

Improving the Health of People with Profound and Multiple Learning Disabilities

March 2007



INVESTOR IN PEOPLE



2005-2006
Getting Closer to Communities

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Executive Summary

This Executive Summary outlines the key findings and recommendations contained in the report of the Overview and Scrutiny Committee's Review on Improving the Health of People with Profound and Multiple Learning Disabilities (PMLD).

Nationally, people with PMLD, as well as those with milder learning disabilities, face clear health inequalities and their numbers are growing. This situation is highly likely to be mirrored within Haringey. There is therefore a sizeable gap that needs closing which is becoming increasingly significant. They are also less able than the wider population to lobby for their needs to be addressed. The Disability Equality Duty should provide an invaluable focus for health and social care services to work towards more equal outcomes. The Panel sees this review and its recommendations as contributing to this overall process and therefore assisting in the important work that is taking place on reducing the health inequalities that currently exist.

The Panel believes that an assertive and proactive approach by service commissioners will be required if the necessary progress in closing gaps is to be achieved. As part of this, consideration should therefore be given by commissioners to new service models and outreach in order to ensure that relevant people receive at least the same standard of healthcare as the wider population. In addition, all providers should be strongly encouraged, through robust standards in contracts, to honour their obligations under relevant disability equality legislation and ensure that their services are fully accessible. Capacity development work also needs to be undertaken to ensure that practitioners are aware of learning disability issues and are able to respond accordingly. There is also a wider need amongst front line staff employed by the Council and its partners to better understand the needs of people with LD.

Joined up working is of particular importance to people for whom communication can be a challenge and who are vulnerable. Health Action Plans should have provided a useful tool to assist. This government commitment has not been delivered to all relevant people as yet but an increase in the use of Health Action Plans within Haringey would help to link health services together as well as providing a holistic plan for improving people's health. There is a specific need to improve liaison with acute care. Clarification over the funding of support and the provision of a specific link person would help to improve this as well as potentially lifting some of the unacceptable burden that can sometimes be placed on carers.

Finally, people with LD are at particular risk from obesity, often have a poor diet and are likely to live on low incomes. Whilst actions to improve public health are very welcome, they can sometimes have the unintended effect of increasing health inequalities as those who suffer from them can be less responsive to their messages or less able to act upon them. The TPCT's obesity strategy should therefore target people with LD as a group at particular risk. Haringey's play and leisure facilities also need to be addressed so that people with LD and PMLD are provided with the same opportunities as others to enjoy and benefit from them.

The Panel reached a number of key findings and recommendations:

Recommendations

Strategic Issues and Co-ordination of Healthcare:

Recommendation 1:

That, as part of further development work on its Disability Equality Scheme (DES) as recommended by the DRC, the TPCT consider the commissioning of appropriate outreach or new service models to ensure that people with LD and PMLD receive at least the same standard of healthcare as that of the wider population.

Recommendations 2:

That, in respect of Health Action Plans;

- A specific target is set by the Learning Disabilities Partnership for increasing the percentage of people with them and that people with PMLD be given the highest priority and are all provided with one within 12 months.
- Annual reviews of people with LD and PMLD undertaken by the Learning Disabilities Partnership of people with LD include a specific monitoring process for Health Action Plan outcomes.

Recommendations 3:

That consideration be given by the Learning Disabilities Partnership to identifying a specific person to provide liaison between hospitals and GPs when people with LD and PMLD are hospitalised.

Recommendation 4:

That the TPCT, as part of the commissioning process with acute trusts, provides clarification on responsibility for the funding of support for people with LD and PMLD when they are admitted to hospital.

Recommendation 5:

That Haringey Learning Disabilities Partnership produce a concise and accessible guidance leaflet for primary care practitioners and other health professionals providing general information and guidance on best practice in working with people with LD and PMLD.

Recommendation 6:

That action be taken to improve take up levels for routine screenings for people with LD and PMLD through:

- the Learning Disabilities Partnership publicising their availability and importance to carers and appropriate support staff and recording and monitoring progress in appropriate care plans, including Health Action Plans; and
- the TPCT, as part of its ongoing work on the DES, recording and monitoring take up levels and setting appropriate targets for improvement.

Recommendation 7:

That all annual reviews of people with LD and PMLD undertaken by the Learning Disabilities Partnership include consideration of the continuing adequacy of aids and adaptations and contingency plans for the continuation of care should carers become unable to continue providing care themselves.

Recommendation 8:

That Carers Assessments undertaken by the Learning Disabilities Partnership routinely assess entitlement to benefits.

Recommendation 9:

That the Learning Disabilities Partnership provide carers with appropriate guidance and training on accessing health services and that relevant information be included within Health Action Plans.

Recommendation 10:

That the Learning Disabilities Partnership considers the establishment of specific support and advocacy for carers to ensure that their needs and welfare are addressed effectively.

Recommendation 11:

That the Council consider signing up to the local authorities charter for the Every Disabled Child Matters campaign.

Service Delivery for People with PMLD

Our recommendations:

Recommendation 12:

That the TPCT works with GP practices within the Borough to ensure that they all have the necessary IT software to create registers of people with LD registered with their practice and that a local target be set by the TPCT for improving the percentage of practices collecting the appropriate information.

Recommendations 13:

That, as recommended by the DRC, the TPCT develops robust disability access and quality standards for inclusion in all contracts with providers in the public, private and voluntary sector to ensure that all services are made fully accessible and sets a specific date by which such new contractual obligations will be introduced.

Recommendation 14:

That the Learning Disabilities Partnership provides advice and guidance to carers and staff escorting people to GP surgeries to routinely request suitable and reasonable adjustments to facilitate access when making appointments for people with LD and PMLD.

Recommendation 15:

That Haringey TPCT, in conjunction with the Learning Disabilities Partnership, provide regular training on LD issues for primary care practitioners, particularly Practice Managers and reception staff, and that people with LD are involved in its planning and design.

Recommendation 16:

That the TPCT consider the nomination of a lead GP for LD issues within each collaborative cluster of GP practices within the Borough and, in particular, the development and sharing of best practice and the provision of appropriate training.

Recommendation 17:

That the LD Partnership review the roles of specialist community nursing in relation to how they support service users and carers accessing general health services and, in particular, acute trusts.

Recommendation 18:

That the reinstatement of dentistry posts within the Community Dental Service that were frozen as part of budget savings required during 2006/7 be made a priority for funding by the TPCT in 2007/8 and that the overall adequacy of current staffing levels within the service be reviewed.

Recommendation 19:

That the obesity strategy currently being developed by Haringey TPCT and its partners specifically address the needs of high risk groups, including people with LD.

Recommendation 20:

That specific targets be set by the Children and Young People's Service in its Play Strategy to monitor progress in achieving equal access to services for children with disabilities.

Recommendation 21:

That the Learning Disabilities Partnership enter into discussion with the Sports and Leisure Service with a view to establishing a scheme for subsidised purchase of active cards for clients.

