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**TRUST STRATEGY**

**Strategy for Patients who have a Learning Disability and/or Autism**

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<b>For use in:</b>	All areas of the Trust
<b>For use by:</b>	All Trust staff
<b>For use for:</b>	People with Learning Disabilities and Autism
<b>Document owner:</b>	Deputy Chief Nurse
<b>Status:</b>	Approved

**Purpose of this document**

The Trust is committed to delivering care to patients that meets their individual needs and recognises that some patients may be disadvantaged in accessing care and treatment due to disability or other health inequalities.

This Strategy sets out the standards of care the Trust wishes to provide to people who have a learning disability and/or autism who access our services.

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## 1.0 INTRODUCTION

At West Suffolk Hospital NHS Trust we are committed to achieving excellence in all we do. We are passionate about providing the highest quality care and aim to be the hospital our local communities choose first, every time. This strategy document demonstrates the Trusts commitment to improving the care and treatment of people with learning disabilities and/or autism (PWLD/A) when accessing the West Suffolk Hospital. It is designed to support staff in seeing a vision for the future of services for PWLD/A.

By providing leadership and working in partnership, this Strategy document provides the West Suffolk Hospital with a firm basis over the next three years, for delivering high quality, person centred, safe acute hospital services for PWLD/A.

A Learning Disability includes the presence of:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- a reduced ability to cope independently (impaired social functioning), which;
- started before adulthood, with a lasting effect on development.

Valuing People (DH 2001)

Learning disability is divided into four classification groups: Mild, Moderate, Severe and Profound. The diagnosis of profound and multiple learning disability (PMLD) is used when the individual has more than one disability (sensory disability, physical disability, complex health needs, mental health issues) with the most significant being a learning disability. People with PMLD will need a carer/s to help them with most areas of everyday life, such as eating and drinking, washing and going to the toilet.

### Autism and Autistic Spectrum Disorders

Autistic Spectrum Disorder (ASD) is the term that is used to describe a group of disorders, including Autism and Asperger's syndrome. The word 'spectrum' is used because the characteristics of the condition vary from one person to another. Autism is a lifelong developmental disability that first appears during infancy or childhood and affects how a person communicates with, and relates to, other people. It also affects how a person makes sense of the world around them. Individuals with autism may also have a learning disability. Those who have Asperger's syndrome tend to have average, or above average, intelligence, but still have difficulty making sense of the world and interacting with others.

People with ASD experience three main difficulties, often known as the 'triad of impairments':

- **Social interaction** - difficulty with social relationships, often appeared distant or detached.
- **Social communication** – difficulty with understanding verbal and non – verbal communication. Body language, gestures, facial expression, tone of voice.
- **Social imagination** – difficulty in the development of play and imagination with others. People with ASD often have a limited number of activities that are possibly copied and performed rigidly and repetitively.

The Autism Act (2009), Autism Strategy (2010) and NICE Autism Clinical Guideline (2012) identify that a significant proportion of adults with autism across the whole spectrum experience social and economic exclusion. The condition has been noted as 'frequently overlooked by health, education and social care professionals, which in turn creates barriers to accessing the support and services needed'. The NICE guidelines offer the best practice advice on the person centred care of adults with autism. It highlights that support and care 'should take into account peoples' individual needs and preferences'. Additionally it states 'people with autism should have the opportunity to make informed decisions about their care, in partnership with healthcare professionals'. Where individuals lack capacity, decisions are made in the individual's best interests according to the statutory requirements set out through the Mental Capacity Act 2005. This strategy sets out how the West Suffolk Hospital NHS Foundation Trust will meet the best practice guidelines to ensure a safe and responsive service for those with ASD.

A range of findings from various enquiries and reports have all identified significant failings by NHS and Social Care agencies in meeting the health needs of PWLD/A, including premature and avoidable deaths. Key reports identifying the health inequalities experienced by people with a learning disability and their families have included the:

- '*Death by Indifference*' Report published by MENCAP in 2007;
- Independent inquiry undertaken by Sir Jonathan Michael, 'Healthcare for All' published in 2008;
- Joint Ombudsman Report '*Six Lives*' published in 2009;
- Equal Access - Department of Health, 2009;
- Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) published by the Norah Fry Research Centre in 2013.

