
Scrutiny Review - Access to Primary Healthcare for People with Learning Disabilities

THURSDAY, 18TH JANUARY, 2007 at 19:00 HRS - .

MEMBERS: Councillors Dogus, Jones (Chair), Oatway, Whyte and Wilson

AGENDA

4. MINUTES (PAGES 1 - 4)

To approve the minutes of the meeting of 11 December 2006 (attached) and 9 January 2007 (to follow).

6. CONCLUSIONS AND RECOMMENDATIONS (PAGES 5 - 22)

To consider appropriate conclusions and recommendations for the review. A paper outlining the key issues from the reivew will be circulated in due course.

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**MINUTES OF THE SCRUTINY REVIEW - ACCESS TO PRIMARY HEALTHCARE FOR PEOPLE WITH LEARNING DISABILITIES
TUESDAY, 9 JANUARY 2007**

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

* Member present

Also present: Dr. Sherman

LC36. APOLOGIES FOR ABSENCE

None.

LC37. URGENT BUSINESS

None.

LC38. DECLARATIONS OF INTEREST

None.

LC39. MINUTES

It was agreed that consideration of the minutes of the meeting of 11 December would be deferred until the next meeting.

LC40. IMPROVING ACCESS TO PRIMARY HEALTHCARE FOR PEOPLE WITH PMLD - FURTHER EVIDENCE FROM STAKEHOLDERS

The Panel received evidence from Dr. Sherman, a local GP. He had practiced in the Bounds Green area for 20 years. His interest in learning disability (LD) issues arose from the role that he had as a clinical assistant at the Edwards Drive respite care centre. Although the unit was intended to provide just respite care, there were some clients who lived there permanently. When long stay hospitals had closed down, patients were brought back into the Borough and some families were unable to cope and some of these patients had been accommodated in the centre. Some of them had developed dementia, which was common amongst older people with LD. In some cases, there was now minimal contact with their respective families.

There was one other GP who took a particular interest in LD and this was Dr. Mary Phimester who was located in the south of the Borough. She had been scheduled to also speak to the Panel but had unfortunately been unable to attend.

GPs did not receive any specific guidance or training on LD issues. The provision of appropriate user friendly guidance by the PCT would assist them. GPs had received local guidelines on other issues from the PCT and were open to such advice. He found working with patients with LD to be a rewarding experience but it could sometimes require some specialist knowledge. There had been a specialist consultant linked to the Learning Disabilities Partnership who could be referred to. One particular additional method of sharing best practice and advice would be through the collaborative clusters of GP practices that existed within the Borough.

GPs had limited amounts of time to undertake learning. They were now subject to appraisal and this had a particular educational component. In addition, the Quality and Outcomes Framework now had some reference to LD within it. One possibility

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would be for specific GPs within practices to adopt particular specialisms but this was only feasible in the larger practices. However, all GPs generally dealt with people with LD and he felt that this was beneficial as it helped to develop their overall awareness. Some patients with LD could become very attached to specific health professionals and in such circumstances it would be better if they saw the same GP. Efforts were normally made to ensure that this was possible.

As far as he knew, LD was not currently an integral part of doctors training – he was not aware of any specific modules relating to it although it might be referred to as part of the mental health component. Generally speaking, whether patients with LD were able to access a GP with particular relevant knowledge was something of a lottery.

The majority of GP practices did not undertake any special measures to accommodate people with LD. GPs did not always know which of their patients had LD and it was often up to receptionists to identify them from their behaviour. Their role was key to how people with LD/PMLD were dealt with within practices. The Practice Managers Forum would therefore provide a useful and effective route for delivering training, developing awareness and sharing good practice.

There was currently no specific responsibility for GPs to routinely review the health of people with LD, unlike the situation with mental health patients. People with LD normally attended surgery with their carers or an advocate. It was generally a matter of judgement whether to address the carer/advocate or the patient but most GPs tried to at least include the patient in the discussion. However, if GPs were pressed for time they could sometimes just communicate with the care/advocate. Whilst carers/advocates could often simplify the consultation, they could sometimes also complicate it.

It would not be easy for surgeries to give people with LD early appointments as these were normally under heavy demand from commuters. Older people and the under 5's were normally given priority. If another group of patients were added to this list, this could lead to longer waiting times for other patients. There were frequently complaints about long waits.

