

Appendix B

Scoping document for Scrutiny review Access to health services for people with learning disabilities

What are the main issues? *What is the policy background?, how does it link to the councils corporate priorities?*

The White Paper, Valuing People 2001 highlighted the need for Primary Health Care to ensure that all people with a learning disability had a health action plan to ensure their health needs were met by primary, secondary and acute health care providers. Very few boroughs ensured that these plans were completed and local research undertaken by Brent PCT, Brent Mencap and Brent Learning Disability could only find evidence of about 40 being completed out of a population of about 1250 people with a learning disability published in 2007.

A report by Royal/National MENCAP in 2004 entitled *Treat me Right* drew attention to the problems faced by people with learning disabilities in accessing health and social care services. The report highlights that this group are more likely to have poorer health than the rest of the population with a higher prevalence of medical conditions such as epilepsy and thyroid problems. Despite their greater reliance on healthcare, this group are more likely to receive a poorer service. Key issues included staff not being trained to deal with patients with learning disabilities. This can lead to poor quality of care as staff are not able to deal or communicate with patients effectively and understand their needs. This was also reinforced by a report commissioned by the then Disability Rights Commission called *Mind the Gap* which highlighted the high level of health inequalities experienced by people with a learning disability and also those with Mental Health Problems

The 2006 Government White Paper “ Our Health, Our Care, Our Say” stated that many people with learning difficulties have a poor experience of using health services and can find it difficult to access mainstream services.

A further report by MENCAP in 2007 entitled *Death by Indifference* featured six case studies where the patients suffered fatal consequences due to the poor services they had received. In some cases, the inability of healthcare professionals to take into consideration the patients learning disabilities was highlighted as a contributory factor.

This amounts to a strong body of evidence highlighting failures across health and social care to provide adequate healthcare services for people with learning disabilities, who are among the most vulnerable adults in society.

In 2008, the Secretary of State for Health set up an independent inquiry chaired by Sir Jonathan Michael to review these issues. His report *Healthcare For All* identified a range of barriers experienced by people with learning disabilities including:

- People with learning disabilities find it much harder than others to access assessment and treatment for general health problems which has nothing to do with their disability.
- Carers of adults with learning disabilities often find their opinions and assessments ignored.
- Health staff often have limited knowledge about learning disability. As a result people with learning disabilities are less likely to receive pain relief and palliative care. There was some evidence of belief amongst some staff that people with learning disabilities have a higher pain threshold.
- Service planning and transition arrangements are often poor for people with learning disabilities

Brent context

In Brent, some children, young people and adults with learning disabilities who are assessed as having critical or substantial needs get services provided by the Learning Disabilities Partnership or the Children with Disabilities team. . These are integrated health and social care teams and provide services such as respite, occupational and speech therapy, physiotherapy, psychological therapies and support with challenging behaviours, unpaid work experience placements, some paid employment support, day centres, job coaching and some limited specialist health services. Many specialist health posts such as were cut by the PCT and the Health Scrutiny Committee will remember the cavalier attitude taken at the time by the PCT which took no account of the extra health needs of people with a learning disability highlighted at the time.

Many Brent people with a learning disability of all ages are not assessed as having critical or substantial needs and do not receive statutory services provided by the teams above. In these cases they rely on specialist services provided by voluntary sector organisations.

Many access mainstream services such as health services where reasonable adjustments are not made by service providers and the service is not suitable or treatment not complied with or symptoms are ignored. This causes distress to the person with a learning disability and extra stress for their unpaid family carers

The Children with Disabilities Teams and The LD partnership have been working with social care and primary care providers to improve service provision for people with learning disabilities. The Learning Disability Partnership Board would welcome an overview and scrutiny review into this area.

Brent MENCAP has drawn attention over recent years to the above reports and the effects of the cuts on local people with a learning disability and has

communicated their concern about the lack of local action to members and the PCT senior officers. They recently circulated their feedback about the lack of evidence that the PCT was meeting the core health competencies with regard to people with learning disabilities to Health Scrutiny Committee Members, Link and other partners. They would welcome a scrutiny review at this time and would support people with a learning disability to also give evidence.

Why are we looking at this area? Have there been recent legislation/policy changes? Are there any performance or budgetary issues?,

Valuing People Now, an updated version of the White Paper was issued in early 2009 and lays down much clearer expectations on both Councils and PCTs to address the continuing poorer health of people with a learning Disability highlighted in the above mentioned reports. It also includes more compulsory performance management indicators to be met by Statutory providers within defined timescales which include health, employment and housing which should drive change.

Tackling health inequalities is a priority within the council therefore it is important that the borough provides high quality services for people with learning disabilities to address the disadvantages experienced by this group.

Also, the number of people with this condition is on the increase, currently around 2.5% of the population in the UK has a learning disability depending on definition. Research within the *Healthcare For All* report highlights that advances in medical care will mean that this figure is likely to rise. Rates are likely to go up by around one per cent per annum for the next ten years and grow overall by over ten per cent by 2020.

It is also expected that there will be a growth in the complexity of disabilities due to increasing use of alcohol and rates of unplanned teenage pregnancy which contributes to the increases in the prevalence of foetal alcohol syndrome.

What should the review cover? Give brief outline of what members could focus on, which partners to engage with, how residents/public can be involved.

The review should:

1. Identify what specialist services are available to meet the health needs of children and adults with a learning disability
2. Identify gaps in specialist health service provision and likely effects of this on long term spending by both Council and PCT.
3. Review the effectiveness of the mainstream health related provision for children and adults with a learning disability
4. Identify what reasonable adjustments have been made or need to be made to services to enable PWLD to access health services
5. Develop and agree a plan to meet the Valuing People Now health

related targets with Brent NHS

6. Review information sharing and transitional arrangements between social care, primary care and secondary care services.

Under the Disability Equality Duty all public bodies are required to produce a Disability equality scheme which sets out detailed plans to address the health inequalities faced by people with learning disabilities. This task group could review the Brent NHS document to ensure that it addresses these issues

The Task Group could gather evidence from:

- Brent Local Involvement Network
- Brent Carers Centre
- National Autistic Society
- Brent MENCAP
- Brent Learning Disability Partnership
- NHS Brent
- Brent Council, Assistant Director for Community Care

What could the review achieve?, influence policy change?, improvement to service delivery?, budget savings?, develop partnerships?.

The review could identify good practice to share between healthcare providers within Brent

The evidence from this review could ensure that this issue is given the appropriate priority within future service planning across the council.