

Trust Board MeetingITEM: 7
DOC: 4

DATE: 28 March 2012

TITLE: Improving health experiences and outcomes for people who have learning disabilities and their families: Following on from Death by Indifference**SPONSOR:** Susan Tokley/Bronagh Scott**REPORT FROM:** Gwen Moulster**PURPOSE OF REPORT:**

1. To update the Board on progress since the Ombudsmen's report: 6 Lives (2008). Healthcare for All (sir Jonathon Michael 2008) and Mencap report: Death By indifference (2007)
2. To identify key areas where further actions are needed
3. To invite the Board to sign the Whittington 'Our Hospitals Charter'

EXECUTIVE SUMMARY:

1. There is evidence that people who have learning disabilities have poorer health outcomes than the rest of the population and are five times more likely to die from preventable disease. This report to the Board identifies the key areas for improvement identified through national reports and guidance and highlights the work being done by Whittington Health to address the targets set by the government.
2. The report includes the results of the self-assessment (SAF) 2011/2012 carried out in partnership with NHS London. Whittington Health has demonstrated improvement since the last assessment for 2009/2010. Examples of our successes are included within the main report and in the attached appendices.
3. The report highlights issues of concern, in particular the recent report by Mencap: Death by Indifference, 74 Deaths and Counting (2012). This shows that people with learning disabilities and their families are still having poor experiences with health care. Some specific areas where we need to improve are identified. We need to get better at training all our staff, especially doctors, about the needs of people who have learning disabilities and their families. We also need to involve people with learning disabilities and their families in the planning and delivery of our services.
4. We need to ensure a consistent approach is embedded across all services and considered in all our strategies, policies, systems and processes, rather than having only pockets of good practice, as is the case currently. This requires an on-going 'Board to ward/community' approach and full support and endorsement by the Trust Board. All the areas where further improvements are needed are identified with action plans for improving our SAF score in 2012/2013 and included in the appendices.



5. The board is asked to sign the “Our Hospitals Charter” (see appendix 7), which endorses the fact that people who have learning disabilities have the same rights to expect good health care and to be well and that the organisation agrees to take a person-centred approach to the care, treatment and support of people who have learning disabilities.
6. An easy read version of the report has also been prepared (see appendix 9).

PROPOSED ACTION:

1. Receive update
2. Agree action plan
3. Board sign up to Charter for Never Events

APPENDICES:

Appendix 1 Haringey SAF Action Plan 2012
Appendix 2 Islington SAF Action Plan 2012
Appendix 3 Whittington Health SAF & CQINN Action Plan 2012
Appendix 4 NHS London CQINN for Vulnerable Adults (Autism and Learning Disabilities)
Appendix 5 Easy Read Haringey Framework for Health Report 2011
Appendix 6 Death By Indifference 74 deaths and counting (summary)
Appendix 7 Our Hospitals Charter
Appendix 8 Easy read version of this report for the Trust Board

DECLARATION

In completing this report, I confirm that the implications associated with the proposed action shown above have been considered – any exceptions are reported in the Supporting Information:

The report makes recommendations that are consistent with government policy and best practice guidance and that also will support compliance with the NHS Self-Assessment, CQC and CQINN processes.

Moving Ahead

This report supports all 5 of the Trust’s strategic goals. The recommendations for the Board ask for engagement with a person-centred approach to both hospital and community based health care for people who have learning disabilities and their families. If the Board signs up to the action plans and the Charter this will contribute to improved health outcomes and enable better delivery of local health care.

Supporting Information**1. Context and background**

- 1.1 The White Paper, Valuing People Now (2009) tasked health Trusts with a number of clear targets to improve the health outcomes and experiences for people who have learning disabilities and their families. This followed the publication of Death by Indifference (Mencap 2007), The Ombudsmen’s report, 6 Lives: the provision of services to people with learning disabilities (2008) and Healthcare for All (Sir Jonathon Michaels 2008). These reports showed that significant numbers of people experienced low standards of care just because of their Learning Disabilities, which led to serious harm and in some cases premature death.

1.2 The government targets are to:

- Include learning disabilities in under and post graduate clinical training.
- Collect data to identify people with learning disabilities who access health care.
- Involve family/carers in the provision of care as a matter of course.
- Provide advocacy and PALS support for patients with learning disabilities.
- Include people with learning disabilities and their families in planning and developing health services.
- Liaise with key staff from other organisations such as primary care across the spectrum of care.
- Develop specific learning disability requirements by inspectors and regulators such as the CQC, against which trusts are monitored.
- Raise awareness in all health care staff.
- Ensure Acute trusts have a representative on their local Learning Disability Partnership Board and other local groups.

