

**SHEFFIELD TEACHING HOSPITALS NHS FOUNDATION TRUST**

**EXECUTIVE SUMMARY**

**REPORT TO THE HEALTHCARE GOVERNANCE COMMITTEE MEETING**

**HELD ON 22 JULY 2013**

|                              |   |
|------------------------------|---|
| <b>Subject</b>               | Learning Disability Annual Report 2012/2013                     |
| <b>Supporting TEG Member</b> | Professor Hilary Chapman, Chief Nurse / Chief Operating Officer |
| <b>Author</b>                | Ms Una Cunningham, Nurse Director                               |
| <b>Status<sup>1</sup></b>    | N   |

**PURPOSE OF THE REPORT**

To provide the Healthcare Governance Committee with an update on performance and service developments across the Trust with regard to the support of people with a learning disability. Particular consideration has been given to the Confidential Inquiry into premature deaths of people with learning disabilities (2013).

**KEY POINTS**

- The Trust has reviewed the recommendations from the 'Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD), 2013.
- There are several on-going developments, which will enhance the care delivered to people with learning disabilities whilst they are accessing our services.

**IMPLICATIONS<sup>2</sup>**

|   | <b>AIM OF THE STHFT CORPORATE STRATEGY 2012-2017</b> | <b>TICK AS APPROPRIATE</b> |
|---|--|----------------------------|
| 1 | Deliver the Best Clinical Outcomes                   | ✓                          |
| 2 | Provide Patient Centred Services                     | ✓                          |
| 3 | Employ Caring and Cared for Staff                    | ✓                          |
| 4 | Spend Public Money Wisely                            | ✓                          |
| 5 | Deliver Excellent Research, Education & Innovation   | ✓                          |

**RECOMMENDATIONS**

The Healthcare Governance Committee is asked to note the contents of this report.

**APPROVAL PROCESS**

| <b>Meeting</b>                  | <b>Date</b>  | <b>Approved Y/N</b> |
|---------------------------------|--------------|---------------------|
| TEG                             | 10 July 2013 |                     |
| Healthcare Governance Committee | 22 July 2013 |                     |

## 1. INTRODUCTION

The quality and effectiveness of health and social care afforded to people with learning disabilities has been shown to be deficient in a number of ways according to numerous investigations and reports. In 2013, another landmark report 'Confidential Inquiry into premature deaths of people with learning disabilities' (CIPOLD, 2013) has been published, that has suggested that the care that people with learning disabilities received in the period leading up to their deaths could be considered sub optimal when compared with that of the general population. The report reviewed the deaths of 247 people with learning disabilities between 2010 and 2013. It also reviewed the deaths of 58 people without learning disabilities to place the findings in context.

The CIPOLD Inquiry found that 42% of the deaths of people with learning disabilities were assessed as being premature. It is acknowledged that people with learning disabilities are a vulnerable group and often have a considerable burden of ill health at the time of their death which may be an influencing factor in their death (Heslop et al. 2013). However the Inquiry's key findings suggested that a factor in premature deaths was the lack of coordination of care across and between disease pathways and service providers, and the episodic nature of care provision. In addition, professionals in both health and social care commonly showed lack of adherence to, and understanding of, the Mental Capacity Act, 2005, in particular regarding assessments of capacity, the process of making 'best interest' decisions and when an Independent Mental Capacity Advocate (IMCA) should be appointed.

A parallel paper commissioned by Mencap 'Improving Health & Lives' (2013) using the same data, calculated that there are more than 1,200 avoidable deaths of people with learning disabilities every year across the country -the equivalent of a 'Mid Staffordshire hospital deaths' scandal every year.

Record keeping was commonly deficient, including Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) orders and basic health assessments i.e. weight and nutrition and there was little attention given to predicting problems.

There was also a lack of coordination in approaching and supporting end of life care.

This inquiry has made a number of recommendations and it is believed if they are individually and collectively implemented this would lessen the risk of premature death in people with learning disabilities.

The significance of this inquiry and its recommendations for acute teaching hospitals are such that this annual report has used it as its framework to review the care given to patients with learning disabilities within the Trust.

## 2. THE KEY RECOMMENDATIONS FROM THE CIPOLD REVIEW OF DEATHS

The report suggested 18 key recommendations, this report will discuss the recommendations that are pertinent to acute care.

