

CARING FOR PEOPLE WITH A LEARNING DISABILITY IN GENERAL HOSPITAL SETTINGS

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FOREWORD

Caring For People with a Learning Disability in General Hospital Settings

These guidelines have been published by the Guidelines & Audit Implementation Network (GAIN), which is a team of health care professionals established under the auspices of the Department of Health, Social Services & Public Safety in 2008. The aim of GAIN is to promote quality in the Health Service in Northern Ireland, through audit and guidelines, while ensuring the highest possible standard of clinical practice is maintained.



This guideline was produced by a sub-group of health care professionals from varied backgrounds and was chaired by Maurice Devine, Senior Nursing Officer at the Department of Health, Social Services & Public Safety (Northern Ireland).

GAIN wishes to thank all those who contributed in any way to the development of these guidelines.

A handwritten signature in black ink that reads "Tom Trinick". The signature is written in a cursive style.

Dr T Trinick
Chairman of GAIN



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CARING FOR PEOPLE WITH LEARNING DISABILITIES IN GENERAL HOSPITAL SETTINGS

Introduction

Going into hospital for any reason is a time of anxiety and stress for any of us. People can find that they are in an unfamiliar environment, with unfamiliar people using unfamiliar language. Alongside this unfamiliarity the person may be suffering significant illness and/or pain and consequently, it is a time when people often feel vulnerable.

On such occasions, children, young people and adults with a learning disability may feel even more vulnerable for a range of reasons, including difficulties they may have in respect of communication, difficulties in expressing feelings of discomfort or pain, difficulties with self-management. In addition a limited understanding of the needs of people with learning disabilities by the hospital staff caring for them increases their vulnerability. Other factors that adds to this vulnerability is that the person may have additional health needs such as epilepsy, mental health issues, sensory impairment, compromised nutrition and be at increased risk of choking, all of which are more common in people with learning disabilities.

Current health and social care policy within Northern Ireland is underpinned by the recognition of people with learning disabilities as equal and valued citizens of the country (DHSSPS 2005). Despite this, a range of key publications discussed within the literature review of this document, have highlighted the difficulties many people can encounter in accessing and using general hospital services, at times, with grave consequences for people with learning disabilities.

It is therefore intended that these guidelines for care delivery, will enhance safe and effective care throughout the journey within the general hospital setting for people with a learning disability.



LITERATURE REVIEW

The next few pages provides a definition of the term 'learning disabilities' and provides an overview of the published literature on the difficulties people with learning disabilities may encounter when accessing general hospital services, alongside the published recommendations to improve the quality of services. The guidelines contained within this document have been developed in response to the evidence within the published literature.

What is Learning Disability?

The formal definition of people with a learning disability used within Equal Lives (DHSSPS 2005), is as follows.

Learning disability includes the presence of a significantly reduced ability to understand new or complex information or 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.

As a consequence, the individual is likely to experience difficulty in understanding new or complex information or learning new skills. The individual may also have difficulties with social and/or communication skills, with carrying out activities of daily living independently, and may have associated physical and sensory disabilities.

Within N. Ireland, there is a population of approximately 26,500 people with a learning disability of whom about half of them are aged between 0 – 10 yrs. For a range of reasons people with learning disabilities are twice as likely to experience admission to general hospitals than the general population. These include higher rates of and vulnerability to, specific health conditions, increasing longevity and the inevitable diseases of "old age", and the increasing complexity of health needs. It has also been projected that the numbers of people with learning disability will increase by 1% each year over the next 15 years and that the number of children and older adults with complex physical health needs will both be large areas of growth (DHSSPS 2005). Against this backdrop, it is clear

that people with learning disabilities will continue to increasingly require services within general hospitals.

People with Learning Disabilities and Contact with General Hospitals

It is the stated objective of Equal Lives (DHSSPS 2005) to 'secure improvements in the mental and physical health of people with a learning disability through developing access to high quality health services, that are as locally based as possible and responsive to the particular needs of people with a learning disability' (Objective 7). This objective is underpinned by 14 recommendations for service developments. Furthermore, legislation over the past decade including the Human Rights Act (1998) and the Disability Discrimination Act (1995), have highlighted the legal requirement of health services ensuring equality, dignity and autonomy. These laws require that reasonable adjustments are made in all their services to ensure they do not 'unlawfully discriminate' against people with learning disabilities which include the provision of accessible information.

Contact with general hospitals for people with a learning disability is a frequent occurrence, with people with learning disabilities being twice as likely to use general hospital settings, compared to the rest of the population (NPSA 2004). Services required can range from emergency care provision, outpatient appointments and day procedures through, to the need for surgical intervention and repeated lengthy admissions due to complex health needs.

Contact by people with learning disabilities with the general hospital service is most often for investigation to assist the diagnosis of learning disabilities, to monitor development and investigate the degree of development delay, in areas such as vision, hearing and mobility. People with learning disabilities also make use of hospital services for medical and surgical interventions, and may also need swift access to emergency services either as a result of the exacerbation of a chronic condition such as epilepsy, respiratory disease or a gastrointestinal disorder, or as the result of an accident (Barr 2004).



Challenges in Accessing and Using General Hospital Services

Despite the above policy objectives access to primary and secondary healthcare services for people with learning disabilities has been a growing concern over the past decade. This has been reflected in a number of reports and inquiries. These reports include The National Patient Safety Agency (NPSA 2004) report "Understanding the patient safety issues for people with learning disabilities" which highlighted the care of people with learning disability in general hospital was a major safety concern.

Following on from *Death by Indifference* (Mencap 2007), a campaign document by Mencap, which chronicled the deaths of six people with learning disabilities in general hospital settings, *The Michael Inquiry* (DH 2008) highlighted the difficulties people with learning disabilities can often have in accessing a range of general health services. This inquiry made a number of recommendations for improvement. The Parliamentary and Health Ombudsman's 'Six Lives' Report (TSO 2009) instigated by *Death by Indifference* found evidence of major failings in the care of the six people with learning disabilities and concluded that on one occasion and possibly a second, that the deaths of the people with learning disabilities were avoidable.

Within Northern Ireland a number of research projects into access to general health care such as *Promoting Access* (Barr 2004) and *Patient People* (SHSCC 2008) together with research specifically into access to Accident and Emergency services (Sowney & Barr 2007) have also identified major challenges in access to general healthcare for people with learning disabilities.

The findings of the above research reports and independent inquiries have in particular highlighted the need to improve the access to and safety within general hospitals. A number of persistent difficulties encountered by people with learning disabilities, their families and staff within general hospital services have been documented. These include:

People with learning disabilities

- Experience difficulty in understanding what was happening.
- Are provided with limited information.
- Do not feel involved in the discussions and decisions which have taken place.
- Have a lack of accessible information for people with learning disabilities.
- Experience confusion and fear arising from limited explanation and uncertainty about what is happening.
- Experience insufficient attention being given to making reasonable adjustments – e.g. addressing communication problems, difficulty in understanding, and anxieties and preferences.

Families and carers of people with learning disabilities

- Often find their opinions and assessments ignored by healthcare professionals. They struggle to be accepted as effective partners in care.
- Experience long waiting times often in inappropriate environments, with limited information prior to and during contact with the hospital.
- Perceive poor quality of care in relation to hygiene, nutrition and maintainance of the safety of the person with learning disabilities.
- Identify that there is limited opportunities for meaningful activities and an environment in which the person with learning disabilities often becomes bored and restless.
- Experience limited forward notice of discharge; poor co-ordination of discharge and little or no support after discharge have been reported.
- Perceive the need to stay in hospital during the period of contact, with little effort made to facilitate their stay in the hospital or make it comfortable.
- Experience negative attitudes and stereotypes about people with learning disabilities This can result in diagnostic overshadowing where doctors and others make mistaken assumptions about people with learning disabilities resulting in failure to diagnose or misinterpretation of symptoms.

