



Guidelines on Caring for People with a Learning Disability in General Hospital Settings

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FOREWORD

In accepting that progress has been made in some services, the equity of access to, the implementation of reasonable adjustments within, and the equity of outcome from general healthcare services for people with a learning disability still requires further development. In 2010, the Guidelines & Audit Implementation Network (GAIN) published its original set of Guidelines on Caring for People with a Learning Disability in General Hospital Settings.

The number of people with a learning disability has increased since 2010 and services continue to become more community based. It is projected that the number of people with a learning disability will continue to grow over the next 10 years, in particular among young adults and older people. This will result in a growing number of people with a learning disability, with a range of abilities and complex health needs, coming into contact with departments within general hospitals, including Outpatients, Day Surgery, Emergency Departments and Inpatient wards.

In 2014, an RQIA review provided an assessment of current practice, identifying both examples of good practice and challenges to the implementation of the guidelines since their introduction in June 2010. The review team noted that, while all five Health and Social Care Trusts reviewed are taking account of and implementing certain aspects of the guidelines, there was inconsistency across services and there is more that needs to be done. Consequently, 19 recommendations were made and where appropriate, the actions relating to these recommendations have been incorporated into the 2018 Guidelines on Caring for People with a Learning Disability in General Hospital Settings.

These revisions of the original GAIN (now RQIA) guidelines and the development of these guidelines were jointly undertaken by Professor Owen Barr, Ulster University; Maurice Devine, Clinical Education Centre; Nicola Porter, RQIA with contributions from a range of health and social care professionals; people with a learning disability; and family members and carers (See Appendix 1).

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Introduction

Being in contact with a general hospital can be 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 many 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 being understood and making their needs and wishes known, difficulties in expressing feelings of discomfort or pain, and difficulties with self-management. In addition, a limited understanding of the abilities and needs of people with a learning disability by the hospital staff caring for them increases their vulnerability. Other factors that add to this vulnerability are that the person may have additional health needs such as epilepsy, mental health issues, sensory impairment, and compromised nutrition, and may be at increased risk of choking, all of which are more common in people with a learning disability.

Current health and social care policy within Northern Ireland is underpinned by the recognition of people with a learning disability 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 has highlighted the difficulties many people can encounter in accessing and using general hospital services with, at times, grave consequences for people with a learning disability.

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

Literature Review

The next few pages provide a definition of the term 'learning disability' and an overview of the published literature on the difficulties people with a learning disability 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” (p.18).

The individual may also have difficulties with social and/or communication skills, and with carrying out activities of daily living independently, and may have associated physical and sensory disabilities.

Accurate estimation of prevalence rates of learning disability is difficult and cannot be definitive (Murphy 2014).

However, it is estimated that 2% of the population will have a learning disability (BILD 2011). The most recent prevalence rates from Mencap state that there are approximately 30,814 adults with a learning disability in Northern Ireland. (Mencap 2018). Based on estimated prevalence needs of children with learning disabilities, when compared with the adult prevalence rates (FPLD 2018), this would mean that there are approximately a further 7,400 children with a learning disability in Northern Ireland. All of this means that there is a potential total population of 38,214 people with a learning disability in Northern Ireland.

For a range of reasons, people with a learning disability are twice as likely to experience contact with general hospitals as 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. The number of people with a learning disability is continuing to increase through a combination of increased survival of premature babies, increased numbers of children with complex disabilities living into adulthood, and the overall increased longevity of adults with a learning disability as a result of increasing access to health promotion, as well as primary and secondary care (DHSSPS 2005). With the wider developments in inclusive community based services and the reduction in general healthcare services within learning disability hospitals, it is clear that people with a learning disability will increasingly have contact with and will require services within general hospitals. Services required can range from outpatient appointments and day procedures through to the need for emergency care provision, medical or surgical intervention and repeated lengthy admissions due to complex health needs.

People with a Learning Disability 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 development. The Service Framework for Learning Disability (DHSSPS 2015) requires that ‘All people with a learning disability should have equal access to the full range of health services including services designed to promote positive health and wellbeing.’ (Standard 19, p13) and ‘hospitals should have an action plan for implementing the GAIN Guidelines for improving access to acute care for people with a learning disability and be able to demonstrate a clear commitment to the implementation of such a plan.’ (p13)

Furthermore, legislation over the past decade including the Human Rights Act (1998) and the Disability Discrimination Act (1995), has 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 a learning disability and that they include the provision of accessible information.

Contact by people with a learning disability with the general hospital service is broadly similar to the general population. Very often, attendance is for investigation to assist the diagnosis of learning disabilities, to monitor development and to investigate the degree of development delay in areas such as vision, hearing and mobility. People with a learning disability 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 (Hatton et al. 2016, 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 a learning disability has been a growing concern over the past 20 years. 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 that the care of people with a 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 a learning disability 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 (Parliamentary and Health Services Ombudsman 2009) instigated as a result of “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, the deaths of the people with a learning disability 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 a learning disability.

In 2013, a major enquiry into the premature deaths of people with a learning disability reported that there were ongoing challenges in the care of people with a learning disability related to delays in diagnosis and further investigation, and the identification of people with a learning disability in hospitals. They specifically felt that staff failing to make reasonable adjustments, compounded by a lack of coordination within and between hospital services, 'were contributing factors in a number of deaths' (Heslop et al, 2013, p4). This enquiry also reported difficulties with the way 'best interests' decisions were made and the availability of advocates. It also reported that 'Many instances were identified of inappropriate or poorly documented DNACPR' and 'Record-keeping was commonly deficient – particularly in relation to fluid intake, nutrition, weight and seizures, and little attention was given to predicting potential problems e.g. when a person was fearful of contact with medical professionals' (p5).

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 a learning disability, their families and staff within general hospital services, has been documented. This includes:

People with a learning disability:

- experience difficulty in understanding what was happening.
- are provided with limited information, and the rights of the people with a learning disability to be actively involved in decision making are not fully considered.
- do not feel involved in the discussions and decisions which have taken place.
- have a lack of appropriate accessible information.
- 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 a learning disability:

- 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 maintenance of the safety of the person with a learning disability.
- identify that there are limited opportunities for meaningful activities, and the environment results in the person with a learning disability often becoming bored and restless.
- experience limited forward notice of discharge, poor co-ordination of discharge, and little or no support after discharge has 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 a learning disability. This can result in diagnostic overshadowing where doctors and others make mistaken assumptions about people with a learning disability, resulting in failure to diagnose accurately or the misinterpretation of symptoms.
- may be over relied on by professional staff to provide care to the person with a learning disability, and their needs as relatives may not be fully responded to.