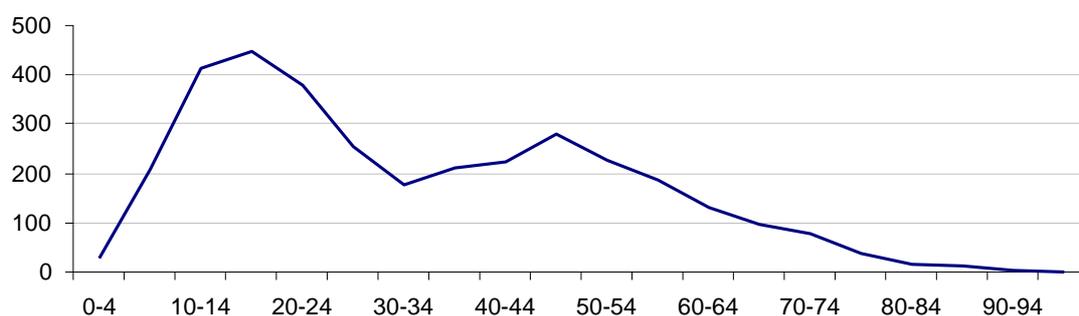
### 2.1 **Clear identification of people with learning disabilities on the NHS central registration systems and in healthcare record systems. (Recommendation 1)**

There were 3,513 children, young people and adults with learning disabilities living in Sheffield at the end of 2011(Sheffield Case Register, 2012). Sheffield's Joint Strategic Needs Assessment (2010) identified trends within the city's learning disabled population, in that we are in the midst of a growth in the numbers of children and young people with

learning disabilities. The numbers of children born with learning disabilities has increased by 6.3% between 2009 and 2012. The greatest increases have been in children with Autistic Spectrum Disorders, speech and language difficulties, severe learning difficulties and Profound Intellectual and Multiple Disabilities (PIMD).

This has a significant impact on the health community in that more children with learning disabilities are surviving into adulthood, including those with complex disabilities, and more adults with learning disabilities are surviving into older age.

**Age profile of people with learning disabilities in Sheffield –  
Sheffield Case Register, September 2011**



Sheffield has excellent information about the learning disabled population, which is helped by the maintenance of the Learning Disability Case Register. From this, we know that the number of people with learning disabilities is increasing and set to rise further over the next decade. At the present time there are 3,513 people with learning disabilities who have Sheffield addresses and are on the case register. When new patients are being entered onto the case register they or their carer are asked whether they consent to allowing Sheffield Teaching Hospitals NHS Foundation Trust (STH) to be notified.

The Sheffield Case Register database is downloaded into the Trust Patient Administration System, Patient Centre, and once the details of a person with learning disabilities are entered, an alert highlights that this person has learning disabilities. There are presently 3,347 patients who have a learning disabilities alert on our systems.

For those patient with learning disabilities who have not consented to having their details passed to Sheffield Teaching Hospitals or who are not on the case register we still make necessary adjustments by identifying individual's needs by working with them, their carers, and other relevant agencies.

From Patient Centre the Trust can monitor admission / attendances.

|   | <b>2010/2011</b> | <b>2011/2012</b> | <b>2012/2013</b> |
|---|------------------|------------------|------------------|
| In-patient admissions                                   | 1205             | 614              | 867              |
| Individual Patient Count/Number - admissions            | 437              | 470              | 617              |
| Out-patient attendances                                 | 1419             | 3587             | 5194             |
| Individual Patient Count/Number-Out patient attendances | 900              | 1931             | 2365             |

Specialities that have a significant number of in-patients with learning disabilities are chest medicine, gastroenterology, general medicine and oral surgery.

Specialities that have a significant number of out-patients with learning disabilities are accident and emergency, diabetes, orthopaedics, audiological medicine, ENT, neurology and ophthalmology.

## **2.2 Reasonable Adjustments required by, and provided to individuals, to be audited annually and examples of best practice to be shared across agencies and organisations. (Recommendation 2)**

The Trust works in partnership with Sheffield Health & Social Care NHS Foundation Trust, Sheffield City Council, NHS Sheffield Clinical Commissioning Group (CCG) and a learning disabled advocate annually to complete a self-assessment, which is returned to NHS North of England. The self-assessment looks specifically at access to mainstream services and specialist health services, safeguarding, partnership working with providers, commissioning, quality and standards, amongst many other standards. This year's performance was extremely favourable given that the benchmark had been raised considerably from previous self-assessments.

At the validation meeting, NHS North of England fed back that the submission from Sheffield was robust, well evidenced and subsequently agreed with the self-assessment, which was 62% as excellent, 36% effective and only 2% less effective -this latter figure being in relation to out of city placement of patients with learning disabilities.

