The Regulation and Quality Improvement Authority

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Review of Implementation of GAIN Guidelines on Caring for People with a Learning Disability in General Hospital Settings

December 2014

Assurance, Challenge and Improvement in Health and Social Care

www.rqia.org.uk

The Regulation and Quality Improvement Authority

The Regulation and Quality Improvement Authority (RQIA) is the independent body responsible for regulating and inspecting the quality and availability of health and social care (HSC) services in Northern Ireland.

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Executive Summary

In June 2010 a GAIN Guideline on Caring for People with a Learning Disability in General Hospital Settings was published. The guideline identified 12 specific areas, which had been prioritised as the most pressing areas of need for people with a learning disability who use general hospital settings.

- Attitudes and Values
- Communication
- Learning Disability Training for General Hospital Staff
- Legal Issues in the Delivery of Care to People with a Learning Disability
- Preparing for an Outpatient Appointment
- The Admission Process and Support During a Hospital Stay
- Discharge Planning
- Attendance at Emergency Care Services
- Support for Carers
- Effective Nutrition and Hydration
- The Assessment and Management of Pain
- Improving the Experience of Children with a Learning Disability

This review aimed to provide an assessment of the implementation of the guideline and also assess current practice, identifying both examples of good practice and challenges.

All trusts have processes in place for both receipt and dissemination of GAIN guidelines. However the review team considers that all trusts need more robust procedures for ongoing implementation, review and monitoring of progress ensuring that there are reporting mechanisms in place at director and trust board level.

The review team found that outdated and stigmatising labels were still in use when dealing with people with a learning disability. Educating staff in the use of correct terminology is an important element in ensuring that people with learning disabilities feel included and valued when in receipt of services. This was mentioned frequently by service users and carers as a problem that immediately creates barriers to good therapeutic and respectful relationships.

Concerns were raised by the review team around misunderstanding and poor practice related to consent, capacity assessment, best interest decisions and in relation to DNACPR (Do Not Attempt Cardiopulmonary Resuscitation) orders. The review team was satisfied that there is sufficient regional guidance, local policy and professional codes to inform and guide clinical practice; however on many occasions it was not followed.

Each HSC trust should have arrangements in place within its triage process to specifically identify if a person has a learning disability. When a person is confirmed or suspected of having a learning disability, the likely impact of this on their understanding and cooperation in the emergency department should be established and factored into any triage assessment, alongside determining their priority for treatment.

The review team found that the process of liaison between general hospital services and learning disability services was irregular and dependent on the insight of individual member of staff, rather than a structured and formalised process. Each HSC trust should ensure that there are clear lines of communication and robust linkages between learning disability services and general hospital wards/departments.

Health passports were identified by all trusts, as an important mechanism to improve communication and patient safety for people with learning disabilities, during their journey through general hospital services. However, evidence of their use during the patient file review was limited.

This review identified many examples of good practice, including the development of innovative resources to improve the experiences of people with a learning disability in general hospitals. The review team considered that the DHSSPS should consider the development of a regional health passport in in line with the Bamford Action Plan and the Learning Disability Service Framework.

The review recommends that all HSC trusts should have clear guidance regarding the process for establishing with the person with a learning disability (where possible), and their family members, the degree of involvement they wish to have in their care. HSC trusts should also establish appropriate, accessible mechanisms whereby people with a learning disability and their families and carers, are able to comment (positively and negatively), on their experience of care, when using general hospital settings.

People with learning disabilities are very clear that healthcare staff should look at, and speak to them first, and focus on them, rather than directing attention to carers or parents. Service users who contributed to the review expressed their negative experiences of staff talking around the person with learning disabilities. The language used should be clear, the information should be provided in manageable segments and the person should be asked if they have any questions.

Recommendations were also made to address identifying and dealing with pain experienced by patients with a learning disability, staff training, documentation such as care plans, general record keeping and other legal issues. The review made a total of 19 recommendations in order to help to raise the level of care experienced by people with a learning disability in general hospital settings.

1 Introduction

1.1 Demographics

Learning disabilities affect about 1.5 million people in the UK[1] and in Northern Ireland there is a population of approximately 26,500 people with a learning disability (unvalidated estimate), of whom half are aged between 0-19 years[2]. It is projected that the number of people with a learning disability will increase by one per cent each year over the next 15 years, and that children and older adults with complex physical needs will both be large areas of growth. The increased support needs of this population will require an associated growth in service provision to meet their complex physical health needs. This increase in population, alongside the fact that people with a learning disability are living longer, means that there will be a greater dependence on health and social care services, including general hospital services.

1.2 Definition of Learning Disability

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.[3]

The British Psychological Society outlines three core criteria for a categorisation of learning disability.[4]

- significant impairment of intellectual functioning
- significant impairment of adaptive/social functioning
- age of onset before adulthood

The Equal Lives Review of Policy and Practice for People with a Learning Disability in Northern Ireland[3] recognises that people with a learning disability are not a homogeneous group, and that the needs of individuals can vary considerably. All services should therefore be encapsulated by inclusive and person centred approaches, which allows for a holistic view of an individual's needs.

[1] RCN (2006) Meeting the health needs of people with learning disabilities. Guidance for nursing staff. Royal College of Nursing. London.
[2] Department of Health, Social Services and Public Safety (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Action Plan 2009-2011. Department of Health, Social Services and Public Safety, Belfast.
[3] Department of Health, Social Services and Public Safety (2005) Equal Lives. Belfast: Department of Health, Social Services and Public Safety. Belfast.
[4] Professional Affairs Board of The British Psychological Society. (2000) Learning Disability: Definitions and Contexts. The British Psychological Society. Leicester.

2 Context for the Review of Care Delivered to People with Learning Disabilities within General Hospital Services

An estimated 26 per cent of people with a learning disability are admitted to hospital, compared to 14 per cent of the general population (National Patient Safety Agency 2004). Services can range from emergency care provision, outpatient appointments and day procedures, through to the need for surgical intervention and repeated lengthy admissions due to complex health needs.

The National Patient Safety Agency[5] also highlighted that simply going into a general hospital was one of the five top risks faced by people with a learning disability.

Considering the policy situation in Northern Ireland, The Equal Lives Review[3] reported that consistent feedback from their consultations indicated that in many instances, acute hospital staff require staff from the learning disability service or a family member, to be present all the time on the ward when the patient is in hospital.

The review found that there are high levels of unmet health needs among people with a learning disability in Northern Ireland, and recommendation 41 proposed: "Further action is required to raise awareness within primary care services and acute general hospitals of the health issues faced by people with a learning disability" and recommended "that each general practice and acute general hospital develop clear arrangements to facilitate equality of access for people with a learning disability" (DHSSPS, 2005, page 73)[3].

Death by Indifference[6] chronicled the events leading to the deaths of six people with a learning disability in general hospital settings. The report considered that the deaths were due to discrimination, indifference, a lack of training and a very poor understanding of the health needs of people with a learning disability.

As a follow on to Death by Indifference, the United Kingdom government commissioned an independent inquiry chaired by Sir Jonathan Michael, Healthcare for All[7]. The inquiry found:

- People with learning disabilities find it much harder than other people to access assessment and treatment for general health problems that have nothing directly to do with their disability.

- There is insufficient attention given to making reasonable adjustments to support the delivery of equal treatment, as required by the Disability Discrimination Act. Adjustments are not always made to allow for communication problems, difficulty in understanding (cognitive impairment), or the anxieties and preferences of individuals concerning their treatment.

[5] National Patient Safety Agency (NPSA 2004) Understanding the patient safety issues for people with learning disabilities. NPSA. London.
[6] Mencap (2007) Death by Indifference. Mencap. London
[7] Michael, J, 2008. Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities.

- Parents and carers of adults and children with learning disabilities often find their opinions and assessments ignored by healthcare professionals, even though they have the best information about, and understanding of, the people they support. They struggle to be accepted as effective partners in care by those involved in providing general healthcare; their complaints are not heard; they are expected to do too much of the care that should be provided by the health system and are often required to provide care beyond their personal resources.

- Health service staff, particularly those working in general healthcare, have very limited knowledge of learning disability. They are unfamiliar with the legislative framework, and commonly fail to understand that a right to equal treatment does not mean treatment should be the same. The health needs, communication problems, and cognitive impairment characteristics of learning disability in particular are poorly understood. Staff are not familiar with what help they should provide or from whom to get expert advice.

- Partnership working and communication (between different agencies providing care, between services for different age groups, and across NHS primary, secondary and tertiary boundaries) is poor in relation to services for adults with learning disabilities. This problem is not restricted to services used by people with learning disabilities, but particularly affects those who may not be able to communicate for themselves, or whose treatment needs careful planning and coordination because they have complex needs.

