

**BOD 49/2016**

(agenda item: 9)

# Report to the Meeting of the

# Oxford Health NHS Foundation Trust

# Board of Directors

**27 April 2016**

**Access to Healthcare for People with Learning Disabilities End of Year Report April 2016**

**For Information**

**Executive Summary**

The Annual Report includes a look back over the past there years briefly documenting the improvements that need to be made to improve access to people with learning difficulties in mainstream services.

This Report highlights we continue to have detailed evidence to underpin a declaration of compliance with the national standards set by MONITOR. In declaring compliance there remain some gaps in assurance regarding the ease of flagging records even in the new carenotes system and the limited success of a recent audit to identify sufficient cases to audit.

There is evidence of individual cases highlighted in routine quality reviews such as routine case note audit and peer reviews which appear to demonstrate care being reasonably adjusted.

In our children’s LD services a full range of quality standards and measures are in place and the CQC inspection found children’s services to be outstanding.

Sufficient dedicated time for corporate leadership in this specialist area has remained a constraint with the Head of Older adult nursing being the designated person with little dedicated time to undertake the role.

It is proposed this will transfer to the Programme Director for Learning Disabilities once they commence in post.

**Recommendation:** To note.

**Author and Title:** John Campbell, Head of Nursing Older Adults Services

**Lead Executive Director:** Ros Alstead, Director of Nursing and Clinical Standards

**Access to Healthcare for People with Learning Disabilities End of Year Report 2015/16**

**1. Background 2012-2015**

* 1. The publication of the ‘Six Lives’ report’ of the Parliamentary Ombudsman followed Mencap’s 2007 report ‘’Death by Indifference’’ and the 2008 inquiry ‘’Healthcare for All’’ which documented serious failings in care for people with Learning Disabilities receiving mainstream NHS Care. A set of national standards were subsequently developed and adopted by MONITOR for Foundation Trusts. A review of how we are meeting these standards and continuously improving access and care for people with LD accessing mainstream services is required to report quarterly to SMT/EEB and on an annual basis through an Annual Report.
  2. OHFT is required to certify that it ‘’meets the six criteria for meeting the needs of people with a learning disability, based on recommendations set out in *Healthcare for All* (DH, 2008)’’ These are specified as :

1. *Does the NHS foundation trust have a mechanism in place to identify and flag patients with learning disabilities and protocols that ensure that pathways of care are reasonably adjusted to meet the health needs of these patients?*
2. *Does the NHS foundation trust provide readily available and comprehensible information to patients with learning disabilities about the following criteria:*

* *Treatment options*
* *Complaints procedures*
* *Appointments*

*c) Does the NHS foundation trust have protocols in place to provide suitable support for family carers who support patients with learning disabilities?*

*d) Does the NHS foundation trust have protocols in place to routinely include training on providing healthcare to patients with learning disabilities for all staff?*

*e) Does the NHS foundation trust have protocols in place to encourage representation of people with learning disabilities and their family carers?*

*f) Does the NHS foundation trust have protocols in place to regularly audit its practices for patients with learning disabilities and to demonstrate the findings in routine public reports?*

* 1. A detailed baseline review took place in 2012 the OHFT used self- assessment though a reporting process to EEB to declare compliance with the requirements of the reports and standards. However certain improvements were required to systems and process and case review.
  2. A significant body of accumulated evidence demonstrated progress against a historical action plan, which included embedding training within induction programmes, improving attendance at learning disabilities training and the provision of easy read information where protocols/mechanisms are fully implemented. However, there remained some key corporate elements that needed to be addressed and applied in practice which were subsequently strengthened during 2013-14.

