Good Practice Guidelines

For staff who work with people with learning disabilities

One of our patients, Will Wickens, is photographed here showing his communication book to Hillingdon A&E nurses, Rudy Genodifa and Obie Azike.

Authors: Head of Safeguarding and Learning Disability Nurse
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1. Good practice guidance at a glance

This section gives a short summary of examples of good practice when handling patients with a learning disability. The Hillingdon Hospitals NHS Foundation Trust will be referred to as “our Trust” or “the Trust” throughout this document.

Appointments:
- Long waiting times and rushed appointments can make people with learning disabilities anxious. Try to hold appointments at the beginning or end of the day and routinely offer double slots. Wherever possible try to ‘fast track’ the patient.
- Change appointment times to facilitate carers if necessary.
- Allow people to wait in different areas from other patients if it helps them.
- Allow enough room in corridors and waiting areas for wheelchairs.
- Tell people in person when it is their turn for their appointment.
- Make sure a person has access to the appropriate transport when they are offered an appointment.
- Make sure the patient has access to the disabled toilets.
- Try to make sure the person sees the same or one of two doctors or health professional where possible.
- Check PAS for LD alert and add if it is not there

When in hospital:
- Make sure you know what people’s needs are – diet, physical and personal care etc, and make sure they know about the Patient Passport and have access to it.
- Check Pas for an LD alert and add if it is not there.
- Let people familiarise themselves with hospitals before they come in.
- Make sure you have the right equipment for the patient’s needs.
- Family carers will need a break and facilities if they are staying with someone.
- Do not assume a family carer can stay for long periods.

Passing on information:
- Ask people what would help them and have a simple, consistent, clear system which holds this information so that people do not have to keep repeating it.
- Make sure that when someone is referred to another service, you tell the service about their specific needs.
- Make sure that you include relevant information about someone’s communication, physical access and sensory needs.
- Ask how someone wants to get their test or screening results, for example; face to face, phone call.

The person:
- Always check someone’s ability to provide and understand information first.
- Talk with the person, not just their carer, but make sure you listen to family/carers too.
- Tell people what their care plan is before doing so.
- Make sure people know how to make a complaint if they want to.
- Never assume that the person has a carer or someone at home to help, if they do not have a carer with them.
- Talk about relaxation techniques if someone is very anxious about some services, for example; blood tests, injections.
2. Executive summary

The term **Learning Disability (referred to as LD throughout this document)** is used to describe a person who has developmental delay or intellectual disabilities which are usually evident from birth or early childhood.

Our Trust’s guidelines also need to reflect the Equality Act of 2010. The Department of Health (DoH) (2001) offered the following definition of a learning disability:

“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.”

There are three core criteria which must be met for the term LD to apply:

- Significant impairment of intellectual function. In other words, an IQ below 70.
- Significant impairment of adaptive and or social function (ability to cope on a day to day basis with the demands of his/her environment and the expectations of age and culture)
- Age of onset before adulthood

People with a LD may present as having:

- difficulties communicating and expressing needs and choices
- difficulty understanding their diagnosis, treatment options or services available to them
- difficulty understanding the consequences their decisions can have on their health status
- difficulties in adapting to a hospital environment and the expectations of hospital staff

LD does **not** include:

- The development of intellectual, social or adaptive impairments after the age of 18
- Brain injury acquired after the age of 18
- Complex medical conditions that affect intellectual and social/adaptive functioning: e.g. dementia, Huntington's Chorea
- Specific learning difficulties: e.g. dyslexia, dyspraxia, literacy or numeracy problems, or delayed speech and language development

The term **Learning Difficulties**, that is often used in educational services to describe people with specific learning problems, does not indicate that a person has a learning disability as defined above.

The Disabilities and Mental Health Services (formerly the Community LD team) provide specialist support for adults with an assessed LD as described above who are eligible to receive services. Their contact details can be found towards the end of this document.

Responsibility for care provided to people with a LD will remain with our Trust for the duration of each individual’s treatment. Therefore, the aim of these guidelines is to make sure that people with LD are able to access high quality healthcare when attending the Trust for diagnostic investigations or treatment/care, and that reasonable adjustments are made as required. Each person with LD should then have a positive patient experience as a result.
3. Background


In this document, NPSA identified five patient safety priorities including:

• The vulnerability of people with LD in general hospital
• The lack of accessible information
• Illness or disease being mis/un-diagnosed, or diagnostic overshadowing
• Dysphasia
• The use of physical interventions

All of the above priorities have potential relevance for people with LD attending hospital.