Staff in general hospitals:

- at times have limited relevant information available about the person with a learning disability on admission.
- report having limited confidence and experience in supporting people with a learning disability, and are not familiar with what help they should provide or from whom to get expert advice to update their knowledge and skills.
- may experience difficulties in achieving informed consent and the required level of cooperation.

- may have undertaken limited continuing professional development on the abilities and needs of people with a learning disability.
- may view 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 a learning disability.

(Barr 2004; Sowney & Barr 2006; Sowney & Barr 2007; DH 2008; SHSSC 2008; Backer et al 2009; Parliamentary and Health Services Ombudsman 2009; Heslop et al 2013)

Consequences of Ineffective Hospital Services for People with a Learning Disability

The consequences of ineffective general hospital services for people with a learning disability can be major for them as individuals, for their families and for service providers. The impact of the limitations of services has been described as distressing at the very least for people with a learning disability, and for some people these limitations have been reported as causing or contributing to their avoidable death, leaving family members with many unanswered questions (Heslop et al 2013). The findings of the Parliamentary and Health Services 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 those involved.
- 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.

These findings have been further reinforced by the findings of the Confidential Inquiry into the Premature Death of People with Learning Disabilities (Heslop et al., 2013) which highlighted that the level of avoidable death is twice as high among people with learning disabilities, and that three times more deaths among people with learning disabilities could

be prevented by 'good quality care' compared to the general population. This Inquiry also concluded that the 'most frequent reasons given for a death to be premature were because of delays or problems with treatment, or because of problems with assessing or investigating the cause of illness' (Heslop et al. 2013, p32). The Annual Report of the Learning Disability Mortality Review Programme (LeDeR, 2017) again reported that people with learning disabilities continue to die younger than people who do not have learning disabilities. This report identified that 'the difference in age at death between people with learning disabilities (aged four years and over) whose deaths were notified to LeDeR, and the general population of England and Wales (all ages, 2010 data) is 22.8 years for males and 29.3 years for females.' (LeDeR 2017, p18).

The Need for Effective Health Services

As noted earlier, there are clear policy and legislative requirements that require people with a 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) and that 'All people with a learning disability should have equal access to the full range of health services including services designed to promote positive health and wellbeing.' (DHSSPS 2015, p13).

We recognise that a number of excellent initiatives have been developed in some Trusts to enhance the person's contact with general hospitals, and many developments have taken place in seeking to implement the 2010 guidelines. However, more work still needs to be done to fully implement the 2010 Guidelines. 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

Based on a review of current published literature on this topic there are 12 areas of improvement identified. These have been prioritised as the most pressing areas of need and focus on specific areas of the person's journey to and through the general hospital 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:

1. Attitudes and Values
2. Communication
3. Training & Education
4. Legal Issues
5. Outpatients
6. Admission Process and Support During the Hospital Stay
7. Discharge Planning
8. Emergency Care
9. Support for Carers
10. Nutrition and Hydration
11. Pain
12. Improving the Experience of Children with a Learning Disability.

Each of these guidelines includes a best practice 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 is 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 in partnership with 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, progress can continue to be made within existing resources, through the actions of services and individual staff members, particularly in how they relate to people with a learning disability and their families.

Attitudes and Values

Best Practice Statement

Every individual with a learning disability using hospital services should have equal access to the full range of services. Staff in a general hospital setting should demonstrate behaviours that are respectful, which include:

- seeing the person as an individual with abilities and needs and not focusing on their disability.
- ensuring that communication is timely and sensitive to the needs and preferences of the person.
- person centred care resulting in safe, dignified, respectful and compassionate care.

Background

A central requirement in the provision of quality hospital care to people with a 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 people 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 five overarching standards that will be central to the achievement of the best practice indicators below. These include a focus being given to; respect, attitude, behaviour, communication and privacy/dignity.

Best Practice Indicators

1. **Equal does not mean the same:** Equality for a person with a learning disability does not necessarily mean treating them in the same way. This will often mean the need for reasonable adjustments that provide additional and alternative methods of support established with the person 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 people who have a learning disability. People must be actively involved in decisions regarding their care and steps should be taken to maximise their contribution to decision making (using appropriate, accessible information such as pictures, information leaflets). This will require hospital staff to have a clear understanding of the legal position around capacity and consent (See Best Practice Statement 4).
3. **Contribution of Carers:** When accessing general hospital services, families/carers have an important and unique contribution to make in discussions of the person's care and treatment, with the agreement of the person with a learning disability. With the permission of the person with a learning disability, 'you should be fully involved as an equal partner at all stages of their treatment including decisions about what needs to happen for a timely and positive discharge. Family members and carers should have a choice about caring for the person when they are in hospital. No assumptions should be made about your willingness to provide care.
4. The importance of listening to the family/carers, recognising their particular knowledge of the person with a learning disability and their ability to communicate with and understand responses can be crucial to effective interventions. Often they are the only people who have a continuous relationship in the person's life and this contribution should be sought, acknowledged, valued, listened to and acted upon.
5. **Advocacy:** Advocacy is the process whereby people who are vulnerable 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 nurse within the hospital. It is important that the person with a learning disability has a choice of someone they want and feel comfortable with. Identifying advocacy arrangements for the person should be a core component of the assessment process in hospital, thereby promoting a person centred approach to care and treatment.
6. **See the person not the disability:** It is vital that health and social care professionals focus on the abilities and needs of the person as an individual and are not distracted by the learning disability, which can sometimes overshadow the presenting condition and may delay the investigation, diagnosis and treatment of their medical condition.

7. **Communication: *Everyone can communicate but some people do not use words.*** Health care professionals should establish, where possible, the person's method of communication and support needs required. Staff should recognise the need to communicate directly with the person 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, p12)

8. **Education:** All staff within general hospital services should receive education that increases their awareness of the abilities and needs of people with a 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, education on learning disability issues should also include people with a learning disability and their family/carer.

9. **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 people with a learning disability. When major decisions around best interests need to be taken, there should be a clear understanding of the legal position and due regard must be given to the opinions and wishes of those closest to the person. Everyday practice should place value on the quality of life of a people with a learning disability.