* Over this period the Learning Disabilities Steering Group identified our electronic health record systems were not able to demonstrate mechanisms in place in our different Electronic health record systems for ‘flagging’ patients with learning disabilities. In addition as at this stage there was not a trust wide protocol for making reasonable adjustments which was approved in 2013/14
* There was a reliance on manual mechanisms to ‘flag’ people with learning disabilities that are accessing Trust services. People with learning disabilities were often identified within the service as a consequence of practitioners’ knowledge of the patient/client rather than through use of the ‘flagging’’ mechanism.
* The Trust carers’ strategy and engagement strategy were under reviewat the time of assessment.
* At this point he Learning Disabilities Steering Group assessed the Trust against the Healthcare for All Report and rated further improvements were needed to demonstrate compliance. The following recommendations were made and agreed with the Extended Executive Team:
* The Trust Carers Strategy would be modified to make explicit reference to the needs of carers of people with learning disabilities and to the protocol for making reasonable adjustments..
* OHFT would modify its engagement strategy to specifically state what Oxford Health FT does or intends to do to achieve representation of people or families of people with a LD, at varying levels of the organisation, protocols were regarded as general and not offering individualization and reasonable adjustment for people with Learning difficulties

**2. Work Programme 2014-15** (See Appendix 1) set out a Programme for the Learning Disabilities Steering Group.

* The development of overall protocol on reasonable adjustments was completed
* The Trust Carers Strategy was modified to make explicit reference to the needs of carers of people with learning disabilities .The Carers Strategy was reviewed and an addendum to the strategy that identifies the actions that the Trust will take to support carers of people with learning disabilities .
* Our engagement strategy was modified to specifically state what Oxford Health FT does to achieve representation of people or families of people with a Learning Disability in our services. An addendum to the Trusts engagement strategy was made All the policy documents are available on the intranet.
* Evidence of these policies in use to provide effective care are also referenced in peer reviews of services and in quality reports such as the CQC Reports. However these tend to be individual cases which are examined and reported upon.

**3. Work programme 2015-16**

A work programme was approved for 2015 -16 (Figure 1.) aimed at further developing processes to track and flag patients with learning disabilities. Some progress has been made however there remain some outstanding areas we will need to continue to develop in the forthcoming year.

**3.1 Objective 1: Establishment of Tracking and Flagging mechanism.**

* OHFT has worked in partnership with Southern Health FT and the Oxford University Hospitals NHS Trust to develop tracking and flagging mechanisms that enable people with learning disabilities that come into contact with our services to be identified.
* A case register was established that identifies people with learning disabilities that are on the caseload of Southern Health FT and consent has been gained from individuals that comprise the Learning Disabilities Fragility Network of most vulnerable people with learning disabilities in Oxfordshire to share personal details with the aim of making assessments of reasonable adjustments to their care

**Key achievements**

* OHFT is contracted to provide services for children with learning disabilities .The CQC review of specialist children’s services found services to be outstanding.
* The content of an easy read letter to people with learning disabilities on the Southern Health Fragility Network requesting consent to share records and information with a view to improving the care they received was agreed and this letter was distributed to people within the Fragility Network.
* The responses in relation to this request for consent were collated and the consented database was shared with Oxford Health Foundation Trust and Oxford University Hospitals Foundation Trust
* The process for developing an Omnivo reportthat triangulated Southern Health patients on the Fragility Network against Oxford Health patients was developed**.**
* Data cleansing and identification of a second cohort was commenced.
* Audit tool reviewed

**Remaining actions**

This audit was not completed as a formal Information Governance investigation was initiated within Southern Health FT that related to sending information requests to families whose relatives were deceased which caused great distress.

In the interim period Oxford Health FT implemented a new Electronic Patient Record system. Once the new system is fully operational the Carenotes project group has been tasked to electronically track this group of patients as optimisation of the system progresses.

**3.2 Objective 2: Implementation of comprehensive audit programme.**

* Individuals with learning disabilities could be tracked on the Rio Electronic Patient Record and an Omnivo report was run that enabled the identification of areas where an audit of records could be undertaken to provide evidence that reasonable adjustments were in place at an individual patient level as well as at a service level.