1. Background To Review

Introduction

- 1.1 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 were invited to bid for funding to undertake “action learning health scrutiny projects”. The purpose of this was to develop innovative projects that not only made 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.
- 1.2 Haringey was one of only 9 local authorities within the country to mount a successful bid in the 3rd. round of this process. The funding was used to provide additional resources for this scrutiny review, which focuses on the health needs of people with PMLD who are a group of people who face very pronounced health inequalities. The funding provided the opportunity to commission work – such as detailed consultation - that would not otherwise have been possible and also undertake a detailed evaluation of our health scrutiny processes.
- 1.3 The project had two strands;
 - A health scrutiny review led by the Review Panel
 - “Action learning” which looked at how the scrutiny review worked. The aim of this is to develop a shared understanding of what works and share these lessons nationally with other practitioners. This evaluation has been undertaken independently and will be reported alongside the scrutiny review.
- 1.4 The scrutiny review focussed particularly on the needs of people with PMLD that are living at home and who can have particular difficulties in accessing primary health care. However, LD covers a range of conditions and needs and many of the issues that affect people with PMLD affect equally people with milder disabilities.

Consultation

- 1.5 Detailed research and consultation was an integral part of the scrutiny review. This was felt to be particularly important as people with PMLD and their carers, as well as those with LD, have few opportunities to air their views. The consultation comprised of:
 - Consultation with individuals; In-depth consultation with a sample group of 8 people with profound and multiple learning disabilities on their views of health services, particularly primary health care, and how they felt that their health needs could better be addressed.
 - Focus Groups; Three focus groups were set up and these aimed to capture the respective perspectives of family carers and health professionals working with families.

- 1.6 This was undertaken by George Sapiets and Bill Love from the National Development Team for Learning Disability. Their role was invaluable. They were able to build an excellent rapport and a trusting relationship with the family carers that they interviewed. Their detailed report on the outcomes of their consultation work is available on request. Its findings and recommendations have been incorporated into our report.

Terms of Reference

- 1.7 The terms of reference for the review were as follows;

"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"

- 1.8 The review looked strategically at the issues in question and focussed on:

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

Aims and Objectives

- 1.9 The overarching aims and objectives of the project were as follows:

- 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.

1.10 The action learning element of the review considers the success of the review in addressing these issues and will enable Overview and Scrutiny to evaluate its processes and make such improvements as might be necessary.

Membership

1.11 The membership of the Review Panel was as follows;

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

1.12 In addition, the Panel was assisted greatly by the input of Helen Warner and Dolphi Burkens from the Haringey TPCT Patient and Public Involvement Forum.

2. Introduction

Learning Disability (LD) and Profound and Multiple Learning Disability (PMLD)

2.1 Learning disability (LD) can be defined as follows:

“A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social function), which started before adulthood and has a lasting effect on a person’s development.”

2.2 This definition is used by Haringey Learning Disabilities Partnership. It is also the one that is used by the Department of Health in its “Valuing People” document on the provision of services to people with a learning disability (LD).

2.3 There are many different types of learning disability and these can be mild, moderate or severe. Some people with a mild learning disability do not need a lot of support whilst other people may need support with a wide range of things, like getting dressed, going shopping, or filling out forms.

2.4 Recent research suggests that 2% of the general population have a learning disability and this currently amounts 1.5 million people in the UK. It is not a condition that people get when they are older – it starts before the age of 18. IQ is generally assessed as being below 70. There is some debate as to whether conditions such as cerebral palsy and autism are in fact learning disabilities. However, the term normally includes Downs Syndrome and a number of other conditions.

2.5 People who have the highest levels of need are often referred to as having “profound and multiple learning disabilities” (PMLD). There are various published definitions of PMLD. The World Health Organisation provides the following one:

“The IQ in this category is estimated to be under 20, which means in practice that affected individuals are severely limited in their ability to understand or comply with requests or instructions. Most such individuals are immobile or severely restricted in mobility, incontinent, and capable at most of only very rudimentary forms of non-verbal communication. They possess little or no ability to care for their own basic needs, and require constant help and supervision”

2.6 People with PMLD generally have lower levels of IQ coupled with some sensory loss and/or physical impairment. There are often particular difficulties with communication.

2.7 By 2021, it is estimated that the percentage of the population with LD will increase to 7%. In addition, there will be a 37% increase in the number of adults with learning disabilities aged over 60 due to an increase in their life expectancy. For example, people with Downs Syndrome had previously only lived until their mid forties but are now living until their early to mid fifties. The oldest person with a learning disability known to Haringey’s Learning Disabilities Partnership is now 83. However, there is a high prevalence of

Parkinson's disease and dementia which means that, although that people with LD are living longer, they are likely to have high overall needs.

2.8 There is general agreement that PMLD is the largest growing part of the population of people with learning disabilities. A number of influences are reported as being responsible for the growth of this part of the population:

- More premature babies surviving
- Medical science prolonging lives that would have been lost in infancy
- People with PMLD are living longer.

Health Inequalities and LD/PMLD

2.9 There is specific evidence to show that people with LD face specific health inequalities.

Research quoted by Mencap has shown that people with LD;

- *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. There are high levels of obesity amongst people with learning disabilities with around 52% being overweight or obese. Only 1 in 10 have a healthy diet whilst 1 in 3 have an unhealthy diet.*

2.10 These findings were also confirmed by the recent report by the Disability Rights Commission (DRC) called "Minding the Gap", which investigates physical health inequalities experienced by people with learning disabilities and/or mental health problems. This found that they are much more likely than other people to have significant health risks and major health problems. Despite being high risks groups, they are also *less* likely to receive the expected checks and treatments than other people.

2.11 The government White Paper "Our Health, Our Care, Our Say" recognises the fact that people with learning disabilities face particular health inequalities and 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 the needs of people with LD. Learning disability organisations report that some doctors believe health problems to be the result of the disability ("diagnostic overshadowing") 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. However, the success of this is dependent on health services having an awareness of these conditions and diagnosing them successfully.

- *They have very low cervical and breast cancer screening rates. For example, the rate of cervical cancer screening is only 19% compared to 77% of the general population.*
- *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.*
- *There is also considerable evidence that that primary care services are not making “reasonable adjustments” in order to make their services more accessible for people with disabilities. These would include simple things like providing information in accessible formats and sending telephone appointment reminders. These have been required by the Disability Discrimination Act since 1999.*
- *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.*

2.12 There is a lack of information on the use by people with LD of primary health care facilities. Research by Mencap also 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.

2.13 The scrutiny review focussed particularly on the needs of people with profound and multiple learning disabilities that are living at home. Their views are rarely sought and are challenging to elicit and, in addition, they have particularly high levels of need. The health and welfare of their carers is also crucial to them and the review also touched upon how their health needs can also be addressed more effectively. 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.