Staff in general hospitals

- Have limited relevant information available about the person with learning disabilities on admission.
- Have limited knowledge, skills, experience and confidence in supporting people



with learning disabilities and are not familiar with what help they should provide or from whom to get expert advice.

- Experience difficulties in achieving informed consent and the required level of co-operation.
- Receive limited training in the needs of people with learning disabilities.
- Perceive partnership working and communication (between different agencies providing care, between services for different age groups, and across NHS primary, secondary and tertiary boundaries) as being poor in relation to services for people with learning disabilities.

(Barr 2004, Sowney & Barr 2006; Sowney & Barr 2007; DH 2008, SHSSC 2008, Backer et al 2009, TSO 2009)

Consequences of Ineffective Hospital Services For People with Learning Disabilities

The consequences of ineffective general hospital services for people with learning disabilities can be major for them as individuals, for their families and for service providers. The impact of the limitations of services have been described as distressing at the very least for people with learning disabilities and for some people these limitations have been reported as causing or contributing to their avoidable death, leaving family members with many unanswered questions. The findings of the Health Ombudsman's investigation (TSO 2009) into the deaths of six people with learning disabilities identified failures in services such as:

- One death was avoidable and another was likely to have been avoidable.
- Distress and suffering for the aggrieved.
- Unnecessary distress and suffering for the families of the aggrieved, in particular about those failings which occurred for disability related reasons.
- Distress at unanswered questions of what difference would have been made if there had been no service failure or maladministration. Would the person concerned have lived longer? Could there have been some improved enjoyment in the last period of their life?
- Distress compounded by poor complaint handling leaving questions unanswered.
- Distress arising from a failure to live up to human rights principles.



The need for effective health services

As noted earlier, there are clear policy and legislative requirements that require people with learning disability to have 'access to high quality health services that are as locally based as possible and responsive to the particular needs of people with a learning disability' (DHSSPS 2005).

We recognise that a number of excellent initiatives have been developed in some Trusts to enhance the patient journey through general hospitals. However, these have mostly been project based, time limited, with no dedicated and recurring resource to secure longevity. We trust that these guidelines are a helpful and informative step in assisting the process of improvement that is required.



STRUCTURE AND PURPOSE OF THE GUIDELINES

Within the GAIN document, there are 12 specific areas of improvement identified. These have been prioritised as the most pressing areas of need, based on a review of current published literature on this topic. The 12 priority areas for improvement focus on specific areas of the persons journey to and through the general healthcare service (e.g. the journey through emergency care), transition processes (e.g. admission and discharge planning), and a number of clinical issues (e.g. nutrition and hydration). They are as follows:

- Attitudes and values.
- Communication.
- Training.
- Legal Issues.
- Outpatients.
- The admission process and support during the hospital stay.
- Discharge planning
- Emergency care.
- Support for carers.
- Nutrition and Hydration.
- Pain.
- Children in hospital.

Each of these guidelines includes a standard statement and a series of best practice indicators relevant to the particular area of improvement. It is important to recognise that the achievement of the best practice indicators, are not solely the responsibility of staff working within general hospitals. It is apparent from reviewing the literature that improved quality and safety in the journey through general hospital settings will also be influenced by the recognition and implementation of the guidelines within local learning disability services, primary care, paid carers, family carers and managers of services. All have their part to play.



Many of the best practice initiatives that have been highlighted can be delivered through better individual care planning, together with improved communication and effective liaison within and between services. There will be some further resource implications in applying some of the best practice indicators and these may require more strategic planning, however, these are in the minority and much progress can be made within existing resources, through the actions of services and individual staff members, particularly in how they relate to people with learning disabilities and their families.



ATTITUDES & VALUES

Standard 1

Every individual with a learning disability using the hospital services should have equitable access. Staff in an acute hospital setting should demonstrate behaviours that are respectful, which includes:

- Seeing the patient not the disability
- Ensuring that communication is sensitive to the needs and preferences of the patient
- Patient centred care
- Dignified, respectful and compassionate care
- Non-judgemental attitudes

Background

A central requirement in the provision of quality hospital care to people with learning disability is underpinned by a philosophy that requires staff to recognise the human worth of a person with a learning disability and to adopt care practices that respect diversity. This creates new challenges for staff within hospital settings and one of the most important is to change attitudes towards patients with a learning disability.

Many of the issues that have been highlighted as poor practice are not resource dependent, but rather, they reflect attitudes that need to be changed. Improving the Patient and Client experience (DHSSPS 2008) identifies 5 overarching standards that will be central to the achievement of the best practice statements below. These include a focus being given to; respect, attitude, behaviour, communication and privacy/dignity.

Best Practice

1. Equal does not mean the same: Equality for a patient with a learning disability does not necessarily mean treating them in the same way. This may mean providing additional and alternative methods of support established with the patient and/or their families/carer in order to achieve a positive outcome.



2. **Autonomy:** All members of hospital staff should respect the wishes and choices of patients who have a learning disability. Patients must be actively involved in decisions regarding their care, and steps should be taken to maximise their contribution to decision making (e.g. using pictures, information leaflets). This will require hospital staff to have a clear understanding of the law around capacity and consent.
3. **Advocacy:** Advocacy is the process whereby vulnerable people should be facilitated to have a voice and be heard. An advocate can be any “appropriate adult” for example, a family member/carer or friend or a link nurse within the hospital. It is important that the patient has a choice of someone they want and feel comfortable with. Identifying advocacy arrangements for the patient should be a core component of the assessment process in hospital, thereby promoting a person centred approach to care and treatment.
4. **See the person not the disability:** It is vital that health professionals look past the learning disability which can sometimes overshadow the presenting condition and may delay the investigation, diagnosis and treatment of their medical condition.
5. **Communication:** Establish, where possible, the patient’s preferred method of communication. Staff should recognise the need to communicate directly with the patient with a learning disability at all times in the format they understand. Safe and person centred care is underpinned by effective and sensitive communication. “Clear communication means understanding and feeling understood.” (DHSSPS 2008)
6. **Training:** All staff within acute hospital services should receive training that increases their awareness of learning disability. Issues such as legal aspects, human rights, discrimination and the importance of good communication, attitudes and values should be included. In line with Best Practice, training on learning disability issues should also include people with learning disabilities and their family/carer as experts through experience.



7. Don't make assumptions about the person's quality of life:
Hospital staff should ensure that they provide a balanced view of all treatment options available to patients with a learning disability. When major decisions around best interest need to be taken, there should be a clear understanding of the law and due regard must be given to the opinions and wishes of those closest to the patient. Everyday practice should place value on the quality of life of a patient with a learning disability.

8. Contribution of carer's: Families/carers have an important and unique contribution in the planning of the patients care and treatment. The importance of listening to the family/carers, recognizing their particular knowledge of the patient with a learning disability and their ability to communicate with and understand responses is significant. Often they are the only people who have a continuous relationship in the patient's life; this contribution should be acknowledged, valued, listened to and acted upon.

