SHEFFIELD HEALTH AND WELLBEING BOARD PAPER

Report of:	Councillor Mary Lea
Date:	12th December 2013
Subject:	*The Confidential Inquiry into premature deaths of people with learning disabilities* (2013): its critical implications for health and health inequalities in Sheffield
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Summary:

The National Confidential Inquiry into premature deaths of people with learning disabilities found that people with learning disabilities died much earlier than the general population of preventable causes, most commonly through problems and delays with health investigations and treatments. There was inadequate 'reasonable adjustments' to services, care co-ordination and record-keeping. There was a failure to follow the Mental Capacity Act, end of life care pathways and Do Not Attempt Cardiopulmonary Resuscitation orders. There was a lack of proactive healthcare and planning in the cases reviewed.

This paper summarises the Confidential Inquiry findings and recommendations, and outlines the responses of local NHS Trusts and the Clinical Commissioning Group.

Questions for the Health and Wellbeing Board:

What further information and action do you need to ensure that people with learning disabilities in the city get access to the same health investigations and treatments as everyone else, and do not die prematurely from causes that could have been prevented or avoided?

Recommendations:

The Board is asked to note the recommendations of the Inquiry, and seek assurance that local partners are taking all reasonable steps to ensure equal access to healthcare for people with learning disabilities in Sheffield.

The Board is asked in particular to invite the Public Health Intelligence Team through their core offer to SCC and the CCG to analyse and research outcomes for people with learning disabilities in Sheffield in respect of:

- Recommendation 7 *(People with learning disabilities to have access to the same investigations and treatments as anyone else, but acknowledging and accommodating that they may need to be delivered differently to achieve the same outcome),* and

- Recommendation 17 (*Systems in place to ensure that local learning disability mortality data is analysed and published on population profiles and Joint Strategic Needs Assessments*)

Reasons for Recommendations:

The Confidential Inquiry is based on intensive research in the South-West of England. We do not really know if the situation is the same, better or worse in Sheffield. Understanding more about the health, healthcare, morbidity and deaths of people with learning disabilities in the city would enable us to take targeted action to improve access to healthcare and address serious health inequalities experienced by this population.

Background Papers:

Confidential Inquiry into premature deaths of people with learning disabilities (University of Bristol, 2013) http://www.bris.ac.uk/cipold/

Government Response to Confidential Inquiry into premature deaths of people with learning disabilities (Dept of Health, 2013) https://www.gov.uk/government/publications/response-to-the-confidential-inquiry-into-learning-disability

Death by Indifference (Mencap, 2007) http://www.mencap.org.uk/campaigns/take-action/death-indifference

Six lives: the provision of public services to people with learning disabilities (Local Government Ombudsman and Parliamentary and Health Service Ombudsman, 2009**)** http://www.ombudsman.org.uk/reports-and-consultations/reports/health/six-lives-the-provision-of-public-services-to-people-with-learning-disabilities/1

THE CONFIDENTIAL INQUIRY INTO PREMATURE DEATHS OF PEOPLE WITH LEARNING DISABILITIES (2013): ITS CRITICAL IMPLICATIONS FOR HEALTH AND HEALTH INEQUALITIES IN SHEFFIELD

1.0 SUMMARY

The National Confidential Inquiry into premature deaths of people with learning disabilities found that people with learning disabilities died much earlier than the general population of preventable causes, most commonly through problems and delays with health investigations and treatments. There was inadequate 'reasonable adjustments' to services, care co-ordination and record-keeping. There was a failure to follow the Mental Capacity Act, end of life care pathways and Do Not Attempt Cardiopulmonary Resuscitation orders. There was a lack of proactive healthcare and planning in the cases reviewed.

This paper summarises the Confidential Inquiry findings and recommendations, and outlines the responses of local NHS Trusts and the Clinical Commissioning Group.

2.0 WHAT DOES THIS MEAN FOR SHEFFIELD PEOPLE?

There are 3,569 people of all ages with learning disabilities in Sheffield, which equates to a prevalence rate higher than the national average. In common with all people with LD nationally, this group experience a higher incidence of health problems than the general population, and many have multiple and complex health needs.

The majority of GPs 61/88 practices (69%) in Sheffield have agreed to provide an Annual Health Check for people with learning disabilities in their practice; over 50% of people eligible for an Annual Health Check received one last year. It is recognised nationally and locally that the quality of the checks can vary.

Sheffield Teaching Hospitals NHS Foundation Trust has worked over a number of years to improve access to its services by people with learning disabilities, identifying people when they attend as inpatients or outpatients. The Trust also takes seriously its duty to make 'reasonable adjustments' to help people access care and treatment, through a number of initiatives, including leadership on LD by a Nurse Director and network of LD nurse leads across the hospital.