3. Strategic Issues and Co-ordination of Healthcare

Introduction

- 3.1 The health needs of people with LD and PMLD are addressed by a range of different health and social care agencies;
- Haringey TPCT commissions services as well as providing some services itself.
 - Local acute trusts, and in particular the Whittington and North Middlesex hospitals, provide a range of services including in-patient care and diagnostics.
 - There is also significant involvement from the Barnet, Enfield and Haringey Mental Health Trust and the Council through its social services.
- 3.2 However, Haringey Learning Disabilities Partnership is possibly the most significant organisation in terms of the provision of basic health and social care services for people with LD. There are currently around 800 people with a learning disability known to it, of which 514 receive a service. The Partnership provides a range of health and social care services for them. Clients vary considerably in the levels of need that they have. Some people may only need assistance for a short period of time once per month whilst other people may need help from two people around the clock. The partnership works with people who are in residential care as well as people who needed continuing support but live at home.
- 3.3 The Partnership is funded by Section 31 agreement which means that the money from a number of different agencies is pooled in order to provide particular services. The services that comprise the Learning Disabilities Partnership are Social Services, Haringey TPCT and Barnet, Enfield and Haringey Mental Health Trust. The majority of learning disability services are now partnerships. In some cases, this can just mean that they share the same premises, but the Haringey service is completely integrated and covers all aspects of the health and social care of clients. People with learning disabilities are involved in the governance of the partnership, with representation on the Board. The partnership includes dentists and chiropodists amongst their team and they can also visit people in day centres. There was previously a GP in the team but when she retired the post was deleted. People with LD and PMLD therefore generally use mainstream GP practices.
- 3.4 Improving the health of people with PMLD, as well as those with milder learning disabilities, and addressing the health inequalities that exist will require a strategic approach and co-ordinated action by relevant health and social care organisations. People with PMLD are likely to have high levels of need requiring input from a range of agencies and the difficulties that they can often have in articulating their needs themselves means that good communication between professionals is particularly important.

The Disability Equality Duty (DED)

- 3.5 The Disability Equality Duty (DED) came into force in December 2006 and should provide the strategic framework for addressing the health inequalities

experienced by people with LD. It requires all public services to actively promote disability equality by involving disabled people and working towards equal outcomes. As part of this, progress in closing gaps will need to be tracked over time at both local and national level. Disability Equality Schemes (DES) had to be produced by December 2006 and set out detailed plans to close these gaps. Haringey TPCT has produced its DES and this includes an Action Plan that specifies targets and timescales for action during the next three years. These cover a range of activities that aim to promote equality and these, either implicitly or explicitly, aim to address the needs of people with LD.

- 3.6 The Disability Rights Commission (DRC) report demonstrates clearly the fact that, on a national basis, people with learning disabilities have high rates of unmet health needs, which may contribute to their early death. There is strong evidence from our consultation that these national findings are also reflected within Haringey. There is a wide gap that needs to be closed and considerable progress is needed before equality can be achieved. In order to achieve the necessary progress, new ways of delivering services and outreach may need to be considered to ensure that people with LD and PMLD receive primary care to at least the same standard required for everyone. This is a key recommendation by the DRC in its "Closing the Gap" report and the Panel is of the view that the TPCT should adopt this recommendation and include it in its ongoing work on its DES.

Recommendation:

That, as part of its further development work on the Disability Equality Scheme and as recommended by the DRC, the TPCT consider the commissioning of appropriate outreach or new service models to ensure that people with LD and PMLD receive at least the same standard of healthcare as that of the wider population.

Health Action Plans

- 3.7 A key issue that became apparent from the consultations with people with PMLD and their carers was the need for improved planning and co-ordination of healthcare. A lack of this can lead to relevant information not being shared between professionals, difficulty in monitoring take up levels and services sometimes not being able to provide necessary assistance and support for people with PMLD and their carers. In particular, carers had a lack of knowledge or access to Health Action Plans or Person-Centred Plans and a lack of information about how to access health care. Concern was expressed by people consulted that, where planning meetings took place, minutes could sometimes take time to be circulated, leading to delay.
- 3.8 The government White Paper; "Valuing People: A New Strategy for Learning Disability for the 21st Century", which was published in 2001, contained the pledge that all people with a learning disability should have the opportunity to have a Health Action Plan by the summer of 2005. The aim of Health Action Plans was to ensure that all people with a learning disability had help to get the services that they needed from the NHS as it was recognised that they often faced challenges in accessing services. They are intended to address what a person with a learning disability can do to be healthy and aim to make sure that they get the services and support to remain so. Included within it is a list of

people that might be able to help a person with a learning disability to be healthy.

Health Action Plans contain all sorts of information about how a person can be healthy and remain so, such as;

- *How people can get information about their health*
- *How they should look after themselves if they have problems with their health*
- *Who to talk to if they are worried about their health or are in hospital*
- *Advice on diet and exercise*
- *How often to get their eyes, ears and teeth checked*

3.9 The person with LD will normally keep a copy of the Health Action Plan and this version might have easy words and pictures or be on tape. Any person with a learning disability can, in theory, get a Health Action Plan by making an appointment with a health worker such as a doctor or nurse and asking them for a Health Action Plan. The person should take their Health Action Plan with them every time they go for a health appointment.

3.10 Unfortunately, Health Action Plans are still largely not in place. The government has stated that it will review how it intends to deliver on this commitment. There are no statistics available on the number of people nationally have now got them. There also is currently no specific responsibility for GPs to routinely review the health of people with LD, unlike the situation with mental health patients.

3.11 The consultation that the Panel commissioned from NDT revealed that very few of those interviewed had Health Action Plans. The lack of monitoring means that we do not know Haringey's position compared to other local authorities but it appears highly likely that it is very similar position elsewhere. The Panel noted that there were difficulties experienced by the Learning Disabilities Partnership in engaging with primary care and acute trusts to promote the plans locally. Difficulties have also been experienced by practitioners in other local authorities.

3.12 The Panel is of the view that the wider availability of Health Action Plans would provide an important means of addressing the health inequalities that currently exist for people with LD and PMLD. Plans will help to improve co-ordination of healthcare as they can include provision for a named person to lead on such issues. They would be particularly helpful when people are hospitalised and assist hospitals in identifying any risk factors and the sort of additional help that might be required. A basic needs hospitalisation plan could be included which includes provision for respite for carers. In addition, Plans could also play an important role in helping to ensure that routine screenings are undertaken.

3.13 The Panel believes that the use of Health Action Plans should be extended. However, they should be seen as the start rather than the end of the process and they therefore should be outcome based so that progress can be

quantified. A key part of this should be ensuring that follow up action from planning meetings is undertaken within specified timescales. The Learning Disabilities Partnership undertakes annual reviews of all people with LD and we feel that this would be the appropriate time for the issue to be considered.

3.14 The Panel feels that targets should be set for increasing the percentage of people with Health Action Plans and all people with LD should ultimately get them. "Valuing People" stated that it was particularly important for some people that they have a Health Action Plan such as people:

- Making plans to leave school or college
- Moving home e.g. leaving their family home and moving into a group home or living on their own
- Whose health is changing.
- Who are getting older (e.g. approaching retirement age).

3.15 The Panel would endorse this view and feel that particular priority should be given at these key points. People with PMLD should be the highest priority as their needs are the greatest. It should be emphasised that the current situation in Haringey is almost certainly no different from that in other local authorities as this is a national issue.

Recommendation:

- **That, in respect of Health Action Plans;**
 - * **A specific target is set by the Learning Disabilities Partnership for increasing the percentage of people with them and that people with PMLD be given the highest priority and are all provided with one within 12 months.**
 - * **Annual reviews of people with LD and PMLD undertaken by the Learning Disabilities Partnership of people with LD include a specific monitoring process for Health Action Plan outcomes.**

Liaison Between Primary and Acute Care

3.16 A particular area of concern that was raised by families consulted concerned the level of support provided when a person with PMLD has to attend hospital or is admitted for treatment. People with PMLD will have high individual personal care needs, such as needing help with eating and toileting. There is also likely to be a need for basic monitoring and supervision as these are often vulnerable people who could be at risk if left alone. Many of those interviewed felt that there was a general assumption by many hospitals that family carers could provide the necessary support for 24 hours a day. In addition, when family members stayed overnight, there was often nowhere where they could rest comfortably. Finally, carers felt that there could also be a general lack of awareness of LD issues within hospitals and, in particular, a lack of appreciation of the challenges posed by communication.