There are a number of health issues affecting people with learning disabilities. Hollins *et al.* (1998) suggest that people with learning disabilities are 58 times more likely to die before the age of 50 than the general population. This is partly because conditions associated with learning disability raise the risk of premature unavoidable death. For example, almost half of all people with Down's syndrome have congenital heart problems, a much higher rate than the general population; they also have a higher risk of developing Alzheimer's disease, gastrointestinal problems and cancer.

Early death may also be associated with difficulties that, to some degree, are preventable. For example, up to a third of people with learning disabilities have an associated physical disability, most often cerebral palsy which puts them at risk of postural deformities, hip dislocation, chest infections, eating and swallowing problems (dysphagia), gastro-oesophageal reflux, constipation and incontinence. They also tend to have osteoporosis younger than the general population and have more fractures.

Approximately a third of people with learning disabilities have epilepsy (at least twenty times higher than the general population) and more have epilepsy that is difficult to control. The risks of sudden unexpected death in epilepsy (SUDEP) are highest in children with learning disability and the NICE audit (2002) indicated that almost 60 per cent of child deaths and almost 40 per cent of adult deaths were potentially avoidable. Poor documentation, communication and information sharing were implicated in a large number of these cases.

## ***Incidence and prevalence of Learning disability***

It is estimated that in the UK there are approximately 1.5 million people diagnosed with learning disabilities. This figure is set to increase, largely due to better neo-natal care for premature babies of those that historically would have failed to thrive. Also people with learning disabilities are living longer. Although it is estimated that they are still likely to die twenty years before the general population (FPLD 2001; Mencap 2004; Hislop *et al.* 2013).

There has been a great deal of evidence to support the fact that people who have a learning disability do not receive equal health care treatment or a good health service. There are significant unmet health needs that often go unrecognised, and this has an impact upon the quality of life and life expectancy of people with a learning disability.

The Mencap report, *Death by Indifference*, was published in 2007 in response to the deaths of six people with a learning disability whilst in the care of the NHS between 2003 and 2005. Its findings provided the impetus to establish the Independent Inquiry into Access to Healthcare for People with Learning Disabilities by Sir Jonathan Michael; and the Inquiry's report, 'Healthcare for All', followed in 2008. It revealed startling inequalities in the provision of care to patients with learning disabilities.

In response to various complaints raised by Mencap on behalf of the families of the deceased patients, The Parliamentary and Health Service Ombudsman Six Lives: the provision of public services to people with learning disabilities report was issued in 2009; and in October 2010 the Department of Health published the Six Lives Progress Report.

These investigations reveal distressing failures and inequalities in the provision of health care for people with learning disabilities, in particular:

- Failure to adapt organisational behaviour to individual needs of patients
- Omissions in the delivery of fundamental care
- Lack of organisational leadership
- Failure to understand the Law in relation to disability discrimination and human rights
- Lack of partnership working with community based care providers
- Ineffective communication between staff, patients, and carers

Moreover, their findings evidenced that those patients with a learning disability are more likely to:

- Die of respiratory disease
- Die prematurely
- Be diagnosed with epilepsy
- Have weight management problems
- Have mental health problems

In response to these investigations, as part of an east of England Quality, Innovation, Productivity and Prevention (QIPP) project, a self assessment framework was implemented across healthcare organisations in the East of England as a means by which to support acute hospitals, commissioners, and partnership agencies in the improvement of service delivery to those patients with a learning disability and/or autism and their carers.

The outcome of these reviews was extremely positive and highlighted areas for improvement in the provision of services to this patient group.

Within the East of England there are examples of excellent practice in a number of key areas. Locally Acute Trusts have been nationally recognised for their work around health inequalities and work regarding care of patients with learning disabilities and/or autism. With this evidence of best practice, recommendations and expectations have been placed on acute trusts to:

- have Acute Learning Disability Liaison Nurses in post
- have systems in place to monitor and report on the effectiveness of reasonable adjustments
- provide information on the specific health needs of people with a learning disability and/or autism
- provide mandatory training in learning disabilities and autism
- involve people with learning disabilities and autism and their carers in the provision of training

As a result of the identified health inequalities, the West Suffolk Hospital has prioritised a range of Strategic Objectives to improve healthcare for PWLD/A throughout 2012 to the present and beyond.