1.3 The NHS Self-Assessment Framework (SAF) was designed to ensure better health outcomes for people who have learning disabilities. This is an assessment of the quality of services delivered to people with Learning Disabilities and their families in acute and community trusts and by local authorities. The framework measured against four top targets:

- 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
- Target 2 – PCTs are working closely with the local Partnership Board and statutory and other partners, to address the health inequalities faced by people with learning disabilities.
- Target 3 – People with learning disabilities who are in services that the NHS commissions or provides, are safe.
- Target 4 – progress is being made in the health service reforms and development described in ‘Valuing People Now’

1.4 People with learning disabilities and their families often need reasonable adjustments to be made to enable their health care to be a safe and positive experience. If these adjustments, including clear and full communication and on-going assessment do not happen, then in addition to the distress caused by poor experiences, people are at risk of poor health outcomes.

1.5 Prior to the creation of Whittington Health the hospital was working closely with the consultant nurse, Gwen Moulster and other professionals from Haringey Learning Disabilities Partnership:

- To raise awareness and train staff so they have the necessary skills and knowledge to care for patients with a learning disability safely and effectively.
- To appropriately involve and support their families and carers.
- To create better, accessible information and approaches to care.
- To support staff around capacity and consent issues and best interest decision making.

1.6 This work is on-going within Whittington Health and has been supported by the appointment of an acute Trust Learning Disability Liaison Nurse, Hellen

Odiembo, who provides training and support to staff, and also assesses and advises on how to best care for individual patients and their families.

- 1.7 Whittington Health employs learning disability nurses, occupational therapists, speech and language therapists and physiotherapists who are seconded to the Haringey Learning Disabilities Partnership (HLDP). The Partnership provides specialist health and social care services to people who have learning disabilities in Haringey. It includes professional staff seconded from Barnet Enfield and Haringey Mental Health Trust and social care staff employed by Haringey local authority.
- 1.8 Islington specialist learning disability services are provided by the Islington community learning disabilities team. Whittington Health employs speech and language therapists and physiotherapists who work within the Islington team. Other professional and social care staff are employed by Camden and Islington Mental Health Trust and Islington Local Authority.

2 Self-Assessment Framework 2011-12

- 2.1 The framework for 2011 required a RAG rating to be made and provision of supporting evidence against a number of key targets. This was carried out on a borough basis.
- 2.2 Overall, the local rating for 2011/2012 was an improvement on the assessment for 2009/2010.

NHS London SAF ratings (Haringey and Whittington)	2009-10	2010-11
People who are or who were formerly in NHS provided long term care have settled accommodation that reflects their person-centred plans and there is a system in place to ensure minimum of annual review .		
Health and social care commissioners are working closely with local Partnership Boards and statutory and other partners, to address the health inequalities faced by people with learning disabilities.		
People with learning disabilities who are in services that the NHS commissions or provides, are safe.		
Implementation of "Valuing People Now 2009" - Progress is being made in developing local services for those needing more help to be healthy (T4.1) (T4.2).		

- 2.3 Whittington Health carried out its own internal assessment within the acute Trust, which was then fed into the borough ratings for both Haringey and Islington. Whittington Health scored ratings of "amber" for all but one target, which was green. Whilst this shows there is still some way to go in almost all areas, it also demonstrates that much has improved.
- 2.4 The Islington Partnership Board has a health working group chaired by Kara Blackwell (Head of Nursing, Whittington Health). The membership includes Julie Teahan (Whittington hospital matron) and Gwen Moulster.
- 2.5 The SAF 2012 action plans are included in the appendices, for Haringey see appendix 1, Islington see appendix 2 and Whittington Health see appendix 3 .

3 CQINN

- 3.1 NHS London are proposing a CQINN for Vulnerable Adults (Autism and Learning Disabilities). See appendix 4.

4 Good Practice: Whittington Hospital

- 4.1 A full time learning disabilities acute liaison nurse post has been created and recruited too. The post reports to Julie Teahan and is linked into the senior nursing professional supervision and management processes. The acute liaison nurse also receives clinical supervision and professional support from Robin Betts, the community learning disabilities matron from HLDP.
- 4.2 The LD consultant nurse, acute liaison nurse and colleagues from within the hospital and from HLDP have been working in partnership to improve the health outcomes and experiences for people who have learning disabilities and their families. This work includes :
- A range of accessible information has been produced to help people who have learning disabilities when they access hospital care. More accessible information is planned.
 - With support from the learning disability specialist speech and language therapist from HLDP, a Whittington Health hospital passport has been created. This will ensure that all people who have learning disabilities using the Whittington will have a hospital passport which will be completed with them and their family on first contact with the hospital – or before if possible and will be regularly updated.
 - Flagging system identifying people who have learning disabilities has been developed on PAS.
 - Learning Disability awareness training has been delivered to numerous staff from different wards and departments. (A&E, Imaging, Out-patients Clinic etc.).
 - Information about people who have learning disabilities is now available on all wards.
 - Advice given at family and carers meetings, on communication and advocacy and how to get access to services provided in the Hospital.
 - Clear and safe discharge package put in place before discharge (Families/cares and LD community team involved in discharge plan meetings).
 - Learning Disability staff champions identified from each ward. Training provided in relation to specific needs to e.g. communication, eating and drinking, managing behaviour that challenges, capacity, consent and best interest.
- 4.3 Whittington Health is part of the regional acute Trust summit. This is chaired by Gwen Moulster and includes senior representation from North Middlesex, Moorfields, Barnet and Chase Farm, Royal Free and University College Hospitals as well as representation from Camden, Islington and Haringey learning disability teams, NHS London and Mencap.
- 4.4 The summit is designed to support the Acute Trusts in meeting the needs of people who have learning disabilities. Work has been done around a number of key areas including reasonable adjustment, best practice initiatives, accessible information and supporting families and carers.