- 3.17 Carers interviewed stated that they would be prepared to travel further if it meant that better in-patient care could be provided. One particular suggestion was the possibility of having specialist care units within hospitals for people with LD and PMLD, which were closely linked to other hospital departments. This would mean that their personal care will be carried out by people who fully understood their needs with medical care will still being carried out by the relevant clinical specialists
- 3.18 The Panel also noted the evidence from Haringey Association for Independent Living (HAIL) who reported that insufficient support whilst in hospital could have long term adverse effects on people. They stated that they were aware of service users who were continent before going into hospital but who came out doubly incontinent, as they had not been supported fully in basic care.
- 3.19 The Panel noted that the London Borough of Barnet has a system whereby a nurse employed by the Disabilities Partnership provides a link between the hospital and the GP when clients are hospitalised and that this appears to work well. It was also noted there is currently a lack of clarity about who is liable for the cost of providing additional support – is it the TPCT or the hospital or, indeed, the Council? The confusion caused by this can result in difficulties in ensuring that appropriate support is provided. This issue needs urgent clarification and the appropriate mechanism for resolving this issue would be through the commissioning process.
- 3.20 A response to the NDT consultations has been received from the North Middlesex Hospital who reported that they were currently reviewing the support that they provided to people with LD. Ideally, they would like to appoint a specific person to co-ordinate support for people with LD but this was unlikely to be feasible in the short term due to the funding position of both the hospital and the TPCT.

Recommendations:

- **That consideration be given by the Learning Disabilities Partnership to identifying a specific person to provide liaison between hospitals and GPs when people with LD and PMLD are hospitalised.**
- **That the TPCT, as part of the commissioning process with acute trusts, provides clarification on responsibility for the funding of support for people with LD and PMLD when they are admitted to hospital.**

General Guidance and Information

- 3.21 It was noted that there is currently no specific local guidance provided by Haringey TPCT. The Panel were very impressed with the leaflet that Shropshire County Council has produced for health professionals outlining the needs of the people with LD and how consultations involving them should be approached. The view of Dr.Sherman (a local GP who was interviewed as part of the review) was that the provision of appropriate guidance would be of assistance - GPs have received local guidelines on other issues and generally welcome such advice. The Panel recognises that health professionals have many competing demands and pressures on their time and it needs to be used

efficiently. It is therefore of the view that local guidance would help in ensuring that they have the information and guidance necessary to provide an accessible and responsive service to people with LD and PMLD and that this should be concise and user friendly.

Recommendation:

That Haringey Learning Disabilities Partnership produce a concise and accessible guidance leaflet for primary care practitioners and other health professionals providing general information and guidance on best practice in working with people with LD and PMLD.

Screening

- 3.22 People consulted by NDT reported a lack of regular routine health checks, such as screening. One factor that can discourage carers from taking people for checks is the need for additional support. In addition, people with LD and PMLD can feel alarmed by the procedures involved. With the exception of cervical screenings, all screenings are arranged by the TPCT.
- 3.23 The DRC report highlights the importance of health checks. It reveals that of 181 people in Wales with LD who received a health check, 51% had newly identified health needs and 9% had serious health problems. Subsequent checks over a year later identified further new health needs among 68% of people, with serious problems in 11%.
- 3.24 Screening is not only very important in helping to prevent serious conditions but can also be very beneficial to people in other ways. The Panel heard from the Community Dental Service that it could also be very productive in other areas. A case of head-banging seen at a routine screening was attributed to behavioural difficulties but was in fact due to untreated dental pain that the patient could not express verbally or be detected readily as the patient would not open his mouth for care staff.
- 3.25 It was noted that there are ethical issues involved in screening people with LD who might be frightened of medical procedures. What was done if they were not happy with being screened depended on an assessment of their competency in making a decision.
- 3.26 The Panel feels that the best ways to increase the take up of routine screening are to advertise its availability and to work closely with carers and support staff to promote it. In addition, once there is wider recording of by GP practices of the numbers of people with LD on their registers, we recommend that the TPCT routinely record and monitor take up levels. Finally, the issue should also be addressed as part of Health Action Plans.

Recommendation:

That action be taken to improve take up levels for routine screenings for people with LD and PMLD through:

- **the Learning Disabilities Partnership publicising their availability and importance to carers and appropriate support staff and recording and**

monitoring progress in appropriate care plans, including Health Action Plans; and

- **the TPCT, as part of its ongoing work on the DES, recording and monitoring take up levels and setting appropriate targets for improvement.**

The Needs of Carers

- 3.27 The focus of support is normally on the person with LD/PMLD but this can lead to the needs of carers being overlooked. Carers are crucial to enabling people with PMLD to retain their independence and live at home. The Panel noted with concern the very high percentage of carers consulted who suffered from serious health problems. It is often exceedingly tough for carers to meet the needs of their loved ones. Many people with PMLD are now living longer lives. This means that carers are looking after their loved ones for longer and that they are more likely to be old, which is likely to have an impact on their health. Nationally, there are now 29,000 people with PMLD living at home with a carer over the age of 70.
- 3.28 One concern identified by carers was what would happen when they are unable to care for their loved ones themselves. The Panel would suggest that a care plan could be written for the care of the person with PMLD for when the carer is no longer able to care for them. This would help to reassure carers that they would not be “letting down” their loved one if they were to become unable to continue providing care.
- 3.29 The consultation by NDT revealed that the aids and adaptations within some households were in need of upgrading and replacement. Personal care supports to some families’ homes are sometimes inadequate and do not address the health needs of parents who may be getting older and have their own health needs.
- 3.30 The Panel was pleased to hear that the performance of the Council in providing aids and adaptations has improved considerably. However, it feels that the adequacy of current aids and adaptations should be reviewed regularly as part of annual reviews undertaken by the Learning Disabilities Partnership in order to ensure that they still meet needs.

Recommendation:

That all annual reviews of people with LD and PMLD undertaken by the Learning Disabilities Partnership include consideration of the continuing adequacy of aids and adaptations and contingency plans for the continuation of care should carers become unable to continue providing care themselves.

- 3.31 Many of the families interviewed survive on benefits and there were concerns about the availability of appropriate benefits advice. Benefit entitlements of all people subject to statutory charges for services are assessed by the Council’s Income Maximisation Team. Many carers of people with PMLD may not be subject to these and therefore not entitled to the service. All carers are entitled to a Carers Assessment and, although take up is not universal, this would

seem to be an ideal opportunity to check that they are receiving their entitlements.

Recommendation:

That Carers Assessments undertaken by the Learning Disabilities Partnership routinely assess entitlement to benefits.