Over the last three years, the West Suffolk Hospital has completed a comprehensive self assessment and performance framework in relation to the healthcare for PWLD/A across the west of the county who access the hospital for care and treatment. Although there continues to be more work to do, good progress has been made within the Implementation Plan to improve acute care services.

In addition, a strong network of clinicians and Learning Disability Partnership Board health sub group representatives has been established across Suffolk. This has led to positive developments in sharing good practice and identifying common themes for further development. An example of this has been the development of a web site to enable mainstream clinicians to access Easy Read health information to provide to patients.

## **1.1 PRINCIPLES**

People with learning disabilities and/or autism have the right to the same level of health care as that provided to the general population. This care should be flexible and responsive and any diagnosis or treatment must take account of specific needs associated with the person's learning disability (Michaels 2008).

For PWLD/A who use the acute hospital services provided by the West Suffolk Hospital NHS Foundation Trust responsibility for the delivery of that care and treatment will remain with the hospital for the duration of the individual's journey.

This strategy has been subject to an Equalities Impact Assessment Screening and all aspects will enhance equality.

**In order to ensure adherence to these principles the main areas of focus will be:**

- to enable staff at the acute Trust to develop a better understanding of people with a learning disability and/or autism and to equip them to deal more effectively with the particular needs of each individual.
- to clarify for residential and other Learning Disability staff attending the hospital with a person with learning disabilities and/or autism their supporting/caring role and the boundaries between their caring role and the nursing role of the professional hospital staff.
- to support parents and carers in implementing successfully the Health Passport for PWLD/A using the hospital services.
- to provide an opportunity for hospital staff and the dedicated Learning Disability Liaison Nurse to work together to develop:
  - Effective communication
  - Training and education
  - Awareness raising
  - Easy to understand information for service users.

## **2.0 STRATEGIC OBJECTIVES**

It is estimated that there are more than 14,500 people (~2.3% of the population) across all age groups in Suffolk with learning disabilities. In the wake of the 'Winterbourne View' abuse enquiry this strategy is very timely. A core concern is to address the well-documented health inequalities faced by people with learning disabilities.

The West Suffolk Hospital has developed a series of strategic objectives aimed at ensuring the experience of PWLD/A that access the hospital for any reason meets their specific needs and is as positive as possible.

We aim to measure performance in the following areas:

- *Reasonable adjustments* made by the organisation to accommodate patients with a Learning disability/autism. (Disability Discrimination Act 2005, Equality Act 2010).
- Systems for flagging patients with a Learning disability/autism and availability of information on their needs.
- Use of the hospital specialist Learning Disability Liaison Nurse role.
- Availability of accessible Easy Read patient information.
- Transition arrangements from child to adult services. Carer support and active involvement with care.
- Partnership working with community health and social care colleagues and organisations.
- Discharge arrangements.
- Training and education records to support all staff working with people with a Learning Disability/autism.
- Policy and process regarding: Safeguarding; Mental Capacity Act; Consent to treatment; Deprivation of Liberty Safeguards.
- Board level awareness and commitment to the needs of PWLD/A.

## **3.0 ROLES AND RESPONSIBILITIES**

### **3.1 MEDICAL DIRECTOR AND DIRECTOR OF NURSING**

#### **Responsible for:**

- Ensuring the Trust provides a health care service to the local population that is accessible, safe and responsive to the needs of patients including those who may have specific needs arising as a result of a learning disability and/or autism.
- Assuring the Trust board and public that there are policies processes and monitoring systems in place so that Trust is compliant in its obligations under the DDA, quality/safety standards and Government requirements.

### **3.2 LEARNING DISABILITY LIAISON NURSE**

The Learning Disability Liaison Nurse's (LDLN) key role is to lead in the improvement of effective, accessible quality care delivery within acute services which are responsive to the needs of people with learning disabilities and/or autism.

Therefore the LDLN will be responsible for providing highly specialist leadership that supports the development of acute hospital service good practice.

This will be through close collaborative working with healthcare and multi-agency professionals and managing the interface between mainstream hospital services, specialist community services, private and voluntary services and families.

### **3.3 CLINICAL STAFF**

Clinical staff who may be involved in the assessment, diagnosis, treatment or care of patients with a learning disability and/or autism must be able to identify the fact and adapt their approach accordingly. Care and treatment plans must be drawn up with the learning disability/autism in mind so that reasonable adjustments are planned and delivered. Clinical staff must also know how to get help and advice, and do so as necessary. Learning Disability Resource Folders have been produced with the assistance of our expert partners in the community. These are available for use on the clinical areas. Staff have also been advised to contact the Learning Disability Liaison Nurse for further information on 'easy read' patient information.