**Key achievements**

* The Shared Care for People with Mental Health Problems and a Learning Disability Policy has been reviewed.
* An Audit was initiated in Older Adult Services as access to urgent care and out of hours care as well as integrated therapies and community nursing are all service where access and reasonable adjustment would need to take place. The audit found there was insufficient data obtained to enable an analysis as it was identified that only one person on the fragility network had been in contact with services. It was agreed that this audit should be withdrawn from the Trust schedule and alternative mechanisms developed in light of the introduction of Carenotes, and peer review visits and case note review processes.
* The Shared Care for People with Mental Health Problems and a Learning Disability Policy requires further review in light of recommendations in the Mazars Report into the reporting of expected and unexpected deaths

**3.3 Objective 3: Leadership and governance for people with LD – The Learning Disabilities Steering Group**

**Achievements**

* Care delivery and oversight of care and governance for children with learning disabilities is embedded within the children and young people’s directorate.
* These specialist teams were awarded an outstanding rating overall by the CQC.
* The Physical Health Group terms of reference currently incorporates improving access to mainstream services for all people with learning disabilities and assurance that people with learning disabilities receive high quality reasonably adjusted care.

**Remaining actions**

* Review the requirement for a standalone Learning Disabilities Steering Group with Trust wide representation. Review terms of reference and membership following changes in governance structure. Agree the 2016/17 work Programme
* Hand over corporate leadership for people with learning disabilities to the new Programme Director of Learning Disabilities who will commence in post in May.
* Maintain the evidence log and quarterly reporting process to SMT/EEB and the Quality Committee and migrate from G drives to Ulysses System
* ‘Tracking and flagging’ mechanisms will need to be identified for all Oxford Health patients in receipt of care in Buckinghamshire as well as Oxfordshire. This should be possible as Southern Health Foundation Trust currently provide care to patients with learning disabilities The Head of Nursing for Older Adults is working with our Head of Social Care for Buckinghamshire to identify action required to enable future audits of reasonable adjustments for Buckinghamshire patients with a learning disability that come into contact with Oxford Health Foundation Trust services.
* Use the new electronic health record to audit the care delivered in universal and adult services and re-establish the partnership with Southern Health FT

**Conclusion**

Ensuring people with Learning Disabilities receive the best reasonably adjusted care and is offered the opportunity to feedback their experience, remains the core responsibility of every clinician and manager in every team and service to meet the national standards

There continues to be a need for a corporate leadership role to ensure that the strategic partnerships and objectives which span many teams continue to be assessed and reported every quarter. In future this will be led by the new Programme Director for LD who will undertake a systemic review once in post. A senior leader with dedicated time to focus on the needs of people with LD



**Appendix 1**

**Appendix 2**

**Protocol for Improving Access to Healthcare**

**For People with a Learning Disability and Making Reasonable Adjustments**

**Contents**

**Page**

**1 Introduction 3**

**2 Overview of protocol context 3**

**3 Purpose of the Protocol 4**

**4 Definition of a learning disability 4**

**5 Pathway of the protocol 5**

**6 Easy Read Materials 5**

**7 Training 5**

**8 Support to Carers 5**

**9 Process of monitoring compliance 6**

**10 Representation of People with a Learning Disability 6**

**11 Dissemination, Implementation, Access and Review 6**

**12 Equality & Human Rights Impact Assessments 6**

**13 Supporting References 7**

**14 Appendix 3 - Reasonable Adjustments 8**

**1. Introduction**

All health services in Oxford Health NHS Foundation Trust are available to people with a learning disability.

Oxford Health NHS Foundation Trust has a responsibility to ensure that all people with a learning disability access appropriate services and that they receive the best treatment available in line with good practice and legal frameworks. Therefore all services will ensure that:

* Reasonable adjustments are made to ensure that each person has the same opportunity for healthcare, whether they have a learning disability or not ([Disability Discrimination Act 2005](http://www.legislation.gov.uk/ukpga/2005/13/contents))
* Assume that each person presented to the service has capacity. If assessment shows they do not, a decision must be made in their best interest ([Mental Capacity Act 2005](http://www.dh.gov.uk/en/SocialCare/Deliveringsocialcare/MentalCapacity/MentalCapacityAct2005/index.htm))
* Everyone has a right to expect and receive appropriate healthcare ([Human Rights Act 1998](http://www.legislation.gov.uk/ukpga/1998/42/contents))

**2. Overview of Protocol Context**

The Department of Health’s consultation paper [***Valuing People Now***](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093377)was published in 2009 and confirmed the founding principles of its White Paper [***Valuing People 2001***](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009153). These principles were set within a human rights framework and stressed issues such as health, people with very complex needs and full and fair access to services for people from different ethnic groups.