The Panel felt that special arrangements to accommodate patients with LD should be a matter for local discretion so that local conditions could be taken into account. One possibility would be to set particular times for such patients in less busy periods. One possible way of accommodate the range of health needs of people with LD would be to hold multi disciplinary sessions for people where they could access a range of healthcare such as chiropody, physiotherapy and dietary advice. This would need to be arranged by the PCT though. It was recognised that there were severe staff shortages in some disciplines such, particularly physiotherapy.

He felt that the best ways to increase the take up of routine screening were to advertise its availability and to work closely with carers and support staff to promote it. There were 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. With the exception of cervical screenings, all screenings were arranged by the PCT.

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GPs could help to support people with LD and PMLD when they were hospitalised by informing the hospital of any special needs that they might have. Care plans for people going into respite care were often very detailed. It would be help GPs and hospitals if this information could also be shared with them.

Training sessions were arranged regularly for GPs in a range of settings. It was, however, up to them if they attended and they often had limited time. He felt that training on LD issues should be part of the under graduate curriculum so that it could be ensured that all doctors received some sort of training on the issue. After they had qualified, they could pick and choose which training that they attended.

He felt that a structured programme of care with clear goals and methodology would help in improving the health and well being of people with LD /PMLD. Primary care practitioners would be assisted by employment of community matrons with special interests in LD/PMLD. In addition, specific training for receptionists would assist as they were normally the first point of contact for people with LD and their carers. Practices would welcome this provided that it was not too time consuming. Finally, there needed to be better links between primary and secondary care.

The Panel thanked Dr. Sherman for his assistance.

LC41. PROGRESS WITH REVIEW

Noted.

LC42. NEW ITEMS OF URGENT BUSINESS

None.

Cllr Emma Jones
Chair

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SCRUTINY REVIEW ON IMPROVING ACCESS TO PRIMARY HEALTHCARE FOR PEOPLE WITH PMLD**18 JANUARY 2007****ISSUES PAPER****1. Introduction**

- 1.1 The purpose of this paper is to highlight the key issues from the evidence received so far in order to assist the Panel in reaching conclusions and recommendations.
- 1.2 The review has received evidence from a number of sources:
- Gary Jefferson, the Head of the Haringey Learning Disabilities Partnership
 - Alex Hendra from the Markfield Project
 - Richard Taylor from Mencap
 - Dolphi Burkens and Helen Warner from Haringey PCT PPI Forum
 - Kevin Dowd from HAIL
 - Gerry Taylor and Steve Simmons from Haringey Teaching Primary Care Trust
 - Andy Briggs, Head of Sports and Leisure
 - Robert Singh from the Childrens and Young People Service
 - A Haringey GP
 - Steve Simmons from Haringey Community Dental Service
- 1.3 In addition, an in depth consultation programme has been commissioned from the National Development Team for Learning Disability. This has included;
- Interviews with a cross section of people with PMLD and their carers
 - Focus groups
 - The keeping of "health diary" by a group of carers to give a snapshot of their experiences.
- Preliminary feedback has been given on the outcomes and a final report will be presented at tonight's meeting.
- 1.4 Although the principal focus of the review has been on PML, many of the issues for people with milder learning disabilities are similar and, in some cases, are indistinguishable.

2. Health and People with PMLD

- 2.1 The Panel received a presentation from Gary Jefferson, the Head of the Learning Disability Partnership on the nature of Learning Disability (LD) and Profound and Multiple Learning Disabilities (PMLD) and how health issues impact on people with these conditions. .
- 2.2 The Partnership is funded under what is referred to as a Section 31 agreement. This 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 amount that each agency contributes is

agreed at the beginning of the year. Once committed, the money cannot be withdrawn. If the budget is overspent, each partner is liable.