Helpful Resources

http://www.dhsspsni.gov.uk/improving_the_patient_and_client_experience.pdf
DHSSPS Improving the Patient & Client Experience November 2008

<http://www.dhsspsni.gov.uk/consent-guidepart4.pdf>
DHSSPS Seeking Consent: Working with people with learning disabilities 2003

http://www.understandingindividualneeds.com/page.php?identity=health_and_wellbeing

Understanding Individual Needs, a web site that aims to help family, friends and professionals provide the best possible care and support to people with learning disabilities and ensuring they have a chance to lead a valued and fulfilling life.

<http://www.nmc-uk.org/aDisplayDocument.aspx?documentID=5082>
MENCAP (2008) Getting it Right.

COMMUNICATION

Standard 2

People with learning disabilities and their families/carers should experience effective and meaningful communication; to support safe and person centred care.

Background

Safe and person centred care is underpinned by effective and sensitive communication. It is well established that the risk of harm increases if there is difficulty in communicating with the patient. Effective communication is multi-faceted and involves communication with the patient, communication with family/carers and communication between professional staff. Effective communication is supported by a number of key principles which include the understanding that

- All people communicate using various means
- People with learning disabilities communicate in a number of ways, both verbal and non-verbal;
- Behaviour is a means of communicating
- The environment and how the person is feeling plays a pivotal role in enhancing or limiting effective communication;
- It is the responsibility of hospital staff to understand, recognise, and take steps to address the challenges of communication;
- A lack of clear and accessible information creates a barrier to accessing safe, effective and person centred healthcare;
- Effective communication may be facilitated by the involvement of family/carers;
- Good listening skills and non-verbal communication are often the most important channels of communicating with people with learning disabilities.

Best Practice Indicators:

1. An assessment of the patients' preferred method of communication should be undertaken and staff should check if the patient has a document that highlights how they communicate (e.g. a health action plan, or hospital support plan. See helpful resources below)



2. The subsequent care plan should highlight the way(s) in which the patient communicates specific needs/problems such as: hunger, thirst, toileting needs etc, or pain or distress
3. Communication should always take place with the patient in the first instance, but staff should discuss (following consent/best interest decision) with family/ carers their role in facilitating communication with the patient. Listen to and respect the advice/information given by the main carer, as they will have a detailed knowledge of the person with a learning disability
4. Staff should adjust their verbal and non-verbal communication to meet the needs of the patient. Consider the following when communicating with patients who have a learning disability:
 - Address the person by their preferred name
 - Speak simply and slowly, and don't shout.
 - Use very straightforward language and don't use medical jargon.
 - Where appropriate the use of gestures, pictures, signs and symbols can help (see Hospital Communication Book in helpful resources section below)
 - The need for extra time to facilitate understanding. Make sure that the individual understands what you have said before moving on to the next topic.
 - Be aware that the patient may have additional hearing or visual impairments.
 - Pay attention to eye contact, body language, facial expression and contact via touch.
5. Staff should make use of, and where necessary develop relevant resources, to assist in the provision of information. A range of easy read information sheets are available in a variety of formats to help patients understand what is going to happen during their stay in hospital. (See helpful resources section)
6. Staff should have regular training on communication skills, particularly centred on the challenges encountered when a patient has cognitive or other sensory impairments.



7. Trusts should develop a resource pack, to support effective communication during the hospital journey. The Hospital Communication Book developed by The Learning Disability Partnership Board in Surrey, provides an excellent template for the development of such a resource.
8. Expressions of concern expressed by individual patients or by family members or carer's must be acknowledged and addressed immediately, using the proper and usual procedures. Complaints processes must be made accessible to patients who have learning disabilities and/or the family/carers. When concerns are addressed and openly discussed at an early stage, there is often no need for formal complaint processes.
9. Effective communication between professionals is central to the safe and effective delivery of care. This is particularly important at key stages during the hospital journey. For example, communication between nursing staff at handover, communication between consultants when a child is moving into adult services, and communication between hospital and community professionals at discharge.

Helpful Resources

www.easyhealth.org.uk: a web site run by Generate, a charity working with people who have learning disabilities, provides very useful resources in terms of easy read information related to health issues.

www.easyhealth.org.uk/FileAccess.aspx?id=757: The Hospital Communication Book that is free to download and provides a comprehensive range of tools and advice to help people who have difficulties understanding and/or communicating get an equal service in hospital.



LEARNING DISABILITY TRAINING FOR ACUTE HOSPITALS STAFF

Standard 3

Every individual with a learning disability has the right to receive care and services from knowledgeable, competent and skilled practitioners, in a timely, safe and caring environment that takes account of their specific needs. The training to support this care must be available to and accessed by all professional and non-professional staff who potentially deliver services to people with a learning disability, in the general hospital setting

Background

The health needs of people with learning disabilities are complex and their health care needs are often misunderstood by health care professionals. Evidence indicates that there is limited understanding and knowledge of the health problems they experience and the risk of harm to patients with a learning disability whilst in hospital (NPSA 2004)

A range of reports and inquiries have identified that training for staff in general hospital settings has been limited and patchy, this is particularly so for medical staff. This has resulted in uncertainty and ignorance in providing safe, effective and appropriate care to people with learning disabilities when they require these services. Also, many staff still fail to understand their duties relating to the laws regarding disability, human rights and equality.

Respective professional Codes of Conduct and common law emphasise that it is every practitioner's responsibility to be knowledgeable, competent and safe in providing treatment and services for all users of that service.

The knowledge, skills, attitudes and values of staff can improve through specific training on learning disability, and the involvement of people with a learning disability in the development and delivery of such training is recommended within the Michael Report (HMSO 2008)

Best Practice Indicators

1. Academic and professional institutions that provide both undergraduate and post graduate clinical training should incorporate Learning Disability Awareness training within their curricula.
2. Learning Disability Awareness Training should be mandatory for all hospital staff that have direct patient contact in order to enhance their knowledge and skills in order to provide safe and effective care to the patients with learning disabilities. Staff should receive regular updated training as necessary.
3. All new staff within Health and Social Care (HSC) services should receive appropriate training in learning disabilities, to include disability equality training as part of their Corporate Induction Programme
4. The training of staff should be designed and delivered in partnership with people with learning disabilities and/or their carers.
5. The Learning Disability Awareness Training should be competence based and` include the following core elements:
 - An overview of learning disability - definitions and concepts
 - The health issues affecting people with learning disabilities and the barriers experienced when accessing generic health services
 - Service users and carers perspectives of equitable access, including personal experiences and proposals for best practice
 - Effective Communication
 - Legislative requirements such as consent and capacity, Disability Discrimination Act, Human Rights Act
 - Influential inquiries and reports - Death by Indifference (Mencap 2007), Patient People (SHSSC 2008)
 - The provision of reasonable adjustments in the general hospital setting
 - How to access support from local learning disability services



6. Additional Training should be provided to key staff identified from within each clinical area/ This would help facilitate them in the role of a Learning Disability Link Nurse to champion the needs of patients with a learning disability in that specific clinical area.

7. The Learning Disability Link Nurse training objectives should incorporate:
 - A greater awareness of the needs of patients with a learning disability
 - An understanding of the risks of harm posed by being in the hospital environment and knowledge of how these risks can be managed
 - An understanding of the difficulties facing patients with a learning disability and their carers when using hospital services
 - Knowledge and skills in caring for patients who have a learning disability and the promotion of person centred care processes at ward level
 - The development of local action plans to improve practice.