Further reports highlighting the problems faced by people with LD include:

‘Death by Indifference’ (Mencap 2007) ‘Six Lives: the provision of public services to people with learning disabilities’ (Local Government Ombudsman, 2009), and the ‘six lives’ follow up report of 2010.

The Government has responded in a number of ways, through legislation such as the Disability Discrimination Act (2005), and an independent enquiry into access to healthcare for people with LD, led by Sir Jonathan Michael. The resulting report, Healthcare for All (2008), has 10 important recommendations which concern the ‘reasonable adjustments’ that are needed to make healthcare services as accessible to people with LD as they are to people without LD.

In addition, the 10 year Carers’ Strategy ‘Carers at the Heart of 21st Century Families and Communities’ (2008) expects carers to be partners in diagnosis, care and discharge planning alongside NHS and social services staff.

This guidance is based on three of the key points at the heart of the many recommendations that have emerged from recent documents about the potential health inequalities that people with LD face:

● Like everyone else, people with LD should get the help they need from health services, though this may mean that reasonable adjustments need to be made.

● Health professionals should listen more to the families and support staff of people with LD because they usually know most about them and the support they need.

● Health staff should not rely on relatives or paid carers of people with LD to provide care whilst they are in hospital without considering their needs and supporting them appropriately.


Valuing People Now is a three year cross government strategy for people with LD. It says that all people with a LD are people first, with the right to lead their lives like any other. It says healthcare is really important to people with LD and their families, and they have the right to good quality healthcare that meets their needs.
The strategy specifically refers to groups who are least often heard and most often excluded, such as people with more complex needs (such as LD); people from black and ethnic groups and newly arrived communities; people with autistic spectrum conditions and offenders in custody and in the community. The strategy sets a challenge for public services and everyone who works with people with LD to take an approach which starts with each individual, their wishes, aspirations and needs, and which seeks to give them control and choice over the support they need and the lives they lead.

4. Care pathways

The care pathways that are used within the Trust are included in Appendices A-C:

- Outpatient attendance
- Emergency/unplanned admission
- Elective/planned admission

4.1 Outpatients (Appendix A)

The Outpatient Department can be contacted before the appointment if specialist equipment and/or services are required. The patient and/or their carer can give the Patient Passport to the named/clinic nurse on arrival and prior to consultation.

The named/clinic nurse will assist during the consultation and will be available post consultation to provide extra information and direct the patient and their carer to other hospital departments as required. They can also arrange transport if it is required for future appointments (subject to clinical need).

Follow up appointments should be avoided unless clinically essential, in cases where the patient presents with distress, extreme anxiety or challenging behaviour in hospital settings. If a follow up appointment is not offered, care arrangements should be discussed and negotiated with the carer who can liaise as necessary with the GP.

LD staff will ensure that they liaise with the relevant named/clinic nurse or consultant and/or identified contact, as appropriate, in order to plan how the appointment will proceed.

Where patients present with phobias/extreme anxieties or challenging behaviour, consideration to the following areas are a necessity in order to meet their health needs:

- Avoid waiting around as this may exacerbate anxiety levels/challenging behaviour - first appointments should be offered and extra time for appointments should be allocated
- Where available, single rooms should be offered to minimise anxiety levels and avoid risks to other patients’ safety.
- Where the patient is likely to exhibit challenging behaviour, the LD nurse, with the carer, will liaise with the relevant nursing/medical staff to review how they can jointly manage these risky situations.

LD patients are identified on the PAS system by an LD flag. If a patient presents with LD and they are not on the system, this should be added on.

Easy-read letters are now sent to patients who are identified as having LD.
4.2 Urgent or emergency admissions (Appendices B and C)

Emergency admissions will usually be admitted via an outpatient clinic or Accident and Emergency (A&E). It would be helpful for the patient/carer to provide the Patient Passport to the clinic nurse or the nurse in charge in A&E who will be able to assist the individual with his/her needs.

If the carer is aware that a service user may need to access A&E, then they should contact the nurse in charge/consultant and/or identified contact within A&E if it is anticipated that the patient may have some significant problems.

For patients with phobias and or challenging behaviours, as far as possible the criteria below (see under section 10.3 for planned admissions) will need to be negotiated. There will be emergency admissions of patients with a LD that the LD nurse will not be aware of. In these circumstances A&E or the receiving ward should contact the relevant LD community team and discuss how any apparent support needs can best be met.