- 2.3 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.
- 2.4 Recent research suggests that 2% of the general population have learning disability and there are currently around 1,000 clients known to the Haringey partnership. They vary considerably in the level of needs that they have. For example, some clients only need assistance for a short period of time once per month whilst other people can require assistance from two people around the clock.
- 2.5 The partnership uses the following definition of learning disability;
- “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.”
- 2.6 This is the same 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. It is not a condition that people obtain in later life – its onset is 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. In addition, there is debate whether the generic term should be learning disability or learning difficulty.
- 2.7 There are various published definitions of PMLD. The World Health Organisation provides the following definition:
- ‘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’
- 2.8 PMLD generally refers to people with the highest levels of need. The partnership works with people who are in residential care as well as people who needed continuing support but live at home. 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.
- 2.9 By 2021, it is estimated that the numbers of people with a learning disability 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 have 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 the Partnership is now 83. However, there is a

high prevalence of Parkinson's disease and dementia. This means that, although they are living longer, there are higher overall needs.

2.10 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.

2.11 "Our Health, Our Care, Our Say" recognises the fact that people with learning disabilities face particular health inequalities. Research has shown that they;

- 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.
- Are generally poor and live on benefits or a low income.

2.12 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. However, the success of this is dependent on health services having an awareness of these conditions and diagnosing them successfully.
- 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.

- 2.13 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. However, these are still largely not in place and the government has stated that it will review how it intends to deliver on this commitment. 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. The Health Action Plan will contain all sorts of information about how that person can be healthy. Plans contain a range of information like:
- 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
 - Emotional health
- 2.14 The person with a learning disability will normally keep a copy of the Health Action Plan and this version might have easy words and pictures or be on tape.
- 2.15 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.
- 2.16 Mr Jefferson felt that one key reason he main reasons why their health was not good was the physical inaccessibility of many health services. The partnership supports people when they go the dentist or their GP. The best GPs were generally those who got people to come in just before the start of their surgeries. Some GPs were felt to not be looking after people with learning disabilities as well as others though. The partnership includes dentists and chiropodists amongst their team and they can visit people in day centres. There has previously been a GP in the team but she had retired.
- 2.17 It was noted that Shropshire County Council has produced a leaflet for health professional outlining the needs of the people with learning difficulties and how consultations involving them should be approached. Whilst this may be a laudable initiative, their needs are, in many ways, no different in many ways from those of the wider population.
- 2.18 It was also noted that there was a specific problem with audiology. Sensory loss can make a big difference. Due to the lack of communication skills that many people with learning disability had, it is sometimes difficult for professionals to

identify the root of a problem. Sometimes problems that appeared to be significant could be resolved, for instance, by simple solutions like syringing of the ears.

3. Evidence from Voluntary Organisations

- 3.1 The Panel received evidence from a number of voluntary organisations on the accessibility of primary healthcare for people with LD and PMLD as well as their overall health needs.

HAIL (Haringey Association for Independent Living)

- 3.2 Kevin Dowd from HAIL felt that people with LD who needed support to access health services automatically faced barriers. People with learning disabilities need clear information and communication was an issue. The wider availability of advocates or people who could communicate with non verbal patients would assist. People with PMLD often find pain or distress difficult to understand. When they experience it, they often communicate this in non standard ways including behaviour which may be seen as difficult to manage and cause further difficulties. Difficulties with transport and waiting times can further add to problems.
- 3.3 He felt that people the needs of people with LD and PMLD are often overlooked and they are not given the same choices as other people. For instance, they often do not receive routine checks and screening. There was arguably a greater need for screening as secondary health problems often arise due to lifestyle and medication, amongst other issues. In addition, some people have difficulties in registering with GP's as they can be reluctant to have people with high needs on their books as it eats into their budgets.
- 3.4 He assumed that GP's training includes little on the needs of people with a learning disability or how to work with people who are non verbal and have additional needs. He recognised that it may be difficult for GPs to diagnose ailments of people with LD/PMLD when testing can be problematic due to their reaction and challenges in interpreting these.
- 3.5 Hospital staff often require carers to support service users and this is often required on a 24 hour basis and health care and general support issues can get confused. He had seen service users who are continent go into hospital but come out doubly incontinent as they had not been supported in basic care. He felt that people who do not communicate verbally were often seen as trouble and therefore ignored. It was not just a case of funding, although the provision of specialist staff would be helpful. It was also the environment and peoples attitudes. Specialist teams also need to do more to ensure that people were put on regular screening programmes.
- 3.6 This may be aided by Health Action Plans but only if services can cope with any additional workload generated. More home visits from doctors and other health professionals would assist but this would be difficult to implement as most GP's have restrictions on appointments and time constraints.
- 3.7 He felt that services needed to change their attitude and accept any person whatever their needs. In addition, measures also needed to be taken to ensure that professionals received appropriate information. Unless carers knew the

system and could work it effectively, they could lose out. He noted that Haringey has been without psychology and other support services for long periods of time.