Clinical staff should always act as the patients advocate ensuring that they are given information about their condition and/or treatment in a way that they can understand in order to make decisions within the limits of their capacity. It is important that clinical staff acknowledge that family members/carers understand the PWLD/A best and work in partnership with them to ensure that the communication needs of the individual are met.



### **3.4 MANAGEMENT AND ADMINISTRATIVE STAFF**

Anyone who is involved in the booking of patients with a learning disability and/or autism must be aware that the person may require reasonable adjustments that must be planned for, such as: -

- Ensuring that relevant clinical staff are made aware that the patient has a learning disability and/or autism: it may be flagged on PAS/HISS or Symphony.
- Providing a first appointment in clinic where possible: Some people will find it very hard to wait, or may find the busy waiting area frightening.
- Booking a longer appointment slot: extra time may be needed to allow the patient to describe their problem and to ask questions, and for the clinician to ensure that the information they provide has been understood.
- Arranging a visit to the relevant ward, clinic or department prior to admission: This will help to allay fear when coming in for an elective admission.

### **3.5 ALL STAFF**

Any member of staff, including volunteers that come into contact with a patient with a learning disability and/or autism must be aware of what this means, how they should be treated and from where they can find more information and help.

## **4.0 KEY PRIORITIES**

### **4.1 The Health Passport**

The West Suffolk Hospital is dedicated to the development & introduction of the Health Passport for PWLD/A. This is a patient held record that accompanies the patient throughout their journey in hospital. It provides key information for staff such as communication needs, allergies, support needs, how pain or distress may be exhibited, likes, dislikes, and behavioural patterns.

This document helps patients and carers highlight specific health and support needs before and during admission. Clinical staff are then able to better assess, plan, manage & evaluate care and treatment using a much more person-centred approach. Each patient is encouraged to complete a Health Passport if they do not have one and all staff are being encouraged to ask the patient for this information on admission. The Passport belongs to the patient and should accompany the person for all hospital appointments and admissions. It should be completed by the individual with the help of carers and advocates.

### **4.2 The Hospital Communication Book**

The Hospital Communication Book has been available to all staff via the Trust Intranet site for a number of years. This resource is also now available on each ward, clinic & department for all staff to use. This is an excellent resource that contains useful information and advice and a range of communication techniques and strategies such as signs & symbols on how to communicate effectively with people who have difficulties with communication.

### **4.3 Pre-admission Information**

There is a drive to improve pre-admission information for patients with a learning disability/autism. The Learning Disability Liaison Nurse is leading this initiative working with the Head of Communication, a Sister from the Emergency Department and a Community Learning Disabilities Nurse from the specialist health team in Stourmead. As part of this initiative, a booklet is being produced and is likely to be divided into planned admission, emergency admission, outpatient and discharge with appropriate images, text and spaces for the reader to write own notes etc. This booklet will be provided in an accessible format and easily available to PWLD/A and their carers.

### **4.4 Accessible Patient information**

In line with Government directives and policy guidance (DDA 1995) the Trust recognises the need to provide accessible information in a range of formats to meet the needs of all patients. A range of Easy Read leaflets will be made available on key aspects of services, procedures and treatments in the hospital and it is suggested that current leaflets are put into Easy Read versions.

All departments and units will be encouraged to develop easy read information in a range of formats including pictorial pathways, letters and the use of other media to promote understanding of the proposed care and treatment pathway and to enable PWLD/A to make informed choices about their care and treatment.

### **4.5 Learning Disabilities & Autism Website**

To develop a section of the hospital's intranet specific to learning disabilities and autism for all staff to access. Much of the content will also be made available to people with learning disabilities/autism and their carers via the Trust internet website. The Learning Disabilities Liaison Nurse is leading on this initiative, with input from the IT department and the Head of Communications.