NHS North of England was particularly impressed to hear that there had been good CCG engagement with the process, through Dr Steve Thomas, the GP clinical lead as well as with other GP leads.

From the self-assessment an action plan for continuing progress has been developed and this will be overseen by the Improving Health Group on which the Trust has representation. Examples of partnership working taken through the Improving Health Group are,

- Staff from the Sexual Health Service have worked with Community Learning Disability Nurses to produce 'Personal Relationships and Sexual Health Guidelines'
- Trust staff have met with the Learning Disabilities 'Parent Carer Forum' to discuss any concerns that they may have about their children moving from receiving their care at Sheffield Childrens Hospital NHS Foundation Trust to STH
- Breast Screening Services have helped develop a training package for carers and agencies, so they can inform the people they work with about the importance of breast screening

## **2.3 A named healthcare coordinator to be allocated to people with complex or multiple health needs, or two or more long term conditions. (Recommendation 4)**

Presently the Trust does not have a dedicated learning disability named nurse, the present system is that a Nurse Director leads on issues relating to the care of patients with learning disabilities on behalf of the Chief Nurse/Chief Operating Officer. Within this role, the Nurse Director represents the Trust on a number of citywide learning disability committees and working groups, is a link with primary care, social care, addresses issues and plans improvements wherever possible. There is also a network of staff in each department and clinical area to share and promote good practice across the Trust's acute and community services.

However, the Sheffield CCG has commissioning intentions which centre on improving the physical health of people with learning disabilities within their business plan. This includes, for example, developing the role of a named learning disability nurse employed by STH working across patient pathways. This role would help to improve coordination of health care for people with complex needs both within the acute and community settings.

#### **2.4 Patient-held records to be introduced and given to all patients with learning disabilities who have multiple health conditions. (Recommendation 5)**

The Hospital Passport was launched in Sheffield in Spring 2012. This is a communication tool developed in partnership with MENCAP, which provides basic but important information about the patient, and their health and support needs, to ensure that the person with learning disabilities gets appropriate care whilst in hospital.

Patients complete this at home, then they bring it with them into hospital. Staff are reminded on the Nursing Care Guideline to ask patients for a copy.

#### **2.5 People with learning disabilities to have access to the same treatment as anyone else, but acknowledging that they may need to be delivered differently to achieve the same outcome. (Recommendation 7)**

The CIPOLD report found that lack of reasonable adjustments to facilitate healthcare of people with learning disabilities, particularly attendance at clinic appointments and investigations, was a contributory factor in a number of deaths.

The Trust has a number of ways that reasonable adjustments are promoted.

- Database of easy read leaflets; these are easily accessible via the STH Intranet site where there is a dedicated Learning Disability page.
- Nursing care guidelines
- Longer appointment times for people with learning disabilities
- Formal systems to support admissions into hospital and attendance at outpatient clinics
- Learning Disability Link staff
- Carers and patients are encouraged to visit clinical areas prior to hospital attendances in order to reduce anxieties and encourage attendance
- Breast screening staff are helping with training for community learning disability staff and users on the importance of breast screening

The Trust is working in partnership with Sheffield Hallam University in undertaking research on 'Promoting Awareness and Early Symptomatic Presentation of Breast Cancer in the Female Learning Disability Population: whose job is it anyway?' The background to this research is that data have identified that whilst screening is available for all women, the uptake rates among women with learning disabilities is poor. Figures obtained from STH screening service report that over the last 36 months 279 women who were eligible for breast screening were classified as having learning disabilities and of these 37.6% did not attend screening, and 14.3% attended screening but withdrew consent once they arrived at the screening centre. It is hoped that this research will give an increased understanding of the barriers to access and compliance for this group and mechanisms designed to overcome these and also allow for more detailed research applications via the NIHR programme.

**2.6 Adults with learning disabilities to be considered a high risk group for deaths with respiratory problems. (Recommendation 9)**

The report indicates that while there was little difference in the prevalence of respiratory disease as the underlying cause of death between people with learning disabilities and the general population, over a third of people with learning disabilities died with respiratory disease, usually pneumonia. The report highlights that for these people with learning disabilities it was respiratory disease that was the final illness from which they died.