Empowerment

- 3.32 Carers interviewed as part of the consultation felt that they often had to battle to obtain services for their loved ones. It is often the case that those people who are best able to articulate their needs and demand the services to which they are entitled get the best services. These people will not necessarily be those with the greatest level of need. The Panel feels that it is very important that carers are empowered so that they are able to advocate as effectively as possible for their needs of their loved ones and themselves. In particular, carers would benefit from improved knowledge of how the system works e.g. who provides clinics and services, where from and how to access them.
- 3.33 There is an additional need for advocacy for carers in order to ensure that they get the support that they need. In particular, it is very important the needs of older carers – those over 60 – are effectively addressed. It was noted that there funding available for breaks for carers and it is felt that consideration should be given by the Learning Disabilities Partnership to using some of this money to provide specific support to carers.

Recommendations:

- **That the Learning Disabilities Partnership provide carers with appropriate guidance and training on accessing health services and benefits and that relevant information be included within Health Action Plans.**
- **That the Learning Disabilities Partnership considers the establishment of specific support and advocacy for carers of people with LD and PMLD to ensure that their needs and welfare are addressed effectively.**

The Every Disabled Child Matters (EDCM) Campaign

- 3.34 The Every Disabled Child Matters (EDCM) campaign is a partnership between Mencap, Contact a Family, the Council for Disabled Children and the Special Education Consortium. The objective of the campaign is to improve services, promote inclusion and increase life chances for all children with disabilities. The campaign aims to lobby the government to address the issue take action to improve provision.
- 3.35 As part of its work for the campaign, Mencap is lobbying for a new right to short breaks for disabled children and their families and Gary Streeter MP has taken up the Disabled Children (Family Support) Bill. The need for the Bill was highlighted by Mencap's Breaking Point survey which found that 8 out of 10 carers of disabled children came close to or reached breaking point. In addition,

the EDCM campaign is supporting the government review of services for disabled children that is due to report in January 2007.

- 3.36 A local authorities charter has been developed. The charter, produced with the support of Children Now magazine, encourages local authorities to commit to providing a range of services for disabled children and their families by January 2008 and also to addressing the needs of disabled children in their strategic planning and local area agreements. The following local authorities have already signed up to this;

Cornwall, Dudley, Enfield, Halton, Hertfordshire, Hull, Kingston upon Thames, Solihull, Southwark, Stockport, Sunderland and Tower Hamlets

Recommendation:

That the Council consider signing up to the local authorities charter for the Every Disabled Child Matters campaign.

4. Primary Care Services for People with PMLD

Introduction

- 4.1 Good quality and accessible primary care is of great importance to people with PMLD who are living at home. They are likely to have specific and possibly high level health needs. High quality services can assist them in remaining independent by helping to prevent illness and promoting good health. In addition, primary care is now taking an increasingly prominent role in healthcare as greater levels of care are now being provided outside of hospital as part of the government's agenda for change. People with PMLD often use mainstream facilities but there are particular challenges that services face in providing care for them.

GP Practices

- 4.2 Perhaps the most important primary care services for people with PMLD are those provided by GP practices. The Panel was interested to note from research undertaken by Mencap, who undertook a survey of GPs in 2004, prior to the publication of their report "Treat Me Right!", that 75% had received no training in LD and 90% felt that a person's LD made it more difficult to give them a diagnosis. In addition, 70% of GPs did not have accessible information in their surgeries.
- 4.3 However, the Panel was pleased to note that the majority of the carers interviewed as part of the consultation undertaken by NDT were very happy with the service provided by their GP. They were seen as very supportive and, in many cases, very good long term relationships had been developed. Although some surgeries are still not physically accessible, family carers are able to make appointments easily and can arrange them at times that suit them and which reduce waiting, which is especially helpful when this is difficult for an individual who may have fears about medical appointments or is unable to understand about waiting. They were also happy to make home visits. However, it was noted that the service can be variable and some GPs appear to not be working quite so well with families.
- 4.4 The Panel received background information from Haringey Teaching Primary Care Trust (TPCT) on how primary care services work with people with LD and PMLD. In respect of GPs, it was noted that they are independent contractors and the TPCT's powers of influence are therefore subject to limitations. Practices approach issues such as accessibility in variable ways and there can sometimes even be differences in approach within the same practice

Recording

- 4.5 According to the DRC report, recording of learning disability in primary care is generally poor and this is borne out by the position within Haringey. This can make it difficult to respond to the needs of people. It also inhibits a better understanding of the health issues that affect people with LD and PMLD as it not possible to track progress and monitor outcomes.
- 4.6 The Panel noted that it is not yet possible to identify how many people with LD and PMLD are registered with GPs within Haringey as only 50% of GP practices are currently able to collect the necessary information. The system

for monitoring such information uses a system of colour coding and not all GP practices within the Borough yet have the appropriate software. The fact that recording is not universal means that GP practices are often unaware of which of their patients have a learning disability. In such circumstances, they may have to rely on receptionists making a value judgement based on the behaviour of patients.

- 4.7 There is now an incentive for primary care services to record the number of people with a learning disability who use their services through the Quality and Outcomes framework and this will hopefully eventually enable services to be better planned.
- 4.8 It is essential that all practices are able to record the necessary information if the needs of people with LD and PMLD are to be addressed better. The Panel takes the view that the TPCT needs to work with GP practices to ensure that they have the necessary software to keep appropriate records and set a target for improving the percentage of GP practices that are recording the number of people with LD who use their services. Only once this information has been collated will it be possible for the TPCT to analyse fully the physical health needs and make appropriate plans to commission services to address the health inequalities that exist for people with LD and PMLD. In addition, the information will assist when people move to a new GP.

Recommendation:

That the TPCT works with GP practices within the Borough to ensure that they all have the necessary IT software to create registers of people with LD registered with their practice and that a local target be set by the TPCT for improving the percentage of practices collecting the appropriate information.

Accessibility

- 4.9 It is a common misconception to assume that the access responsibilities provisions within the Disability Discrimination Act refer to *physical* access. The Act actually refers to the need to make *services* rather than buildings accessible and there is an obligation to make “reasonable adjustments” to make services accessible to all.
- 4.10 Physical accessibility is nevertheless important and the Panel noted the view of the Learning Disability Partnership that the lack of it in respect of many health services was a key reason the health of people with LD and PMLD is often not good. The TPCT has undertaken a mapping exercise on the physical accessibility of primary care facilities and it has been found that a range of GP practices need improvement. The Panel noted that there are also particular issues concerning the physical access of dentists, many of whom are situated in premises above shops. Further work is planned by the TPCT on other areas of primary care to ensure that they are physically accessible as part of the DES.
- 4.11 Physical accessibility is only part of the issue. There are other reasons why people with LD and PMLD may be put off from visiting their GP:

Visiting the GP can be a stressful experience for people and their carers;

- *Many people with LD find making appointments difficult. Some people quoted in the DRC report said that they did not make appointments even when they were ill as it was too difficult. People may not be good on the phone and find it difficult to respond to questions.*
- *They may not understand why they are at their GP's surgery and become alarmed by some medical procedures.*
- *They may find it difficult to wait for very long.*
- *People with LD/PMLD can often find pain or distress difficult to understand. It may mean that when they experience it they can only communicate it in non standard ways, including behaviour which may be seen as difficult to manage and cause difficulties.*
- *Difficulties in communication might also mean that it takes the doctor longer to identify what the ailment is*

4.12 An additional challenge is that, as previously mentioned, GP practices do not always know which of their patients have LD. In such circumstances, they may not be aware of the particular needs of their patient and the need to adapt their approach.