Helpful Resources

- DHSSPS (2008) Improving the Patient & Client Experience. http://www.nipec.hscni.net/download/projects/previous_work/highstandards_practice/patientexperience/PatientEx-standards.pdf
- DHSSPS (2003) Seeking Consent: Working with people with learning disabilities. Seeking Consent: Working with people with learning disabilities.
- Mencap Easy Read Health Statement <https://www.mencap.org.uk/about-us/what-we-think/health-what-we-think>
- People with learning disabilities – Making reasonable adjustments: The website provides a range of documents with examples of reasonable adjustments, including information relation to cancer screening, constipation, obesity and weight management, health checks, dysphagia, and substance misuse. <https://www.gov.uk/government/publications/reasonable-adjustments-for-people-with-learning-disabilities>

COMMUNICATION

Best Practice Statement

Everyone can communicate but some people do not use words.

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

Background

Safe, effective and person centred care is underpinned by timely, effective and sensitive communication. It is well established that the risk of harm increases if there is difficulty in communicating with the person with a learning disability. Effective communication is multi-faceted and should be focused on direct communication with the person with a learning disability, communication with family/carers (with the agreement of the person with a learning disability when personal information is being shared) and communication between professional staff. Effective communication is supported by a number of key principles which include the understanding that:

- all people can communicate and may use a variety of different means; many people with a learning disability have communication support needs, with half having significant difficulties. There is a wide range of communication difficulties but the barriers to successful communication are often due to the environment and other people.
- many people with profound and multiple learning disabilities are able to communicate but may have extremely limited communication which may be restricted to behaviours such as eye gaze and changes to facial expression.
- all people with a learning disability communicate in a number of ways, both verbal and non-verbal.
- behaviour, including behaviours that challenge is often a means of communicating.
- the environment and how the person is feeling play 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 for communicating with people with a learning disability.

Best Practice Indicators

1. Staff should check if the person has a document that highlights how they communicate (e.g. HSC Hospital Passport). Further information regarding the person's method of communication and their communication support needs should be sought from the person, families/carers, and if necessary the community learning disability team (See helpful resources below).
2. The subsequent care plan should highlight the way(s) in which the person communicates specific wishes/needs/problems, for example: activities to do, hunger, thirst, toileting needs, pain or distress.
3. Communication should always take place with the person with a learning disability in the first instance.
4. Staff should adjust their verbal and non-verbal communication to meet the needs of the person. Consider the following when communicating with people who have a learning disability:
 - a. Address the person by their preferred name.
 - b. Speak slowly and don't shout.
 - c. Use very straightforward language and don't use medical jargon.
 - d. The use of inclusive communication supports e.g. gestures, pictures, photos, symbols, objects, body language, facial expression and Makaton, can help (see Hospital Communication Book helpful resources section below).
 - e. 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.
 - f. Be aware that the person may have additional hearing or visual impairments.
 - g. Pay attention to eye contact, body language, facial expression and contact via touch.

Staff should make use of and, where necessary, develop relevant resources to assist in the provision of information.

1. A range of easy read information sheets is available in a variety of formats to help people with a learning disability understand what is going to happen during their stay in hospital. Staff may seek advice from a Speech and Language Therapist and other staff who may be experienced in developing accessible information (e.g. Registered Nurses for people with learning disabilities) when producing easy read/accessible information (See helpful resources section).
2. Staff should have regular education and skills development on communication skills, particularly centred on the challenges encountered when a person has cognitive or other sensory impairments.
3. Trusts should develop a resource pack to support effective communication during the hospital journey. The Easy Health website (see below) provides a range of helpful resources for this purpose.
4. Staff should discuss (following consent/best interest decision) with family/carers their role in facilitating communication with the person with a learning disability. Staff should listen to and respect the advice/information given by the main carer, as they will have detailed knowledge of how to communicate best with the person with a learning disability.
5. Expressions of concern by people with a learning disability, family members or carers must be acknowledged and addressed immediately, using the proper and usual procedures. Complaints processes must be made accessible to people who have a learning disability and/or the family/carers. When concerns are addressed and openly discussed at an early stage, this is often reduces the need to progress to formal complaint processes.
6. 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 administrative and 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 that provides very useful resources in terms of easy read information related to health issues.
- <http://www.publichealth.hscni.net/publications/hsc-hospital-passport-and-guidance-notes> This is the Regional HSC Hospital Passport for use throughout Northern Ireland. It replaces all previous Hospital Passports for people with a learning disability. The document can be completed electronically and printed or printed and completed by hand. Guidance notes on completing the Hospital Passport are also available here.
- www.rcslt.org/news/docs/good_comm_standards
- www.makaton.org
- A guide to communicating with people with profound and multiple learning disabilities https://www.mencap.org.uk/sites/default/files/2016-06/2012.340%20Raising%20our%20sights_Guide%20to%20communication_FINAL.pdf

Training & Education

Best Practice Statement

Every person 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 education 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 a learning disability are complex and their health care needs are often misunderstood by health care professionals. Evidence indicates that there is limited confidence, experience, understanding and knowledge of the health problems they experience and the risk of harm to people with a learning disability whilst in hospital (Heslop et al 2013, Parliamentary and Health Services Ombudsman 2009).

A range of reports and inquiries has identified that education for staff in general hospital settings has been limited and patchy. This has resulted in uncertainty in providing safe, effective and appropriate care to people with a learning disability 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 regulators 'Codes' of professional behaviour 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 (DH 2008, Heslop et al 2013).

Best Practice Indicators

1. Academic, professional institutions and third sector organisations that provide both pre and post registration clinical education should incorporate Learning Disability Awareness training within their curricula.
2. Learning Disability Awareness education should be mandatory for hospital staff who will or may have direct contact with people using the hospital services in order to enhance their knowledge and skills in providing safe and effective care to people with a learning disability.
3. All new staff within Health and Social Care (HSC) services should receive appropriate education in learning disabilities, to include disability equality training as part of their Corporate Induction Programme.
4. HSC Trusts and other organisations should have access to the regional e-learning programme that has been developed by GAIN to support the implementation and application of this guideline. The link to this e-learning programme is provided in the helpful resources section below.
5. The education of staff should be designed and delivered in partnership with people with a learning disability and/or their carers. Learning Disability Awareness education, should provide participants with increased knowledge and understanding of the abilities and needs of people who have a learning disability, to enhance safe and effective care throughout their contact with general hospital settings. This education should include the following minimum content areas:
 - Define the meaning of learning disability and the range of ways it impacts on an individual.
 - Describe the changing patterns of mortality and morbidity among people with a learning disability.
 - Use of examples from people with a learning disability to provide an overview of the challenges they may encounter when in contact with general hospital settings.
 - Identify and explore how to implement the best practice guidelines as indicated in reviewed Guidelines, “On Caring For People With A Learning Disability In General Hospital Settings” 2018.
 - Discuss approaches to establish effective communication with a person with a learning disability in a general hospital setting.