Helpful Resources

www.gain-ni.org the Southern Trust Learning Disability Awareness Training Pack and The Southern Trust link Nurse Programme.



LEGAL ISSUES IN THE DELIVERY OF CARE TO PEOPLE WITH A LEARNING DISABILITY

Standard 4

Staff working in general hospitals will understand and apply the relevant legal and professional framework(s) and principles in the delivery of care to children and adults with a learning disability, ensuring that care is delivered in a safe, effective, personalised and non-discriminatory manner.

Background

From the review of the literature and the various reports/inquiries that have identified failings in care delivery to people with learning disabilities within general hospital settings, three areas of concern have been frequently highlighted:

a) Human Rights: People with a learning disability are not being afforded the same **human rights** as everyone else, in respect of being treated with dignity, equity,, respect and consideration of autonomy. Consequently and as a result, individuals with a learning disability have been subject to and are at risk of prolonged suffering and inappropriate care.

b) Reasonable Adjustments: Under the Disability Discrimination Act (DDA 1995), public health service providers have a duty to make **reasonable adjustments** to ensure that their services are fully accessible to people with a learning disability. Failures on the part of any hospital to make adjustments that take account of a patient's level of cognitive or communication needs may be considered to be a breach of the Act (SHSSC 2008).

c) Consent and Capacity: A number of recent reports have suggested that health professionals working in general hospital settings do not understand the law in relation to **consent and capacity** as it applies to people with a learning disability. Consequently treatment may be delayed or denied (Mencap 2007).



Best Practice Indicators:

1. Staff working in general hospitals should receive specific training on the Disability Discrimination Act (1995), with particular emphasis given to the making of reasonable adjustments (at a practice, policy and organisational level). Human rights and consent training is also vital, with emphasis given on their application to people with learning disabilities. This training needs to be provided for healthcare staff working in both children and adult settings.
2. Reasonable adjustments should be considered not only in terms of physical barriers such as ramps and wheelchair access. Other practice, policy and procedural adjustments may require to be made such as:
 - Providing information in a format that is most likely to aid understanding,
 - The provision of longer appointments (e.g. in outpatients),
 - Effective communication with the individual and/or carers.
 - Appropriate mechanisms in place to identify pain and/or distress.
 - The level and type of discharge planning required.
 - Appropriate complaint handling.
 - The level and extent of involvement of others, such as family members, paid cares, and advocates.
 - Communication and multi-disciplinary working.
 - Identifying the reasonable adjustments that are required within the individual care/treatment plans.
3. For planned admissions, a pre-admission meeting involving the person with a learning disability, and those close to them (family and/or paid carers, and/or advocate) and perhaps the local community learning disability team will help to explore issues of consent, capacity, confidentiality and reasonable adjustments required.
4. Staff within general hospitals should make use of the skills and expertise of those who work in learning disability services and of advocates where there is confusion and/or uncertainty.



5. Individuals with a learning disability should first and foremost be presumed to have capacity to make healthcare related decisions unless proven otherwise. Where there is doubt about capacity, this must be assessed by the professional responsible for the intervention
6. Where an individual is deemed **not to** have capacity, a best interest's meeting should be convened to discuss specific decisions that need to be taken.
7. Every hospital ward/clinical setting should have access to the document "Seeking Consent: Working with People with Learning Disabilities" (DHSSPS 2003)
8. For staff who work with children who have learning disabilities, the ward or clinical environment should have access to the document "Seeking Consent: Working with Children" (DHSSPS 2003).
9. Effective communication is key in the process of consent, and therefore all staff should refer to the specific Communication guideline within this document (Guideline No.2).
10. With the agreement of the person with a learning disability inform and advise carers (both paid and unpaid) fully in any discussions or decisions about care or treatment.
11. Treatment decisions must **NEVER** be based on individual assumptions about the person's quality of life. This is of particular relevance if and when Do Not Resuscitate (DNR) decisions are being considered.
12. Do Not Resuscitate decisions must follow the exact same legal and professional pathways for people with a learning disability as for everyone else.



Helpful Resources:

<http://www.dhsspsni.gov.uk/consent-guidepart4.pdf>

DHSSPS (2003) Seeking Consent: Working with People with Learning Disabilities

<http://www.dhsspsni.gov.uk/consent-guidepart2.pdf>

DHSSPS (2003) Seeking Consent: Working with Children

<http://www.nmc-uk.org/aDisplayDocument.aspx?documentID=5082>

MENCAP (2008) Getting it Right.



PREPARING FOR AN OUTPATIENT APPOINTMENT

Standard 5

All people with learning disability who has an outpatient appointment at a general hospital will have an opportunity to be supported in preparing for this. Account should be taken of their abilities and needs, together with the implications of these to facilitate examination, treatment and care.

Background

The majority of contact patients have with hospitals is known about in advance and often relates to outpatient appointments for initial assessment, investigation or treatment.

It has been regularly noted within published literature that people with learning disabilities experience difficulties during their contact with general hospital services. This is often related to limited preparation that does not take full account of the abilities and needs of the patient and the implications of this for general hospital services.

Best Practice Indicators

1. When arranging an appointment the referrer should provide an indication of any additional support that maybe required.
2. Where a patient is to attend for their first outpatient appointment they or their main carer should be invited to make advanced contact with the clinic nursing staff to discuss details of the organisation and nature of the appointment.
3. A structured approach in an agreed format (e.g. Traffic Light assessment or hospital passport. See helpful resources section) should be used to gather the information necessary to support the appointment; this should include key information about the patient's communication abilities, physical care needs, behaviour when distressed and other factors that may need to be considered in arranging the appointment time and the duration of the appointment.



4. Appointments should be planned to take account of the possibility that extra time may be required for explanation, discussion, providing reassurance and maintaining cooperation. Consideration should be given to offering the first or last clinic appointments.
5. All information about what to expect should be provided to people with learning disabilities and their family/carers in appropriate accessible formats, providing contact details for key staff that may be able to provide or organise support if required. Staff working in learning disability services will have a key role to play in the provision of this support.
6. Directions sent to the patient and signage within the hospital site should provide clear accessible information that will allow the patient to easily find the correct department.
7. There should be flexibility in the waiting arrangements that take account of the abilities and needs of the patient; specific consideration should be given to minimising distractions/noise, providing a quiet waiting area (e.g. a vacant consultation room), providing space to walk around, or leave the waiting area for short periods and be called back for their appointment.
8. The process of the appointment should be explained to the patient in plain language, outlining the sequence of events.
9. Throughout the appointment staff should monitor the patient's level of comfort, anxiety, distress and understanding of what is happening.
10. At the end of the appointment staff should provide a clear explanation of the next steps in the process of care.

Helpful Resources

<http://www.nnldn.org.uk/a2a/>: Access to Acute: a network for staff working with people with learning disabilities to support access to acute medical treatment

www.easyhealth.org.uk: a web site run by Generate, a charity working with people who have learning disabilities, provides very useful resources in terms of easy read information related to health issues.

www.gain-ni.org The Traffic Light Assessment tool that has been developed by the Southern Trust provides important information about people with a learning disability to hospital staff

www.healthpassport.co.uk/: This website provides a free downloadable version of a health passport used in Buckinghamshire. It was made by and for people with learning disabilities, and will help them access health appointments or when they need to go into hospital.

www.easyhealth.org.uk/FileAccess.aspx?id=2058 "Your next patient has a learning disability" can be accessed at An excellent resource leaflet for healthcare professionals who are unfamiliar with the needs of people with a learning disability.