For patients with known Dysphagia or who have moderate to severe LD, please refer to the Trust Speech and Language Therapist (SaLT) for a Dysphasia evaluation.

Further information on SaLT in relation to LD patients is in the further information section on page 16.

4.3 Elective admissions

Consideration should be given to combine procedures, wherever possible. During anaesthesia there could be opportunities to undertake blood tests or other procedures to avoid any further distress to the patient.

The pre-assessment appointment is to be planned with as much time before admission as possible, to ascertain the patient’s information and required care levels to disseminate to the admitting ward.

Provision should be made for a side room if the carer staying overnight where possible. The LD nurse will liaise between relevant carers and hospital staff to review all aspects of support needed within the hospital environment.

An easy-read letter will be sent from the Trust (admissions department) via PAS to inform the service user of an admission.

These letters can only be sent if there is an alert on the PAS system to highlight that the patient has LD, or if the referral letter from the GP mentions that the patient has LD, and, in addition, if any reasonable adjustments needs to be made.

On admission, the Patient Passport (where available) should be incorporated within the admissions procedure. All relevant information, particularly information relating to specific needs for support, should be made available and accessible to all ward staff.

Liaison between relevant disciplines, e.g. Occupational Therapy (OT), Speech and Language Therapy (SaLT) and Physiotherapy (PT) will be established as needed and, if further support required, will be agreed, e.g. joint working between community and hospital therapy staff. If joint working is agreed, clinical responsibility rests with hospital staff who will determine the appropriate treatment for the person with a LD, with the LD nurse providing a support role.
5. Care of Adults with Learning Disabilities attending Theatre and Recovery

Nursing staff from the pre-admission clinic should contact Theatres/Antaesthetics to advise them of the planned surgery date. Nursing staff from the ward should contact the relevant operating department 24 hours in advance where possible to discuss any specific patient needs. This information should also be conveyed to the Recovery Room staff.

The Learning Disability Community Team is available to offer support and advice to the Theatre and Recovery Room Team (Mon-Fri. 09.00 – 17.00 hrs). Theatre staff will inform the Acute Pain Nurse and request a pre-operative visit.

PREPARATION FOR THEATRE

The following issues should be covered during the pre-operative visit between, patient, nursing staff and main carer:

- The patient's previous experience of anaesthesia and surgery
- Behavioural patterns during recovery of anaesthesia
- The patient's communication needs
- The main carer, parent or guardian may wish to accompany the patient to anaesthetic room and/or be in attendance during recovery
- The ward nurse should remain in the anaesthetic room to provide continuity
- Is the procedure or investigation to take place under local anaesthetic? If yes - Arrange, if possible, for the patient to be accompanied to theatre by someone known to him or her

RECOVERY

- Once the procedure is complete the recovery nursing staff should contact the ward to notify the main carer that the procedure is complete
- If necessary the main carer may be present in the Recovery Room
- Where possible, the patient should be escorted back to the ward by a recovery nurse or ward nurse who is known to them

Recovery Staff to make patient a priority for pre-operative visit

6. Communication

Communication impairments are commonly associated with LD. It is likely that staff will have to adapt their communication to meet the needs of people with LD.

The following ideas may help you to make sure that your communication is appropriate to the needs of people with LD.
Some people with LD are unable to communicate verbally and rely on other methods such as gestures, pointing or facial expressions to communicate their needs. Problems with communication can result in difficult or challenging behaviour which can then present a barrier to accessing appropriate healthcare.

An individual’s capacity to understand and communicate can be affected by a number of factors, including anxiety, pain and distress, unfamiliar people and environments. People with a LD may also be unable to adequately describe their symptoms, degree and site of discomfort and may inform staff that they feel fine even when clearly unwell. This can lead to diagnostic overshadowing.

It is essential that there are clear communication channels identified between the hospital and specialist learning disability services and contact information for the relevant teams and hospital departments should be made readily available. A contact sheet for the community team is attached as the Appendix. The Patient Passport will assist in ensuring that relevant information about a person’s health status and support needs can be made available to hospital staff. The Hillingdon Hospital Communication Book (available on wards/clinical areas) should also be used as appropriate.

7. Patient Passport

The Patient Passport is a document that provides clear and concise information in an easy to understand format regarding the person’s health and support needs. The Patient Passport belongs to the service user and should accompany the person for all hospital appointments and admissions. It is reviewed and updated regularly by the carers to provide a record of the individual’s health management. If the passport is not brought in, please ask the service user/carer to bring it into the hospital. Blank copies are available to download from the LD intranet and internet pages. (intranet for LD intranet page.)