- Define and explore the requirement to make “reasonable adjustments” to ensure people with a learning disability have equal access to all services in the general health setting.
- Discuss the requirements in relation to the process of obtaining consent from a person with a learning disability.
- Understand how to access support from local learning disability services.

Helpful Resources

- DHSSPS (2003) Seeking Consent: Working with People with Learning Disabilities <https://www.health-ni.gov.uk/publications/consent-guides-healthcare-professionals>
- RCN (2013) Meeting the health needs of people with learning disabilities. Guidance for nursing staff. London, Royal College of Nursing. <https://www.rcn.org.uk/professional-development/publications/pub-003024>
- People with learning disabilities – Making reasonable adjustments: The website provides a range of documents with examples of reasonable adjustments, including information relation to cancer screening, constipation, obesity and weight management, health checks, dysphagia, and substance misuse. <https://www.gov.uk/government/publications/reasonable-adjustments-for-people-with-learning-disabilities>
- The e- learning programme - Caring For People With a Learning Disability In General Hospital Settings: This programme has been developed in Northern Ireland to support and complement these guidelines. This programme has input from people with a learning disability, parents of people with a learning disability and from a range of professional staff. They provide an excellent educational resource and can be accessed by anyone who has an interest in this topic.

The e-learning programme can be accessed **by anyone**. You can apply by visiting the e-learning section of the HSC Clinical Education Centre website <http://cec.hscni.net/Courses/Category/23>

Legal Issues

Best Practice Statement

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 a learning disability within general hospital settings, three areas of concern have been frequently highlighted:

- a) **Human Rights:** People with a learning disability frequently, are not afforded the same human rights as everyone else, in respect of being treated with dignity, equity, respect and consideration of autonomy. As a result, individuals with a learning disability have been subject to, and are at risk of, prolonged suffering and inappropriate care.
- b) **Equality of Opportunity and Reasonable Adjustments:** The literature review has highlighted that there have been significant failures on the part of hospitals to provide equality of opportunity and to make adjustments that take account of a person's level of cognitive or communication needs. Under Disability Discrimination legislation (DDA 1995) and Section 75 of the Northern Ireland Act (1998), public health service providers have a duty to make reasonable adjustments and to ensure that their services are fully accessible to people with a learning disability.
- c) **Consent and Capacity:** A number of recent reports have suggested that health professionals working in general hospital settings do not understand the legal position in relation to consent and capacity as it applies to people with a learning disability. Consequently, treatment may be delayed or denied and affect the effectiveness of outcomes (The Parliamentary and Health Service Ombudsman 2009).

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 requirement to make reasonable adjustments (at a practice, policy and organisational level). Education about human rights and consent is also vital, with emphasis on its application to people with a learning disability. This education needs to be provided for health and social care staff working in both children and adult settings.
2. Reasonable adjustments should be considered in terms of physical barriers such as ramps and wheelchair access, and other practice, policy and procedural adjustments that may require to be made such as:
 - a. providing information in a format that is most likely to aid understanding.
 - b. the provision of longer appointments.
 - c. effective communication with the person and/or carers.
 - d. appropriate mechanisms in place to identify pain and/or distress.
 - e. appropriate complaint handling.
 - f. the level and extent of involvement of others such as family/carers/advocate.
 - g. identifying and implementing the reasonable adjustments that are required within the individual care/treatment plans.

Examples of reasonable adjustments that have made a difference to people with learning disabilities can be accessed at: <https://www.gov.uk/government/publications/reasonable-adjustments-for-people-with-learning-disabilities>

3. For planned admissions, a pre-admission meeting involving the person with a learning disability and those close to them (family/carers/advocates) and perhaps local community learning disability services, will help to explore issues of consent, capacity, confidentiality and reasonable adjustments required.
4. Staff within general hospitals should seek the advice and expertise of those who work in learning disability services and of advocates in situations where there is confusion/uncertainty.

5. People 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 for a particular decision, this must be assessed by the professional responsible for the intervention. Family/carers should be involved in this process.
6. Where a person is deemed not to have capacity to make a specific decision at a specific time, a best interests meeting should be convened to discuss specific decisions that need to be taken. However, in emergency/life threatening situations, health care staff can apply the doctrine of necessity which allows for immediate decision making that is deemed to be in the person's best interest.
7. Every hospital ward/clinical setting should have access to, and staff should have a clear understanding of, 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. 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.
10. Treatment decisions must be based on objective information and should never be based on professional assumptions about the person's quality of life. This is of particular relevance if and when Do Not Resuscitate (DNR) decisions are being considered.
11. Do Not Resuscitate decisions must follow exactly the same legal and professional pathways for people with a learning disability as for everyone else.

Helpful Resources

- DHSSPS (2003) Reference guide to consent for examination, treatment or care
<https://www.health-ni.gov.uk/publications/consent-guides-healthcare-professionals>

DHSSPS (2003) Seeking Consent: Working with People with Learning Disabilities
<https://www.health-ni.gov.uk/publications/consent-guides-healthcare-professionals>

- DHSSPS (2003) Seeking Consent: Working with Children
<https://www.health-ni.gov.uk/publications/consent-guides-healthcare-professionals>

Royal College of Nursing (2017) Principles of consent: Guidance for Nursing staff.
<https://www.rcn.org.uk/professional-development/publications/pub-006047>

- People with learning disabilities – Making reasonable adjustments: The website provides a range of documents with examples of reasonable adjustments, including information relation to cancer screening, constipation, obesity and weight management, health checks, dysphagia, and substance misuse.
<https://www.gov.uk/government/publications/reasonable-adjustments-for-people-with-learning-disabilities>

Outpatients

Best Practice Statement

Many people with a learning disability have frequent contact with general hospital via the Outpatients department. All people with a learning disability who have 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 people with a learning disability have with hospitals is known about in advance and often relates to outpatient appointments for initial assessment, investigation or treatment. However, it has been regularly noted within the literature referred to in the introduction to this document that people with a learning disability 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 person 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 may be required.
2. Managers of Outpatients Departments should take steps to facilitate contact for the person in advance of the appointment to discuss relevant details of the organisation and the nature of the appointment.
3. A structured approach in an agreed format (e.g. HSC Regional Hospital passport) should be used to gather the information necessary to support the appointment. This should include key information about the person'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 appointment of a session or early clinic appointments. If clinic appointments are running behind time, people with a learning disability should be informed and if the delay is causing the person problems, further reasonable adjustments may need to be made to ensure the person is seen on time and any distress limited.
5. All information about what to expect should be provided to people with a learning disability 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 may have a role to play in the provision of this support.
6. Directions sent to the person with a learning disability and signage within the hospital site should provide clear accessible information that will allow the person to find the correct department easily.
7. There should be flexibility in the waiting arrangements that take account of the abilities and needs of the person. 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 the opportunity to 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 person in plain language, outlining the sequence of events.
9. Throughout the appointment staff should monitor the person's level of comfort, understanding of what is happening, anxiety and distress.
10. At the end of the appointment staff should provide a clear explanation of the next steps in the process of care and should consider the need to liaise with local learning disability services.