<http://www.hft.org.uk/Resources/Home%20Farm%20Trust/Family%20Carer%20Support/Documents/WorkingTogether.pdf> Home Farm Trust (2008) Working together: easy steps to improving how people with a learning disability are supported when in hospital.



THE ADMISSION PROCESS & SUPPORT DURING A HOSPITAL STAY

Standard 6

When a person with a learning disability needs to be admitted to hospital, steps should be taken to prepare them, the hospital staff and the ward to ensure that they receive safe and effective care during their hospital stay.

Background

The changing patterns of morbidity among people with learning disabilities largely reflect the changes in the general population. Many people with learning disabilities also have additional health needs that may require an inpatient admission to hospital. The period of admission can range from a few hours (for day surgery) to several weeks. Often such admissions are known about in advance and this provides an opportunity for the preparation of people with learning disabilities and staff in the hospital to facilitate a safe journey.

Albeit that there are opportunities for planning admissions, there are some reported persistent limitations in the care of patients with learning disabilities, which have resulted in unnecessary distress/suffering, discomfort, and inequity which may have grave consequences for them.

Best Practice Indicators

The best practice indicators below build on the guidelines for communication (guideline no. 2) for outpatient care (guideline no. 5), and for emergency care (guideline no. 8)

1. People with learning disability should have the opportunity for a pre admission meeting/ward visit prior to any planned admission. In this meeting, staff should make use of all available information, including any personalised health documents (Health passports, or Traffic Light assessments. See helpful resources section below) and the information available from family and members of the local learning disability services (day care/community learning disability team).

2. In these planned circumstances local learning disability staff in conjunction with family carers should ensure that the relevant hospital staff are informed of key needs that the patient may have and hospital staff should ensure that the clinical area is as prepared as possible for the person's admission. This preparatory phase should consider the possibility of the need for specific equipment to meet the patient's needs.
3. There should be a coordinated approach in the handover of information to ward staff on admission and throughout the hospital stay. This may be provided by staff within the local community learning disability team which should highlight the patient's abilities and needs and details of any additional support that may be required, or any risks that may need to be managed. This information should direct subsequent care planning.
4. Each hospital ward should gather resources that can help when a person with a learning disability is admitted, and ensure that this is accessible to all staff. For example, information regarding the contact points of local learning disability services, easy read information about the ward, the hospital and certain procedures such as blood tests and x-rays.
5. An up to date list of key contacts for staff in learning disability services should be available in all departments within general hospitals in order to facilitate prompt contact with these staff or services if required.
6. Some hospitals have identified a member of staff to take on a lead, link or champion role in this area. in wards that are frequently used by people with a learning disability
7. The individual patient should have a clearly identified named nurse who is responsible for nursing care during the duration of the hospital stay.



8. Hospital staff should introduce themselves to the patient and their carers. Patients should be shown the ward layout, including toilet facilities, nurses' station and other important features of the ward. They should also be shown how to summon help if required.
9. The admission process and any planned investigation, treatment and care should be explained in plain language, outlining the sequence of events. This should include the opportunity to ask questions. A range of resources to help hospital staff provide understandable information can be accessed from the easy health website (see helpful resources section below).
10. All care should be provided in a manner consistent with the current Standards for Improving the Patient & Client Experience, ensuring the provision of respectful and dignified care (DHSSPS 2008).
11. Care should be taken to fully investigate the patient's presenting signs and symptoms and care should be taken to avoid the risk of "diagnostic overshadowing" which means not attributing the current condition to the presence of learning disabilities.
12. Medical and nursing care should be delivered on the basis of standard evidence, good practice and guidelines and in response to identified clinical need.
13. Hospital staff should continually explain procedures, changes in circumstances, medication etc. and ensure that the patient and carer's understand what they have been told and have the opportunity to ask questions.
14. When the patient is required to undergo surgery particular activities should include. a pre-operative visit by theatre/recovery nursing staff to the patient and their family at an agreed time. The theatre staff undertaking the pre-operative visit will discuss the following issues with the ward nursing staff, patient and main carer. If the patient is admitted on the day of the operation, the following information would need to be collected in another way.



- The patient's previous experiences of anaesthesia and surgery
- Any known behavioural patterns which may become evident when the patient recovers from the anaesthetic
- The patient's communication needs
- Whether the main carer wishes to accompany the patient to the anaesthetic room and/or to be present in the recovery room shortly after the patient recovers from the anaesthetic
- Whether a ward nurse/carer needs to stay with the patient in the anaesthetic room until the patient is asleep to provide continuity of care and support.

15. Hospital staff should consider the need for increased clinical observation of changes in the health condition a patient with learning disabilities, given that some people may have less ability to articulate changes in how they are feeling. In such circumstances it is the responsibility of the ward staff to provide or commission additional resources to fulfil this need should it arise.

Helpful Resources

<http://www.nnldn.org.uk/a2a/> : Access to Acute: a network for staff working with people with learning disabilities to support access to acute medical treatment

www.easyhealth.org.uk: a web site run by Generate, a charity working with people who have learning disabilities, provides very useful resources in terms of easy read information related to health issues.

www.gain-ni.org The Traffic Light Assessment tool that has been developed by the Southern Trust provides important information about people with a learning disability to hospital staff

www.healthpassport.co.uk/ : This website provides a free downloadable version of a health passport used in Buckinghamshire. It was made by and for people with learning disabilities, and will help them access health appointments or when they need to go into hospital.



www.easyhealth.org.uk/FileAccess.aspx?id=2058 "Your next patient has a learning disability" can be accessed at an excellent resource leaflet for healthcare professionals who are unfamiliar with the needs of people with a learning disability.

<http://www.hft.org.uk/Resources/Home%20Farm%20Trust/Family%20Carer%20Support/Documents/WorkingTogether.pdf> Home Farm Trust (2008) Working together: easy steps to improving how people with a learning disability are supported when in hospital.

http://www.rcn.org.uk/data/assets/pdf_file/0004/78691/003024.pdf RCN (2006) Meeting the health needs of people with learning disabilities. Guidance for nursing staff. London, Royal College of Nursing.

Barr O, Gates B (2009) Oxford Handbook of Learning and Intellectual Disability Nursing. London, Oxford University Press.



DISCHARGE PLANNING

Standard 7

Individuals with a learning disability and where appropriate his/her family/carer, will have a through and coordinated approach to discharge planning that meets their specific needs. Discharge planning will begin on the day of admission and will be evidenced within the patient's plan of care.

Background

People with learning disabilities access and avail of in-patient hospital services more often than the general population, yet, they are discharged from hospital more quickly. Evidence highlights that the discharge processes experienced by patients with a learning disability and their family often falls short of what would be regarded as good practice (Mencap 2007).

Issues, such as untimely discharge (too early or delayed), inappropriate management of the process and discharge to unsafe environments are associated with a greater risk of harm to the individual (Mencap, 2007, Michael, 2008, Parliamentary and Health Service Ombudsman 2009).

Good discharge planning is known to reduce the length of hospital stay, reduce the likelihood of unplanned readmissions, and achieve good patient outcomes and experiences (Shepperd et al 2004. See helpful resources below).

Best Practice Indicators

1. For scheduled admissions, the discharge process should be a partnership approach involving ward staff, the patient, his/her family/carer (where appropriate) and the Community Learning Disability Team (CLDT) and should commence prior to admission.
2. In the case of unscheduled admissions, discharge planning should also be a partnership approach, beginning in the assessment period, then communicated and documented in the plan of care.



