

**Six Lives Panel Project / NHS London health self-assessment  
Report for the Health Scrutiny Panel**

**1. Introduction**

This briefing sets out the background to both the Six Lives Panel Project and the subsequent NHS London health self-assessment for learning disabilities.

**2. Death by Indifference**

In March 2007 Mencap published a report entitled *Death by Indifference* which examined the cases of six individuals who died whilst receiving NHS care. Whilst the families of the six individuals had lodged formal complaints to the Healthcare Commission, Mencap called on the government to launch an independent investigation into all six deaths and address their claim that there is institutionalised discrimination against people with learning disabilities within the NHS.

**3. The Six Lives Report**

In July 2008 the Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities (also known as the Six Lives Report) was published following the independent inquiry chaired by Sir Jonathan Michael. The Inquiry concluded that people with learning disabilities were less likely to receive the most effective care to meet their needs, and whilst there were examples of good practice in some areas, this was not mainstreamed. In short, there was often a gap between policy, the law and the delivery of effective health services.

In response to the publication of the Six Lives report, the Ombudsmen made three recommendations in March 2009. Of most relevance for NHS and Local Authorities was that all NHS and social care organisations in England should urgently review:

- The effectiveness of the systems they have in place to enable them to understand and plan to meet the full range of needs of people with learning disabilities in their areas, and;
- The capacity and capability of the services they provide and/or commission for their local populations to meet the additional and often complex needs of people with learning disabilities; and:
- Should report accordingly to those responsible for the governance of those organisations within 12 months of the publication of the Ombudsmen's report.

**4. The Six Lives Panel**

In order to respond to the Ombudsmen's recommendations it was proposed that Tower Hamlets hold a Six Lives Panel meeting in order to fulfill our obligations. The Panel were made up of a variety of professionals from across

the NHS / social care sector (primary care, acute care and commissioning), along with an independent Chair, David Morris. (David was selected due to his considerable experience of the disability rights movement and links to the borough. He was involved with the process from its inception, until he sadly passed away in April 2010).

The Learning Disabilities Partnership Board took a lead on the Panel Project with a view to it being a starting point for establishing a Health sub-group. One of the key outcomes of the Panel was to draw up an action plan. This would then form the basis of the Health sub-group's work programme and they would be responsible for taking this work forward.

Also key was the involvement of service users and carers. To this end a number of workshop sessions were held prior to the Panel to ask people about their experiences of accessing healthcare services. The Rix Centre, a learning disability multi-media advocacy organisation, ran and facilitated these sessions in conjunction with three service user 'champions'. These individuals were trained in consultation techniques and the use of camera / recording equipment. This approach allowed those who may not have felt comfortable attending the Panel meeting to give their views.

The Panel took place in November 2009. Service users and carers were in attendance to ask questions and recount their experiences, and the Panel were also shown a DVD of the workshop sessions run by the Rix Centre and the champions. The Panel meeting itself was also filmed and the footage subsequently edited with that of the workshops to produce the *My Health My Say My Way: Communicating effectively with people with learning disabilities* DVD.

Following the meeting it was intended that members of the Panel would report back to their organisations and reconvene in early 2010 to report progress and agree an action plan to take forward.

##### **5. The NHS London health self-assessment process**

NHS London was responsible for co-ordinating a Health Self Assessment of services for people with learning disabilities across all London PCTs, to meet the Ombudsmen's recommendations.

Each PCT was asked to convene a Big Health Check Up Day where people with learning disabilities, their family members and professionals were to be involved and have their say, by March 2010. Given the similarities between this and the Six Lives Panel, the decision was taken to combine the two processes and for the reconvened meeting of the Panel to be the Big Health Check Up Day for Tower Hamlets.

As part of the self-assessment process, staff from within the Council and NHS Tower Hamlets undertook a joint exercise to gather data and evidence to inform our assessment of access to healthcare services for people with learning disabilities in the borough. As a requirement preparatory work was undertaken in the form of 'Getting Ready Meetings' which involved talking to

service users, carers, providers and the Learning Disabilities Partnership Board about how they rate services. All of this information and views were considered as part of our submission.