8. Consent and best interest decision-making

8.1 The Mental Capacity Act

The Mental Capacity Act (MCA) 2005 which fully came into effect in October 2007, provides a statutory framework to empower and protect people who may lack the capacity to make some decisions for themselves, e.g. people with LD, dementia, mental health problems, stroke or head injury. The MCA applies to all people who work in health and social care involved in the treatment,
care or support of people over the age of 16 who are unable to make all or some decisions for themselves.

The MCA is accompanied by a statutory Code of Practice which provides guidance on how the MCA works on a day to day basis. Anyone working in a professional or paid role with people who lack capacity, has a legal duty to have regard to the Code of Practice. It can be found at: [www.dca.gov.uk/legal-policy/mental-capacity/index.htm](http://www.dca.gov.uk/legal-policy/mental-capacity/index.htm)


**The MCA is underpinned by five key principles:**

<table>
<thead>
<tr>
<th>Principle</th>
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<tr>
<td>8.2 Capacity to consent to medical treatment</td>
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<td>The MCA describes the following two stage test to determine capacity:</td>
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<td>• Is there an impairment of, or disturbance in the functioning of the person's mind or brain? If so,</td>
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<tr>
<td>• Is the impairment or disturbance sufficient that the person lacks the capacity to make that particular decision?</td>
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<td>A person is considered able to make a decision if he/she is able to:</td>
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<tr>
<td>• understand the information relevant to the decision</td>
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<td>• retain that information</td>
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<td>• use or weigh that information as part of the process of making the decision, or</td>
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<td>• communicate his/her decision (whether by talking, using sign language or any other means)</td>
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Consent can only be said to be valid if it is voluntary, the person knows what they are consenting to and has a real option of saying yes or no.

Please refer to the document “Making Decisions – Helping people who have difficulty deciding for themselves”. It is a guide for healthcare professionals that contains more information on assessment of capacity. It can be found at: [www.dca.gov.uk/legal-policy/mental-capacity/index.htm](http://www.dca.gov.uk/legal-policy/mental-capacity/index.htm)

Healthcare professionals must assume that the person has capacity to make decisions. The emphasis is on staff establishing the reasons why they consider that the person lacks the capacity to make each particular decision at the time it has to be made. This must be based on reasonable belief.
Healthcare professionals must make every effort to help and support the person to maximise their potential to make their own decisions or, at least, to participate as fully as possible. Staff must consider how much information to convey to the person and how to make the most of the abilities that the person has. This may include choosing the best time and location for the assessment, allowing the person sufficient time to become familiar with the issues and communicating in simple language or through the use of pictures and photos.

### 8.3 Particular needs of people with a LD in relation to decision making

People with a LD may have particular difficulties in relation to decision making for some of the following reasons:

- Difficulty understanding relevant information requires the use of receptive language skills and cognitive ability. For example, if a person has difficulty processing information, understanding complex sentences or instructions, attention then comprehending relevant information could be compromised.
- Difficulty retaining relevant information.
- Difficulty appreciating the personal significance of information.
- Difficulty with reasoning and use of information to arrive at a decision (e.g. concreteness, difficulties with abstracting and generalising).
- Lack of experience of decision making.
- Tendency to acquiescence and suggestibility, and difficulties being assertive.
- Emotional factors such as fear, anxiety.
- Difficulties in expressing choices.

Some of these difficulties relate to the person’s LD in that their cognitive function is limited in some areas. Others reflect the person’s social and psychological experience (e.g. relative powerlessness) and represent “secondary handicaps”. Support should be provided to maximise the person’s ability to participate as fully as possible in decisions about their own life.

### 8.4 Medical treatment

Doctors proposing treatment for a patient have a personal responsibility to judge whether that person has capacity to give consent, and a duty to explain the treatment, benefits, risks and any alternatives. The doctor has ultimate responsibility for ensuring that an explanation has been provided to the patient and that their consent has been obtained, involving other members of the clinical team as appropriate. Healthcare professionals can and should provide treatment without consent for people who lack the capacity to consent, if it is considered to be clinically necessary and in the **best interests** of the patient.

The benefits should be weighed against the burden of undergoing that treatment. Healthcare professionals have no authority to make any other sorts of decisions such as personal or welfare decisions.

A mental capacity assessment must be carried out (not to be confused with the Mini mental score) (see Appx.)
8.5 Determining best interest

Determining someone’s best interests means trying to find out what is best for the individual, what is most important to him/her, and what he/she would have wanted, NOT what would make life easier for the people involved in their care.