Sheffield Health and Social Care NHS Foundation Trust provides a specialist multi-disciplinary learning disability service that both delivers assessments and interventions for people with complex needs, and provides enabling support and advocacy to help people with learning disabilities access primary and secondary healthcare.

Sheffield Childrens Hospital NHS Foundation Trust provides specialist assessments and interventions for children and young people with learning disabilities. Its Ryegate Centre and Community Paediatricians provide healthcare co-ordination for children with complex and multiple health problems.

Sheffield CCG has a lead GP on the Governing Body with leadership responsibility, and a GP Clinical Executive Team Lead, who leads the Mental Health, Learning Disability and Dementia Portfolio.

3.0 MAIN BODY OF THE REPORT

3.1 The Confidential Inquiry (CIPOLD) into premature deaths of people with learning disabilities was recommended by Sir Jonathan Michael following Mencap's report into the deaths of six people in NHS care (*Death by Indifference*, 2007) and the subsequent report by the Joint Ombudsmen (*Six Lives*, 2009.)

3.2 CIPOLD retrospectively investigated all known deaths of people with learning disabilities (233 adults and 14 children) across five PCT areas over two years to June 2010, alongside 58 comparator cases.

3.3 The age range of the people with learning disabilities was from 4 – 96 years. Over half (58%) were male, 93% were single and 96% White British. 40% had mild learning disabilities, 31% moderate learning disabilities, 21% severe learning disabilities and 8% had profound and multiple learning disabilities.

3.4 Men with a learning disability died on average 13 years earlier than the general population (median age at death was 65 years). Women died 20 years younger (median age at death was 63 years).

3.5 The most common immediate causes of death in people with learning disabilities were respiratory problems (34%) and heart and circulatory disorders (21%). The most common underlying reasons for people with learning disabilities dying were heart and circulatory disorders (22%) and cancer (20%).

3.6 The percentage of deaths classed as 'avoidable' (48.5%) was twice the rate seen in the general population. One in four of these were 'preventable mortality', which could have been influenced by public health interventions. 'Amenable mortality' deaths (27.5%) could have been avoided through good quality healthcare. Some deaths fell into both categories.

3.7 Amenable mortality was influenced by factors such as the person's age, severity of learning disability, underlying cause of death and access to a significant partner or friend. In total, 42% of the deaths of people with learning disabilities were classed as premature. Younger people were more likely to die prematurely, as a result of problems assessing, investigating or treating their illness.

3.8 People with learning disabilities experienced delays in the care pathway because of a lack of 'reasonable adjustments', coordination of care across and between different disease pathways and service providers and
effective advocacy for people with multiple conditions and vulnerabilities.

3.9 Contributory factors were identified, which helped inform CIPOLD's local and national recommendations. The recommendations are shown below with comments to illustrate work already underway or planned in Sheffield.
The Government broadly supported the Inquiry report but did not fully endorse all the national recommendations in its response.

3.10 LD lead officers and senior clinicians from the local NHS Trusts, Sheffield Teaching Hospitals NHS Trust and Sheffield Health and Social Care NHS Trust, and the Sheffield Clinical Commissioning Group (CCG), presented their initial responses to CIPOLD to the Learning Disability Partnership Board in November 2013.

3.11 Local response to the Confidential Inquiry recommendations

Recommendation 1 – Clear and consistent recording and identification of people with learning disabilities across all heath record systems
Local implementation of this recommendation is achieved because of the existence and use of the Sheffield Case Register. This provides information for the Teaching Hospital and GPs to enable them to identify people with learning disabilities in their care.

Recommendation 2 – Reasonable adjustments identified, recorded and audited
This does not happen routinely across all services at present, although the Teaching Hospital can demonstrate good practice in some areas and reports on the delivery of reasonable adjustments annually. The CCG is planning to strengthen its contractual monitoring of reasonable adjustments. NHS England plans to develop a standard letter for GPs referring to secondary care across South Yorkshire and Bassetlaw.

Recommendation 4 – Healthcare coordinator to be allocated to people with complex/multiple health needs, or two or more long-term conditions
The Children's Hospital provides a named healthcare co-ordinator for children with complex needs, but this does not extend into adult life. Further work is needed in the city, including development of the care management role in primary care and changes to contracts with providers, if this recommendation is to be met. The CCG intends to invest in hospital liaison posts and is extending the 'Helena' team for children with complex needs model from December this year for people aged 17 and upwards who have very complex health needs.