Content will include:

- Information on Learning Disabilities and Autism
- Factsheets
- Protocols/Pathways/Flowcharts
- Easy read leaflets
- Top tips (how to support and communication advice)
- Reasonable Adjustment information
- Guidance on mental capacity, consent, safeguarding, Deprivation of Liberty Safeguards
- Frequently Asked Questions
- Downloadable information
- Relevant Policies
- Useful resources/documents/links

#### **4.6 Ethnic minority groups**

The Trust is committed to meeting the needs of all minority groups (Ethnicity Policy). Staff must be aware that PWLD/A who are also from an ethnic minority group may have specific difficulties in communicating their cultural needs and wishes e.g. diet, dignity, same sex care.

#### **4.7 Training and Education**

The Trust has a Staff Development Framework in place which aims to improve the knowledge, skills and awareness of all staff who are involved in or who contribute to the patient pathway for PWLD/A. The training is coordinated by the Learning Disability Liaison Nurse and is aimed at all staff across the Trust such as consultants, clinicians, receptionists, bed managers, porters, ambulance staff etc.

The framework offers four levels of training starting from Level 1 - awareness raising at induction through to specific skills and knowledge training for ward and departmental based learning disability 'champions' at Level 4.

Topics include:

- Introduction to learning disability and autism
- How to identify learning disabilities
- Communication issues & strategies
- Top tips when working with people with learning disability/autism
- Guidance on reasonable adjustments
- Advice & guidance on the Mental Capacity Act 2005, best interests, role of the IMCA, consent to treatment, Safeguarding and Deprivation of Liberty.

#### **4.8 Partnership working**

Multi-agency and multi disciplinary partnership working is essential to ensuring positive health outcomes for PWLD/A. Working together with other health providers such as the Learning Disabilities Integrated Delivery Team who frequently provide support and health education in the community, social care providers such as Social Workers and Home Care providers and family carers requires effective communication and information sharing which is paramount to safeguarding the individual and prevent harm. Family carers and support workers must be included in planning for both admission and discharge to ensure all information is passed on effectively and avoids things being missed.

It is important that we develop an agreed pathway & protocol or Service Level Agreement between local learning disability services, GPs & social care services to ensure seamless service provision, system wide learning and collaboration.

## **4.9 Diagnostic Overshadowing**

PWLD/A can sometimes experience 'diagnostic overshadowing'. This is the concept that when a diagnosis of a major condition is made; there may then be a tendency to attribute all other problems to that diagnosis, therefore leaving all other co-existing conditions undiagnosed. In the context of PWLD/A it means that 'symptoms of physical ill-health are mistakenly attributed to mental health/behavioural problems or inherent in the person's learning disabilities' (Emerson and Baines 2010).

This may occur for a number of other reasons including:

- Difficulty describing symptoms
- Attitudes of medical and nursing staff
- Lack of co-operation when undergoing investigations/examination
- Poor access to screening services
- High/low pain thresholds
- Atypical physical presentation
- Assumptions based on the specific disability

PWLD/A must not be excluded from diagnostic tests or treatments based on their learning disability and/or autism.

## **4.10 Flagging Alert System**

To continue to improve and add to the Flagging Alert system for learning disabilities and to include 'Autism' & Autistic Spectrum Disorder to the flags.

## **4.11 Learning Disability Maternity Pathway**

Increasingly there is a need for people with a learning disability to access maternity services. Around 7% of adults with a learning disability are parents, most having a mild to borderline learning disability, which may mean they do not have a formal diagnosis and may be difficult to identify. Studies show that around 40% of parents with a learning disability do not live with their children. Children of parents with a learning disability are more likely than any other group to be removed from their parents care. Fear of the involvement of social care services may lead to the avoidance of maternity care. Therefore good support mechanisms and antenatal education are vital for parents with learning disability who will have their parental competence assessed.

To ensure that women with learning disabilities and/or autism have the necessary support, advice and guidance when accessing the maternity services at the West Suffolk Hospital a specific maternity pathway will be developed by the Children and Maternity services in collaboration with the Learning Disability Liaison nurse.

## **4.12 Transition**

Transition from paediatric to adult health services poses a number of challenges. Not only is the individual dealing with the social, psychological and biological transitions of adolescence they are also managing their transition to new care provision which can be very daunting for both the adolescent and the family carer. People with intellectual disabilities are more likely to experience additional transitions in their lifetime such as with the diagnosis of new co-existent medical conditions.

Evidence suggests that transition programmes improve health outcomes and quality of life and that inadequate transition has been associated with poorer prognosis.