In January 2009, the Government published [***Valuing People Now: from progress to transformation***](http://www.google.co.uk/#hl=en&cp=27&gs_id=1u&xhr=t&q=valuing+people+now+from+progress+to+transformation&pf=p&sclient=psy-ab&source=hp&pbx=1&oq=valuing+people+now+from+pro&aq=0&aqi=g2g-v2&aql=&gs_sm=&gs_upl=&bav=on.2,or.r_gc.r_pw.&fp=55b17cf936632d8d&biw=1024&bih=571), a new three-year strategy on the provision of services for people with learning disabilities. That strategy made clear the need for better commissioning of specialist care for people with learning disabilities and emphasised the need for strong leadership at all levels to make change happen.

The independent inquiry into access to healthcare for people with learning disabilities, led by Sir Jonathan Michael, published its findings in[***Healthcare for all***](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_099255)in July 2008. This and the subsequent Ombudsman’s report [***Six lives***](http://www.ombudsman.org.uk/improving-public-service/reports-and-consultations/reports/health/six-lives-the-provision-of-public-services-to-people-with-learning-disabilities), called for an urgent review of primary and non-specialist inpatient healthcare for people with learning disabilities, and drew together the themes from Mencap’s [***Death by Indifference***](http://www.mencap.org.uk/node/5863)report, which told the stories of six people with a learning disability who died while in NHS care. This drew attention to continued health inequalities experienced by people with learning disabilities and highlighted examples of neglect in general hospital settings that were profoundly disturbing. This report stipulated Board responsibility for ensuring that people were informed, involved and treated fairly.

**3. Purpose of the Protocol**

This protocol will support clinicians to determine if a service user[[1]](#footnote-1) and or their carer/parent might have a learning disability and ensure that treatment is provided to all individuals regardless of their disability. Every reasonable effort will then be made to ensure that all treatment provided is based upon the best interest of the individual and that reasonable adjustments are made to ensure accessibility and to meet their needs. The protocol is not intended as a diagnostic tool and sound clinical judgement should be applied in all cases. The Trust Learning Disabilities Steering Group will be responsible for monitoring how the Trust is achieving standards in relation to ***improving access to healthcare*** and ***good practice in improving access to mental health services.***

**4. Definition of Learning Disability**

The [Department of Health (DOH)](http://www.dh.gov.uk/en/index.htm) defines a learning disability as including the presence of:

* A significantly reduced ability to understand new or complex information, to learn new skills (impaired intellectual functioning) with;
* A reduced ability to cope independently (impairment of adaptive/ social functioning);
* Which started before adulthood, with a lasting effect on development

([Valuing People DOH, 2009](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093377)).

The DSM 4 states that as well as intellectual functioning being markedly below average (IQ of 70 or less) and that difficulty functioning in 2 or more of the following areas would be expected:

* Communicating
* Caring for self
* Living at home
* Relating to others
* Directing self
* Using community resources
* Academic functioning
* Working
* Health and safety

***And that the condition started before the age 18.***

**5. The pathway of the protocol**

If a service user carer/ parent with a learning disability (or a suspected learning disability) is referred to the service, staff will consider whether any additional support **(reasonable adjustment)** is required in order to ensure that the service user receives a meaningful package of care based on their individual needs. Staff will ensure that the person has an **alert/flag on the clinical record system,** RiO, System One etc. to highlight that they have a learning disability and may need reasonable adjustments

* All service users with a Learning Disability will have an alert on the clinical record system to ensure that additional support required will be made available when they access the service in future;
* Reasonable adjustments which were helpful, to be documented in the clinical record for future reference;

**6. Easy Read Materials**

Easy read appointment letters and information leaflets are available on the Trust intranet. Should staff need to download leaflets for topics other than those available, there is a link to [Easy Health](http://www.easyhealth.org.uk/).