In the last year there have been 126 people with learning disabilities admitted to chest medicine/general medicine at STH and it is probable that a high number of these patient's will have a diagnosis of pneumonia or chest infection. Senior clinical and management staff within the Emergency Care Group are aware that this is a vulnerable group for premature deaths and have put systems in place to support patients with learning disabilities. For example:

- Home visits and working with families and agencies for patients who are regularly admitted, to develop individualised care pathways that support hospital admissions
- Best interest meetings to discuss nutritional support

The Trust has also supported the community physiotherapists with the development of postural guidelines with a view to reducing aspiration pneumonias.

**2.7 Mental Capacity advice to be easily available 24hrs a day. (Recommendation 10)**

There are senior nurses on duty 24hrs a day who can provide support and advice with issues arising relating to mental capacity.

Detailed information and all the relevant documentation necessary to comply with the Mental Capacity Act is available to all staff via the Mental Capacity Act page within the Sheffield Teaching Hospital intranet site.

**Mental Capacity Act (MCA) training and regular updates to be mandatory for staff involved in the delivery of health and social care. (Recommendation 12)**

The Trust has a MCA Practice Development Facilitator who commenced on 6<sup>th</sup> August 2012. The purpose of this post is to;

1. Audit compliance with the MCA throughout the Trust
2. Implement a training programme for MCA (2005)
3. To offer support, advice and guidance to staff

The Corporate Training Programme commenced in October 2012 and the following table indicates the number of Trust staff who have accessed the training;

| <b>SUBJECT</b>                      | <b>No.s Trained</b> |
|-------------------------------------|---------------------|
| Overview of the Mental Capacity Act | <b>124</b>          |
| Assessing Mental Capacity           | <b>113</b>          |
| Best Interests Decision Making      | <b>65</b>           |
| Deprivation of Liberty Safeguards   | <b>44</b>           |

The Mental Capacity Act, including mental capacity assessment and best interest decision making has been introduced onto the Trust Induction Programme for clinical staff, thus highlighting the importance of all staff accessing the corporate training programme.

However the Mental Capacity Act 2005 is a statutory instrument, therefore compliance is a duty – currently the Trust does not regard training as mandatory, however in light of the CIPOLD report further discussion may be required as to whether Mental Capacity training should be mandatory.

Initially there was intensive training on the contents of the Mental Capacity Act prior to its implementation in 2007, but at this time it was difficult for organisations to grasp its practical application as there was no legal precedence to guide staff or organisations.

Following on from the initial training an e-learning programme was developed for staff to access. Whilst e-learning is useful for raising awareness of the MCA, it alone, cannot always illustrate the complexities that can arise in individual cases.

There are still some challenges regarding compliance with the Mental Capacity Act throughout the Trust, in particular with assisting people with capacity issues to participate in the process of assessing their capacity and involvement in best decision making. There is a lack of understanding around the involvement of relatives / family in best interest decision making from both staff and the relatives themselves. Adequate documentation in patient records has also been an issue, which is being addressed by new documentation developed by the MCA facilitator. This documentation is on the MCA intranet site and promoted on Trust induction and through MCA training.

Staff have shown great enthusiasm for the training, a number of nurse/deputy nurse directors have been keen to support staff to access the training and have attended themselves. Staff from all professional backgrounds and levels have accessed the training including consultants.

There are examples of some excellent work and development of systems that will assist compliance with the MCA in some areas of the Trust which can be used to influence practice in other areas. An example of good practice is within the Ophthalmology department who have embraced the concept of the MCA. They have a lead clinician and they have developed a specialist clinic which focuses on all the right elements required to comply with the MCA, i.e. documentation, longer appointments, and reasonable adjustments. The facilitator highlights areas of good practice such as these within her training.

There will also be an MCA audit through June/July 2013 that will provide Directorate specific feedback which will help identify both areas of good practice and areas that may require improvement.

It is important to continue to develop staff's confidence in working with the MCA as it is a statutory obligation and will be the focus of the Care Quality Commission (CQC) in future inspections, particularly in acute hospital settings.

**2.8 Advanced health and care planning to be prioritised. Commissioning processes to take this into account, and to be flexible and responsive to change. (Recommendation 14)**

The Trust will continue to work in partnership with the key stakeholders on developing a duty of care framework for Sheffield to support people to access appropriate health care. The implementation of Health Action plans and Hospital passports will contribute to this, but more work will need to be progressed across health and social care to address the findings of this report.