The Trust will develop a Transition Policy for the transfer of children with a learning disability and/or autism to adult acute healthcare services. A Transition Pathway is also proposed which will identify a key worker or identified professional within the multi-disciplinary team who is responsible for co-ordinating transition from the Early Stage of transition (13/14 years) through to transition into adult services (16-19 years). This will ensure that there is a preparation period in place and make sure that the young person is not transferred to adult services before they are able to function in an adult setting. Full and active participation from both paediatric to adult health services is required in order to ensure successful transition.

## **4.13 Implementation of the Autism Strategy**

This is key to effectively extending improvements in access and outcomes to people with autism.

## **5.0 SUMMARY**

The West Suffolk Hospital NHS Foundation Trust believes that acute health services must be accessible and equitable for all people, including those with learning disabilities and/or autism.

We are committed to developing our services to the highest standard. This includes the representation of people with all abilities in the development of our services and in our workforce.

The Trust has shown its commitment to people with learning disabilities and/or autism by supporting and appointing a dedicated Learning Disability Liaison Nurse.

The Trust believes that partnership working is a major key to a comprehensive system to support people with learning disabilities and autism as patients and colleagues. We ensure that we collaborate closely with our colleagues in health, social care and education to push the boundaries of knowledge and practice in this field.

We work particularly closely with Specialist Services for both children and adults with learning disabilities to ensure a consistent approach to meet health needs in hospital and in the community.

Our Learning Disability Liaison Nurse is fully involved in networking with other acute trusts to ensure best practice is shared, and that we are updated and informed about the regional and national learning disabilities agenda. The Learning Disability Liaison Nurse is a member of the national and regional Access to Acute (A2A) network and is working with the NHS East of England team to develop services related to QIPP to ensure that people with learning disabilities and/or autism across the region receive consistently high standards and access to health services.

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## 6.0 REFERENCES

CQC (2009) *Position statement and action plan for learning disability 2010-2015*. London: The Care Quality Commission.

Department of Health (2001) *Valuing People. A new strategy for learning disability for the 21st century*. London: The Stationery Office.

Department of Health (2009) *Valuing people now: a new three year strategy for people with learning disabilities. 'Making it happen for everyone'*. London: The Stationery Office.

Department of Health (2009) *The Autism Act 2009*. London: The Stationery Office.

Disability Rights Commission (2006) *Equal Treatment: Closing the Gap. A formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems*.

Hislop, P., Blair, P., Fleming, P., Hoghton, M., Marriott, A. & Russ, L. (2013) *Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD)*. Bristol: Norah Fry Research Centre.

MENCAP (2004) *Treat Me Right! Better healthcare for people with a learning disability*. London: Mencap.

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

MENCAP (2012) *Death by indifference: 74 deaths and counting - A progress report 5 years on*. London: Mencap.

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

NHS EOE (2010) *Better health and wellbeing for people with a learning disability and their families: The vision for achieving the best, together in the east of England 2011-2021*. Cambridge: NHS East of England.

National Patient Safety Agency (2004) *Understanding the patient's safety issues for people with a learning disability*. London: HMSO.

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

## APPENDIX 1

### THE TEN RECOMMENDATIONS FROM 'HEALTHCARE FOR ALL' (MICHAEL, 2008)

#### RECOMMENDATION 1

Those with responsibility for the provision and regulation of undergraduate and postgraduate clinical training must ensure that curricula include mandatory training in learning disabilities. It should be competence-based and involve people with learning disabilities and their carers in providing training.

#### RECOMMENDATION 2

All healthcare organisations, including the Department of Health should ensure that they collect the data and information necessary to allow people with learning disability to be identified by the health service and their pathways of care tracked.

#### RECOMMENDATION 3

Family and other carers should be involved as a matter of course as partners in the provision of treatment and care, unless good reason is given, and Trust Boards should ensure that reasonable adjustments are made to enable them to do this effectively. This will include the provision of information, but may also involve practical support and service co-ordination.

#### RECOMMENDATION 4

Primary care trusts should identify and assess the needs of people with learning disabilities and their carers as part of their Joint Strategic Needs Assessment. They should consult with their Local Strategic Partnership, their Learning Disability Partnership Boards and relevant voluntary user-led learning disability organisations and use the information to inform the development of Local Area Agreements.