- 3.8 Health professionals needed clear health plans to work with and this needed to be coordinated through the health service. Planned intervention should be involved than simply responding to illness or problems. In addition, information should be accessible for carers as well as service users and community services should compliment hospital services.
- 3.9 Wider health needs and well-being (e.g. diet/exercise/emotional support) could be addressed by individual planning through Person Centred and Health Action Plans as well as greater awareness in staff and carers in regard to healthy lifestyles. More could be done with access to sporting opportunities, including swimming, and also for day services to adopt active and creative activities. Services should also be aware of support which incorporates information and inclusion. Healthy Lifestyles should be included within policy and procedure. This should be at national and local/service level. There also needed to be more government work to actively include disabled people into mainstream health issues and a clearer recognition that people with learning disabilities are part of the community.
- 3.10 Carers needed to have more support as they play a huge part in supporting people who are not in receipt of services from statutory bodies. They often ignored their own health needs for those of the people they support.

MENCAP

- 3.11 Richard Taylor from Mencap reported that they had indirect experience of dealing with health professionals. They felt that there were a lot of issues in respect of communication and, in particular, a lack of accessible information. In addition, health professionals suffered from a lack of experience in dealing face to face with people with LD and could have difficulty making themselves understood. More training would assist as would wider availability of advocates. There was a particular lack of understanding of autism.

PPI Forum

- 3.12 The PPI Forum had not looked at the issue in detail and there was no evidence that work had been done nationally on the issue either. The access problems appear to be similar to those experienced by the wider population. Appropriate training was very important for health professionals. It was possible that the new GP commissioning clusters would help to improve the situation and would facilitate the provision of better training. The appointment of a specific GP within each cluster with responsibility for training would assist with this. The service that people received often could depend on how assertive people were. Action to make carers more aware of the rights and entitlements of their loved ones as well as encouragement for them to be assertive would help. One option would be for people with LD to help train GPs and other primary care practitioners. People with LD could also sometimes be used as advocates.

The Markfield Project

- 3.13 Alex Hendra from the Markfield Project stated that reported that Markfield service users had reported the following issues in relation to primary healthcare:

- Inaccessible information in primary health care venues. There needed to be improved use of pictures, symbols and easy to read literature.
- There was a mixed response from users about whether primary care health providers related to them directly or to their carers. There was a clear distinction between experience of more independent users and those with PMLD
- People spent a long time waiting for appointments and waiting to be seen in clinics and hospitals. There could be insufficient explanation about this and about what the person should expect.
- Better use of advocates would assist but there was a mixed response in respect of access to these. People were not consistently able to access advocates.

3.14 She felt that more access to exercise and recreation generally would benefit the overall health and well being of people with PMLD. They should be able to expect same access to play and leisure services as non-disabled peers. This would require commitment and funding from local authority in order to achieve the basic level of provision that non-disabled people already expect.

3.15 There were big issues around healthy eating and obesity. Programmes were needed which targeted the training of people with LD so they could learn about these issues. People also needed access to advocates to work with people on Health Improvement Plans. In addition, providers needed to be trained on how to recognise disabled people's needs and make services and information accessible to them.

3.16 The needs of carers were often overlooked. In particular, there was limited access to respite and huge stresses on carers to meet care needs with insufficient breaks from caring or support. Carers often used family support when they could not get help.

3.17 It was noted that it appeared that very few carers had been given a carers assessment although there was a statutory right to have one. The Mental Health Carers Support Association estimated that only 3% of mental health carers had received such an assessment.

3.18 There was a particular issue in respect of access to mental health services for people with LD. Mental illnesses were often not recognised in people with LD. Some people had severe behavioural difficulties and this could result in them being excluded from services.

4. Consultation with Users and Carers

4.1 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.

4.2 It is mainly women who were the principal carers for those people who had been interviewed. It is possible that the impressions that people had of services

might be influenced by their expectations which could be affected by cultural issues.