3. Where clinically appropriate patients should be placed on the recognised care pathway related to their condition and a potential date of discharge should be communicated to the patient and family.
4. Staff also need to be aware of the potential distress that a patient with a learning disability (and particularly those with autism) may experience if an expectation of being discharged on a specific date does not become reality.
5. Staff should provide the patient with a clear explanation of the discharge process and respect the right of the patient to be actively involved in all decisions regarding their care.
6. As soon as is practically possible, a discharge planning meeting should be organised by the hospital social worker, involving the patient and should include the family, paid carer's, relevant hospital and community/primary care staff to identify:
 - The potential date and time of discharge in order to plan the recommencing of normal daily activities, or recommended new care package..
 - Any potential difficulties the patient may experience on the day of discharge, such as waiting for lengthy periods in a discharge lounge.
 - Where the patient is being discharged to and the suitability of this environment
 - Any other community/primary care staff who need to be informed of the patients discharge
 - The support that the patient and the family/carers may require to help the patient remain within their own home environment (wherever home is).
7. Prior to discharge, hospital staff should ensure that the patient, and where appropriate, the family/carers have been provided with clear, understandable information on the diagnosis, treatment given, and any follow up treatment, appointments or specialist assessments that may be required. Of particular importance is information around medicines, and the need to follow particular instructions such as bed rest, no lifting or any other requirements.



8. The above information must be communicated in a format that is understood. The easy health website (see helpful resources section) provides a wide range of information and booklets regarding health information and procedures that could be utilised.
9. Hospital staff should provide the patient with a contact number should they require further advice or information regarding their care following discharge.
10. Hospital staff should invite the patient, family, and/or paid carer's to provide evaluation or feedback of their experiences during their stay in hospital.

Helpful Resources

<http://www.hft.org.uk/Resources/Home%20Farm%20Trust/Family%20Carer%20Support/Documents/WorkingTogether.pdf> Home Farm Trust (2008) Working together: easy steps to improving how people with a learning disability are supported when in hospital.

Cochrane Database Systematic Review. Shepperd S, Parkes J, McClaren J, Phillips C.(2004) Discharge planning from hospital to home, 2004;(1):CD000313



ATTENDANCE AT EMERGENCY CARE SERVICES

Standard 8

Every patient with a learning disability using the emergency care service should receive timely, safe and effective care that takes account of their specific health needs.

Background

People with learning disabilities have greater health care needs than the general population, which increases their contact with the emergency care service.

Unlike planned admissions, these attendances often happen unexpectedly and the pace of work in this unfamiliar environment can increase anxiety and distress, adding to the patients' vulnerability. This fast moving environment creates the potential for limited information sharing and inadequate communication is known to increase the risk of harm to the patient.

Best Practice Indicators

1. Staff within Community Learning Disability Teams should take a more proactive role in raising awareness and training of staff within the emergency care service around the needs of people with a learning disability.
2. Staff within emergency care departments should develop a specific care pathway/ protocol for identifying and caring for patients with a learning disability
3. It is important for staff to assess the patient's needs and gain an understanding whether the patient can wait in the public waiting area, without undue distress. Fast tracking arrangements for all children and adults with a learning disability should be considered. Where fast tracking cannot be applied, emergency care staff should consider using quieter waiting areas.
4. Staff within emergency care departments should check with the patient or family/ carer if they have documentation that identifies their individual method of communication and other relevant information that will be useful to support their assessment, investigation and provision of safe care (e.g. a patient passport or traffic light assessment. See helpful resources section below).

5. During triage, staff need to allow extra time to assess the patients needs, to effectively communicate the proposed plan of care and to seek consent for examination, treatment and care. Where appropriate, support from the family/ carers may be required to facilitate effective communication to help inform decision making.
6. Where possible the same nurse should remain with the patient throughout their journey within the emergency care department.
7. Staff should be aware that all behaviour is a means of communicating and that people with learning disabilities may express feelings of fear, anxiety and/or pain through odd or unusual behaviours.
8. All information on the diagnosis, investigations and care must be provided in a format that is understood to the patient in the first instance. Health professionals can access a range of informative, easy to read leaflets that help explain procedures such as x-rays, blood tests and other procedures which are available from the easy health website (see helpful resources section below).
9. Careful consideration needs to be given to the admission/transfer/discharge planning, whether it is admission to a ward within the hospital, transfer to another hospital or discharge home. It is essential that time is taken to ensure that relevant information is passed on to: other wards/departments/hospitals and healthcare professionals. Specific care needs to be taken to ensure that the individual and/or the carer(s) are familiar with and understand the discharge advice, including any medication, treatments or follow-up arrangements.
10. Staff within emergency care service should familiarise themselves with the contact information of their local Community Learning Disabilities Team (CTLD). A referral can be made to the Community Learning Disabilities Team where the named nurse has any of the following concerns:
 - a) the patient's safety,
 - b) mental health and/or challenging behaviour,
 - c) the patient's ability to comprehend instructions or follow medication regimens



11. If the individual is a frequent user of emergency care departments, planned preparatory work can be carried out by the local Community Learning Disability Team (CLDT) to help emergency care staff understand specific needs, when such circumstances arise.

Helpful Resources:

www.easyhealth.org.uk/FileAccess.aspx?id=757: A Hospital Communication Book that is free to download and provides a comprehensive range of tools and advice to help people who have difficulties understanding and/or communicating get an equal service in hospital.

www.gain-ni.org The Traffic Light Assessment tool that has been developed by the Southern Trust provides important information about people with a learning disability to hospital staff.

www.healthpassport.co.uk/ : This website provides a free downloadable version of a health passport used in Buckinghamshire. It was made by and for people with learning disabilities, and will help them access health appointments or when they need to go into hospital.

<http://www.nmc-uk.org/aDisplayDocument.aspx?documentID=5082>
MENCAP (2008) *Getting it Right*.

<http://www.dhsspsni.gov.uk/consent-guidepart4.pdf>
DHSSPS (2003) *Seeking Consent: Working with People with Learning Disabilities*

<http://www.dhsspsni.gov.uk/consent-guidepart2.pdf>
DHSSPS (2003) *Seeking Consent: Working with Children*



SUPPORT FOR CARERS

Standard 9

When a person with a learning disability is required to use the general hospital setting, carers should be engaged as healthcare partners throughout the pathway of care, alongside, not instead of, healthcare staff.

Background

We know that people with a learning disability are vulnerable when they use hospital services and therefore the involvement of those who are closest to the patient in their care, will provide them with some reassurance during a time of anxiety, distress and upset. Family members and/or paid care staff can make a major contribution to the effectiveness of treatment and support by providing medical and other key information. For example, they are likely to possess skills that allow them to carry out clinical or other nursing activities with the patient that perhaps the nurse or doctor cannot do. They can also identify risk areas.

However, there can be a tendency for health care professionals to discount the involvement of carer's, and not to consult with them. Mencap (2007) highlighted this in their Death by Indifference report, suggesting that lack of involvement of families and carer's can result in poor prognosis, wrong diagnosis, and potentially, avoidable deaths.

Alternatively, it is also too often expected or assumed by health care professionals that family members or paid carers will continue their support and care delivery to people with learning disabilities when they go into hospital.

Family carers, paid support staff and hospital staff should be working together, within the parameters of the patient's expressed wishes, his or her capacity, and within the parameters of the law around consent and confidentiality, to achieve the best outcomes for patients with a learning disability.