#### RECOMMENDATION 5

To raise awareness in the health service of the risk of premature avoidable death, and to promote sustainable good practice in local assessment, management and evaluation of services, the Department of Health should establish a learning disabilities Public Health Observatory. This should be supplemented by a time-limited Confidential Inquiry into premature deaths in people with learning disabilities to provide evidence for clinical and professional staff of the extent of the problem and guidance on prevention.

#### RECOMMENDATION 6

The Department of Health should immediately amend Core Standards for Better Health, to include an explicit reference to the requirement to make 'reasonable adjustments' to the provision and delivery of services for vulnerable groups, in accordance with the disability equality legislation. The framework that is planned to replace these core standards in 2010 should also include a specific reference to this requirement.



## **RECOMMENDATION 7**

Inspectors and regulators of the health service should develop and extend their monitoring of the standard of general health services provided for people with learning disabilities, in both the hospital sector and in the community where primary care providers are located. The aim is to support appropriate, reasonable adjustments to general health services for adults and children with learning disabilities and their families and to ensure compliance with and enforcement of all aspects of the Disability Discrimination Act. Healthcare regulators and inspectors (and the Care Quality Commission, once established) should strengthen their work in partnership with each other and with the Commission for Equality and Human Rights, the National Patient Safety Agency and Office for Disability Issues).

## **RECOMMENDATION 8**

The Department of Health should direct primary care trusts (PCTs) to secure general health services that make 'reasonable adjustments' for people with learning disabilities through a Directed Enhanced Service. In particular, the Department should direct PCTs to commission enhanced primary care services which include regular health checks provided by GP practices and improve data, communication and cross-boundary partnership working. This should include liaison staff who work with primary care services to improve the overall quality of health care for people with learning disabilities across the spectrum of care.

## **RECOMMENDATION 9**

Section 242 of the National Health Service Act 2006 requires NHS bodies to involve and consult patients and the public in the planning and development of services, and in decisions affecting the operation of services. All Trust Boards should ensure that the views and interests of people with learning disabilities and their carers are included.

## **RECOMMENDATION 10**

All Trust Boards should demonstrate in routine public reports that they have effective systems in place to deliver effective, 'reasonably adjusted' health services for those people who happen to have a learning disability. This 'adjustment' should include arrangements to provide advocacy for all those who need it, and arrangements to secure effective representation on PALS from all client groups including people with learning disabilities.

## **IMPORTANT NOTE:**

These recommendations concern the '**reasonable adjustments**' that are needed to make health care services as accessible to people with learning disabilities as they are to other people. An annual health check; support when a visit to hospital is needed; help to communicate; better information, and tighter inspection and regulation will all work to reduce inequalities in access to and outcomes from healthcare services (Michael, 2008).

# Getting it right charter

## See the person, not the disability

All people with a learning disability have an equal right to healthcare.

All healthcare professionals have a duty to make reasonable adjustments to the treatment they provide to people with a learning disability.

All healthcare professionals should provide a high standard of care and treatment and value the lives of people with a learning disability.

**By signing this charter, we pledge to:**

- ✓ make sure that hospital passports are available and used
- ✓ make sure that all our staff understand and apply the principles of mental capacity laws
- ✓ appoint a learning disability liaison nurse in our hospital(s)
- ✓ make sure every eligible person with a learning disability can have an annual health check
- ✓ provide ongoing learning disability awareness training for all staff
- ✓ listen to, respect and involve families and carers
- ✓ provide practical support and information to families and carers
- ✓ provide information that is accessible for people with a learning disability
- ✓ display the *Getting it right* principles for everyone to see.

For guidance on implementing this pledge, please visit [www.mencap.org.uk/gettingitright](http://www.mencap.org.uk/gettingitright)

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Consultation:	A2A Network Key Stakeholders
Issue no:	1
File name:	LD Strategy.pdf
Supercedes:	Nil
Equality Assessed	Yes
Implementation	Key stake holders Intranet Green sheet
Monitoring: (give brief details how this will be done)	Strategy will be distributed by the Deputy Chief Nurse to General Managers, Service managers, and all Ward/Department Managers and will be available on the Trust Intranet Site
Other relevant policies/documents & references:	Policy for the Care and Management of Patients with a Learning Disability [PP(11)275] Safeguarding Vulnerable Adults at Risk of Abuse Policy
Additional Information:	