4.3 The issues that had been raised by people interviewed were as follows:

Positives:

- Many GP's are seen as supportive – even if some surgeries are not accessible – will make appointments easily or arrange specially to suit individual and family or make home visits
- Community Dental Service has been very helpful
- Key individuals can make a difference – a community nurse/a physiotherapist/a speech therapist or a key worker
- Support from Day Services and Respite mainly seen positively
- A positive/respectful/understanding attitude and a good knowledge of the person can make all the difference!

Key issues of concern:

- Lack of co-ordination of healthcare - named person
- Lack of knowledge or access to Health Action Plans or Person-Centred Plans
- Lack of information about how to access/co-ordinate health care
- Lack of regular health checks – especially if individual may require extra support during the appointment
- Low standard of appropriate support from hospital departments:
 - Outpatient and inpatient departments are not geared up to accommodate someone who has specialised needs
 - Long waiting periods/lack of 'fast tracking'
 - Unwelcoming/insensitive attitude/lack of respect for expertise of parents
 - Lack of information/training about range of disabilities
 - Lack of appreciation of communication skills needed
 - Lack of basic support during period in hospital. Individual personal care needs such as help with eating/toileting and basic monitoring/supervision of vulnerable individuals who could be at risk if left alone – it is often assumed parents can provide this 24 hours a day!
- Some hospital services are difficult to access either by distance or transport
- Some surgeries are not accessible and not 'person-centred' in arranging appointments /waiting times

- Lack of input from some specialist health services (e.g. nursing/physiotherapy/speech therapy)
- Aids and adaptations need to be reviewed more regularly and upgraded/replaced
- Personal care supports to some families' homes are sometimes very inadequate and are not addressing the health needs of parents who may be getting older and have their own health needs
- Need for improved input/co-ordination from community dentist to local dental practices
- Historically treatment by some past clinicians and hospital staff has been very poor. There had been some stories of poor standard of healthcare in the past when subjects were much younger and were seeking clear diagnosis/treatment and ongoing support.

4.4 In respect of Health Action Plans, only 23% of relevant people currently had them. They are 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 are 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.

4.5 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.

4.6 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.

4.7 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.

5. Evidence from Primary Care and Services

Primary Care

6.1 Gerry Taylor from Haringey PCT provided some general background on the role of primary care. There is no specific guidance for primary care practitioners on

dealing with people with learning disabilities and profound and multiple disabilities. Good practice would however be shared across the four primary care collaboratives which now provided a useful means of communication.

- 6.2 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 enable services to be better planned. In addition, the financial rewards that now follow satisfaction levels of patients may provide an incentive for GPs to consider appropriate appointment times and length for people with LD and PMLD.
- 6.3 GPs are independent contractors and the PCT's powers of influence are therefore subject to limitations. Practices approached issues such as accessibility in variable ways and there could sometimes even be differences in approach within the same practice. In terms of training, practices made their own arrangements for attendance at events. Although the PCT encouraged attendance at relevant events, they could not make it mandatory. However, issues could be raised as part of the assessment process that GPs were required to go through and as part of their assessment.
- 6.4 The PCT has undertaken a mapping exercise on the physical accessibility of primary care facilities. It has been found that a range of GP practices needed improvement. One particular area that requires attention is signage and improvements in communication are currently being looked at. The PCT has also recently begun work with the local authority on the provision of appropriate training for health staff on making services more accessible. This will cover a range of staff and not just clinicians.
- 6.5 The PCT is currently developing an obesity strategy. There had been a specific NRF funded scheme on obesity and the results of this would be fed in. It was agreed that Ms. Taylor would provide information on the project to the Panel. The PCT had not specifically targeted people with LD in the work that it had done so far. It was noted that obesity was also an issue for people with mental health issues.

GP Perspective

- 6.6 The Panel received evidence from Dr. Sherman, a local GP. He had practiced in the Bounds Green area for 20 years. His interest in learning disability (LD) issues arose from the role that he had as a clinical assistant at the Edwards Drive respite care centre.
- 6.7 There was one other GP who took a particular interest in LD and this was Dr. Mary Phimester who was located in the south of the Borough. She had been scheduled to also speak to the Panel but had unfortunately been unable to attend.
- 6.8 GPs did not receive any specific guidance or training on LD issues. The provision of appropriate user friendly guidance by the PCT would assist them. GPs had received local guidelines on other issues from the PCT and were open to such advice. He found working with patients with LD to be a rewarding experience but it could sometimes require some specialist knowledge. There had been a specialist consultant linked to the Learning Disabilities Partnership who could be referred to. One particular additional method of sharing best

practice and advice would be through the collaborative clusters of GP practices that existed within the Borough.