A specific examination of the six cases within Death by Indifference by The Parliamentary and Health Ombudsman (Six Lives Report: 2009) considered that there were some significant and distressing failures within both general hospital settings and community/primary care settings in these circumstances. It outlined the devastating impact of organisational behaviour which did not adapt to individual need, or follow procedures designed to maintain a basic quality of service for everyone. This report 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 were avoidable.

Within Northern Ireland, a number of research projects into access to general health care, such as Promoting Access[8] and Patient People[9], alongside some specific research into access to Accident and Emergency Services[10] have also identified major challenges in access to general hospital services, for people with learning disabilities.

[8] Barr O (2004) Promoting Access: *The experience of children and adults with learning disabilities and their families/carers who had contact with acute general hospitals in the WHSSB Area and the views of the nurses in these hospitals.* Western Health and Social Services Board.
[9] Southern Health and Social Care Council (2008) Patient People: *Experiences of adults with a learning disability as hospital in-patients in Craigavon Area Hospital and Daisy Hill Hospital.* SHSCC. Lurgan.
[10] Sowney, M., Barr, O. (2007) *The challenges for nurses within the accident and emergency care service communicating with and gaining valid consent from adults with intellectual disabilities.* Journal of Clinical Nursing. 16 (9): 1678-1686

When combined, it is clearly apparent that a large number of difficulties are encountered by people with learning disabilities, their families and staff when they try to access, or when they use general hospital services. These include:

People with Learning Difficulties

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

Families and Carers of People with Learning Disabilities

- often find their opinions and assessments ignored by healthcare professionals
- 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 learning disabilities
- identify that limited opportunities for meaningful activities and the environment, results in the person with learning disabilities becoming bored and restless
- experience limited forward notice 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, or make it comfortable
- experience negative attitudes and stereotypes about people with learning disabilities. This can result in doctors and others making mistaken assumptions about people with learning disabilities, resulting in failure to diagnose accurately or the misinterpretation of symptoms

Staff in General Hospitals

- have limited relevant information available about the person with learning disabilities
- have limited knowledge, skills, experience, and confidence in supporting people with learning disabilities and are not familiar with what help they should provide, or from whom to get expert advice
- experience difficulties in achieving informed consent and the required level of cooperation
- receive limited training in the needs of people with learning disabilities
- perceive partnership working and communication (between different agencies providing care between services for different age groups, and across NHS primary and tertiary boundaries), as being poor in relation to services for people with learning disability

More recently, considering health inequalities faced by people with a learning disability in a broader context, The Confidential Inquiry into the Premature Deaths of People with Learning Disabilities[11] reviewed the deaths of 247 people with learning disabilities over the period 2010-2012. The inquiry findings made it very apparent that people with a learning disability were a very vulnerable group in the context of health needs. Significantly more (17 per cent) were underweight than the general population (2 per cent), even after excluding those who had lost weight in their final illness. Two-thirds lacked independent mobility, half had problems with vision, a quarter had problems with hearing, over a fifth (21 per cent) had problems with both vision and hearing, 30 per cent had limited verbal communication, and 22 per cent did not communicate verbally at all.

Almost all (97 per cent) had one or more long-term or treatable health condition, including 43 per cent with epilepsy (31 per cent had had a seizure in the previous five years), 39 per cent with cardiovascular disease, 22 per cent with hypertension, 14 per cent with dementia and 13 per cent with osteoporosis. The inquiry also found that:

- the average age of death for men with learning disabilities was 65 years, 13 years younger than men in the wider population
- the average age of death for women with learning disabilities was 63 years, 20 years younger than women in the wider population
- 22 per cent of people with learning disabilities died before the age of 50 years, opposed to nine per cent in the wider population
- the more common underlying causes of death were heart and circulatory disease 22 per cent and cancer 20 cent (both below that in the wider population)

It is clearly apparent that the quality and effectiveness of health and social care given to people with learning disabilities has been shown to be deficient in a number of ways. Despite all of these investigations and reports, “many professionals are either not aware of, or do not include in their usual practice, approaches that adapt services to meet the needs of people with learning disabilities” (Heslop et al 2013 page 5). As a consequence, it was felt necessary and appropriate to develop and publish within Northern Ireland, GAIN guidelines that would support the delivery of high quality and safe care when people with a learning disability use our general hospital services.

[11] Heslop P. et al, 2013 The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). Norah Fry Research Centre, University of Bristol. Bristol.

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

Based on a literature review, including the reports already referenced in this report, a GAIN Guideline was developed for Northern Ireland in June 2010. The guideline identified 12 specific areas for improvement, which had been prioritised as the most pressing areas of need for people with a learning disability who use general hospital settings.

Each improvement area contains a best practice statement and a series of best practice indicators. The 12 areas for improvement and best practice statements are summarised as follows:

(i) Attitudes and Values

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

- seeing the person not the disability
- ensuring that communication is sensitive to the needs and preferences of the person
- person centred care
- dignified, respectful and compassionate care
- non-judgemental attitudes

(ii) Communication

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

(iii) Learning Disability Training for General Hospital Staff

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

(iv) Legal Issues in the Delivery of Care to People with a Learning Disability

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.

(v) Preparing for an Outpatient Appointment

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.

(vi) The Admission Process and Support During a Hospital Stay

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.

(vii) Discharge Planning

Individuals 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 patient's plan of care.

(viii) Attendance at Emergency Care Services

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.

(ix) Support for Carers

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

(x) Effective Nutrition and Hydration

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

(xi) The Assessment and Management of Pain

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.

(xii) Improving the Experience of Children with a Learning Disability

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.

Implementation Plan

The guideline contained a possible implementation plan that was available for use by trusts and also contained a suggestion that RQIA should consider conducting a specific regional review, within three years of its publication. This timescale would allow sufficient time for implementation by trusts. As a result the review was included in the 2012-2015 RQIA review programme.

Dissemination of the GAIN Guidelines

The guideline was launched and published in June 2010 and disseminated by GAIN to health and social care trusts for implementation.

The guideline has since been referenced in two DHSSPS policy documents.

Section 19 of The Learning Disability Service Framework[12] (DHSSPS 2011) states that *"*all acute hospitals should have an action plan for implementing the GAIN guidelines and be able to demonstrate a clear commitment to the implementation of such a plan*".*

The 2012 -2015 Bamford Action Plan[13] (DHSSPS 2012) commits to the need for services to "improve the experience of people with LD using acute general hospitals based on the GAIN Guidelines on Caring for People with a Learning Disability in General Hospital Settings."

3 Terms of Reference

The terms of reference for the review were agreed as follows:

- Evaluate the arrangements that have been put in place to implement the GAIN Guidelines on Caring for People with a Learning Disability in General Hospital Settings.
- Assess the current position in relation to the best practice statements within the GAIN guidelines.
- Identify any lessons learned from the implementation, report on the findings and make recommendations as appropriate.

4 Methodology

There were four key stages in completing this review:

- HSC trusts were asked through self-assessment to:
    - provide information regarding the processes in place for implementation of GAIN Guidelines on Caring for People with a Learning Disability in General Hospital Settings
    - outline the progress that has been made in achieving the twelve best practice statements contained in the guideline
- A file review was carried out of a number of service users' files, from a number of different settings within general hospitals in all five HSC trusts. It examined files from a number of different departments, including; emergency

[12] Department of Health, Social Services and Public Safety (2011) The Learning Disability Service Framework. Department of Health, Social Services and Public Safety. Belfast
[13] Department of Health, Social Services and Public Safety (2012) The 2012 -2015 Bamford Action Plan. Department of Health, Social Services and Public Safety. Belfast

care, medical/surgical wards, paediatric wards and out-patients. This file review helped to:

  - confirm if the records provided an alert to the presence of a learning disability
  - identify links between general hospital services and relevant community services
  - identify and review the use of reasonable adjustments
  - highlight the effective use of fundamental care principles such as effective communication, consent processes, pain management, and support to and involvement of carers

- Validation meetings took place with trust learning disability staff and members of trust senior teams.
- A regional seminar was organised for people with learning disabilities, their family members, carers and advocacy organisations that support people with learning disabilities.

5 Self-Assessment Questionnaire Responses

5.1 Process

The first stage of data collection in the review provided the opportunity for each HSC trust to complete a self-assessment questionnaire. This questionnaire was designed to collect information regarding the processes in place and any actions taken to progress the implementation of GAIN Guidelines on Caring for People with a Learning Disability in General Hospital Settings (Appendix 1). It gave each HSC trust the opportunity to outline the progress that they believed had been made in implementing the twelve best practice statements contained in the guideline.

This section of the report provides an overview of the information in the completed questionnaires, outlines good practice and highlights the areas identified requiring further development.

5.2 Arrangements for Implementation the GAIN Guidelines

Four of the five HSC trusts reported that a named person within their trust had been identified to lead on the implementation of the GAIN Guidelines. The Western Trust had not identified a named person to lead. These named individuals were at a senior level within the HSC trusts and worked with other trust colleagues to take forward the implementation of the guideline.