Helpful Resources

- www.easyhealth.org.uk is a web site run by Generate, a charity working with people who have a learning disability, provides very useful resources in terms of easy read information related to health issues.
- <http://www.publichealth.hscni.net/publications/hsc-hospital-passport-and-guidance-notes> This is the Regional HSC Hospital Passport for use throughout Northern Ireland. It replaces all previous Hospital Passports for people with a learning disability. The document can be completed electronically and printed or printed and completed by hand. Guidance notes on completing the Hospital Passport are also available here.
- <https://www.keele.ac.uk/nursingandmidwifery/mnphald/toolkitcontents/ynphald.pdf> “Your next patient has a learning disability” can be accessed as an excellent resource leaflet for healthcare professionals who are unfamiliar with the needs of people with a learning disability.

Admission Process and Support

Best Practice Statement

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 a learning disability largely reflect the changes in the general population. Many people with a learning disability 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 a learning disability and staff in the hospital to facilitate a safe journey.

Albeit that there are opportunities for planning admissions, there are some reported persistent failings in the care of people with learning disabilities which have resulted in unnecessary distress/suffering, discomfort and avoidable death (The Parliamentary and Health Service Ombudsman 2009, Heslop et al 2013).

Best Practice Indicators

1. People with a 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 (e.g. HSC Hospital Passport, 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 abilities and needs that the person 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 person's needs.

3. There should be a coordinated approach to the handover of information to ward staff on admission and throughout the hospital stay. This may be provided by staff within local learning disability services, and should highlight the person'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/department should gather resources that can help when a person with a learning disability is admitted and ensure that this is accessible to all staff. These resources may be in hard copy or electronic and should include: The HSC Hospital Passport; The Hospital Communication Book; Easy read complaints/comments leaflet; The reviewed guidelines: On Caring For People With A Learning Disability In General Hospital Settings 2018 (previously 2010 GAIN guidelines); and visual menus. In addition, each ward/department should have access to a range of accessible information for the common procedures that may be undertaken within that care environment (many examples are available at <http://www.easyhealth.org.uk>) for example information regarding the contact points of local learning disability services, and 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 Health and Social Care Trust 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. In wards that are frequently used by people with a learning disability, the hospital should identify staff to take on a link or champion role specific to the care of the person with a learning disability.
7. The person with a learning disability should have an identified nurse who is responsible for nursing care for the duration of their hospital stay. Where appropriate, the person with a learning disability may be given a picture of the nurse responsible for their care on each shift.

8. Hospital staff should introduce themselves to the person and their carers. People 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 Easyhealth website <http://www.easyhealth.org.uk> (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 investigate fully the person'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. All 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 provide an ongoing explanation of procedures, changes in circumstances and interventions. This information should be provided in a format that the person with a learning disability understands. Health and social care staff should ensure that the person with a learning disability and carers understand the information that they have been given and have the opportunity to ask questions.
14. When the person is required to undergo planned surgery, opportunities should be provided for a pre-operative visit by theatre/recovery nursing staff to the person with a learning disability 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, person with a learning disability and main carer. If the person is admitted on the

day of the operation, the following information would need to be collected in another way:

- a. The person's previous experiences of anaesthesia and surgery;
- b. How to manage the process of 'nil by mouth'/'fasting';
- c. Any known behavioural patterns which may become evident when the person recovers from the anaesthetic;
- d. The person's communication abilities and needs;
- e. Whether the main carer wishes to accompany the person with a learning disability to the anaesthetic room and/or to be present in the recovery room shortly after the person recovers from the anaesthetic;
- f. Whether a ward nurse/carer needs to stay with the person in the anaesthetic room until they are anaesthetised, to provide continuity of care and support.

15. Hospital staff should consider the need for increased clinical observation to discuss changes in the health condition of a person with a learning disability, 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

- www.easyhealth.org.uk a web site run by Generate, a charity working with people who have a learning disability, provides very useful resources in terms of easy read information related to health issues.
- RCN (2013) Meeting the health needs of people with learning disabilities. Guidance for nursing staff. London, Royal College of Nursing.
<https://www.rcn.org.uk/professional-development/publications/pub-003024>
- <http://www.publichealth.hscni.net/publications/hsc-hospital-passport-and-guidance-notes>
This is the Regional HSC Hospital Passport for use throughout Northern Ireland. It replaces all previous Hospital Passports for people with a learning disability. The document can be completed electronically and printed or printed and completed by hand. Guidance notes on completing the Hospital Passport are also available here.
- People with learning disabilities – Making reasonable adjustments: The website provides a range of documents with examples of reasonable adjustments, including information relation to cancer screening, constipation, obesity and weight management, health checks, dysphagia, and substance misuse.
<https://www.gov.uk/government/publications/reasonable-adjustments-for-people-with-learning-disabilities>

Discharge Planning

Best Practice Statement

People with a learning disability, and where appropriate their family/carers, will have a thorough 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 person's plan of care.

Background

People with a learning disability 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 people with learning disabilities and their family often falls short of what would be regarded as good practice (The Parliamentary and Health Service Ombudsman 2009). 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 (Michael, 2008, Parliamentary and Health Service Ombudsman 2009).

Personalised discharge planning is known to reduce the length of hospital stay, reduce the likelihood of unplanned readmissions and achieve good outcomes and experiences for the person (Gonçalves-Bradley et al 2016).