4.13 A service may still not be accessible to a person with LD despite it being physically accessible. Providing a service which is accessible could mean, for instance, providing accessible information so that they know when to attend for an appointment or alternative means of making appointments. There are many things that can be done to improve access which are simple, do not cost very much and can bring considerable benefits such as preventing avoidable health crises.

4.14 The Panel noted the view of Dr Sherman that the majority of GP practices do not seem to make any special measures to accommodate people with LD. Research undertaken on behalf of the TPCT in the preparation of their DES also revealed that service users have a perception that few "reasonable adjustments" are being made for people. This seems to contradict the views of family carers interviewed by NDT who were generally very positive about the assistance provided by GP practices - one possible explanation for this is that people may have low expectations. However, it seems clear that at least some GP practices are not making any special arrangements.

4.15 The Learning Disabilities Partnership often supports people when they go and see their GP and it is their view that the best practice was shown by those GPs who arranged for people to come in just before the start of their surgeries. However, it is recognised that it may not be easy for surgeries to give people with LD and PMLD early appointments. Dr Sherman stated that these appointments are normally under heavy demand from commuters. Older people and the under 5's are normally given priority by surgeries at the moment. If another group of patients were added to this list, this could possibly

lead to longer waiting times for other patients. Long waits can be a source of friction and there are often complaints about them.

- 4.16 Although the Panel is pleased to note that at least some GP practices are taking specific measures to make their services accessible, it is incumbent on *all* primary care practitioners to make “reasonable adjustments”. The average surgery within the Borough is likely to have comparatively small numbers of patients with LD on its books – probably no more than 20. Special measures, such as allowing double length appointments, would therefore be very unlikely to have a major impact on other patients. Several simple and imaginative measures are outlined in the DRC report and have been used successfully by practices. The Panel is, however, of the opinion that they should be a matter for local discretion so that individual conditions and circumstances can be taken into account.
- 4.17 The Panel feels that the TPCT should work with primary care practices to encourage them to make the necessary arrangements and that appropriate advice on this should be included in best practice guidance to primary care practitioners and other health professionals. In particular, issues of access should also be addressed fully as part of the commissioning process, as recommended by the DRC.
- 4.18 The DRC recommends that people should be given the option of recording their access needs so that they appear in patient records and can therefore be easily identified and met. This would seem to be a simple and sensible way of improving access and assisting health professionals and we would endorse this recommendation. This option is currently being investigated by the TPCT as part of their DES Action Plan.
- 4.19 One particular area that requires attention is signage and improvements in communication are currently being looked at by the TPCT. Work has also recently begun with the local authority on the provision of appropriate training for health staff on making services more accessible and this will cover a range of staff and not just clinicians.
- 4.20 An additional means of encouraging GP practices to make accommodations could be through empowering carers. If practices are, for instance, routinely asked to provide longer appointment times by carers, as well Learning Disabilities Partnership staff escorting people to surgeries, it may help to persuade those practices not making any special arrangements to revise their approach.

Recommendations:

- **That, as recommended by the DRC, the TPCT develops robust disability access and quality standards for inclusion in all contracts with providers in the public, private and voluntary sector to ensure that all services are made fully accessible and sets a specific date by which such new contractual obligations will be introduced.**
- **That the Learning Disabilities Partnership provides advice and guidance to carers and staff escorting people to GP surgeries to routinely request suitable and reasonable adjustments to facilitate access when making**

Training of Primary Care Practitioners

- 4.21 The Panel was surprised to note that there appears to be little specific training given to doctors on LD. Dr Sherman stated that, as far as he was aware, LD is not currently an integral part of doctors training. He felt that whether patients with LD were able to access a GP with particular relevant knowledge was something of a lottery. This view is borne out by evidence given by local voluntary organisations such as HAIL and the previously mentioned Mencap survey.
- 4.22 Training sessions are arranged regularly for GPs in a range of settings. It is, however, up to individual GPs if they attend and they are often faced with considerable pressures on their time. It would therefore be preferable for training on LD issues to be part of the undergraduate curriculum so that it can be guaranteed that all doctors receive at least some training on the issue. The TPCT cannot oblige GPs to attend training events but they are now subject to appraisal and this has a particular educational component.
- 4.23 GP's receptionists are normally the first point of contact for people with LD and PMLD and their carers. Their role is therefore key to how people with LD/PMLD are dealt with within practices and the Practice Managers Forum might therefore provide a useful and effective route for delivering training, developing awareness and sharing good practice. The Panel noted that view of Dr Sherman that practices would welcome this, provided that it was not too time consuming. The Panel is of the view that people with LD and carers should be involved in the design of such training programmes. This is not only good practice but will help ensure that training addresses relevant issues.
- 4.24 In addition to primary care practitioners, there is also a need for improved training for clinicians and nurses in secondary care services who also receive limited input as part of their basic training on LD issues. The sheer numbers of them would make providing training for them all not feasible. However, good practice and appropriate guidance should be shared them.

Recommendations:

That Haringey TPCT, in conjunction with the Learning Disabilities Partnership, provide regular training on LD issues for primary care practitioners, particularly Practice Managers and reception staff, and that people with LD are involved in its planning and design.

- 4.25 Dr. Sherman's special interest in learning disability (LD) issues arose from the role that he had as a clinical assistant at the Edwards Drive respite care centre. There is currently one other GP within the Borough with a particular interest in LD and this is Dr. Mary Phimester who is located in the south of the Borough. All GPs generally deal with people with LD and this may well be beneficial as it helps to develop their overall awareness. However, working with patients with LD can sometimes require some specialist knowledge.

4.26 The Panel is of the view that the overall awareness of LD issues and the sharing of knowledge and best practice could be improved by working through the collaborative clusters of GP practices that now exist throughout the Borough. There are now four of these and they provide a very useful means of sharing best practice and improving communication. A lead GP has been appointed within each cluster to lead on mental health issues and it is felt that a similar approach should now be followed for LD.

Recommendation;

That the TPCT consider the nomination of a lead GP within each collaborative cluster of GP practices within the Borough to lead on LD issues within it and, in particular, the development and sharing of best practice and the provision of appropriate training.

4.27 One other means of improving services could be through the use of Community Nurses (also known as health visitors). These are registered nurses who work in the community in people's homes, in schools and in local surgeries and health centres. They are particularly concerned with people whose health may be especially vulnerable such as older people, children or people with learning disabilities. They can provide help and advice on a wide range of health issues and also visit people at home to provide nursing care. In addition, they may also teach families and carers basic care giving skills. They work closely with GPs, local social services and hospitals. The Learning Disabilities Partnership employs specialist Community Nurses to work with people with LD and their carers. The Panel feels that they could play a useful role in providing support in accessing mainstream health services and, in particular, acute services.

Recommendation:

That the LD Partnership review the roles of specialist community nursing in relation to how they support service users and carers accessing general health services and, in particular, acute trusts.

