MINUTES OF THE SCRUTINY REVIEW - ACCESS TO PRIMARY HEALTHCARE FOR PEOPLE WITH LEARNING DIFFICULTIES
TUESDAY, 3 OCTOBER 2006

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

* Member present

Also present: Mr. G. Jefferson (Head of Haringey Learning Disability Partnership)

LC7. APOLOGIES FOR ABSENCE

None.

LC8. URGENT BUSINESS

None received.

LC9. DECLARATIONS OF INTEREST

There were no such declarations.

LC10. MINUTES

AGREED:

That the minutes of the meeting of 5 September 2006 be confirmed.

LC11. ACEESS TO PRIMARY HEALTHCARE FOR PEOPLE WITH PROFOUND AND MULTIPLE LEARNING DISABILITIES

The Panel received a presentation from Gary Jefferson, the Head of the Learning Disability Partnership, on the nature of learning disability and how health issues impacted on people with learning disabilities.

He stated that the Partnership was funded under what was referred to as a Section 31 agreement. This meant that the money from a number of different agencies was pooled in order to provide particular services. The services that comprised the Learning Disabilities Partnership were Social Services. Haringey PCT and Barnet, Enfield and Haringey Mental Health Trust. The amount that each agency would contribute was agreed at the beginning of the year. Once committed, the money could not be withdrawn. If the budget was overspent, each partner was liable.

The majority of learning disability services were now partnerships. In some case, this might just mean that they just shared the same premises, but the Haringey service was completely integrated and covered all aspects of the health and social care of clients.

People with learning disabilities were involved in the governance of the partnership, with representation on the Board. Linked into the Board, were a number of forums with one each for carers, service users and voluntary sector partners.

The partnership used 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."

This was the one used by the Department of Health in its "Valuing People" document on the provision of services to people with a learning disability. Learning disability was not a condition that people obtained in later life – its onset was before the age of 18. IQ was generally assessed as being below 70. There was some debate as the whether conditions such as cerebral palsy and autism were in fact learning disabilities. However, the term normally included Downs Syndrome and a number of other conditions. In addition, there was debate whether the generic term should be learning disability or learning difficulty.

There were currently around 1,000 clients known to the service and they varied considerably in the level of needs that they had. For example, some clients only needed assistance for a short period of time once per month whilst other people could require assistance from two people around the clock. Profound and Multiple Learning Difficulties (PMLD) generally referred to people with the highest levels of need. The service worked with people who were in residential care as well as people who needed continuing support but lived at home.

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

During the past decade, life expectancy had improved for people with learning disabilities. For example, people with Downs Syndrome had generally lived until their mid forties but were now living until their early to mid fifties. The oldest person with a learning disability known to the service was now 83. However, there was a high prevalence of Parkinson's disease and dementia. This meant that, although they were living longer, there were higher overall needs.

There were high levels of obesity amongst people with learning disabilities with around 52% being overweight or obese. In addition, there were:

- Low levels of testing for cervical cancer and other conditions.
- Higher rates of psychiatric illness
- A prevalence of epilepsy
- Poor eyesight
- Only 1 in 10 had a healthy diet whilst 1 in 3 had an unhealthy diet; and
- Prescribing costs for patients of long stay hospitals were 6 times more.

Shropshire County Council had 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 was a laudable initiative, their needs were no different in many ways from those of the wider population.

One of the main reasons why their health was not good was the physical inaccessibility of many health services. The partnership supported people when they had to 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 included dentists and chiropodists amongst their team and they could visit people in day centres. There had previously been a GP in the team but she had retired.

There was a specific problem with audiology. Sensory loss could make a big difference. Due to the lack of communication skills that many people with learning disability had, it was 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.

We thanked Mr. Jefferson for his presentation.

LC12. PROGRESS WITH REVIEW

It was noted that a meeting had taken place between NDT, who were undertaking the detailed consultation on behalf of the Review Panel, and a group of parents and carers who had been selected to take part in the exercise. The purpose of the meeting was to explain the process and answer their questions. It had been clear from the meeting that many parents and carers had concerns about healthcare and, although there had been some cynicism about the exercise, they had all agreed to take part. The group had been selected in order to get a representative cross section of the local population.

Mr. Jefferson reported that recruitment of a person with a learning disability to sit on the Review Panel was going ahead.

It was noted that the next meeting would be taking place on 31 October and representatives from the voluntary sector and patient organisations would be invited to give their views. It was agreed that the starting time would be brought forward to 6:00 p.m. in order to avoid clashes with later meetings.

LC13. NEW ITEMS OF URGENT BUSINESS

There were no such items.

Cllr Emma Jones
Chair