Best Practice Indicators

1. For planned admissions, the discharge process should be a partnership approach involving ward staff, the person with a learning disability, their family/carer (where appropriate) and the Community Learning Disability Services and should commence prior to admission.
2. In the case of unplanned 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, people should be placed on the recognised care pathway related to their condition and a potential date of discharge should be communicated to them and their family.
4. Staff also need to be aware of the potential distress that a person 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 person with a clear explanation of the discharge process, respecting and supporting the right of the person 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 staff, involving the person and should include the family/carers and the relevant hospital and community/primary care staff to identify:
 - a. the potential date and time of discharge in order to plan the recommencing of normal daily activities, or recommended new care package;
 - b. any potential difficulties the person may experience on the day of discharge, such as waiting for lengthy periods in a discharge lounge;
 - c. the location and suitability of the environment to which the person is being discharged;
 - d. any other community/primary care staff who need to be informed of the person's discharge;
 - e. the support that the person and the family/carers may require to help the person remain within their own home environment (wherever home is);
 - f. where certain procedures need to be carried out in the home environment, with identified need for training related to care delivery at home, this should be initiated and coordinated by the hospital staff prior to discharge.

NB. In some cases (e.g. following a short uncomplicated stay in hospital) it may be appropriate to proceed by telephone arrangement, particularly if convening a formal discharge planning meeting may delay discharge.

7. Prior to discharge, hospital staff should ensure that the person 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, exercise activities or any other requirements.
8. The above information must be communicated in a format that is understood by the person with a learning disability, carers and family members (when appropriate). The Easyhealth website provides a wide range of information and booklets regarding health information and procedures that could be used.
9. Hospital staff should provide the person with a learning disability with a contact number should they require further advice or information regarding their care following discharge.
10. Hospital staff should invite the person with a learning disability, family/carers to provide evaluation or feedback of their experiences during their stay in hospital.

Helpful Resources

- www.easyhealth.org.uk a web site that provides very useful resources in terms of easy read information related to health issues.

Emergency Care

Best Practice Standards

Every person 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 is likely to increase 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 vulnerability of the person with a learning disability. This fast-moving environment creates the potential for limited information sharing and it is acknowledged that inadequate communication increases the risk of harm to the person with a learning disability.

Best Practice Indicators

1. Staff within emergency care departments should check with the person or family/carer if they have brought along a HSC Hospital Passport or system documentation that identifies the individual's method of communication and other relevant information that will be useful to support their assessment, investigation and provision of safe care. The HSC Hospital Passport should be read before any assessment, treatment or care is undertaken. If they have not brought a HSC Hospital Passport along, one should be provided for them to complete. These should be available in hard copy with the department and can be downloaded from <http://www.publichealth.hscni.net/publications/hsc-hospital-passport-and-guidance-notes>.
2. Staff within emergency care departments should develop a specific care pathway/protocol for identifying and caring for people with a learning disability. This should clearly consider the need for reasonable adjustments for the person with learning disabilities in order to ensure they receive timely, safe and person centred care.

3. It is important for staff to assess the person's abilities, needs and safety requirements.
4. During triage, staff need to allow extra time to assess the person's abilities and needs in order to communicate effectively 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.
5. Where possible, the same nurse should care for the person throughout their journey within the emergency department.
6. Staff should be aware that all behaviour is a means of communicating and that people with a learning disability may express feelings of fear, anxiety and/or pain through odd or unusual behaviours. This may be documented in the HSC Hospital Passport.
7. All information on the diagnosis, investigations and care must be provided in a format that is understandable to the person with a learning disability in the first instance. Health and social care 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 Easyhealth website (see helpful resources section below).
8. When people taken to emergency departments as a 'place of safety' during mental health related crises, a person who has suitable training or experience in completing a mental health assessment or mental state examination should be available so that the person's needs can be identified in a timely manner.
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 health and social care professionals. Specific care needs to be taken to ensure that the person with a learning disability and/or their family/carers are familiar with and understand the discharge advice, including any medication, treatments or follow-up arrangements.

10. Staff within emergency departments should familiarise themselves with the contact information of their local Learning Disabilities Services. A referral can be made to the Community Nursing Learning Disabilities Services where the named nurse has any of the following concerns:
- a. the safety of the person with learning disability when in hospital;
 - b. mental health and/or challenging behaviour;
 - c. the person's ability to comprehend instructions or follow medication regimens.
11. If the person is a frequent user of emergency departments, planned preparatory work (including sharing information on any physical and/or mental health conditions, crisis management plans and protective/coping strategies) can be carried out by local Learning Disability Services to help emergency care staff understand specific needs when such circumstances arise.
12. Where people with a learning disability attend emergency departments and specific additional needs such as alcohol misuse, homelessness, or a breakdown in care are identified, a hospital social worker should liaise with community learning disability team members to share information in relation to any identified needs.

Helpful Resources

- [http://www.easyhealth.org.uk/listing/communication-\(leaflets\)](http://www.easyhealth.org.uk/listing/communication-(leaflets)) This site provides a comprehensive range of tools and advice to help people who have difficulties understanding and/or communicating get an equal service in hospital.
- <http://www.publichealth.hscni.net/publications/hsc-hospital-passport-and-guidance-notes> This is the Regional HSC Hospital Passport for use throughout Northern Ireland. It replaces all previous Hospital Passports for people with a learning disability. The document can be completed electronically and printed or printed and completed by hand. Guidance notes on completing the Hospital Passport are also available here.

Support for Carers

Best Practice Statement

When a person with a learning disability needs to use any general hospital setting, carers, both family and paid carers, should, where appropriate, be engaged as healthcare partners throughout the pathway of care.

Background

People with a learning disability may be vulnerable at times when they use hospital services and therefore, the involvement of those who are closest to the person with a learning disability in their care may provide them with some reassurance during a time of anxiety, distress and upset. Family/carers 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 will gain the cooperation of the person receiving clinical or other nursing procedures. They can also identify risk areas in relation to aspects of care. However, there can be a tendency for health care professionals to discount the advice of carers and not to consult with them (Michael Report 2008).

Alternatively, it is also too often expected or assumed by health care professionals that family/carers will continue their support and care delivery to the person with a learning disability when they go into hospital. Family/carers and hospital staff should be working together, within the parameters of the person with a learning disability's expressed wishes, his or her capacity and within the parameters of the legal position around consent and confidentiality, to achieve the best outcomes for the person with a learning disability.

If they decide to, the family/carers with the necessary confidence and skills can also be involved in a range of helpful activities during the hospital stay such as, helping with meals, interpreting what the person is trying to say and keeping the person with a learning disability meaningfully occupied.