- 6.9 GPs had limited amounts of time to undertake learning. They were now subject to appraisal and this had a particular educational component. In addition, the Quality and Outcomes Framework now had some reference to LD within it. One possibility would be for specific GPs within practices to adopt particular specialisms but this was only feasible in the larger practices. However, all GPs generally dealt with people with LD and he felt that this was beneficial as it helped to develop their overall awareness. Some patients with LD could become very attached to specific health professionals and in such circumstances it would be better if they saw the same GP. Efforts were normally made to ensure that this was possible.
- 6.10 As far as he knew, LD was not currently an integral part of doctors training – he was not aware of any specific modules relating to it although it might be referred to as part of the mental health component. Generally speaking, whether patients with LD were able to access a GP with particular relevant knowledge was something of a lottery.
- 6.11 The majority of GP practices did not undertake any special measures to accommodate people with LD. GPs did not always know which of their patients had LD and it was often up to receptionists to identify them from their behaviour. Their role was key to how people with LD/PMLD were dealt with within practices. The Practice Managers Forum would therefore provide a useful and effective route for delivering training, developing awareness and sharing good practice.
- 6.12 There was currently no specific responsibility for GPs to routinely review the health of people with LD, unlike the situation with mental health patients. People with LD normally attended surgery with their carers or an advocate. It was generally a matter of judgement whether to address the carer/advocate or the patient but most GPs tried to at least include the patient in the discussion. However, if GPs were pressed for time they could sometimes just communicate with the care/advocate. Whilst carers/advocates could often simplify the consultation, they could sometimes also complicate it.
- 6.13 It would not be easy for surgeries to give people with LD early appointments as these were normally under heavy demand from commuters. Older people and the under 5's were normally given priority. If another group of patients were added to this list, this could lead to longer waiting times for other patients. There were frequently complaints about long waits.
- 6.14 The Panel felt that special arrangements to accommodate patients with LD should be a matter for local discretion so that local conditions could be taken into account. One possibility would be to set particular times for such patients in less busy periods. One possible way of accommodate the range of health needs of people with LD would be to hold multi disciplinary sessions for people where they could access a range of healthcare such as chiropody, physiotherapy and dietary advice. This would need to be arranged by the PCT though. It was recognised that there were severe staff shortages in some disciplines such, particularly physiotherapy.
- 6.15 He felt that the best ways to increase the take up of routine screening were to advertise its availability and to work closely with carers and support staff to

promote it. There were 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. With the exception of cervical screenings, all screenings were arranged by the PCT.

- 6.16 GPs could help to support people with LD and PMLD when they were hospitalised by informing the hospital of any special needs that they might have. Care plans for people going into respite care were often very detailed. It would help GPs and hospitals if this information could also be shared with them.
- 6.17 Training sessions were arranged regularly for GPs in a range of settings. It was, however, up to individual GPs if they attended and they often had limited time. He felt that training on LD issues should be part of the undergraduate curriculum so that it could be ensured that all doctors received at least some sort of training on the issue.
- 6.18 He felt that a structured programme of care with clear goals and methodology would help in improving the health and well being of people with LD /PMLD. Primary care practitioners would be assisted by employment of community matrons with special interests in LD/PMLD. In addition, specific training for receptionists would assist as they were normally the first point of contact for people with LD and their carers. Practices would welcome this provided that it was not too time consuming. Finally, there needed to be better links between primary and secondary care

Dental Services

- 6.19 Steve Simmons from the PCT reported that the Primary Care Trust Dental Service (PCTDS) provided specialist and specialised dental care for children and adults with LD and PMLD, across both Haringey and Enfield PCT areas. This catchment secured enough workload to justify the specialised services provided. The components are:
- Screening assessment at schools, special schools, care homes, etc. This includes 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 much better that dental advice and necessary care is proactive, starting as young as possible and before school age. It is important to involve the whole family. Referrals are also received from doctors, specialist nurses, health visitors, school nurses, directly from Great Ormond Street, and local dentists. Screening can be very productive when targeted. 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 and could not be readily detected as the patient wouldn't open his mouth for care-staff.
 - Prevention. The service provides an expert oral health promoter to work with schools, care homes and families to prevent oral disease and to prepare learning materials for use in schools, care homes etc. Training for care staff is provided in care homes.
 - Treatment: this is carried out at St Ann's using local anaesthetic and/or sedation. For more profound cases with multiple problems, the dental staff

have a session in operating theatre at North Middlesex Hospital and at Chase Farm Hospital, where patients can be treated under general anaesthesia when clinically necessary.