Belfast and South Eastern trusts reported that arrangements had been put in place for joint working between general hospital services and learning disability services to, implement the guideline. However, at the time of the review, the other 3 trusts had not put any specific or formal arrangements in place for collaborative working between general hospital and learning disability services to implement the guideline. Similar variation in the extent of collaborative working between these services is also reported in relation to the findings from the file audit and trust interviews.

5.3 Good Practice

All HSC trusts reported actions that they believed had taken forward the implementation of the GAIN Guidelines. These included:

- putting arrangements in place for the implementation of the guidelines
- development of accessible information
- making guidelines more accessible to staff members
- links with service user groups
- support for carers
- developments in children's services
- links with learning disability services

5.3.1 Development of Accessible Information

All HSC trusts reported the development of accessible information that could be used by staff to provide clearer information to people with learning disabilities. This included the development of hospital passports and information about specific examinations and treatments. Three HSC trusts also reported the provision of accessible information for use with people with learning disabilities, which included

relevant guidance documents, such as consent guidance and the hospital communication book in hard copy at department level and on the trust intranets.

5.3.2 Service User Involvement

All HSC trusts reported active engagement with people with learning disabilities in the development of accessible resources to assist people with learning disabilities, who may be in contact with general hospitals. This included the development of hard copy information in an accessible format with the use of pictures, symbols and clear wording. Two trusts reported the active involvement of speech and language therapists in the development of this type of material. Three trusts reported the active involvement of people with learning disabilities in the education of trust staff about learning disability issues. Two of these trusts reported the use of drama groups to assist in delivering this material.

5.3.3 Support for Carers

All trusts reported the provision of additional support for family members of people with learning disabilities, who may wish to be present when they are in hospital. This support included longer visiting hours, use of hospital restaurants and the provision of light refreshments at ward level. Meal vouchers were reported as being provided if appropriate but no further details were given. This information was provided in the context of support for all carers and no information was provided in respect of specific arrangements for family members / carers of people with learning disabilities, many of whom may be older parents.

5.3.4 Children's Services

All trusts provided examples of developments within children's services which they highlighted as supporting the implementation of the GAIN Guidelines. However, these had not been put in place as a result of the publication of the GAIN Guidelines and many of these facilities and resources were developed as a result of other developments within children's services. There was a consistent response from trusts which indicated that services for children with learning disabilities were more developed than services for adults with learning disabilities, particularly in relation to accessible information and support for family carers and making reasonable adjustments.

5.3.5 Links with Learning Disability Services

All HSC trusts reported links between staff working in general hospitals and staff working in learning disability services. In two HSC trusts, these links appeared to be directly related to joint responsibilities for leading and overseeing the implementation of the GAIN Guidelines. Links between general hospital staff and speech and language therapists within learning disability services and nurses for people with learning disability was also reported. In two trusts, these links appeared to be formal arrangements to support people with learning disabilities in contact with day case units for dental treatment. In the other three HSC trusts, links between frontline staff in general hospitals and learning disability services were reported, but largely in the context of links being developed on an individual basis rather than a formal arrangement between services.

5.4 Areas Requiring Further Development

All HSC trusts noted within their completed questionnaires that they recognised further work was needed to continue to progress the implementation of the GAIN Guidelines within their trust. In addition, it was clear to reviewers from the information provided within the completed questionnaires that some areas required development across a number of HSC trusts.

5.4.1 Identification of People with Learning Disability

All HSC trusts noted their reliance on this information being provided in the referral letter from general practitioners (GPs) or by parents, carers or learning disability services. If the person was previously known to general health staff, it may be that their learning disability was recorded either on the electronic record or in their hard copy notes. However, it was clear from the information within the questionnaires that these electronic systems did not routinely identify all people with a learning disability. Often the fact that the person has a learning disability is not known to staff in the general hospital before the person arrives at the hospital department. In order to make reasonable adjustments to support people with learning disabilities it is first necessary to be aware that a person has learning disabilities.

5.4.2 Specific Information about Reasonable Adjustments contained in Appointment Letters

Two HSC trusts noted that the person or family member referring the patient to the general hospital department were given the opportunity to inform the general hospital staff of the presence of learning disabilities and the possible need for reasonable adjustments, as it was mentioned in their appointment letter. However, despite all HSC trusts reporting the development and or availability of accessible information in hard copy and two HSC trusts having developed DVDs, no specific information about support for people with learning disabilities, or other accessible information that may be relevant, was sent out with appointment letters.

5.4.3 Views of Parents/Carers

Previous research has highlighted many issues with the active involvement of parents and other family members as partners in support provided to people with learning disabilities, when in contact with general hospitals. In their questionnaires, all trusts reported the range of support they could provide to family carers who are present when the person with learning disabilities is in contact with the general hospital. However, no trust routinely sought feedback from family carers or carers from other services as part of their evaluation of their experience of contact with the hospital. However, South Eastern Trust advised that they had piloted the use of a user feedback questionnaire to measure the experience of the individual post discharge which requires further review for any planned future use. No accessible feedback material was reported as being available for people with learning disabilities.

5.4.4 Staff Training

All HSC trusts reported the importance of mandatory equality and diversity training for staff and noted that this was relevant to supporting people with learning disabilities. Two trusts reported the involvement of people with learning disabilities

or family carers in some aspects of such training. However, only South Eastern Trust reported specific ongoing training for hospital staff in supporting people with learning disabilities. The Southern Trust reported that education had previously been available for staff in general hospitals but was no longer routinely provided.

5.4.5 Reduction in Previous Activities

It was also noted from the responses of a number of HSC trusts that previously available support was no longer in place, even though this had been highly valued by staff working in general hospital settings. New and innovative developments such as the appointment of an acute liaison nurse in Western Trust and the development of link nurses in Southern Trust have ceased in recent years. The reasons given included, competing priorities, lack of recurring finance and changes of staff within services.

5.4.6 Development of Separate Resources by Individual HSC Trusts

All HSC trusts reported the development and availability of accessible information for people with learning disabilities in contact with general hospitals. These developments are welcomed and can add to the wide range of resources already available. However, it can be shown from the information provided by trusts that these accessible resources are being developed within separate trusts, with no clear mechanism for preventing duplication and maximising the benefit of working with colleagues in other HSC trusts. In addition there is a potential problem with the development of resources with similar names such as hospital passports. Although similar in what they are trying to achieve, there is a range of different documents, in different formats and with differing content.

6 Review of Patients Files

6.1 Process

All trusts were asked to make available up to 25 sets of file notes relating to both children and adults who were categorised as having a learning disability. Files were requested from a range of general hospital settings including emergency care, outpatients, paediatrics and inpatients (both surgical and medical). RQIA reviewed a total of 79 files across the five HSC trusts. The team spent one day in each trust reviewing files. Due to the complexity of certain files, the total number reviewed was less than planned.

The file audit focused primarily on the most recent contact or admission of the person with a learning disability. However, on occasions it was necessary to audit other aspects of the file, in order to get a complete picture of an individual's pathway of care.

The GAIN Guidelines on Caring for People with a Learning Disability in a General Hospital Setting was issued to trusts in June 2010. Only patient files where the latest episode of care happened after 1 July 2012 were reviewed. The review team considered that this allowed sufficient time for implementation of the guidelines.

A specific audit tool was developed by the review team for this review to record audit findings and this template is available at Appendix 2.

The focus of the file audit was to consider findings in the context of the best practice statements within the GAIN guidelines. For example:

- Did the records provide an alert to the presence of a learning disability?
- Identify links between general hospital services and relevant community services.
- Identify and review the use of reasonable adjustments.
- Highlight the effective use of fundamental care principles such as effective communication, consent processes, pain management, and support to and involvement of carers.

Although the main focus was on the content of the files in relation to the GAIN guidelines, it was impossible not to note quality in terms of broad standards of record keeping, such as:

- legibility
- appropriate date and signature
- effective assessment and care planning
- demonstration of logical flow
- evidence that notes were contemporaneous

During the file audit process, a number of examples of poor record keeping practice were found. The review team considered that these are important learning points for all trusts to consider and so they are outlined at the end of this section.

On summarising the file audit findings, it was apparent that the majority of the highlighted issues were, to some extent, common across all trusts. Therefore, with the exception of good practice examples, the issues highlighted are not directed at any specific trust; rather they are highlighted for all trusts to consider, review practice and where necessary, take action.

6.2 File Review Findings

6.2.1 Areas of Good Practice

The review team found examples of good practice and innovation in each of the five file audits undertaken, and these are briefly summarised below in order to encourage shared learning:

- The use of the succinct All About Me assessment format used by the South Eastern Trust and evidenced within some of the files used by general hospital staff in the trust.
- The use of pain assessment tools for those who are cognitively impaired evidenced in some wards within Western Trust.
- The checklist of basic needs form used within Southern Trust.
- The summary of needs form introduced by the Northern Trust for patients being admitted into hospital from private nursing homes.
- The developments within the Mater Hospital (Belfast Trust) to support the pathway of care, for people with learning disabilities, through the emergency department.