Access to Specialist Services

4.28 The consultations undertaken by NDT revealed that there could be difficulties in getting appropriate input from specialist services such as speech therapy, and physiotherapy. The Learning Disabilities Partnership has a range of health professionals within it, including dentists and chiropodists. Access to some of these services can be provided via day centres. However, the Panel noted that there are shortages of suitably qualified staff in several of these areas. Physiotherapy is a particular example.

4.29 Access to regular physiotherapy treatment is vital for many people with PMLD. Although the Learning Disabilities Partnership is supposed to have provision for 1.6 specialist physiotherapists, there has been, until recently, been none in post. There are several reasons why recruitment has proven difficult:

- Working with people with learning disabilities is not sufficiently included in the basic professional training.

- Teams where there is only one post find recruitment more difficult as there is perceived to be less support and more caseload pressure.
 - Lack of staff makes it difficult to offer placements to students so they do not have the opportunity to experience working with PMLD. Posts have had to be filled with a senior clinician and there are relatively few opportunities for newly qualified health staff to gain experience working in this field.
 - The Partnership also has to compete with a range of other potential employers, many of which are able to offer more attractive employment packages
- 4.30 In some cases, parents have had to resort to paying for private physiotherapy due to lack of availability. Many of the above mentioned issues also apply to the recruitment of other specialist health professionals.

Dentistry

- 4.31 The consultations by NDT revealed that the Community Dental Service was highly regarded. However, carers felt that there needed to be greater liaison between them and mainstream dental services.
- 4.32 The Panel received detailed feedback on dental services from the Community Dental Service. Screening assessments take place at schools, special schools, care homes and other locations. They have an integrated relationship with the paediatric assessment unit at St Ann's, where LD and PMLD children are dentally assessed at an early stage. It is felt much better that dental advice and necessary care is proactive, starting as young as possible and before school age and involving the whole family. Referrals are also received from doctors, specialist nurses, health visitors, school nurses, directly from Great Ormond Street, and local dentists.
- 4.33 The service provides an expert oral health promoter to work with schools, care homes and families to prevent oral disease and prepare learning materials. Training is also provided for staff in care homes. Treatment is carried out at St Ann's using local anaesthetic and/or sedation. For more profound cases with multiple problems, the dental staff have sessions in operating theatres at the North Middlesex Hospital and Chase Farm Hospital, where patients can be treated under general anaesthesia if clinically necessary.
- 4.34 People with mild LD people can access high street dentists and this is encouraged to normalise their care as far as possible. LD patients may sometimes visit a dental practitioner first, before being referred to St Ann's when problems arise or if the dentist foresees difficulties. The more profound LD patients are well outside the range of skills, experience and facilities of general dental practice and are referred to St Ann's.
- 4.35 The Panel noted that access for PMLD children has been sustained chiefly due to the long-standing policy of initiating care early and containing/preventing further oral disease and complications. Dental access for LD and PMLD adults has reduced and emergency dental care is currently being given priority. Routine dental care currently has a waiting list of 12 weeks. Screening of adult care homes cannot be done at present due to lack of staff and provision of adult dental home-care advice to care staff is very limited, also due

to lack of staff. Due to the TPCT's current financial position, a dentist and dental nurse were made redundant, 60% of a vacant full-time dentist post cut and another full time dentist post frozen. It is hoped that the frozen posts will be reinstated for 2007/8.

- 4.36 Promotion of the prevention of oral disease by good dental home-care is important for people with LD and PMLD, not just to avoid needless suffering but also because their access to dental treatment is limited and, for some, may involve a major procedure in hospital that is not without risk. Tooth brushing with electric brushes can familiarise patients with mechanical procedures and sensations in the mouth and make dental check-ups easier without recourse to sedation/anaesthesia. It may even allow minor dental treatment, such as cleaning or single surface fillings, being tolerated in the normal way.
- 4.37 The Panel noted the view that more dental staff would help the service to cope with the workload for LD and PMLD adults. There is concern that the need for and supply of adult LD and PMLD dental care is drifting further out of balance for a care group who may not be as able as others to articulate their need to access specialised dental care.
- 4.38 The Panel is concerned that an effective service to a very vulnerable group of patients has been eroded and would recommend that the above mentioned frozen posts be reinstated by the TPCT and made a priority for funding in 2007/8.

Recommendation:

That the reinstatement of dentistry posts within the Community Dental Service that were frozen as part of budget savings required during 2006/7 be made a priority for funding by the TPCT in 2007/8 and that the overall adequacy of current staffing levels within the service be reviewed.

5. Healthy Living

Introduction

- 5.1 The DRC report states that people with LD, as well as people with mental health problems are at greater risk from the effects of unhealthy lifestyles, than the wider population. They have high rates of obesity, often have poor diets and can find difficulty in accessing suitable leisure and recreation facilities. The Panel noted that the TPCT is currently developing an obesity strategy but has not specifically targeted people with LD in the work that it had done so far. Encouraging people with LD to follow a healthy diet and exercise regularly may require a specific strategy if progress is to be made. There are particular challenges in communication issues that need to be addressed. Families are more likely to live on low incomes and this may mean that it is more difficult for them to afford healthy food and take advantage of exercise facilities. The Panel therefore feels that targeting should be considered. Failure to do this may perpetuate and possibly even exacerbate health inequalities.

Recommendation:

That the obesity strategy currently being developed by Haringey TPCT and its partners specifically address the needs of high risk groups, including people with LD.

- 5.2 Whilst obesity is a problem for many people with LD, people with PMLD are more likely to be underweight as swallowing difficulties affecting eating and drinking are common, leading to poor nutrition. The Panel noted that access to dietician services can be patchy. In addition, access to the videofluoroscopy department at the North Middlesex is not possible for people with PMLD as they room is not wheelchair accessible and they therefore have to go to the Whittington Hospital instead.

Recreation and Play

- 5.3 The Panel received evidence from the Markfield Project on the availability of recreational provision for people with LD and PMLD. Whilst there are some examples of good access to recreation and exercise for adults with LD, these are not necessarily accessible to people with PMLD. Some Markfield users had reported using leisure centres for regular exercise, assisted by support from their key workers but people with more profound disabilities appear to have less access to this kind of facility. There are some specialist recreation services commissioned by the Learning Disabilities Partnership such as Markfield's Art Engine and Markfield at Nite Projects but the number of places available for people with PMLD and high support needs is limited. Day centres also provide a range of recreation activities for adults with LD.
- 5.4 Markfield were able to give the Panel detailed evidence on the lack of access to recreation and exercise as they were commissioned to undertake an audit of supervised play provision in March 2006. This found that, despite DDA requirements to make services accessible to disabled people, access to play and youth provision within the Borough is severely limited for children with disabilities. Many providers, including the six local authority run centres, are physically inaccessible to children with mobility difficulties. There is a severe

shortage of play places for disabled children – for example, there are only enough inclusive places for half the number of children registered as disabled within the Borough. There is a particular shortage of term time places for disabled 3-12 year olds with a sum total of only 59 places available across the whole Borough. When children are offered holiday play provision, it is generally for shorter amounts of time than for their non-disabled peers and term time provision was often only for one day per week, as opposed to the full time places offered to non-disabled children.