**7. Training**

Training on understanding the needs of people with a learning disability will be made available to all staff in Oxford Health NHS Foundation Trust. This will include Valuing People, Disability and Discrimination Act, diversity awareness, communication and understanding challenging behavior, mental capacity & consent and safeguarding training. Learning Disability training is part of the trust induction programme.

**8.** **Support to Carers**

The Trust policy on supporting carers has an addendum which highlights the support available locally for carers of people with a learning disability.

**9. Process for monitoring compliance**

To maintain compliance with the Care Quality Commission and Monitor targets “Access to Healthcare for People with a Learning Disability”, there are regular audits of the experiences of people with a learning disability accessing mental and physical health services by the Trust audit team. These are part of the annual audit plan.

**10.** **Representation of People with a Learning Disability**

People with a learning disability and their carers must have access to representation within the Trust. Carer and user involvement polices reflect this Local policies and consultation need to take this into consideration. Particular attention should be given to involving people with a learning disability in development of new services and implementation of service reviews. To do this people may require additional support and consideration should be made to the meetings being accessible**.** Trust wide groups will make reasonable adjustments to ensure that people with a learning disability can have access and have their views heard.

**11. Dissemination, Implementation, Access and Review**

This protocol will be available on the Trust intranet.

**12. Equality Analysis/ Equality Impact Assessment**

The Public Sector Equality Duty (Equality Act 2010) requires public authorities like Oxford Health to have due regard to the aims of the general equality duty. This means eliminating discrimination, advancing equality of opportunity and fostering good relations between people who share a relevant protected characteristic and those who do not. The protected characteristics defined in the act are age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation. The protected characteristic of disability includes people with a learning disability.

In order to demonstrate due regard, Oxford Health endeavors to understand the impact of its polices, practices, activities and decisions on equality. The trust has developed an [equality impact assessment tool](http://obmhintranet.obmh.nhs.uk/TR/default.aspx) to help staff achieve this understanding and evidence the process.

In relation to delivering improvements for patients with a learning disability, responsible managers must carry out an equality analysis or impact assessment as part of the process of developing and implementing key actions. This analysis will include the identification of the specific needs of people with a learning disability and indicate how policies and decisions ensure that people with a learning disability can access and receive services without discrimination. This may include treating people with such a disability more favourably than others because of the disadvantage they experience.

**13. Supporting References / Links**

Care Quality Commission [Access to health care for people with a learning disability](http://www.cqc.org.uk/periodicreview/nationalcommitmentsandpriorities2009/10/mentalhealthtrusts/accesstohealthcareforpeoplewithalearningdisability.cfm).

Equality Act [2010](http://www.homeoffice.gov.uk/equalities/equality-act/)

‘[Healthcare for All’](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_099255): Report of the Independent Inquiry into access to healthcare for people with a learning disability. Sir Jonathan Michael (2008).

[Human Rights Act 1998](http://www.legislation.gov.uk/ukpga/1998/42/contents).

[Mental Capacity Act 2005](http://www.dh.gov.uk/en/SocialCare/Deliveringsocialcare/MentalCapacity/MentalCapacityAct2005/index.htm), Department of Health.

[Valuing People Now:](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093377) A New Three Year Strategy for people with a learning disability, ‘Making It Happen for Everyone’. Department of Health (2009).