The review team noted the robust arrangements in place in all trusts for dealing with children with a learning disability using general hospital services. It is recognised that regional guidance related to the complex physical health care needs of children[14] has positively influenced standards and practice, but there is much in children's services that adult services and wards could learn from and implement in the context of adults with a learning disability.

For example, linkage and liaison between hospital and community personnel is much more structured and formalised in paediatric wards. An example is the ability to quickly prioritise children, ensuring quick flow through departments. The involvement of and support to carers was more robust and apparent than in adult wards and discharge planning appeared to be more considered and coordinated for children with a learning disability compared to adults.

6.2.2 Areas for Development

As stated earlier, the majority of issues identified from the file audit, highlighting the need for improvement, were apparent to a greater or lesser extent across all trusts.

[14] Department of Health, Social Services and Public Safety (2009) Integrated Care Pathway for Children and Young People with Complex Physical Healthcare Needs. Department of Health, Social Services and Public Safety, Belfast.

The following areas are specifically highlighted due to the frequency that they were found in the file audit, the potential impact they could have on the delivery of safe and effective care and because of the potential for learning and improvement across all trusts.

(i) Use of Appropriate Terminology

Although the review team was satisfied that in the majority of circumstances there was adequate identification of a patient's learning disability and sharing of this information throughout the journey within general hospital settings, it was apparent that inaccurate and sometimes stigmatising terminology was used. Terms such as learning difficulty, mental handicap and mental disability were used frequently and interchangeably and it is important that trusts take action to ensure that proper and appropriate terminology is used.

(ii) Identification of Learning Disability

In certain cases, the presence of a learning disability be apparent, however, often it is not. The review team noted that, on admission to hospital some systems of information gathering (for example, during emergency care triage) were less successful in providing information that would alert the service to the fact that the individual has a learning disability. The review team found a range of different versions of the new regional nursing documentation that is currently under development. Only one of these versions asked directly whether the individual has a learning disability.

(iii) Hospital Passports

Hospital passports have been identified in a range of reports throughout the United Kingdom, as an important communication tool and a vital safeguard to the effective prevention of risk, when individuals with a learning disability use general hospital settings. While the majority of trusts, in the self-assessment questionnaire and at interview, referenced the use of hospital passports within their care system, evidence of their use during the hospital journey was not recorded in any of the patient notes, the exception being South Eastern Trust.

(iv) Consent and Capacity

In all trusts, there was evidence of inadequate practice related to capacity assessment, provision of consent and best interest decision making. It is important that all general hospital staff understand that consent is a process. A signature on a form is only evidence that the patient has signed the form, however, it is not proof that the consent is valid.

From the review of patient notes, the review team noted occasions when correct consent forms had not been used. In some circumstances the review team found there was no detailed explanation of the rationale behind best interest decisions and there was no clear documented evidence of an assessment process that clearly determined decision making with regard to capacity to consent.

Individual practitioners should be careful that they do not try to justify conservative treatment solely on the basis that an individual has a learning disability. It is essential in such circumstances that there is a documented account of the

assessment of the individual's level of capacity and if appropriate, only provide such treatment if it is in their best interests.

Seeking consent on a day to day basis was evident occasionally within progress/continuation sheets but it was noticeable that this practice is more frequently applied by allied health professionals (AHP) than other professional groups such as nursing and medicine.

(v) Do Not Attempt Cardiopulmonary Resuscitation Orders (DNACPR)

The review team paid particular attention to the decision-making and review processes for Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) orders. In those trusts that had provided files in which DNACPR orders were evident, flaws in the following of trust policy and good professional practice were apparent.

These are summarised as follows:

- There was often no clear documentation, either within the relevant DNACPR form or within the medical and/or nursing notes outlining the main clinical problems and reasons why DNACPR was in the patient's best interest.
- There were occasions when it was not evident what communication had taken place with the patient (and if not, why not?) and/or the patient's family, carers or friends.
- There was frequently no evidence of DNACPR orders being reviewed or revoked.
- The review team noted/identified situations where nursing staff delivering care appeared to be uncertain about the DNACPR status, due to the absence of a DNACPR form in the patient's file.

While, the review team was not in a position to determine the appropriateness of DNACPR orders, it considered that all trusts should urgently review/audit practice and the process of documentation in this area.

(vi) Reasonable Adjustments

Based on self-assessment responses validated through interviews, the review team noted that reasonable adjustments are considered and applied in many situations, to support the delivery of care to people with learning disabilities. All trusts provided a range of examples of innovative and individualised reasonable adjustments. These included:

- offering first or last outpatient appointments
- offering a specific slot on theatre lists
- pre-admission visits
- family support during the theatre and recovery pathways
- specific pathways within the Belfast and Northern trusts for dental surgery
- the provision of single rooms

However, although stated as part of the self-assessment process and during face-to-face validation meetings with all trusts, many of the reasonable adjustments offered to people with a learning disability were not apparent from the file audit. The review team accepts that it may not be standard practice to note all the reasonable

adjustments provided and that some of these happen routinely. The review team also believes that there are some crucial elements of fundamental care provision, that require to be routinely documented within nursing care plans, to provide evidence of application.

For example, evidence within patient files of specific adjustments being made to support communication needs was rarely seen. Although trusts had informed the review team of the use of easy read, adjusted or pictorial information to support communication, there was little evidence of this within files. In the context of adjusting for communication, the review team also noted the lack of evidence of, or reference to hospital passports within patient files.

Other common, effective and expected reasonable adjustments, such as the use of specific tools i.e. pain assessment scales for those with cognitive impairment were apparent in the files of only two of the five trusts.

Another reasonable adjustment that is crucial, relates to the involvement of family and other carers of people with learning disabilities, in information giving and decision making, particularly for those with more profound communication and/or cognitive impairments. This involvement was more evident in the files of children than in adults.

During the file review, the review team did not find recorded examples in any trust, where hospital staff were prompted by the variety of assessment templates used, to consider the reasonable adjustments required for individual patients.

(vii) Effective Liaison with Local Learning Disability Services

In all trusts, there was evidence of liaison and linkage between general hospital services and local learning disability services. However, the evidence for this varied from file to file, and from trust to trust. In some cases the review team found evidence of effective liaison that facilitated the admission and discharge processes. In these circumstances, it was apparent that communication was enhanced, which should lead to a reduction in fear and anxiety with regard to challenging behaviour and assisted compliance with treatment regimes.

However, the review team found that the process of liaison was limited and dependent on individual insight, rather than being a structured and formalised process. To support improvement in this area, the review team recommends that all trusts consider developments elsewhere in the United Kingdom, where many hospitals have invested in dedicated staff such as acute liaison nurses. These nurses are not only the conduit between services, but also a source of advice, guidance and support to all staff in general hospitals, when delivering care to people with learning disabilities.

(viii) General Record Keeping Practice

The following general record keeping issues were noted by the review team.

- The inappropriate use of generic or core care plans, many of which, when examined had not been individualised to the patient.
- Assessment needs not being linked to care planning documentation or actions.

- A focus on the technical aspects of care needs during assessment and care planning and limited addressing of psychological, social, spiritual, emotional and communication needs.
- Important documentation templates incomplete (for example, discharge planning documentation, manual handling assessments, nursing assessment templates).
- Lack of attention to detail and sometimes trust/regional policy not followed in key aspects of care such as consent and DNACPR processes.
- Nursing students completing full assessments without evidence of countersignature by registered nurses.
- A range of different formats of the regional nursing documentation template in use across all trusts.

7 Validation Interviews with HSC Trusts

Interviews were held with each of the five trusts, which provided an opportunity to further clarify and explore data and information gathered as part of the self-assessment questionnaire and file audit process. The interview process also allowed for a more detailed examination and acknowledgement of local successes and the specific challenges encountered in implementing the GAIN guidelines and sustaining their impact.

During the interviews a number of broad themes/issues emerged that had relevance across all trusts. For example:

- All five trusts, although at different stages in the journey of full implementation, have been influenced by the guidelines in making improvements for people with a learning disability who use general hospital settings. The review team was impressed and encouraged by the enthusiasm and the commitment of individual staff in all trusts. It was also encouraged by the variety of initiatives, projects and innovations that are in place, or being planned to ensure that people with learning disabilities receive the safest and most effective care when using general hospital settings.