The Six Lives Panel Big Health Check Up day was held in February 2010. This involved members of the original Panel along with service users and carers meeting to discuss the issues in detail and vote on what they felt was an appropriate RAG rating for our self-assessment submission. This interactive day was again filmed by the Rix Centre and involved around seventy service users from a range of backgrounds talking frankly about their experiences of a range of health related issues, from healthy lifestyles to hospital admissions.

#### **6. Key headlines from the self-assessment**

The PCT and LBTH had already agreed to complete a Joint Strategic Needs Assessment for Learning Disabilities (this was completed in April 2010). The NHS London Self Assessment process for Tower Hamlets was completed on the 28th May 2010. Tower Hamlets received an overall AMBER rating for its self-assessment.

A Health Sub Group of the Learning Disabilities Partnership Board has been established to develop an action plan to tackle areas highlighted in the self-assessment exercise, the Six Lives Panel and the Joint Strategic Needs Assessment.

#### **7. Health Scrutiny Panel input**

The Health Scrutiny Panel are asked to review the self-assessment results attached at appendix A and agree the action plan of the newly established Learning Disabilities Partnership Board Health Sub Group.

## Results from the Self-Assessment for Tower Hamlets

### Feedback from NHS London

- The Big Health Check Day was a great success with good representation from service users and carers and also of staff from varied health and social care backgrounds.
- NHS London wish to use NHS Tower Hamlets as a gold standard example for reporting returns for next year and also to use our DVD on the Big Health Check event.
- Reports and evidence to support the self assessment were supplied in a very thorough, structured and systematised way, which made it easier to review and analyse. It was evident that a lot of hard work went into completing the exercise.
- From the evidence supplied there is a sense that services within Tower Hamlets are working well together. It was reported that 94 % of GP's are signed up to the local enhanced service, good work is going on with the acute and mental health sectors and the dementia strategy includes the needs of people with learning disabilities.

### Identified Priorities for 2010-2011

*Target 1 – Plans are in place to meet the needs of people who are no longer receiving treatment which requires in-patient care in an acute/long-stay residential facility or hospital*

- There are no people from Tower Hamlets living in long stay hospitals and no one is living in NHS campus accommodation. Three people are reported to be in mental health units for assessment and treatment under restricted sections of the Mental Health Act.
- It will remain important to review people in Assessment and Treatment beds and to have Person-Centred Discharge Plans to reduce the potential for delayed transfers of care and to minimise the potential for resources remaining tied up in beds, rather than being used imaginatively to prevent admissions.

*Target 2 – PCT's are working closely with the local Partnership Board and statutory and other partners, to address the health inequalities faced by people with learning disabilities.*

- To improve the information available in Primary Care regarding the particular health needs of people with learning disabilities and their family carers, through the use of existing data collection processes.
- To increase the numbers of people who have a Health Action Plan and to link this explicitly to the Annual Health Check.
- To produce accessible information on available health services, as well as information which informs people of their rights and mechanisms through which they can give feedback to organisations about their experiences using services.

- To improve the range and accessibility of health promotion and education opportunities for people with learning disabilities and their carers.

*Target 3 – People with learning disabilities who are in services that the NHS commissions or provides, are safe.*

- To improve access to acute hospitals through working with colleagues across organisations and teams to review the progress of current initiatives, and then identify actions which will move this target forward.
- To conduct an audit of acute trusts on issues of treatment and significant care decisions for patients who have learning disabilities and to assess staff knowledge and skills in this area (to be completed by March 2011)
- To pro-actively utilise PALS and PPI to seek feedback from service users and their carers, and for this to be included in annual complaint and compliment reporting. In this way, organisations will also be able to demonstrate 'reasonable adjustment' of existing Complaints Processes.

*Target 4 – progress is being made in the health service reforms and development described in 'Valuing People Now'*

- To work with the Learning Disabilities Partnership Board to develop strategies which will improve the care of people with a range of conditions, including Challenging Needs, Mental Health and Autistic Spectrum Disorder, as well as to improve the experiences of young people in Transition to Adult Services.