8.6 Consent to treatment

No one – spouses, partners, relatives, carers or advocates – can legally give or withhold consent to medical treatment on behalf of another adult and should never be asked to sign a consent form on behalf of another person.

The only situation where a person can give consent on the behalf of another adult is if they have been granted Power of Attorney by the person prior to the incident. Relatives and carers should be consulted about the patient’s best interests though only where this is commensurate with the duty of confidentiality and the patient’s wishes.

Be aware that family members may have a different view and perspective of the patient’s wishes and views to that of paid carers, therefore it is important to consult all those closely involved with that person and consider all views. The person, though, has a right to confidentiality and may not wish certain people to be involved in the decision making process.

8.7 Resolution of disputes

If there is significant disagreement regarding the treatment of a patient who may lack capacity, the courts have identified certain circumstances when healthcare professionals or others must make an application to the High Court.

These are:

- Where there is serious uncertainty about the patient’s capacity to consent, or their best interests
- Where there is serious unresolved disagreement between a patient’s family and health professionals

If consensus cannot be reached, or if someone wishes to challenge a determination about best interests made by a decision maker, there are a number of options that could be explored, including:

- involving an advocate who is independent of all the parties involved in the decision to act on behalf of the person lacking capacity (Independent Mental Capacity Advocate)
- Getting a second opinion (for medical treatment)
- Holding a formal or informal case conference
- Attempting mediation – though reaching consensus will not necessarily determine best interests of the person lacking capacity

If there is disagreement between the LD Nurse, carers, family and the Trust about the proposed treatment or non-treatment of a person with a LD, an independent advocate (IMCA) should be instructed.
9. Complaints

If the service user/carers have any query or concern during an episode of care at the Trust, in the first instance they should speak to the nurse in charge to rectify the issue. If they are not satisfied with the response given, they should then be encouraged to speak to the Matron, or Clinical Site Practitioner, (CSP) or Head of Department.

Service users and/or carers should be supported to use the Trust’s complaints procedure if there are concerns that cannot be addressed by ward or hospital staff. The Patient Advice and Liaison Service (PALS) can assist with addressing concerns and issues on behalf of service users and carers.

The PALS service provides a central point of contact where patients, relatives and carers can obtain a wide range of information about the hospital services as well as guidance on accessing other health information. Patients, relatives and carers are also able to involve this service if there should be any issues or concerns that arise that cannot be resolved by discussion with hospital staff. PALS will support service users and carers to access and use the hospital complaints procedure or provide information on independent advocacy services if needed. PALS can be contacted on 01895 279973 or pals@thh.nhs.uk

10. Preparation for visits / admissions / discharge

Many people with a LD are very anxious about medical treatment and hospital environments, and this anxiety can sometimes be expressed in behaviour that can be challenging for staff to manage. Before any planned hospital appointment or admission, the carers will make sure that the person is offered the individual support required to facilitate the visit. If necessary, this will involve ward procedure familiarisation/desensitisation. However, on occasion the use of sedation may be required to manage anxiety but only under the guidance of a medical practitioner, in compliance with the Trust restraint policy.

The carers of the person with LD should ensure that all relevant information, including the Patient Passport, details of medication or any specialist advice or guidelines, is made available to Trust staff.

11. Discharge planning (Appendix D)

On admission a patient and/or their carer will be advised of a provisional date for discharge. This date will be reviewed on a daily basis and may involve a number of staff from the Trust team. The nurse in charge will liaise with the individual and/or their carer about safe discharge to home from hospital.

The relevant discharge co-ordinator should be informed of any admission of a person with a LD and dialogue established with the community team duty social worker. Any factors which may prevent discharge back to the person’s home should be flagged to the discharge co-ordinator as soon as possible.

Prior to discharge, a multidisciplinary meeting of all key parties (including family members as appropriate) involved in the care of the person should be convened to plan the discharge, especially where there has been a significant change in the patient’s health needs. The LD nurse may have to co-ordinate training for carers as required to manage the changing health need and/or review the need for temporary respite care or a permanent alternative placement. The LD nurse/carer may also need to provide details of specialised equipment that is used regularly such as; wheelchair, feeding equipment, splints etc.
12. The role of ward staff

The wards at the Trust are managed by a sister or charge nurse. Teams of nurses will provide 24 hour individualised care to meet the requirements of people with a LD. In addition to nursing staff, a person with a LD will meet doctors on a regular basis and they may ask for physiotherapists, occupational therapists, dieticians and speech therapists to assist in individual care. This is the same for patients without a LD.