Recommendation 5 – Patient-held health records to be introduced and given to all patients with learning disabilities who have multiple health conditions
There is a system of Hospital Passports in the city which contain key health and support information, but not everyone has one or uses one.

Recommendation 6 – Standardisation of Annual Health Checks and a clear pathway between Annual Health Checks and Health Action Plans
The Annual Health Checks are provided by GPs, who are mostly commissioned by NHS England rather than the CCG. However, the CCG is monitoring the number and quality of Annual Health Checks more closely and has asked GPs across the city to identify themselves as LD champions. The Government Response to the Confidential Inquiry undertakes to review the minimum standards and guidance for health checks as part of wider GP contracting and consultation.

Recommendation 7 – People with learning disabilities to have access to the same investigations and treatments as anyone else, but acknowledging and accommodating that they may need to be delivered differently to achieve the same outcome
The CCG is currently looking into the question of access to secondary care, through primary care data, but it is recommended that a wider health equalities review is needed through the Public Health Intelligence Team and their core offer to SCC and the CCG.

Recommendation 8 – Barriers in individuals' access to healthcare to be addressed by proactive referral to specialist learning disability services
Sheffield Health and Social Care Trust provide specialist learning disability services which can help people access healthcare. A review will include consideration of whether these services are effectively utilised.

Recommendation 9 – Adults with learning disabilities to be considered a high-risk group for deaths from respiratory problems
The Teaching Hospitals Trust has raised awareness of this high risk factor in staff providing care for respiratory diseases. Specialist support is available for dysphagia and postural management, both of which were found in the Inquiry to contribute to premature deaths. However, more could be done to cover this risk factor in Health Action Plans.

Recommendation 10 – Mental Capacity Act advice to be easily available 24 hours a day
Further work is needed to determine how this could be achieved for all agencies in the city.

Recommendation 12 – Mental Capacity Act training and regular updates to be mandatory for staff involved in the delivery of health or social care
The Teaching Hospitals Trust has a Mental Health Facilitator who provides training for staff, whilst advice on the Mental Capacity Act, training and updates are available to staff in Sheffield Health and Social Care Trust and Sheffield City Council. The Care Trust is currently reviewing its training in light of the Confidential Inquiry.

Recommendation 14 – Advanced health and care planning to be prioritised. Commissioning processes to take this into account, and be flexible and responsive to change
There has been work piloted on a Risk Stratification Tool and the Care Planning Approach by Sheffield CCG and local GPs. We will review this in relation to this CIPOLD action. However, further clarification of this recommendation is needed.

Recommendation 15 – All decisions that a person with learning disabilities is to receive palliative care only should be supported by the framework of the Mental Capacity Act and the person referred to a specialist palliative care team
The Teaching Hospital ensures palliative care decisions are only made in the framework of the Mental Capacity Act. Specialist Cancer Services have been involved in Macmillan's One-to-One Support Implementation Project. However, MCA implementation still needs further work across the city.

Recommendation 17 – Systems in place to ensure that local learning disability mortality data is analysed and published on population profiles and Joint Strategic Needs Assessments
Sheffield has this information, but further analysis through the Public Health Intelligence Team and their core offer to SCC and the CCG. would provide more relevant information on the causes of death of people in Sheffield.

Recommendation 18 – Establishment of a National Learning Disability Mortality Review Body
This set of recommendations link national and local actions. Some learning disability information is included in the Joint Strategic Needs Assessments. Addressing health inequalities for different population groups, including people with learning disabilities, is one of the JSNA's priorities. Further analysis of local learning disability mortality data and population profiles for people with learning disabilities in the city, for example utilising the Case Register, could be beneficial.

3.12 National recommendations

- Recommendation 3 – NICE Guidelines to take into account multi-morbidity
- Recommendation 11 – The definition of Serious Medical Treatment and what this means in practice to be clarified

- Recommendation 13 – Do Not Attempt Cardiopulmonary Resuscitation Guidelines to be more clearly defined and standardised across England.
- Recommendation 16 – Improved systems in place nationally for the collection of standardised mortality data about people with learning disabilities

4.0 QUESTIONS FOR THE BOARD

What further information and action do you need to ensure that people with learning disabilities in the city get access to the same health investigations and treatments as everyone else, and do not die prematurely from causes that could have been prevented or avoided?

5.0 RECOMMENDATIONS

The Board is asked to note the recommendations of the Inquiry, and seek assurance that local partners are taking all reasonable steps to ensure equal access to healthcare for people with learning disabilities in Sheffield.

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6.0 REASONS FOR THE RECOMMENDATIONS

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