If they decide to, the family or paid carer's can also be involved in a range of helpful activities during the hospital stay, such as helping with meals, interpreting what the patient is trying to say and keeping the patient meaningfully occupied.



Best Practice Indicators

1. The crucial role that carer's play is highlighted throughout all of the guidelines within this document, and their involvement in the journey of care must be acknowledged, valued, and listened to by hospital staff within the parameters of the patient's expressed wishes, his or her capacity, and within the parameters of the law around consent and confidentiality. By doing so, will help achieve the best outcomes for patients with a learning disability when they have to use general hospital services
2. It is important that there is no expectation that family members and/or support staff from learning disability services are **required** to remain on the ward throughout the admission of a child or an adult with a learning disability and to provide direct care and support. First and foremost, the provision of direct care and support to the patient is the responsibility of the hospital staff. There will of course be circumstances when this additional support is provided (e.g. when the patient is a child, when the family carer chooses to do so, or in circumstances where the patient may have very specific needs related to their learning disabilities). It is therefore important that hospital staff establish at an early stage the role family / carers are able and willing to play in the provision of care and support during the patient's hospital stay.
3. All staff on the ward must be made aware of any additional support provided by family members or carer's and should facilitate the presence of carer's; including agreed arrangements for visiting, breaks and refreshments. Staff should also remain alert to the fact that carers may also be concerned or worried about the patient.
4. The poor management of complaints has been highlighted in many of the reports and enquiries that have examined the care of people with learning disabilities in hospitals. When concerns are raised or complaints are made, steps should be taken immediately to make individual patients and/or their carer's aware of the process and of their rights. Easy read information should be developed to support this. Effective and speedy investigation, and empathetic and timely responses and apology where necessary, will help resolve concerns locally with a more sensitive and personal approach.

5. Family/cares should collect useful information in the form of a Traffic Light Assessment or Health Passport (see helpful resources), prior to admission. A copy of this can be held in the patients' medical record for future planned or unplanned admissions.
6. Family and paid carer's have a key role to play in the process of effective communication, and in particular in identifying or interpreting indicators of distress.
7. Hospital staff should also ask if independent advocacy is available for the patient who has a learning disability, particularly when there are difficult or contentious decisions. Although it is recognised that family and paid carers advocate strongly on behalf of the individual they provide care for, independent advocates provide the potential to provide both the patient, and their families and carers with additional support.
8. Family carer's and individuals with a learning disability themselves should be involved in the provision of training to health care professionals.
9. Staff should consider whether family carer's would benefit from a carers assessment.

Helpful Resources:

<http://www.hft.org.uk/Resources/Home%20Farm%20Trust/Family%20Carer%20Support/Documents/WorkingTogether.pdf> Home Farm Trust (2008) Working together: easy steps to improving how people with a learning disability are supported when in hospital.

www.carersuk.org Carers UK is the voice of carers, and aim to improve their lives by providing advice, information and support and campaigning for change.

www.mencap.org.uk/page.asp?id=1946 Mencap helps people with a learning disability, and those that care for them to have their voices heard in decisions that affect their lives. They may be able to provide local advisors to provide independent advocacy support in a range of circumstances.



EFFECTIVE NUTRITION & HYDRATION

Standard 10

People with a learning disability will receive high quality nutritional care based on individually assessed needs, which may be additional and more complex than that required by the general population. Quality nutritional care will involve appropriate screening, assessment, planning, monitoring, serving, and where necessary, safe practical help with eating and drinking.

Background

The importance and effects of meeting (or not meeting) the nutritional needs of patients with a learning disability in acute hospital settings has been highlighted in all the reports and inquiries mentioned in the literature review of this document. It is recognised that good nutrition and hydration in hospital is as crucial to well being and recovery as the medicines and other treatments that patients may receive.

The nutritional needs of people with a learning disability varies, depending on the severity of their disabilities and sometimes associated conditions. The challenges to meeting the nutritional needs can be exacerbated by communication difficulties whereby the individual is unable to articulate his/her need for food or fluids, likes/dislikes of food/fluid or feelings of nausea/pain. People with a learning disability may also be unable to exercise real choice as they may not have the means or the opportunity to do so. Due to their learning disability and sometimes additional communication difficulties, their opinion on menu choice is at risk of not being sought.

The incidence of eating, feeding and swallowing problems is higher in people with learning disabilities than in other population groups, with at least half of the adults with learning disabilities suffering from dysphagia. This has been highlighted as a major patient safety issue in the care provision to people with a learning disability (NPSA 2004). Therefore if nutritional needs are not assessed and managed effectively this can have detrimental health consequences, especially when the individual's health is already compromised. The following best practice indicators are reflective of the DHSSPS Get your 10 a day: Standards for Patient Food in Hospital (DHSSPS 2007).

Best Practice Indicators

- Staff within the hospital setting should ascertain if the person being admitted has a traffic light assessment/health action plan (which is likely to include details of the need for nutritional health interventions/support to the person with a learning disability.). There may also be useful information from the Speech and Language therapist within the local community learning disability team.
- Family members and carers (both formal and informal) should be recognised as having expert, unique and specialist knowledge of the person being admitted. Therefore this knowledge should be incorporated into the individual's care plan and used to plan and implement care while the patient is in an acute hospital.
- All children and adults admitted to general hospital should be screened to determine their nutritional status.
- Following screening by nurses, patients who are identified as malnourished or at risk of malnutrition will be referred for and receive a nutritional assessment appropriate to their level of need.
- Patients who require support with eating and drinking should be clearly identified and receive safe assistance as required.
- Staff should strive to promote independence with individuals with a learning disability who require aids whilst feeding, such as plate guards and non slip mats.
- Specific and specialist assessment, support and monitoring will be required for those individuals who suffer from swallowing difficulties, and/or require to be fed via enteral/parenteral routes.
- Patients who have a learning disability should have their food and/or fluid intake monitored and have this activity carried out in a way that is informative, accurate and up-to-date.



- Additional support may be necessary to assist patients with menu choice. Pictorial menu cards for patients with a learning disability who are unable to understand written menus should be available so that the individual can be helped to choose. Use of personal place mats (highlighting likes/dislikes, risks, nutritional and nursing support) will be beneficial in assisting patient choice.
- Meals should be presented in an appealing and appetising manner with minimal disruption at mealtimes.

Helpful Resources:

http://www.bapen.org.uk/pdfs/must/must_full.pdf Malnutrition Universal Screening Tool (MUST)

DHSSPS (2007) Get your 10 a day: The nursing care standards for patient food in hospital. DHSSPS. Belfast.



ASSESSMENT & MANAGEMENT OF PAIN

Standard 11

People with a learning disability will be thoroughly assessed for pain, with attention focused on both verbal and non-verbal indicators of pain and/or distress. Their pain should be fully investigated and treated according to clinical need.

Background

First and foremost it is important to dispel the myth that people with a learning disability have a higher pain threshold than the general population. This is untrue, and there is no evidence base for this suggestion.

Many people with learning disability will be able to describe their pain. However, some people, particularly those with severe and profound disabilities may have difficulty verbalising their pain, and therefore will use other means to communicate their pain. These can include:

- Increased agitation
- Constant or frequent crying
- Withdrawal
- Fidgeting and/or repetitive movements
- Self injurious behaviour
- Tensing or body bracing to achieve a pain easing posture
- Increased sweating, heart rate or breathing
- Changes in eating or sleeping habits
- Changes in frequency and type of seizures
- Inappropriate laughing
- Other behaviours that may challenge staff

What is also important to consider are those indicators that may infer that the individual feels well and is not experiencing pain, distress or discomfort.