**Appendix 3**

**Reasonable Adjustments**

Additional support or reasonable adjustments that could be considered when a person with a learning disability accesses a Trust service:

* Ensure that an alert is added to the clinical record immediately;
* Contact the service or trust Learning Disabilities Lead for guidance and advice;
* Encourage the support and contribution of the parent /carer.
* Consider the need for Independent Mental Capacity Advocate;
* Consider Advocacy;
* Spend time with the individual to gain an understanding of their preferences for treatment;
* Consider the persons physical and sensory needs;
* Consider anything that would distress the person or make things easier for them
* Send them an Easy Read appointment letter;
* Call the person the day before an appointment to remind them;
* Allow them additional outpatient time or double appointment slot;
* Call them in to their appointment by their name rather than expect them to read their name on an electronic screen;
* Ask for their patient passport;
* Provide additional support to assist with communication, this support will be available via Easy Read material /and/ or audio equipment;
* Contact the local learning disability service for support and advice;
* Avoid bed or ward moves;
* Carefully consider day and time of discharge;
* Ensure that the local Learning Disability service has prior notice for discharge CPA meeting;
* Easy Read discharge plan;
* Enter recent contributions to the individuals Health Action Plan;
* Ensure that pharmacy speaks to the person with their carer re discharge medication;
* Easy Read medication leaflets
* Provide the person with an Easy Read emergency crisis card on discharge;
* Provide easy read information that signposts patients /carers and parents to wider support networks
* Ensure follow up is carried out;
* Inform GP of the admission and progress to discharge via a discharge plan;
* Consider who else should have a copy of the discharge plan;
* Have a named contact for the person to contact to avoid unnecessary anxiety and distress;
* All service users with a Learning Disability will be flagged up on the clinical record to ensure that additional support required will be made available when they access the service in future;
* Document any reasonable adjustments made which were helpful in the clinical record for future reference.

**Appendix 4**

**Carers of people with learning disabilities and parents/carers with a learning disability**

Oxford Health NHS Foundation Trust recognises the significant contribution that carers of people with learning disabilities and carers with learning disabilities make to the quality of the experience that people with learning disabilities have when accessing our services. A key aim of the trust is to make things better for carers of people with learning disabilities in order to help people with learning disabilities to have a better life. The Trust endeavours to support families in their caring role and wishes to ensure that carers of people with learning disabilities and carers with a learning disability know about their right to an assessment of their needs and that services are appropriately provided to carers in response to such assessments.

As part of its regular learning disability audits the Trust will collect information on carers’ assessments for people with learning disabilities and report to the Learning Disabilities Steering Group on reasonable adjustments that are made to meet carers’ needs. The Trust makes explicit reference to the needs of carers of people with learning disabilities and carers with a learning disability in its learning disability training sessions.

As part of the Carers’ Strategy the trust will undertake work to find out what information carers of people with learning disabilities and carers with learning disabilities find most useful and will increase the accessibility of this information.

**Appendix 5**

**Addendum to engagement strategy: People with Learning Disabilities.**

A key aim of the Trust engagement strategy is to generate and maintain an open dialogue with staff and all stakeholders across the trust, Oxford Health NHS Foundation Trust recognizes that giving information is vital to help people with learning disabilities making choices but it casts the health professional as ‘expert’ although people with learning disabilities and carers of people with learning disabilities are also expert information givers. Consultation processes allow choice between limited options and the nature of learning disabilities means that people with learning disabilities may have their choice further limited when accessing services if such approaches are used .Engagement strategies that approach engagement and involvement from a perspective of ‘deciding together’ suggests that people negotiate decisions from positions of equal weighting which may not be the case for people with learning disabilities. The approach used by OH is one of ‘acting together ‘with people with learning disabilities and their carers to help identify solutions and implement them, the key ingredients of this approach are being trust and equality in power.

The Trust will develop partnerships with locally formed and led interest groups to help improve the quality of service it delivers to people with learning disabilities. There is an on-going commitment from the Trust tor regularly review action and progress to ensure that the views and experiences of people with learning disabilities are taken on board at all levels of the Trust.

The Trust will seek to involve members of such groups in Board meetings and other sessions with senior staff to discuss issues of particular relevance to people with learning disabilities to enable to and highlight issues that affect them.

1. The term service user may refer to carers and parents in addition to those receiving direct care [↑](#footnote-ref-1)