MINUTES OF THE SCRUTINY REVIEW - ACCESS TO PRIMARY HEALTHCARE FOR PEOPLE WITH LEARNING DIFFICULTIES
TUESDAY, 31 OCTOBER 2006

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

- Member present

Also in attendance; Ms. A Hendra (The Markfield Project), Mr. R. Taylor (Mencap), Ms. D. Burkens and Ms. H. Warner (Haringey PCT PPI Forum)

LC14. APOLOGIES FOR ABSENCE

None.

LC15. URGENT BUSINESS

None received.

LC16. DECLARATIONS OF INTEREST

There were no such declarations.

LC17. MINUTES

AGREED:

That the minutes of the meeting of 3 October 2006 be confirmed.

LC18. ACEESS TO PRIMARY HEALTHCARE FOR PEOPLE WITH PROFOUND AND MULTIPLE LEARNING DISABILITIES - EVIDENCE FROM VOLUNTARY SECTOR ORGANISATIONS

The Panel received evidence from Alex Hendra from the Markfield Project, Richard Taylor from MENCAP and Helen Warner and Dolphi Burkens from the Patient and Public Involvement Forum for Haringey PCT.

The Markfield Project

Ms.Hendra stated that her organisation was primarily concerned with the provision of leisure and recreation opportunities for people with learning difficulties and therefore most of her comments related to this rather then directly to health care.

There were some examples of good access to recreation and exercise for adults with learning disability (LD) but these were not necessarily accessible to people with profound and multiple learning disabilities (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 seemed to have less access to this kind of facility.

There were 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 was limited. Day centres also provided a range of recreation activities for adults with LD.

In respect of children with LD, Markfield were able to give more 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 was severely limited for children with disabilities. Many providers, including six local authority run centres, were physically inaccessible to children with mobility difficulties. There was a severe shortage of play places for disabled children – for example, there were only enough inclusive places for half the number of children registered as disabled within the Borough. There was 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 were offered holiday play provision, it was 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.

Markfield were 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. There were 112 disabled children identified as needing a play scheme service who were not allocated any provision at all over the summer. 39 of these were referred by Social Workers, 6 by CAMHS, 4 by Harts, 3 by Parental Involvement Workers; and 2 by schools. The rest were parent referrals.

This lack of provision disproportionately affected children with PMLD. A large number of the children with no play scheme place had 1 to 1 support needs. In addition, 9 of these were referred by social workers defining them as at risk of family breakdown, and 6 were on the Child Protection Register or had existing protection concerns.

The Panel noted that a response to the audit was still awaited from the Children's Service.

There were a number of barriers to accessing 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.

In respect of accessing primary health care, Markfield service users had reported:

- 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

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.

There were big issues around healthy eating and obesity. Programmes needed which target training of people with LD to 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.

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. The Panel 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.

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.

Mencap

Mencap had indiredt experience of dealing with health professionals. 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 difficult making themselves understood. More training would assist as would wider availability of advocates. There was a particular lack of understanding of autism.

PPI Forum

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 appeared 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.

We thanked Ms. Hendra, Mr. Taylor, Ms. Burkens and Ms. Warner for their assistance.

AGREED:

1. That the Children and Young Peoples Service be asked to respond to the outcomes of the play audit and specifically the shortfall in places on play schemes for children with LD and PMLD.

2. That Haringey PCT be requested to report back on the level of training that is offered to primary care practitioners on LD and PMLD.

LC19. PROGRESS WITH REVIEW

It was agreed that Children and Young People's Service would be invited to come along to a future meeting of the Panel to respond to the issues raised by the Markfield Project concerning the availability of play provision for children with LD and PMLD.

LC20. NEW ITEMS OF URGENT BUSINESS

There were no such items.

MINUTES OF THE SCRUTINY REVIEW - ACCESS TO PRIMARY HEALTHCARE FOR PEOPLE WITH LEARNING DIFFICULTIES
TUESDAY, 31 OCTOBER 2006

Cllr Emma Jones
Chair