These can include:



- The individual feeling and looking relaxed
- The individual shows pleasure
- The individual is alert and responsive
- The individual responds to the company of others
- The individual is eating and sleeping well
- The individual is cooperative to the requests of others

Best Practice Indicators

1. Staff should be aware of possible indicators and expressions of pain that may be different than those usually seen and are specific to the individual receiving care. This includes non verbal expressions of pain and changes in behaviour.
2. For planned admissions, a pre-admission meeting involving the person with a learning disability and those close to them (family and/or paid carers, and/or advocate) and perhaps the local community learning disability team will help to consider and explore the assessment and management of pain and distress.
3. In accurately assessing pain, the combined use of careful history taking, close observation of the individual, accurate interpretation of the communicative behaviour and clinical judgement are vital
4. Staff should consider using the pictorial formats available in The Hospital Communication Book to help them identify the presence; location and severity of the pain being experienced (See helpful resources below).
5. Hospital staff should utilise the skills and expertise of specialist pain nurses if they are available. This will be particularly important in circumstances such as treatment for cancer related disorders or palliative care.
6. Staff should directly communicate with the patient and use straightforward questions about the presence of pain. They should be aware that the patient may need more time for responses.



7. Staff must communicate with family / carers well known to the patient, paying particular attention to baseline indicators of comfort and contentment, descriptions of changes in behaviour or previous similar episodes.
8. Investigate indicators of pain and distress fully. Do not assume that the patient is refusing to co-operate. Take time to explain any plans for investigations, familiarise the patient with the environment and consider the assistance of family / familiar carers during investigations.
9. Staff should rule out physical causes (such as pain and/or distress) for behaviour changes before attributing these changes to other reasons that may be associated with the learning disability or mental health issues.
10. Consider the need for regular analgesia rather than 'as necessary'. Be watchful for a response to analgesia, looking for indicators of well being or a reduction in pain indicators.
11. Be aware of possible side effects of medication and observe for these. Some people with learning disabilities may be more susceptible to side effects, and some may find this difficult to articulate. Others may be taking other medication for other conditions and it is vital that possible drug interactions are considered.
12. During the assessment process it is vital that staff consider that the person may be indicating distress as a consequence of other emotional factors rather than simply physical pain.
13. Pain assessment tools, using self report or observational methods and proxy reports, have been designed for young children (Wong 1998), and for adults with a learning disability (e.g. Disability Distress Assessment Tool (DISDAT) and staff should give consideration as to their benefit and utilisation in each individual circumstance. (See helpful resources below).



Helpful Resources

www.easyhealth.org.uk/FileAccess.aspx?id=757 A Hospital Communication Book that is free to download and specifically designed to help people who have difficulties understanding and/or communicating get an equal service in hospital.

www.disdat.co.uk/ A distress assessment tool designed by St. Oswald's hospice designed to help health professionals assess and identify distress indicators in people who have limited communication.

http://www.painknowledge.org/physiciantools/opioid_toolkit/components/Wong-Baker_Scale.pdf The Wong-Baker FACES rating scale has been developed for children over 3 years and is particularly helpful for patients who may be cognitively impaired. It offers a visual description for those who do not have the communication skills to explain their symptoms and how they feel.



IMPROVING THE EXPERIENCE OF CHILDREN WITH A LEARNING DISABILITY

Standard 12

Children and young people with a learning disability who use acute general hospitals will receive coordinated, safe, effective and child/family centred services that are age appropriate and based on assessed needs.

Background

All of the other guidelines within this document will apply to children as well as adults, but there is a need to highlight a number of important best practice indicators that have particular relevance for children. Although it is recognized within policy and legislation that disabled children should always be regarded as children first, children with any type of significant disability may require a range of additional support beyond the type and amount required by children in general. Children with a learning disability use acute general hospitals on a similar basis as other children (e.g. accidents, tonsillectomy, heart defects etc), but will often be frequent users as a consequence of complex physical healthcare needs. In these circumstances, all staff involved should refer to the DHSSPS (2008) Guidance on Developing Services to Children and Young People with Complex Physical Healthcare Needs.

The findings of the “Care at its Best” report (DHSSPS, 2005) should also be noted. This is the report of a Northern Ireland wide multidisciplinary inspection of the service for disabled children in hospital. The findings of the inspection informed the development of the document “Standards for the Care of Disabled Children in Hospital (DHSSPS, 2010) which contains detailed standards covering key aspects of hospital care for disabled children regardless of the child’s disability or the hospital setting. The “Improving the Experience of Children with a Learning Disability” standard which is presented here should therefore be read in conjunction with the more detailed guidance found in the “Standards for the Care of Disabled Children in Hospital (DHSSPS, 2010).

Best Practice Indicators

1. If at all possible a pre-admission assessment should be completed, which will involve the child, parent’s/carer’s and relevant hospital and community staff.



Important information should be collated at this stage (e.g. using the Traffic light assessment format – see helpful resources), as this will help hospital staff to understand and effectively meet the child's needs.

2. There should be fast tracking procedures in place for learning disabled children who use hospital frequently, or who have difficulty coping with prolonged waiting periods, particularly in departments such as Emergency Care.
3. Every child or young person who has a learning disability must have an agreed discharge/transition plan that starts on admission and involves hospital personnel, community services (specialist and universal services), the child and the family.
4. There should be an identified community key worker who will be the point of contact with the hospital staff during the period of admission. This is most likely to be a community children's nurse or a community learning disability nurse. This individual should provide an appropriate level of community in-reach to the hospital.
5. Parents/carer's should be acknowledged as having expert, unique and specialist knowledge of their child's needs. The child and their parents/carer's should be involved in all assessment, care planning and discharge processes. They should be encouraged to ask questions and should receive relevant information in a format they can understand.
6. Families should be supported to maintain contact with their child in hospital. There should also be an appropriate level of support and provision for family members who need to, or wish to be with their child during the night.
7. Children and young people who spend extended periods in hospital should have access to a range of special provisions such as free access to television, therapeutic leisure activities, and/or music and art therapy.
8. Where extended periods in hospital occur, the child should be enabled to engage in appropriate play and social activity programmes during their stay, and where appropriate, there should be adequate education provision, delivered by relevant hospital and/or educational staff.



9. Where certain procedures need to be carried out in the home environment, competency based training to family, or other essential carers, should be initiated and overseen in hospital prior to discharge.
10. Particular attention needs to be given at particular transition points such as the transition from acute hospital to community services, and transitions between child to adult services within acute hospitals. Key standards for these circumstances are available in the DHSSPS (2008) Integrated care pathway for children and young people with complex physical healthcare needs.
11. All staff working within acute paediatric wards should have access to relevant training on learning disability, with specific emphasis given to communication skills, co-morbidity such as epilepsy and autism, and key patient safety issues such as medicines management, child protection and identifying deterioration
12. The contact numbers of local Community Learning Disability Teams should be provided to all paediatric wards within general hospitals.

Helpful Resources

www.gain-ni.org The Traffic Light Assessment tool that has been developed by the Southern Trust provides important information about people with a learning disability to hospital staff.

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Membership of the GAIN Sub-Group looking at Improving access to general hospital care for people with Learning Disabilities

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