Following admission to hospital, a Patient Passport will be passed to the patient’s ward and the nurse in charge/ward sister will liaise with him/her and or his/her carer to discuss individual health requirements.

The Matron (during daytime hours) and the CSP (during out of hours) will be the point of contact for any patient with LD either admitted or using outpatient/day surgery facilities. This senior person will have received the appropriate training to take responsibility for co-ordinating and managing the care pathway for this group of patients and will communicate directly with the LD nurse as necessary.

A risk assessment form of patients with LD is currently being developed (September 2011) and will be added to the guidelines once ratified.

13. Sharing information

All patients have a right to privacy and to control information about themselves. Where the person lacks capacity, this right must be balanced with protection of their interests. Although carers will be involved in best interests, decisions should not be widespread disclosure of personal health information without the person’s valid consent and information should be shared on a need to know basis.

Information pertinent to any change in the person’s support needs should be shared with the carers, but detailed clinical information should be treated sensitively and disclosed only when necessary and to those who need to know it.

It must not be assumed that the person’s next of kin is the primary carer. Many people with LD live in registered care homes or supported environments and the care provider is responsible for the health and well being of the person. Care staff would expect to be involved in best interests discussions where the person with a LD lacks capacity. Many people with a LD have limited or intermittent contact with family members, therefore care should be taken to ensure that information is disclosed appropriately and with the relevant people.

Any issues relating to the patient’s capacity (including a Mental Capacity Assessment where indicated) must be clearly and concisely documented in the patient’s medical notes. Any information written must be dated and signed clearly with the designation of the healthcare professional.

Wherever possible, patients should be consulted about who they wish to be included in discussions about clinical matters. Clinical information will be shared as appropriate by professional colleagues, therapist to therapist, etc, to ensure continuity of care.
14. Roles and responsibilities of the Trust’s Learning Disability Nurse

To directly support Trust patients with LD and their carers by ensuring that their needs are met through:

- Coordinating discharge planning meetings as appropriate for people with LD whose needs may require input after discharge from hospital,
- Facilitate additional meetings or case conferences as appropriate to address particular changes in patient care needs,
- Partnership working with all relevant stakeholders when a patient with LD is admitted to hospital,
- Promote and encourage appropriate implementation of the Mental Capacity Act on the treatment of patients with LD in the hospital,
- Promote and encourage the use of Patient Passports in the Trust,
- Promote the involvement of families and carers in the treatment and care of patients with LD in the Trust,
- To support and advise hospital staff with appropriate information to promote evidence based practice and effective service provision that ensures implementation of reasonable adjustments and person centred care.
- To contribute towards the development of care pathways in the Trust for patients with LD.
- To follow-up post discharge patients as appropriate to ensure continuity of care in the community and assess if additional support is required to prevent unnecessary hospital readmission.
- To support the carers (paid or unpaid) when they support patients with LD during hospital admission or when accessing hospital services.
- To contribute to the development of easy-read information for patients with LD, this includes information on treatment options and health promotion
- To provide and facilitate ongoing learning disability awareness training for hospital staff and involve people with LD.
- To monitor and audit the admission rates of patients with a LD at the Trust. This information will be fed back at regular intervals at the Trust’s Disability Action Group (DAG).

15. Conclusion

These guidelines set the context for our Trust and community services to work together in meeting the health needs of this group of vulnerable people, many of whom have been failed by services in the past. It will enable more co-ordinated and individually tailored care to be provided, enabling people with a LD to have their health needs met as fully as possible. Joint working arrangements,
joint training and closer liaison will foster greater knowledge and understanding of the respective roles of Trust and community services.

16. References and bibliography

- DoH (2003) ‘Valuing Health for All’
- Disability Discrimination Act (2005)
- Hollins S., Avis A., Cheverton S (1998) ‘Going into Hospital’ Gaskell / St George’s Medical School
- Hollins S., Bernal J., Gregory M (1998) Going to Out-patients, Gaskell / St George’s Medical School
- Mental Capacity Act (2005)
17. Further information

Valuing People is the government's plan for making the lives of people with LD, their families and carers better. It was written in 2001, and it was the first White Paper for people with LD for 30 years. It is based on people having:

- their rights as citizens
- inclusion in local communities
- choice in daily life
- real chances to be independent

http://valuingpeople.gov.uk/dynamic/valuingpeople145.jsp

Easy Health produces accessible information to help someone prepare for health appointments and medical procedures:

www.easyhealth.org.uk

The Royal College of Psychiatrists: ‘Books Beyond Words’. (Picture books that have been developed to aid communication and discussion around topics such as health needs). For further information:

www.rcpsych.ac.uk/publications/booksbeyondwords/aboutbbw.aspx

British Institute of LD:

www.bild.org.uk

Down’s Syndrome Association:

www.downs-syndrome.org.uk

Foundation for People with LD:

www.learningdisabilities.org.uk

Health Information Resources (search for ‘learning disabilities’):

www.library.nhs.uk

Mencap:

www.mencap.org.uk

People with Profound and Multiple LD:

www.pmldnetwork.org

The National Autistic Society:

www.nas.org.uk
The Disabilities and Mental Health Services  
(Formerly the Hillingdon community team for People with LD):

Tel: 01895 556633  
Fax: 01895 250215  

Includes:

- Community Learning Disability Nurses  
- Speech and Language Therapist  
- Psychologist  
- Care Managers  
- Duty Care Managers  
- Positive behaviour support team (can be contacted through Duty Care Managers)

Riverside Centre, Learning Disabilities Psychiatry Service:

Tel: 01895 279774  

Other community support services:

- OWL Outreach: Tel: 07974 175 883  
- SCOPE Outreach: Tel: 01895 438358
Speech and Language Therapy (SaLT) Guidelines for Adult Patients with LD

Introduction and background

Difficulty swallowing (dysphagia) is a serious problem for many adults with learning disabilities. Hickman (1997) quoted the incidence of dysphagia in people with learning disabilities as high as 40%. (1)

Respiratory-related mortality is known to be disproportionally high in this patient population. Hollins (1998) found that 52% of adults with a learning disability die from respiratory diseases compared to 16% of the general population. (2)

The National Patient Safety Agency (NPSA) reported that between April 2004 – April 2007 they received 605 reports of choking-related incidents involving adults with learning disabilities. 58% of these took place in IN-PATIENT setting. This is likely due to the fact that these patients decompensate when they come into a busy, unfamiliar hospital setting with perhaps an infection or specific ill-health issues and are less able to adequately convey their needs or answer questions reliably.

Dysphagia can lead to malnutrition, dehydration, diminished quality of life, aspiration and choking. (3)

There is evidence that through early intervention and successful management of dysphagia the risks of the above factors associated with dysphagia can be significantly reduced. (4)

Protocol

When an adult with learning disabilities is admitted to hospital, the local THH best practice should be as follows:-

1. As the patient should be known to the Community Learning Disabilities Team, you should ask the patient, or look at their Patient Passport or ask their relative/carer for up-to-date information on their Eating and Drinking status. This would include any modified diet they may have been prescribed by the Community SALT and any likes or dislikes they have with regard to their food and drink preferences.
2. You should continue with the current Eating and Drinking recommendations from community whilst the patient is in hospital.
3. If the patient reports or is observed to be having difficulties when eating and drinking, for example, coughing/choking/signs of possible aspiration – PLEASE REFER TO SALT.
4. Please do not routinely refer all learning disability patients to SALT.
5. Learning Disability patients should not normally be referred to SALT for their long-term communication problems. Only if there has been a new neurological event.
6. If a referral to Acute SALT has been made during an admission, the patient’s SALT care will formally be transferred back to Community SALT on discharge.
References:

Flow Chart for Care of Patient with LD attending Outpatients at the Trust

Appendix A

The appointment letter will advise patient or main carer to contact Outpatients Appointment Centre (OAC) to arrange first appointment and to discuss details of the appointment e.g. double appointment time slot. If there are any arrangements which need to be met in OPD e.g. Hoist the appointment booking agent will add a note into free text on PAS.

HCA preparing notes for appointment will check for LD alert and check free text box on PAS. If necessary they will inform the Sister/ Charge Nurse in charge of any special requirements that have been requested. She/ he will then consider methods or equipment required in order to minimise any patient anxiety that may be induced by lengthy wait in an unfamiliar environment. Consider:
- Preparation of the room including removing unnecessary equipment from the room that may be alarming.
- Communication needs e.g. the need for pictures and models.
- Consent (Refer to Consent Policy and Mental Capacity Act)

LD present on PAS
- HCA preparing the clinic will stamp the top of the COS with red LD alert sign.

COS given to Reception at start of clinic session.

Clinic Nurse refers to the clinic attendance list for any free text notes and will ensure that any requested arrangements are in place prior to the patient’s arrival.