5 Good Practice: Haringey Learning Disabilities Partnership

- 5.1 The HLDP health professionals have been involved in working to improve health outcomes for people who have learning disabilities. This work includes:
- Providing advice, training and support to GPs and primary care staff and hospital staff in The Whittington, North Middlesex and Moorfields hospitals.
 - Providing skilled clinical interventions to enable and support people to access better generic health care.
 - Health promotion, health surveillance, health facilitation and health education to people who have learning disabilities and their families and carers.
 - Providing specialist person-centred clinical interventions where appropriate.
 - The development of person-centred accessible information.
 - The development of community assessment and treatment options for people who have mental health problems or behaviours that challenge. These are designed to reduce the likelihood of placement breakdown and admission to hospital.
 - The development of a complex health needs pathway designed to help people who have multiple and profound disabilities who frequently access primary and secondary health care and who are at risk of serious ill health and early death.
- 5.2 The Haringey Learning Disabilities Partnership Board has a delivery group for health chaired by the LD Consultant Nurse. The group has developed a Framework for Health. The latest report and action plan includes more detail of the on-going work of the health professionals within HLDP. An easy read version of the report is attached see appendix 5.

6 Current Concerns

- 6.1 Mencap has recently published an update, Death by Indifference: 74 lives and counting (2012). This report suggests that although there are many examples of improved practice, there are still numerous incidences of poor health treatment, untreated pain, serious harm and premature deaths.
- 6.2 The Mencap report says 'It is vital that all NHS staff take responsibility for challenging underlying assumptions. They must give the same quality of care and treatment to all patients, including those with a learning disability'. See appendix 6
- 6.3 In Whittington Health it has been difficult to engage some professional and support staff groups, especially senior medical staff in training and development and initiating changes in practice. This is consistent with evidence from other acute Trusts.
- 6.4 There are recent anecdotal examples of people being identified as Do Not Resuscitate (DNR) without best interest discussion with family and friends being evidenced. This is consistent with some attitudinal problems occasionally seen where the person with a learning disability is assumed not to have a reasonable quality of life because they have a learning disability.
- 6.5 Similarly on occasion, pain relief is not necessarily considered because the assumption is made that the person is not in pain. This can be because the physiological signs and symptoms may differ in a person with learning disabilities and insufficient attention is paid to the views of the family or carer.

- 6.6 Families and carers need to be more involved in decision making and planning of services.

7 Recommendations

- 7.1 The necessary actions required to ensure that all the targets in the SAF are met and gain a green rating and to enable achievement of the CQINN requirements have been set out in the attached action plan (appendix 3). Much of the work is around ensuring that our approach is consistent and embedded across all services, and considered in all our strategies, policies, systems and processes, rather than having only pockets of good practice, as is the case currently. This requires an on-going 'Board to ward' approach and the full support and endorsement by Trust Board.
- 7.2 The Board is therefore asked to sign the "Our Hospitals Charter" see appendix 7, which endorses the fact that people who have learning disabilities have the same rights to expect good health care and to be well. This charter is based on the national Mencap version, but has been adapted for local use by the North Central London Acute Trusts LD forum and is recognised by NHS London. By signing up to the Charter the Board will help demonstrate that the organisation agrees to take a person-centred approach to the care, treatment and support of people who have learning disabilities in hospital.
- 7.3 It would also be of great benefit if the LD work programme was supported by a dedicated non-executive director who would champion further developments and raise awareness.

8 References

Department of Health (2001) *Valuing people: a new strategy for learning disability for the 21st century*. London: The Stationary Office.

Equality Act. (2010) London: The Stationary Office Limited.

Mencap (2007) *Death by Indifference. Following up the Treat me right! report*. London: Mencap.

Mencap (2012) *Death by indifference: 74 deaths and counting*. London: Mencap.

Michael, J (2008) *Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities*. London: Department of Health.

Parliamentary and Health Service Ombudsman (2009) *Six Lives: the provision of public services to people with a learning disability*. London: The Stationary Office.