Best Practice Indicators

1. The crucial role that family/carers play is highlighted throughout all of the 12 areas 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 expressed wishes of the person with a learning disability, his or her capacity and within the parameters of the legal position around consent and confidentiality. Doing so, will help achieve the best outcomes for the person with a learning disability.
2. Family/carers should be made aware of their rights as carers to have their needs assessed and planned for.
3. It is important that there is no expectation that family/carers 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 person with a learning disability is the responsibility of the general hospital staff. There will of course be circumstances when this additional support is provided (e.g. when the person is a child, when the family/carer chooses to do so, or in circumstances where the person may have very specific needs related to their learning disabilities). It is therefore important that hospital staff establish at an early stage the degree to which the person with a learning disability wishes and the extent of the role family/carers are able and willing to play in the provision of care and support during the person's hospital stay.
4. All staff in the clinical area must be made aware of any agreed additional support provided by family/carers and should facilitate the presence of family/carers including agreed arrangements for visiting, breaks and refreshments. Staff should also remain alert to the fact that family/carers may also be concerned or worried about the person with a learning disability and provide the necessary support to them.
5. The poor management of complaints has been highlighted in many of the reports and inquiries that have examined the care of people with a learning disability in hospitals. When concerns are raised or complaints are made, steps should be

taken immediately to make the person and/or their family/carers aware of the process and of their rights. Easy read information should be developed to support this. Effective and speedy investigation, empathetic and timely responses together with an apology where necessary, will help resolve concerns locally.

6. Family/carers could compile useful information in the form of a HSC Hospital Passport prior to admission. A copy of this should be updated for subsequent contact with hospital.
7. Family/carers may have a key role to play in the process of effective communication and, in particular, in identifying or interpreting indicators of distress. Hospital staff should engage with family/carers to recognise these communication signals.
8. Hospital staff should also ask if independent advocacy is available for the person 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 have the potential to provide both the person and their family/ carers with additional support.
9. Family/carers and individuals with a learning disability themselves, should be involved in the provision of education to health care professionals.
10. Staff should consider whether family/carers would benefit from a carer's assessment.

Helpful Resources

- 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.
- <https://northernireland.mencap.org.uk/> 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.

<http://www.publichealth.hscni.net/publications/hsc-hospital-passport-and-guidance-notes>

This is the Regional HSC Hospital Passport for use throughout Northern Ireland. It replaces all previous Hospital Passports for people with a learning disability. The document can be completed electronically and printed or printed and completed by hand. Guidance notes on completing the Hospital Passport are also available here.

- <https://www.health-ni.gov.uk/publications/carers-guidance> This webpage provides useful information for carer to understand their rights, the information they should be provided with and conversations that they should be involved in prior to a person being discharged from hospital.

Nutrition and Hydration

Best Practice Statement

People with a learning disability will receive high quality nutritional care based on individually assessed abilities and 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 people with a learning disability in general hospital settings have been highlighted in many reports and inquiries mentioned in the literature review of this document. It is recognised that good nutrition and hydration in hospital are as crucial to wellbeing and recovery as the medicines and other treatments that people may receive.

The nutritional needs of people with a learning disability vary depending on the severity of their disabilities and associated conditions. The difficulties in meeting nutritional needs can be exacerbated by challenges in communication in which hospital staff are unable to understand what the person with a learning disability is communicating about their need for food or fluids, likes and dislikes of food and fluid or feelings of nausea and pain. People with a learning disability may also not be given the opportunity or means to exercise real choice. Due to hospital staff perception of a person's learning disability and the limitations of the ability of hospital staff to understand the person, , there is a risk that reasonable adjustments will not be put in place to enable the menu options and the opinion of the person with learning disabilities on food choices to be appropriately sought.

The incidence of eating, drinking and swallowing problems is higher in people with learning disabilities than in other population groups. People with dysphagia are at risk of food or drink 'going down the wrong way' and entering the lungs which can cause chest infections, pneumonia, choking and death. A person with dysphagia may also be at risk of not eating or drinking enough to maintain weight or hydration This can be a major patient safety issue in the care provision to people with a learning disability. Therefore, if nutritional needs are not assessed and managed effectively, this can have detrimental health consequences,

especially when the person's health is already compromised. The following best practice indicators are reflective of the "Get your 10 a day: Standards for Patient Food in Hospital" (DHSSPS 2007).

Best Practice Indicators

1. Staff within the hospital setting should ascertain if the person being admitted has a HSC Hospital Passport (which includes information about communication, eating and drinking). There may also be useful information from the Speech and Language therapist within the local Learning Disability Service.
2. Family/carers (both formal and informal) should be recognised as having important knowledge of the person. This knowledge should be incorporated in the person's care plan and used to implement care while the person is in a general hospital.
3. Children and adults admitted to general hospital should be screened as per standard and routine policy related to MUST nutrition screening, to determine their nutritional status.
4. Following screening, people 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.
5. People who require support with eating and drinking should be clearly identified and receive safe assistance as required.
6. Staff should strive to promote the independence of a person with a learning disability to eat and drink, providing the required reasonable adjustments in discussion with Occupational Therapists, such as accessible menus, plate guards and non-slip mats.
7. Specialist assessment, support and monitoring by a dietician, will be required for those people who have swallowing difficulties and/or require to be fed via enteral/parenteral routes. Specialist assessment and support by a Speech and Language Therapist will be required for people who have swallowing difficulties.
8. People who have a learning disability should have their food and/or fluid intake accurately monitored and reviewed.
9. Additional support may be necessary to assist people with menu choice. Pictorial menu cards for people with a learning disability who are unable to understand written menus should be available so that the person can be helped to choose. Use

of personal place mats (highlighting likes or dislikes, risks, nutritional and nursing support) will be beneficial in assisting choice.

10. 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.
- Choking awareness website – <http://helpstopchoking.hscni.net>
- <http://www.publichealth.hscni.net/publications/hsc-hospital-passport-and-guidance-notes>

This is the Regional HSC Hospital Passport for use throughout Northern Ireland. It replaces all previous Hospital Passports for people with a learning disability. The document can be completed electronically and printed or printed and completed by hand. Guidance notes on completing the Hospital Passport are also available here.

Pain

Best Practice Statement

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 other people. This is untrue and there is no evidence base for this suggestion.

Many people with a 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 manifestations of pain 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 read the person's HSC Hospital Passport which will raise awareness of possible indicators and expressions of pain that may be different than those usually seen and are specific to the individual receiving care. These include nonverbal 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/carers/advocate) and perhaps staff from local learning disability services, 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 is vital.
4. Pain assessment tools, using self-report or observational methods and proxy reports have been designed for adults and children with a learning disability (e.g. Disability Distress Assessment Tool (DISDAT) for adults and the NCCPC – R (Non-communicating Children's Pain Checklist – Revised) for children. Staff should give consideration to their benefit and utilisation in each individual circumstance (See helpful resources below).
5. Staff should consider using pictorial formats to help them identify the presence, location and severity of the pain being experienced (See helpful resources below).
6. 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 physical pain.