- 5.5 Markfield were also commissioned by the Children's Service to coordinate places for disabled children for the summer play scheme in 2006. In doing this, they discovered that the average amount of provision for a disabled child was two weeks across the summer holidays as opposed to five for non-disabled children. There was also a severe shortage of places: they were able to identify only 103 disabled children who received a play scheme service. This was only just over half the number of places providers said they hoped to provide when questioned in the play audit in March 2006.
- 5.6 This lack of provision disproportionately affects children with PMLD as a large number of the children with no play scheme place have 1 to 1 support needs. The Panel noted that a response to the audit was still awaited from the Children and Young People's Service.
- 5.7 There are a number of barriers to improving play provision:
- Physical access.
 - Unstable funding arrangements for service providers and last minute agreements of funding.
 - Lack of information about the number of people with disabilities who are waiting to access recreation and exercise.
 - Transport.
 - Lack of access to funding for support staff for people who need 1 to 1 support.
 - Insufficient training to manage particular needs, especially complex health needs and behavioural management issues.
 - Attitudes to disability and discrimination.
- 5.8 The Panel heard from Robert Singh, the Children's Networks Coordinator from the Children and Young People's Service, who responded to these concerns. He reported that the local authority had been asked to develop a play strategy and, as part of the process for drafting this, the Markfield Project and Haringey Play Association were asked to undertake an audit of current provision. The work undertaken by the Markfield Project had shown there to be a shortfall in provision for people with disabilities and, in particular, learning disabilities. The draft strategy had referred to the need to remedy this.
- 5.9 Funding was a major issue, especially in the case of children whose needs were at the high end of the spectrum and therefore often required one to one support. The issue was currently being addressed and a bid had been made to

the Big Lottery Fund for appropriate projects. It was, however, a very costly service and that was especially true of children with PMLD. At the moment, two places for children with severe disabilities within each play centre were all that could be afforded. It was currently not possible to meet the needs of all such children and there were now approximately 100 children on the waiting list. However, 8% of places in play centres were for children with disabilities, which compared well with provision in other local authorities.

- 5.10 The play strategy was being further developed and consideration could be given to the setting of an appropriate target for children with disabilities if this was felt appropriate. It was noted that the TPCT was working with the Children and Young People's Service on this issue.
- 5.11 The Panel feels that there is a need to improve the availability of places for children with disabilities as a whole as it is unacceptable that they should have poorer access to appropriate provision than other children. Access should be targeted according to need with particular priority given to children whose carers are less able to care for them or who are in need of respite. In addition, statistics should be kept on the number of disabled children accessing play provision who have a learning disability.

Recommendation:

That specific targets be set by the Children and Young People's Service in its Play Strategy to monitor progress in achieving equal access to services for children with disabilities.

- 5.12 The Panel also received evidence from the Sports and Leisure Service on the measures that they took to encourage the use of their facilities amongst people with LD and PMLD. It was noted that Sports and Leisure's swimming pools had hoists to assist access for people who had physical as well as learning disabilities. In addition, Tottenham Green currently used the beach area, which was a walk in shallow pool. Gyms at Tottenham Green and Park Road had equipment that had been accredited for use by the Inclusive Fitness Initiative (IFI). Park Road and Tottenham Green Leisure Centre facilities were both audited as part of the IFI process in order to gauge accessibility and, after implementing recommendations, were awarded IFI accreditation. They were 2 of only 7 centres in London to possess this award.
- 5.13 The service has a specific fitness instructor with responsibility for developing links with disability organisations and encouraging people with disabilities to use the Council's facilities. Part of the IFI accreditation meant that they needed to ensure that 6% of users were people with disabilities. Work was also being undertaken with Haringey's learning disability day centres to encourage greater use by their clients. This included use of the pools, the studio for the Special Olympics and hosting the Disability Awareness Day. One particular initiative was an ongoing booking with the Moselle School to provide coached sessions in the SHOKK gym. However, as with many organisations, funding remained an issue for the service.
- 5.14 The Panel were pleased to note that access to sports and leisure facilities in Haringey has increased greatly recently with some excellent local projects that cater for the needs of people with PMLD. However, evidence was received

that new disabled toilet facilities at Tottenham Green do not fully meet the needs of many PMLD people, who require a changing bench and hoist. The only changing table is in the poolside toilet and it is currently damaged. In addition, Many PMLD benefit from hydrotherapy as the warm water allows muscles to relax and allows more freedom of movement. Ordinary pool temperatures are too cold. Hydrotherapy is available in special schools, but there is currently no facility for adults.

- 5.15 Sports and Leisure are willing to enter into discussions to develop a scheme similar to one in development with the Children in Care team, whereby the Children's Service were purchasing active cards for all of their clients at a subsidised price. The Service was also aware that Out of School Providers would like to participate in the holiday programme but were restricted by funding allocations which restricted options and the number of places available. It was felt that a greater emphasis on marketing and publicity and literature to disability groups and organisations could help to further encourage usage. In addition, raising awareness of the use of the natural environment e.g. parks and open spaces for recreation and leisure, could also assist in improving the health and fitness of people with LD.
- 5.16 There was little evidence so far of health professionals referring people to the Sports and Leisure Service for therapeutic purposes although an NRF funded referral scheme was scheduled to start shortly. This would enable GPs in the area in question to refer patients to the service. The service felt that there was much that could be done with people with disabilities as the facilities were now very accessible.
- 5.17 The Panel feels that one option would be to include recommendations on exercise and diet within Health Action Plans. It was recognised however that, irrespective of the accessibility of exercise facilities, the time and effort involved in getting a person with PMLD to and from a leisure centre could be a daunting prospect for a carer. In such circumstances, the use of parks and open spaces might be a more realistic option.

Recommendations:

That the Learning Disabilities Partnership enter into discussion with the Sports and Leisure Service with a view to establishing a scheme for subsidised purchase of active cards for clients.

Appendix A

People interviewed or providing evidence to the Panel as part of the review:

Ms. D. Burkens and Ms. H. Warner - Haringey Teaching Primary Care Trust Patient and Public Involvement Forum
Mr. S. Simmons and Ms. G. Taylor - Haringey PCT
Mr. K. Dowd – Haringey Association for Independent Living
Mr. K. Taylor - Mencap
Ms. C. Eastwood, Mr. G Jefferson and Ms. E. Lovell - Haringey Learning Disabilities Partnership
Dr. L. Sherman - Haringey GP
Mr. A Briggs - Head of Sports and Leisure
Mr. R. Singh - Children and Young People's Service

In addition, independent in depth qualitative consultation was undertaken with 8 families and carers as well as focus groups of carers and professionals working with people with PMLD.

Bibliography/Background Papers:

Haringey Teaching Primary Care Trust Disability Equality Scheme (December 2006 – December 2009)

Equal Treatment: Minding the Gap – Disability Rights Commission

Valuing People with Profound and Multiple Learning Disabilities (PMLD) – PMLD Network

Our Health, Our Care, Our Say: A New Direction for Community Services – Department of Health White Paper (2006).

Our Health, Our Care, Our Say: A New Direction for Community Services – Mencap Response

Valuing People – Department of Health White Paper (2001).

Valuing People review submission – Mencap

Treat me right! Better healthcare for people with a learning disability – Mencap

Healthy Lives – Health Action Planning in a Person Centred Way: Including Health in Person Centred Planning – Foundation for People with Learning Disabilities (2004)