All trusts were intent upon, or actively taking action to:

- Improve the identification of people with a learning disability, marking their notes with an appropriate flag, particularly at key entry points such as emergency care.
- Enhance the communication process for people with learning disabilities and/or their families and carers, through the use of hospital passports, easy read information and hospital communication packs/books.
- Address the need for further action to strengthen and improve their processes and practice around consent, capacity assessment and best-interest decision making.
- Maintain and build upon robust and sustained systems that ensure that the GAIN guidelines best practice indicators are applied to children with learning disabilities who use general hospital settings.
- Taking action to liaise with a variety of service user and carer groups (including Compass, TILII (Tell It Like It Is), Lilliput Theatre and ARC (Association for Real Change)) to assist them in a variety of initiatives related to the care of people with learning disabilities in general hospital settings.

However, the review team considered that GAIN guidelines in general, are only one of many competing priorities for staff time, resources and funding. Also the GAIN guidelines do not receive a high enough priority on the commissioning agenda and that accountability for implementation and action could be more structured and formalised at a local level.

7.1 Validation Interview with the Belfast Health and Social Care Trust

The review team was impressed by the strong interdisciplinary focus given to the guidelines by Belfast Trust. The review team interviewed front line staff up to director level, included a range of professional groups (including nurses, AHPs,

social workers, doctors and dentists), was cross-directorate and included carer representation. The interview response from the Belfast Trust states that there was high level accountability for implementing the guidelines, their relevance across disciplines was reflected and that cross programme working was acknowledged, accepted and starting to become more coordinated and embedded.

The review team also noted the emphasis given by the Belfast Trust to actively developing their staff, at all levels, in the context of values, attitudes, person-centeredness and customer care.

The Belfast Trust highlighted effective pathways of care within dentistry and orthopaedics, which had been specifically developed and adapted for people with a learning disability. In this context, the trust had also developed some service provision in Muckamore Abbey Hospital to assist in addressing the needs of those with the most complex needs.

The trust is to be commended for specific initiatives such as the development of a DVD to support people with a learning disability, through the emergency care pathway within the Mater Hospital, the development of hospital passports and the introduction of link nurses/ champions in various settings. However, the review team considered that these initiatives need to become more embedded and utilised in day-to-day practice across the trust.

There is also the need for a concerted effort in the provision of education and training, particularly for general hospital care staff, to enhance their awareness and competence in delivering care to people with a learning disability.

7.2 Validation Interview with the Northern Health and Social Care Trust

The Northern Trust, in its self-assessment and through interviews with the review team, outlined a number of initiatives that had been, and were currently in place to improve access, safety and effective care delivery to people with a learning disability, using their general hospital services.

Of particular note was the work that had been introduced in acute dental services. Here, there was clear coordination and linkage between the acute dental surgery service and the local community learning disability services. The Northern Trust interview team also outlined the development of a pictorial communication book, providing easy read information regarding the pathway through dental services.

The trust had also been part of a project developed in conjunction with Muckamore Abbey Hospital (managed by the Belfast Trust), which had resulted in a range of positive developments. These included: inpatient protocols; additional support arrangements; and regular meetings between the two organisations to discuss, plan and implement service improvements for people with learning disabilities from Muckamore Abbey Hospital, who required the services of Antrim Hospital.

Both initiatives pre-dated the GAIN guidelines, and while the dental initiative has been sustained, the link between Antrim Area Hospital and Muckamore Abbey is no longer formally in place. This is as a consequence of the continued resettlement process and the retraction of the hospital.

The Northern Trust representatives provided an assessment of current standards in the context of the GAIN guidelines. They reported areas of good practice, good linkage and evidence of reasonable adjustments being applied. However, such initiatives were reported and accepted to be provided on an ad hoc basis, dependent upon the commitment and interest of one or two individuals, and tended to be driven by community services rather than acute services.

The review team was reassured that services for children with a learning disability routinely met many of the best practice indicators within the GAIN guidelines, compared to their adult counterparts.

The Northern Trust representatives reassured the review team that RQIA's review has prompted action within the trust, and that the Executive Director of Nursing is planning to lead an initiative to review current practice and identify key priority areas for development and improvement in the context of the GAIN guidelines.

The review team noted that the most pressing priorities within the Northern Trust centred on the need for education and training; awareness within wards of the relevant contact points within community learning disability services; the introduction of hospital resource packs for all wards and departments; and the need to target medical staff as an integral component of all of the above.

From the interview with trust staff, it was apparent to the review team that there are a number of staff within community learning disability services who are committed to helping and supporting their hospital-based colleagues in achieving improvement. The review team considers that these staff should be encouraged to contribute towards this area of service improvement. For example, the review team was presented with evidence of a range of documents, developed by speech and language therapists within the learning disability directorate, to aid communication and enhance information provision during the general hospital pathway. Although developed by staff within learning disability services, these were not routinely used or accessible to staff in other settings.

7.3 Validation Interview with the South Eastern Health and Social Care Trust

The South Eastern Trust outlined a structured, coordinated, phased and pragmatic approach to the introduction and implementation of the GAIN guidelines. It is the view of the review team that this approach to implementation, is an example of best practice.

Two senior managers, (from learning disability services and from acute services) have taken the lead for implementation of the guideline, and this joint accountability process has been a crucial factor for success.

The phased approach used by the trust, allowed for gradual and managed implementation, learning lessons from one phase and applying them as the next phase progressed. This allowed for the effective management of resource, the development of key staff and implementation of new processes and systems of care.

Once again, the review team noted there was apparent engagement across disciplines and across programmes, this was good practice. This linkage had permeated through to front line staff and there was increasing active and regular

dialogue between ward sisters in general hospital wards and local community learning disability teams.

The South Eastern Trust advised the review team that it had initially identified practical areas for implementation, based on a quick-win approach, with minimal resources making a high impact. For example, the provision of a leaflet in acute wards, providing contact details of all local learning disability teams, has enhanced communication between services, resulting in improved formal and informal linkage between the wards and the teams. South Eastern Trust has produced a communication book, Improving Communication with People who have Learning Disabilities in Health Care Settings. This is available on the wards in all of the hospitals within the trust and can also be accessed via the speech and language department on request or the trust intranet. These books include relevant pictures, symbols, signs for use with people with learning disabilities in health care settings and also include a visual pain chart.

The trust reported multidisciplinary development and the introduction of hospital passports, called All About Me, for individuals with a learning disability has led to care for these frequent users of general hospital settings being prioritised.

The review team also welcomed the approach taken to education and training in the context of the GAIN guidelines. For example, a training presentation has been made available to the ward sisters. Since the start of this service improvement initiative, the trust has involved an education provider as part of the core implementation team, and training has been delivered on a bespoke basis throughout a number of general hospital settings. For example, in emergency care departments, training has been delivered outside of the usual 9am to 5pm period, to facilitate the shift patterns and weekly arrangements of staff working in these settings.

The trust acknowledged concerns raised by the review team in the context of do not resuscitate and consent processes that were identified as part of the file audit. The review team was assured that those issues would be brought back to relevant individuals in the trust for action.

The trust had reviewed the use of link nurses but their approach was to use clinical coordinators as champions for people with a learning disability. The trust also acknowledged the need for further consideration and development of link nurses and/or champions.

7.4 Validation Interview with the Southern Health and Social Care Trust

The Southern Trust had outlined, in its self-assessment questionnaire, a range of developments and initiatives that had pre-dated the publication of the GAIN guidelines. These initiatives had been implemented following a local review of acute service provision for people with learning disabilities, Patient People[9].

- A number of link nurses from acute settings had been identified and provided with bespoke training/education to act as champions for safe and effective care when people with learning disabilities accessed general hospital settings in the trust.
- A range of specialised equipment was purchased to facilitate those who had additional complex needs.

- An educational programme, involving service users, was developed and delivered to a considerable number of multidisciplinary staff who worked in general hospital settings.
- Hospital passports were developed to support communication and the delivery of safe and effective care for people with learning disabilities using general hospital services.

However, at the validation interview, the review team was informed that these developments have not been sustained, and that momentum has been lost in all of these areas. The Southern Trust advised that education and training is now minimal in the context of the GAIN guidelines, hospital passports are no longer used and the concept of the link nurse is no longer as active as it was. Trust representatives considered that the trust had once been regarded as a regional example of good practice in this area, but expressed disappointment that this was no longer the case.

Competing priorities, pressures and resource limitations were cited as the predominant reasons for the loss of momentum in implementation of the GAIN guidelines.

From the interview, it was apparent to the review team that these initiatives had left a positive legacy. The majority of Southern Trust staff interviewed by the review team were ward sisters from the acute programme of care. All were of the view that the care delivered to individuals with a learning disability in the trust was respectful, caring, safe and effective. They were able to cite a number of examples of good person-centred care that reflected the regular and creative use of reasonable adjustments. However, as a consequence of the dissolution of the original initiatives, it was suggested that links with learning disability services were not as well established as they should be. The Southern Trust advised that the use of hospital passports was rare. There was confusion and a lack of clarity around consent processes for people with learning disabilities, limited opportunities for education and training in this area, and a view that people with learning disabilities and their families were not as well catered for within the current system as they used to be.

