that Leisure Services would be invited to come along to feed back on how they met the needs of people with PMLD and LD as this was relevant to the issue of well being. It was noted that the Children and Young Persons Service had also been invited to come along to the meeting to feed back on the issues raised by the Markfield Project at the last meeting on play provision.

AGREED:

That representatives from the Community Dental Service and Leisure Services be invited to attend the next meeting of the Panel to outline how they provide services for people with LD and, specifically, PMLD.

LC26. ITERIM RESULTS OF CONSULTATION WITH PEOPLE WITH PMLD AND THEIR CARERS

George Sapiets from the National Development Team (NDT) fed back to the Panel on the preliminary results of the consultation that they had undertaken with people with PMLD and their family carers (a short paper outlining the key issues raised during these consultations is attached).

The NDT was originally set up by the Department of Health to bring together expertise on learning disability issues and specialised in assisting a range of clients on such issues. The interim response that they were making would be supplemented by a fuller report in due course. The people that they had spoken to needed other people to facilitate communication and in many ways the responses represented the impressions of the families who had assisted with the consultation.

The Panel noted that it was mainly women who were the principal carers for those people who had been interviewed. It was agreed that efforts would be made to identify a male carer to consult with on some of the remaining two consultations. It was felt possible that the impressions that people had of services might be influenced by their expectations which could be affected by cultural issues.

In respect of Health Action Plans, the Panel noted that only 23% of relevant people currently had them. These were intended to be "person centred" plans that looked at an individuals needs holistically. They were expected to be written by a person who knew the client well. They would be particularly helpful in situations where people were admitted to hospital and would assist in identifying any risk factors and the sort of additional help that might be required. Whilst parents were able to stay with their children whilst they were in hospital, carers of people with PMLD were often effectively obliged to stay with their loved ones all of the time that they were in hospital. This was due to the fact that it was often difficult to provide the level of care necessary to enable them to have some temporary respite.

Transport was often an issue in accessing health provision with some services – e.g. Moorfields Eye Hospital – particularly difficult to get to. It was often hard to get treatment from specialist health services. The Panel noted that there was currently a severe shortage of physiotherapists. Although the Learning Disability Partnership was supposed to have provision for 1.6 specialist physiotherapist, there were currently none in post although efforts were currently being made to recruit. In some cases, parents were paying for private physiotherapy.

There appeared to be a lack of knowledge about entitlement to benefits amongst some family carers. The Panel noted that the Income Maximisation Team in Social Services undertook assessments of entitlements of those people that might be subject to charges for services.

It was noted that the health and well being of carers interviewed had been variable. Some of the carers were getting old and it was important that carer's assessments were regularly updated so that they reflected current circumstances. There were mixed responses concerning the availability of respite with some carers saying that they could not always access it.

The Panel thanked Mr. Sapiets for his presentation. It was agreed that the NDT would be invited to present their final report to the meeting of the Panel scheduled for 18 January.

AGREED;

That NDT be invited to present the final outcomes of the consultation undertaken on behalf of the Panel to the meeting on 18 January.

LC27. PROGRESS WITH REVIEW

Noted.

LC28. NEW ITEMS OF URGENT BUSINESS

None.

CIIr Emma Jones

Chair