7. 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.
8. Staff should directly communicate with the person with a learning disability and use straightforward questions about the presence of pain. They should be aware that the person may need more time to respond.
9. Staff must communicate with family/carers well known to the person, paying particular attention to baseline indicators of comfort and contentment, descriptions of changes in behaviour or previous/similar episodes.
10. Investigate indicators of pain and distress fully. Staff should not assume that the person is refusing to co-operate. Take time to explain any plans for investigations, familiarise the person with the environment and consider the assistance of family/carers during investigations where appropriate.
11. 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.
12. Consider the need for regular analgesia rather than 'as necessary' prescriptions. Be watchful for a response to analgesia, looking for indicators of wellbeing, a reduction in pain indicators and undesired effects of the medication.
13. Be aware of possible undesired effects of medication and observe for these. Some people with a learning disability may be more susceptible to undesired effects and some may find this difficult to articulate. Some people may be taking other medication for other conditions and it is vital that possible drug interactions are considered.

Helpful Resources

- [http://www.easyhealth.org.uk/listing/communication-\(leaflets\)](http://www.easyhealth.org.uk/listing/communication-(leaflets)) This site provides a comprehensive range of tools and advice to help people who have difficulties understanding and/or communicating get an equal service in hospital.
- <http://www.stoswaldsuk.org/how-we-help/we-educate/resources/disdat/disdat-tools.aspx> A distress assessment tool and monitoring sheets designed by St. Oswald's Hospice designed to help health professionals assess and identify distress indicators in people who have limited communication.
- <http://www.wales.nhs.uk/sitesplus/documents/862/FOI-286f-13.pdf> The Abbey Pain Scale is a potential resource for the measurement of pain in people who cannot verbalise.
- <https://www.gov.uk/government/publications/reasonable-adjustments-for-people-with-learning-disabilities> People with learning disabilities – Making reasonable adjustments: The website provides a range of documents with examples of reasonable adjustments, including information relation to cancer screening, constipation, obesity and weight management, health checks, dysphagia, and substance misuse.
- http://www.community-networks.ca/wp-content/uploads/2015/07/PainChkIst_BreauNCCPC-R2004.pdf The NCCPC is an observational tool for assessing pain in children with cognitive impairment who are unable to communicate verbally. It is intended to be usable by any person involved in a child's care, whether they are familiar with the individual child or not.
- <http://www.publichealth.hscni.net/publications/hsc-hospital-passport-and-guidance-notes>
This is the Regional HSC Hospital Passport for use throughout Northern Ireland. It replaces all previous Hospital Passports for people with a learning disability. The document can be completed electronically and printed or printed and completed by hand. Guidance notes on completing the Hospital Passport are also available here.

Improving the Experience of Children with a Learning Disability

Best Practice Statement

Children and young people with a learning disability who use 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. It is recognised within policy and legislation that children with a disability should always be regarded as children first, but 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 general hospitals on a similar basis as other children (e.g. accidents, tonsillectomy, heart defects), but will often be frequent users as a consequence of complex physical healthcare needs. In these circumstances, all staff involved should refer to the document, "Developing Services to Children and Young People with Complex Physical Healthcare Needs." DHSSPS (2009a).

Best Practice Indicators

1. If at all possible, a pre-admission assessment should be completed which will involve the child, parents/carers and relevant hospital and community staff.
Important information should be collated at this stage (e.g. HSC Hospital Passport–see helpful resources) as this will help hospital staff to understand and effectively meet the child's needs.
2. 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.
3. 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 nurse should provide an appropriate level of community in-reach to the hospital.

4. Parents/carers should be acknowledged as having expert knowledge of their child's needs. The child and their parents/carers 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.
5. 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, or wish, to be with their child during the night.
6. 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 activities. Where appropriate, any existing therapeutic development programmes, which were in place prior to admission, should be continued when the child is in hospital.
7. 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 educational and/or hospital staff.
8. Where certain procedures need to be carried out in the home environment after discharge, any identified need for training related to care delivery at home, should be initiated and coordinated by the hospital staff prior to discharge.
9. Particular attention needs to be given at transition points, such as the transition from general hospital to community services and transitions from child to adult services within general hospitals. Key standards for these circumstances are available in the document "Integrated Care Pathway for Children and Young People with Complex Physical Healthcare Needs" DHSSPS (2009b).
10. All staff working within Children's wards should have access to relevant education 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.

11. The contact numbers of local Community Learning Disability Services should be provided to all children's wards within general hospitals.

Helpful Resources

- DHSSPS (2009) Developing Services to Children and Young People with Complex Physical Healthcare Needs. <https://www.health-ni.gov.uk/publications/developing-services-children-and-young-people-complex-physical-healthcare-needs>
- DHSSPS (2009) Integrated Care Pathway for Children and Young People with Complex Physical Healthcare Needs <https://www.health-ni.gov.uk/publications/integrated-care-pathway-children-and-young-people-complex-physical-healthcare-needs>
- <http://www.publichealth.hscni.net/publications/hsc-hospital-passport-and-guidance-notes>

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Implementation and Audit

We recommend all staff involved in supporting people with a learning disability to access and make use of general health services, including staff within Health and Social Care Trusts and Independent Sector providers should read and implement these Best Practice Statements. Staff should seek to ensure the people with a learning disability have equity of access to and equity of outcome throughout their contact with general hospital services.

We recommend that relevant departments within HSC Trusts and Independent sector organisations that support people with a learning disability should audit the implementation of these Best Practice Statements. Staff within these departments may wish to use a rolling programme to audit specific Best Practice Statements, thereby ensuring these all audited in a timely manner.

Finally, we recommend that staff across HSC Trusts and relevant Independent Sector providers should share good practice and successful innovations with each other in order to support the embedding of these Best Practice Guidelines across Northern Ireland.

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Appendix 1

Review of the Best Practice Statements on Caring for People with a Learning Disability in Contact with General Hospitals was undertaken by:

Name	Designation	Organisation
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Deirdre O'Donnell	Personal and Public Involvement (PPI) Representative	Parent carer
Anne-Marie Phillips	Senior Education Manager	HSC Clinical Education Centre
Briege Quinn	Nurse Consultant, Mental Health & Learning Disability	PHA
Avril Redmond	Professional Lead for Nursing Medicine/Unscheduled Care	NHSCT
Janet Schofield	Chief Executive Officer	Compass Advocacy Network
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