The review team was advised that there is an intention in the trust to start another process of service improvement in this area. The trust representatives advised the review team that before the end of 2013, a working group will be established. Work was ongoing with regard to improving the identification of people with a learning disability when they enter the general hospital system and communication folders were being developed for all general hospital wards. However, it was not clear to the review team or to the trust staff, who was leading and driving this resurgence of activity.

Similar to other trusts, the review panel was satisfied that within the Southern Trust the care of children with learning disabilities, for the most part, met the standards within the GAIN guidelines. It is hoped that the newly established working group in Southern Trust will begin to address the apparent discrepancy between children and adults who use general hospital services in the trust.

7.5 Validation Interview with the Western Health and Social Care Trust

During interview, the Western Health and Social Care Trust identified that they had been the only trust in Northern Ireland to have previously appointed a dedicated

acute liaison nurse for one of their general hospital sites. Although this post no longer exists, all in attendance agreed that it had been an excellent resource that had provided a positive impact in providing linkage between acute services and local community learning disability services.

This appointment had enhanced the confidence and competence of acute care staff and ultimately had improved patient safety and clinical effectiveness. Creation of the post had provided momentum for improvement and development, aligned to the expectations of the GAIN guidelines. However, due to a range of other pressures and priorities, there was a general sense that the momentum had ceased with the cessation of the post after a six month period.

The review team was advised that a new working group has been recently established within the trust, chaired and coordinated by the Assistant Director of Nursing (Governance, Quality and Performance). This group is taking active steps to develop systems, initiatives and ways of working to improve the pathway of care for people with a learning disability within general hospital settings.

The review team was also advised that the trust had recently commissioned from the local Lilliput Theatre Company (a group of local actors who have a learning disability), the development of a DVD that will be used as part of an educational programme, planned for acute hospital staff throughout Western Trust. The programme is designed to enhance knowledge, skills and competence of staff when caring for individuals with a learning disability.

It was apparent from the interview and the trust's self-assessment return that until recently there had been limited awareness of the GAIN guidelines, and a lack of understanding and clarity regarding responsibility for implementation and accountability processes.

There was no representation from Western Trust Learning Disability Services amongst the staff who met the review team, who found that linkages between general hospital and learning disability services appeared to be limited. Many of those in attendance from Western Trust were ward sisters, but were unaware of the people, location and contact numbers of learning disability services. Paediatric services were the exception in this regard.

The review team was also informed of a number of initiatives in place in the Western Trust designed to improve access to general hospital services for people with learning disabilities. These include the development of hospital passports, priority fast-tracking cards and easy read information. However, it seems that such developments have tended to be localised to particular areas within the trust, or have been developed and driven by the initiative of one or two people and are not being used routinely or consistently across the trust.

The Western Trust interview also provided an opportunity to explore a number of record keeping issues highlighted in the review of patients' files. These centred primarily on the process of using core care plans that had not been individualised appropriately. The review team was reassured that those issues had been brought to the attention of relevant individuals and services and action taken to address the deficits highlighted.

8 Views of Service Users, Families and other Stakeholders

A key component of this review was consultation with people with learning disabilities, family members, paid carers and a range of learning disability advocacy groups. In some cases, family members were interviewed, and a regional workshop was held to elicit the views and opinions of service users, with regard to their experiences of care within general hospitals in Northern Ireland.

Many positive experiences were highlighted, supporting the review findings that there is much good practice within hospital services in Northern Ireland. However, people also felt anxious when having to avail of these services as at times they described negative encounters. Positive experiences of hospital care included:

- pre-admission visits (particularly prior to surgery)
- taking time to speak with and explain things to the person with a learning disability and also their family members
- allowing family members or carers to stay
- shorter waiting times for services/treatment
- the provision of quiet areas or single rooms
- use of hospital passports
- people being asked for their consent

The priority areas for improvement included:

- The need to treat patients as people first, rather than as disabled. To talk to patients clearly and in a respectful manner. People with learning disabilities felt that alternative methods of communication were infrequently used or provided to them. People with learning disabilities also reported that staff performed tasks on them that they did not understand.
- The need for hospital staff to take more time with people with learning disabilities, and their families or carers. There was frequent reference to staff appearing busy and at times used this as a reason for not spending time with people. As a consequence, care delivery felt rushed and people with learning disabilities and their family or carers did not feel they had enough time to ask questions.
- The importance of asking people with a learning disability for their permission, particularly in relation to sharing information with relatives and/or carers, and to the care or treatment that is being provided.
- The need for improvements in the availability of independent advocacy, particularly in supporting individuals/families when they have concerns.
- The expectations placed on family members and paid carers by ward staff. These expectations ranged from staying with the person throughout the whole admission or communicating on their behalf.
- The need to ensure appropriate provision of education and training to all professional hospital staff, not just nurses. Examples were provided of how one carer was asked to speak to student nurses who were preparing to become registered nurses. It was felt that this should be available to all health care professional groups during pre-registration training.
- Ensuring that people with a learning disability receive the same standard of clinical care as the general population. It was considered by the review team,

that this standard was not being met with regard to areas such as medicines management, pain management, hydration and nutrition.

The draft recommendations arising from this review (see section 10) were shared with and considered by service users and other stakeholders at a regional workshop in June 2014 after the field work was concluded. The review team sought the validation of the participants of the draft recommendations. The participants were in agreement that the recommendations adequately captured the key priority areas that needed to be addressed, to ensure that hospital care for people with learning disabilities was of the highest possible standard.

9 Summary, Conclusions and Recommendations

During this review, a range of methodologies were used that enabled RQIA to achieve a broad regional view of how the care of people with learning disabilities in general hospitals is being delivered since the publication of the GAIN guidelines in 2010.

The review aimed to provide an assessment of current practice, identifying both examples of good practice and challenges to the implementation of GAIN guidelines since its introduction in June 2010.

The review team noted that while all trusts are taking account of, and implementing certain aspects of the guidelines, there is much more that needs to be done.

9.1 Implementation

All trusts have processes in place for both receipt and dissemination of GAIN guidelines.

The review team considers that all trusts need more robust processes for:

- ongoing implementation, review and monitoring of progress of the guideline
- coordination and allocation of actions to implement and embed the guideline
- holding to account processes in the implementation of the guideline
- process for ensuring that there are reporting mechanisms in place that reach director and trust board level

In some trusts, aspects of the guidelines were led by existing clinical teams; in others, specific teams were established to lead and coordinate implementation; while in others no nominated lead(s) had been identified. The review team accepts that each trust may take a different approach to the implementation of guidelines. However, with the exception of the Belfast Trust, there was no evidence of robust upward reporting to director and trust board level.

It was also highlighted by a number of trusts that while they accept that GAIN guidelines are an important element of supporting evidence-based practice, there remains a view that GAIN guidelines do not have a strong influence in terms of commissioning. Consequently, the GAIN guidelines are less of a priority in comparison to other strategic policy drivers and guidelines (e.g. NICE guidelines).

The review team was assured that the drive to implement this guideline is enhanced by its inclusion in policy documents such as the Bamford Action Plan 2012-15[13] and the Learning Disability Service Framework[12]. While this is a positive development to support their implementation, such links may not be present for other GAIN guidelines, which may need consideration by GAIN.

Recommendation 1:

All trusts should have in place a clear accountability process for implementation and review of all GAIN guidelines that are disseminated to them for implementation.

9.2 Terminology

Preventing the use of outdated and stigmatising labels is an important element in ensuring that people with learning disabilities feel included and valued when in receipt of services. This issue was also frequently mentioned by service users and carers as one that immediately creates barriers to good therapeutic and respectful relationships. The correct terminology is learning disability, which should be reflected in discussion and in documentation.

Recommendation 2:

All trusts should ensure that appropriate terminology is used in the context of learning disability.

9.3 Legal Issues

The review team was particularly concerned around misunderstanding and poor practice related to the application of proper processes around consent, capacity assessment, best interest decisions in relation to DNACPR orders. While the review team was satisfied that there is sufficient regional guidance, local policy and professional codes to inform and guide clinical practice in this regard, the practice of all professional groups, with the exception of AHPs in a single trust, was not adequate.

People with learning disabilities who contributed to this review were unfamiliar with the concept of DNACPR, and considered that general hospital staff should always try to save people. However, all stakeholders involved in the service user seminar, stated that learning disability should not be a consideration in such decisions. These should be based on the medical assessment of an individual's health at the time, and should be reviewed regularly.

The key area for improvement highlighted by service users was their right to make choices and decisions about health care interventions within general hospital settings.

There is a legal requirement to make appropriate reasonable adjustments in services under disability discrimination legislation. The proactive use of reasonable adjustments in the delivery of day to day care is a good indicator of the quality of care provided to people with disabilities. Whilst each trust outlined a range of adjustments in self-assessment returns and at validation interviews, this was rarely reflected in the files reviewed.