2.9 **All decisions that a person with learning disabilities is to receive palliative care only to be supported by the framework of the Mental Capacity Act and the person referred to a specialist palliative care team. (Recommendation 15)**

Specialist Cancer services have been involved with the Macmillan 1-1 projects, and have developed a new service linking hospital to home for people with learning disabilities. The focus is on patients with cancer who are discharged from Haematology or Oncology (WPH) with complex palliative care needs. The Complex Case Managers (CCMs) will work into the Specialist Palliative care MDT to pick up appropriate patients. The vision is that the managers will have the skills to support each patient's complex symptom management needs, thus allowing an earlier discharge, avoid unnecessary readmission and enhance the patient experience. When this project is evaluated it will be important that any learning and/or good practice is rolled out so that patients with learning disabilities who have palliative care needs without a cancer diagnosis are equally well supported.

It is envisaged that when the Mental Capacity Act audit is undertaken there will be a focus on particular services. In light of the CIPOLD report it will be important to look at palliative care for assurance that decisions about care had been made within the MCA framework.

2.10 **Systems to be put in place to ensure that local learning disability mortality data are analysed and published on population profiles and joint needs assessments. (Recommendation 17)**

The joint strategic needs analysis is undertaken by the Director of Public Health in collaboration with the Local Authority therefore the Trust will contribute to this through the existing citywide meetings for discussing issues relating to the care of people with learning disabilities.

Within the Trust as the new framework for Mortality and Morbidity Review meetings is developed, deaths and serious incidents involving patients with learning disabilities should be considered as a potential triggers within Directorate meetings for a detailed review. In particular the inquiry identifies that adults with learning disabilities should be considered a high risk group for deaths from respiratory problems. Further work needs to be undertaken across the Trust to look at the deaths that have occurred and whether any preventative measures could have been put in place i.e. risk assessments for aspiration, referral to Speech and Language therapist, swallow assessment and the availability of immunisation.

**3. FURTHER ACHIEVEMENTS 2012-2013**

**3.1 Research/Service evaluation**

A review of service provision for people with learning disabilities in the department of psychological services was undertaken in 2012. This service evaluation identified that all of the psychologists within the Breast Service felt well equipped when working with people with learning disabilities and because of this it was found that a number of reasonable adjustments had been made in order to improve the patient experience. The STH department of psychology are forming a task group to take forward the recommendations put forward from this service evaluation.

### 3.2 Education

Autism – The Autism Act 2009 committed the Government to publish an adult autism strategy to transform services for adults with autism. One of the key areas in the Autism Strategy (2010) and that of the NICE Guidelines for Autism which were published in June 2012 was that of increasing awareness and understanding of autism.

The Trust now has an e learning package, which was formulated as part of a working group with the Yorkshire and Humber region on which the Trust was represented. The package is titled 'Hidden Impairments' it is a 30 minute programme and provides a basic awareness of the needs of people with autism as well as other hidden impairments such as dyspraxia and Attention Deficit Hyperactivity Disorder (ADHD). It contains powerful patient stories including one from a Sheffield resident.

This will be launched using the Directorate leads and at safeguarding and patient experience meetings. However it is acknowledged that e-learning uptake can sometimes be low. To address this, it is envisaged that the new learning management system-personal achievement and learning management system (PALM) will allow the identification of key groups of staff through training needs analysis, where it is deemed such training is essential and then managers can monitor compliance against this.

### 3.3 Service Development

- The Sheffield Hearing and learning Impairment Service has worked closely with the Community Learning Disabilities Team to facilitate greater access to Audiology services, which has resulted in a significant increase in clients having hearing assessments and management. New techniques have also been introduced which have enabled hearing to be assessed for clients who were previously unable to be fully assessed.
- Day case surgery has introduced a time line of flash cards to describe the patient journey.
- Weston Park has a designated learning disability group who have developed a system of pre-treatment visits to the day care unit.
- Bev Stokes Day Surgery has worked with the Community Learning Disability team to facilitate an open day to prepare clients and carers for their future treatment.
- A dedicated Learning Disability Midwife has forged links with Sheffield Health and Social Care NHS Foundation Trust and improved the provision of easy read patient information for pregnant women.

## 4. CONCLUSION

People with learning disabilities have a right to the same quality of healthcare as those without learning disabilities; however it has been acknowledged that their life expectancy is lower than people without disabilities. To address this, the Trust is continuing to address issues such as assessing mental capacity and reviewing the deaths of people with learning disabilities through mortality and morbidity meetings.

The Trust will continue to take forward initiatives that improve the experience of people with learning disabilities and their families, particularly addressing issues/complaints that arise, promoting awareness of 'reasonable adjustments' and never becoming complacent about the care of vulnerable people.

## 5. **REFERENCES**

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