- 6.20 People with mild LD people can access high street dentists and this was encouraged to normalise their care as far as possible. LD patients may well 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 PCTDS
- 6.21 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. However demand from new patients is continua. Many patients are from overseas and from a family with a language barrier. This means there is no respite from providing urgent care.
- 6.22 Dental access for LD and PMLD adults has reduced. 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 due to lack of staff. Due to the PCT's current financial difficulties, 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.
- 6.23 He suggested several possible improvements to provision;
- Prevention of oral disease by good dental home-care is important for LD & 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 & 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.
 - More contacts and better liaison with Care Home managers to ensure dental home-care (prevention) is provided.
 - Obviously more dental staff would help cope with the workload for LD & PMLD adults. Dental staff are concerned 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.

6. Well Being

Sports and Leisure

- 6.1 Mr Briggs reported on the measures that the Sports and Leisure Service 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 were equipped with 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. The improvements made included converting a toilet to a disabled changing room and upgrading of current facilities and equipment to include tactile and Braille signage.

- 6.2 The service had 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 Mosselle School to provide coached sessions in the SHOKK gym. However, as with many organisations, funding remained an issue for the service.
- 6.3 Sports and Leisure were 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. He 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. He 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.
- 6.4 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. He felt that there was much that could be done with people with disabilities as the facilities were now very accessible.
- 6.5 The Panel felt that one option would be to include recommendations exercise and recreation 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.
- 6.6 Alex Hendra reported that, there were 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.

- 6.7 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.
- 6.8 Markfield were able to give detailed evidence on the lack of access to recreation and exercise as they had been commissioned to undertake an audit of supervised play provision in March 2006. This had 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 six local authority run centres, are physically inaccessible to children with mobility difficulties. There are 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.
- 6.9 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.
- 6.10 This lack of provision disproportionately affected children with PMLD and a large number of the children with no play scheme place had 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.
- 6.11 There were a number of barriers to accessing play provision:
- Physical access. She felt that the local authority needed to set targets for bringing the physical accessibility in Borough owned buildings up to Disability Discrimination Act (DDA) standards and to ensure this was done by providers who were commissioned.
 - Unstable funding arrangements for service providers and last minute agreements of funding. This led to a lack of planning, difficulties providing services to full capacity and drawing in match funding e.g. from trusts. This could be remedied by establishing longer term funding arrangements.
 - Lack of information about the number of people with disabilities who are struggling to access recreation and exercise. Providers needed to be encouraged to keep more accurate data. In addition, there needed to be needs based auditing of disabled people in Haringey.
 - 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. Inclusion training programmes for key staff needed to be established. Disabled people could be involved in setting up and running such training. In addition, mystery shopper type models for assessing accessibility and attitudes could also be set up and run by disabled people.

6.12 Robert Singh from the Children and Young People's Service 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.

6.13 One particular issue was the funding arrangements for groups working with such children, which were frequently complex and unstable. 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.

6.14 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 although they currently did not provide any specific funding for the service.

SOME KEY ISSUES:

- *Increasing the awareness of GP'S of LD/PMLD*
- *Improving the level of information on people with LD/PMLD e.g. numbers etc.*
- *Enhancing the "patient experience" e.g. appointment times/lengths*
- *Co-ordination of health issues – communication between professionals*
- *Provision of health information and advice for people with LD/PMLD and their carers*
- *Liaison with hospitals*

- *Improving take up of screening*
- *Access to specialist services e.g. physiotherapy/chiroprody/audiology*
- *Reviews of aids and adaptations*
- *Benefits advice*
- *Obesity and how to link people with LD into the wider strategy*
- *Encouraging suitable exercise*
- *Updating of carers assessments*

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