Recommendation 3:

All trusts should take the appropriate action to ensure that clinical practice and documentation among all professional groups, reflects the highest standard of legal, policy and professional requirements in relation to consent and DNAR processes.

Recommendation 4:

Each HSC trust should ensure that all staff understand the legal requirements related to reasonable adjustments. They should ensure that these are

considered fully in the context of caring for people with a learning disability; are applied when appropriate to do so; and are reflected within clinical documentation, including nursing care plans.

9.4 Documentation

In the majority of files reviewed, general record keeping standards were noted to have fallen short of good professional practice. While this issue applies to the care of all people, the review team considered this an area for improvement.

The absence of evidence related to the provision of reasonable adjustments was of particular note.

Recommendation 5:

All trusts should have appropriate educational and audit arrangements in place to ensure that clinical/professional assessments and interventions are fully documented in an accurate and concise manner.

Recommendation 6:

Where core or generic care plans are used, staff must individualise these around the specific and holistic needs of the patient.

Recommendation 7:

Trust documentation should ensure that at key points of access (for example, on arrival at the emergency department and/or on admission to a ward) staff are prompted to ask whether an individual has a learning disability

9.5 Links with Learning Disability Services

Each HSC trust should have arrangements in place within its triage process to specifically identify if a person has a learning disability. When a person is confirmed or suspected of having a learning disability, the likely impact on this person's understanding and cooperation in the emergency department should be established and factored into the triage assessment, alongside their clinical need for each individual in determining their priority for treatment.

The review team found that the process of liaison between general hospital services and learning disability services was irregular and dependent on the insight of individual member of staff, rather than a structured and formalised process. Each HSC trust should ensure that there are clear lines of communication and robust linkage between learning disability services and general hospital wards/departments.

Many UK hospitals have invested in dedicated staff such as liaison or link nurses. These nurses are not only the conduit between services, but can also be source of advice, guidance and support to all staff in general hospitals, when delivering care to people with learning disabilities. This is a particular requirement for the adult learning disabled population.

Recommendation 8:

Commissioners and HSC trusts should assess and consider the benefit of investing in the appointment of acute liaison nurses to support people with learning disabilities using their general hospital services.

Recommendation 9:

As an interim measure, all trusts should develop appropriately trained link nurses/champions to support staff and carers, when people with learning disabilities are receiving care in general hospital settings.

Recommendation 10:

Each general hospital ward should be provided with the names and contact details of key staff within their local community learning disability team.

9.6 Health Passports

Health passports were identified by all trusts as an important mechanism to improve communication and patient safety for people with learning disabilities during the journey through general hospital services. However, evidence of their use during the patient file review was limited.

Health passports are one form of reasonable adjustment that routinely used in many hospital services throughout the United Kingdom. They enhance the communication process by documenting important information about the patient with a learning disability, and are written mainly for the use of the staff within the hospitals. It may contain information on, for example, how best to communicate with the person, individual likes and dislikes, how he or she shows pain, and the best way to give medication.

Recommendation 11:

All trusts should develop a concise hospital passport for use by both adults and children with a learning disability who use their general hospital services. These should be available routinely for all inpatient admissions.

9.7 Sharing Best Practice

This review identified many examples of good practice and the development of innovative practices and resources, to improve the experiences of people with a learning disability in general hospitals, but often duplication of similar resources was noted. Northern Ireland needs a vehicle for sharing best practice, for example the DHSSPS should consider the development of a regional health passport in supporting their requirement under the Bamford Action Plan and the Learning Disability Service Framework.

Recommendation 12:

DHSSPS should consider how current resources (e.g. one regional, rather than several local hospital passports) can be maximised and examples of best practice can be shared across all HSC Trusts.

9.8 Family Involvement

Research has highlighted concerns with the active involvement of parents and other family members, as partners in support provided to people with learning disabilities when in contact with general hospitals. Key issues relate to: the expectation that family and/or paid carers remain with the person with a learning disability throughout their stay in hospital; issues around confidentiality and the sharing of information; and the raising or expressions of concern.

We know that people with a learning disability are vulnerable when they use hospital services and therefore, the involvement of those who are closest to the patient in their care will provide them with some reassurance, during a time of anxiety, distress and upset. Family/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 facilitate the cooperation of the person to receive 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 involvement of carers and not to consult with them. Mencap highlighted this in its Death by Indifference[6] report, which suggests that lack of involvement of families and carers can result in poor prognosis, wrong diagnosis and, potentially, avoidable deaths.

Within this review, in certain cases, it is expected or assumed by health care professionals that family/carers will continue their support and care delivery to people with learning disabilities when they go into hospital. Family members of people with a learning disability in a general hospital should not be explicit or implicitly expected to actively contribute to the care of their relative, any more than the relatives of any other patient.

Family members/carers stated that they wished to work with hospital staff to achieve the best outcomes for patients with a learning disability, within the parameters of the patient's expressed wishes, his or her capacity and the law around consent and confidentiality.

Recommendation 13:

All HSC trusts should have clear guidance on the process for establishing with the person with a learning disability (where possible), and their family members, the degree of involvement they wish to have in their care.

9.9 Complaints and Advocacy

The poor management of concerns and complaints has been highlighted in reports and inquiries that have examined the care of people with learning disabilities in hospitals. When concerns are raised or complaints are made, immediate steps should be taken to make individual patients and/or their carers aware of the process and of their rights. Easy read information in an accessible format should be developed to support this. Effective and timely investigation, empathetic and timely responses, together with an apology where necessary, will help resolve concerns locally.

There was limited evidence of the routine seeking of specific feedback from people with learning disabilities and/or their carers, related to their experience of care within general hospitals.

During the engagement process with service users, their families and other carers, it was highlighted that people with learning disabilities will very infrequently raise concerns or complain, due to a lack of confidence, limited communication skills or limited insight. Therefore, adjustments need to be made to encourage and facilitate this.

Family members advised the review team that sometimes they perceived that raising concerns could have a detrimental effect on the quality of care their relative would subsequently receive.

It is therefore crucial that all possible efforts are made to ensure that some form of independent advocacy is available, to provide advice and support during such circumstances.

Recommendation 14:

All HSC trusts should establish appropriate, accessible mechanisms whereby people with a learning disability and their families and carers are able to comment (positively and negatively), on their experience of care, when using general hospital settings.

Recommendation 15:

HSC trusts should routinely provide information to people with learning disabilities and their family members and carers, related to the availability of and contact numbers for local, independent advocacy services

9.10 Staff Training

A number of reports and inquiries have identified that training for staff in general hospital settings has been limited and sporadic. This was also the overall summary found in this review.

All HSC trusts reported the importance of mandatory training of staff in equality and diversity, and noted that this was relevant to supporting people with learning disabilities. Two trusts reported the involvement of people with learning disabilities or family carers in some aspects of such training. However, only South Eastern Trust reported specific ongoing training for hospital staff in supporting people with learning disabilities. The Southern Trust reported that a strong programme of education and practice development had previously been available for staff in general hospitals but was no longer routinely provided.

Limited education and training can result in uncertainty in providing safe, effective and appropriate care to people with learning disabilities, when they require these services. Also, many staff still do not understand their legal duties regarding disability, human rights and equality.

The knowledge, skills, attitudes and values of staff can improve through specific training in learning disability. The involvement of people with a learning disability in the development and delivery of such training is recommended within Healthcare for All[7].

During the engagement process with service users, families and carers, they highlighted the need to ensure that this education and training is not solely targeted at nurses, and that other professional groups, particularly, doctors, need to receive appropriate education and training.

Recommendation 16:

Each HSC trust should have a coordinated and planned training programme in place, related to the content of the GAIN guidelines, for all staff from general hospitals who work with people with a learning disability.

9.11 Communication

People with learning disabilities are very clear that healthcare staff should look at and speak to them first, and focus on them, rather than directing attention to carers or parents. Service users who contributed to the review expressed their negative experiences of staff talking around the person with learning disabilities.

The language used should be clear, and the information provided in manageable segments and the person asked if they have any questions. Abbreviations and the use of medical/nursing jargon should be avoided, or explained where necessary.

If the person with learning disabilities is not able to speak, they should have the opportunity to use sign language, visual aids or point and use pictures. During the assessment process, staff need to be clear about finding out how the person with learning disabilities communicates, for example speaking, sounds, pointing, pictures or sign language.

Several people provided examples of when their personal information was shared with staff and parents without their permission, which was upsetting and embarrassing.

Recommendation 17:

Each HSC trust should ensure that relevant wards/departments and staff are equipped with the necessary competencies and resources (e.g. hospital communication folders), to ensure people with a learning disability, their families and carers receive high quality communication throughout the pathway of care

9.12 Pain

The challenges of meeting the clinical needs of people with learning disabilities can be exacerbated by communication difficulties. 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. These may include non-verbal expressions of pain and changes in behaviour.