When the patient arrives the Receptionist will:
- Check that the patient demographics are correct
- Place the COS with LD alert in the clinic collection box
- If clinic delayed the Receptionist will verbally notify the Nurse of the patient’s arrival.
- If LD alert not on PAS the Receptionist will stamp COS with LD alert and also notify PAS team via e-mail of the need to add LD alert.

Clinic Nurse will:
- Introduce herself
- Explain clinic process whilst making an assessment of patients needs,
- Call upon a RN if necessary
- Implement any identified arrangements e.g. Fast track.

Once consultation complete she will:
- Make necessary arrangements to ensure positive outcome for follow up appointment, investigation or inpatient admission.
- Consider a referral to Community Learning Disability Team for support and assistance with preparation of the patient.
- Liaise with staff in the department responsible for the investigation.
- Ensure patient and carer understand the outcome of the consultation.
Flow Chart for Care of Patient with LD attending A&E at Hillingdon Hospital

Appendix B

PLANNED ATTENDANCE

RELATIVE/ CARER TO call the hospital in advance & ask for BLEEP 5836 – (shift leader) via switchboard

Shift Leader (Bleep 836) to advise the carer to bring Patient Passport and any Support Plans

Shift Leader informs MATRON 5591 and A/E reception. When patient arrives - triaged to GP or A/E, if GP to be seen next.

If triaged to A/E - A&E Matron/ Charge Nurse to identify a named nurse to the patient and arrange appropriate cubicle in relevant area

PATIENT ASSESSMENT
Involve patient and/or carer where possible. Complete Patient Passport if not already done so & ask for support plans used in the community etc.

The Named Nurse to ensure that the patient is ‘FAST TRACKED’ – through all areas of the department, communicating proactively

FOR ADMISSION
Named Nurse to INFORM MATRON SPECIALITY OR CSP BLEEP 5838 (out of hours)

FOR DISCHARGE HOME
Named Nurse to handover patient to the receiving ward, to include Patient Passport, any support plans, carer involvement and any other relevant information

Named Nurse to LIAISE WITH CARER, if they came on their own (COPY OF CAS CARD TO TAKE HOME)

Carer to FOLLOW-UP as REQUIRED

Learning Disability Information file is situated in the Sisters Office. LD INFORMATION ON INTRANET. Link Nurse in the A&E Department: Wendy Stevens Claire Picton Tracy Lyall

Named Nurse to liaise with Community Learning Disability Nurses if necessary (Mon – Fri, 9 – 5pm) 01895 556633
Appendix C
UNPLANNED ATTENDANCE

PATIENT ARRIVES AT A&E RECEPTION, TRIAGED TO GP OR A&E. IF TRIAGED TO GP TO BE SEEN NEXT.

Pull careplan if alert on PAS/MDV

If triaged to A&E - reception to Bleep 5836 (shift leader) to notify about hospital attendance

Shift Leader (Bleep 5836) GREET AND ESCORT PATIENT TO ALLOCATED AREA. Introduce Named Nurse in that area

PATIENT ASSESSMENT
Involve patient and/or carer where possible. Complete Patient Passport if possible, ask for support plans.

Named Nurse to ‘FAST TRACK’ – through all areas of the department, communicating proactively

FOR DISCHARGE
HOME

LIAISE WITH CARER-
IF ALONE COPY OF CAS CARD TO TAKE HOME

Carer to FOLLOW-UP as REQUIRED

Liaise with Community Learning Disability Nurses if necessary (Mon – Fri, 9 – 5pm) 01895 556633

FOR ADMISSION
To follow similar pathway for PLANNED ADMISSION
Discharge planning

Appendix D

The plan for elective admission should be for same day discharge if this is possible. TTAs should be written up in advance ideally at pre-admission clerking / outpatient clinic so that there is no delay on the day of discharge.

If the person’s needs have changed, good practice deems that wherever possible patients with LD have discharge planning meetings to establish after care, support and environmental needs are in place. People attending may include: the multidisciplinary team, family, carers, community-based professionals, social workers or community nurses as appropriate.

The Discharge Co-ordinator, with if necessary, the LD Service will assess professionals required at meetings on an individual basis, as to whether they need to attend. Section 2 & 5 will need to be completed if care needs changing and the person needs increased or differing care to that received prior to admission. Once again if the person lacks capacity an appropriate relative must be involved or a referral to The Independent Mental Capacity Advocate Service (IMCA) actioned.