The use of reasonable adjustments, such as pain assessment scales for those with cognitive impairment, were only recorded in the files of two trusts.

Hospital staff should ensure that the skills and expertise of specialist pain nurses, if they are available, are considered for people with learning disabilities. This is particularly important in circumstances such as treatment for cancer related disorders or palliative care.

Recommendation 18:

Each HSC trust should ensure that people with a learning disability are 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. Appropriate, adapted pain assessment tools should be available for use with any patient with a learning disability, who is experiencing pain.

9.13 Transition to Adult Services

While this review found that the care of children with learning disabilities in general hospitals was positive, the issue of transition from children's hospital services into adult hospital services was highlighted by a number of parents who contributed to the review. They stated that the process of transition can be frightening the young person and their families. The review found that there are variances with regard to the age limit for transition across HSC trusts, and also found that the levels of coordination between services, of family involvement in care/treatment decisions and reasonable adjustments offered, reduced following the transfer to adult hospital services.

Recommendation 19:

Each HSC trust should have clear plans in place for the transition of children with a learning disability into adult services, at the same age as for other children. These arrangements should be developed and explained to the person with a learning disability and their family members, in a manner that provides confidence that adult services are suitable for their needs.

10 Summary of Recommendations

10.1 Implementation

Recommendation 1:

All trusts should have in place a clear accountability process for implementation and review of all GAIN guidelines that are disseminated to them for implementation.

10.2 Terminology

Recommendation 2:

All trusts should ensure that appropriate terminology is used in the context of learning disability.

10.3 Legal Issues

Recommendation 3:

All trusts should take the appropriate action to ensure that clinical practice and documentation among all professional groups, reflects the highest standard of legal, policy and professional requirements in relation to consent and DNAR processes.

Recommendation 4:

Each HSC trust should ensure that all staff understand the legal requirements related to reasonable adjustments. They should ensure that these are considered fully in the context of caring for people with a learning disability; are applied when appropriate to do so; and are reflected within clinical documentation, including nursing care plans.

10.4 Documentation

Recommendation 5:

All trusts should have appropriate educational and audit arrangements in place to ensure that clinical/professional assessments and interventions are fully documented in an accurate and concise manner.

Recommendation 6:

Where core or generic care plans are used, staff must individualise these around the specific and holistic needs of the patient.

Recommendation 7:

Trust documentation should ensure that at key points of access (for example, on arrival at the emergency department and/or on admission to a ward) staff are prompted to ask whether an individual has a learning disability

10.5 Links with Learning Disability Services

Recommendation 8:

Commissioners and HSC trusts should assess and consider the benefit of investing in the appointment of acute liaison nurses to support people with learning disabilities using their general hospital services.

Recommendation 9:

As an interim measure, all trusts should develop appropriately trained link nurses/champions to support staff and carers, when people with learning disabilities are receiving care in general hospital settings.

Recommendation 10:

Each general hospital ward should be provided with the names and contact details of key staff within their local community learning disability team.

10.6 Health Passports

Recommendation 11:

All trusts should develop a concise hospital passport for use by both adults and children with a learning disability who use their general hospital services. These should be available routinely for all inpatient admissions.

10.7 Sharing Best Practice

Recommendation 12:

DHSSPS should consider how current resources (e.g. one regional, rather than several local hospital passports) can be maximised and examples of best practice can be shared across all HSC Trusts.

10.8 Family Involvement

Recommendation 13:

All HSC trusts should have clear guidance on the process for establishing with the person with a learning disability (where possible), and their family members, the degree of involvement they wish to have in their care.

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Review of GAIN Guidelines

Profiling Questionnaire

The Regulation and Quality Improvement Authority

A Review of GAIN Guidelines:
Caring for People with a Learning Disability in General Hospital Settings

The review covers the implementation arrangements and the trusts current position in relation to the GAIN Guidelines: Caring for People with a Learning Disability in General Hospital Settings. This review excludes MH&LD Hospitals. There will be a review of the patients' notes, interviews with RQIA to validate the trust's response and further explore areas of the 12 best practice statements. In this questionnaire, service user refers to a person with a learning disability.

Please complete only one copy of the questionnaire for your trust. The document is protected to make completion less difficult, only enter text into the grey cells within text boxes.

Please return a single document in Microsoft word format; do not create a pdf document. Please do not to paste whole documents or links into this questionnaire. Submission of documents should include question number. For example, when submitting a document called "Results of trust audit of xxx" rename the file "Section 3 Q2 Results of trust audit of xxx".

Please ensure that the declaration is completed and signed by your Chief Executive and returned to RQIA no later than **Friday 2nd August 2013**. If you have any questions please contact: David Philpot, Project Manager, RQIA. Tel: 02890517517 or email: david.philpot@rqia.org.uk

APPENDIX 1

CONTENTS

SECTION 1: Implementation Process

Q.1 Please describe the actions taken by the trust on receipt of the GAIN Guidelines: Caring for People with a Learning Disability in General Hospital Settings.

Q.2 Who did the trust nominate as a responsible person(s) to lead the implementation?

Q.3 Please provide details of any teams established to implement the GAIN Guidelines.

Q.4 Please submit any evidence from working groups, minutes, action plans, audits etc. to show the implementation work undertaken and planned for the GAIN Guidelines.

SECTION 1: Implementation Process

Q.5 Are there any variations in practice in implementing the guidelines in your trust?

Q.6 Please list and attach the protocols and procedures your trust developed to support the implementation of the GAIN Guidelines?

Guidelines

Q.7 Please outline any involvement that the trust has used service users/carers in the implementation of the GAIN Guidelines?

Q.8 Please describe any service user feedback received by the trust in relation to the GAIN Guidelines as well as any evaluation of their experience?

SECTION 1: Implementation Process

Q.9 Please indicate any reporting mechanisms for implementing the Guidelines?

Q.10 Please indicate if and in what area, the trust has had difficulty implementing the GAIN Guidelines?

Q.11 Have concerns been raised by your staff with regard to implementing the GAIN Guidelines?

Q.12 Please describe these and action taken to respond to these concerns.

SECTION 2: Attitudes and values

Q.1. Please describe any measures taken by the trust to provide additional or alternative methods of support for the patient with learning disabilities and/or their families/carer in order to deliver safe and effective care when they use general hospital services.

Q.2. Please describe the process for identifying advocacy arrangements for the patient when using your general hospital services.

Q.3 Please outline how people with learning disabilities and/or their carers are involved in the decision making process when using general hospital services.

SECTION 3: Communication

Q.1 Please describe any action taken by the trust to establish a person's preferred method of communication during their contact with general hospital services

Q.2 Do hospital staff check if the patient has brought a document that highlights how they communicate?

Q.3 Does the patient care plans highlight the way(s) in which the person communicates specific needs/problems such as: hunger, thirst, toileting needs, or pain or distress?

Q.4 Describe any relevant resources used to assist in the provision of information to people with learning disabilities. Please attach copies.

SECTION 3: Communication

Q.5 Does the trust use any specific resources to support effective communication during the hospital journey? If yes, please submit a copy.

Q.6 How has the trust made the complaints processes accessible to patients who have learning disabilities and/or the family/carers?

SECTION 4 : Education & Training

Q.1 Do all new trust staff receive appropriate training in learning disabilities, to include disability equality training as part of their corporate Induction Programme?

Q.2 How many staff have received this training from April 2011 to April 2013?

Q.3 Does the trust provide Learning Disability Awareness Training for all hospital staff who have direct patient contact?

Q.4 Is this training mandatory?

SECTION 4 : Education & Training

Q.5 How many staff have received this training from April 2011 to April 2013?

Staff Group	Number of staff
Medical	
Nursing	
Admin	
AHP	
Support Services	
Midwives	
Other - please state	

Q.6 Has the awareness training been designed and/or delivered in partnership with people with learning disabilities and/or their carers?

Q.7 Is the trust Learning Disability Awareness Training competence based (i.e. includes skills development)?

SECTION 4 : Education & Training

Q.8 Does the training include the following core elements:

Core Element	Included
a) An overview of learning disability - definitions and concepts;	
b) The health issues affecting people with learning disabilities and the barriers experienced when accessing generic health services;	
c) Service users' and carers' perspectives of equitable access, including personal experiences and proposals for best practice;	
d) Effective Communication;	
e) Legislative requirements such as consent and capacity, Equality of Opportunity, Disability Discrimination Act, Human Rights Act;	
f) Influential inquiries and reports	
g) The provision of reasonable adjustments in the general hospital setting;	
h) How to access support from local learning disability services.	

Q.9 Is additional training provided to key staff (i.e. Learning Disability Liaison/Link Nurse/Champions) identified from within each clinical area?

Q.10 How many staff have received this training?

SECTION 4 : Education & Training

Q.11 Please provide an overview of this training

Q.12 Does the Learning Disability Link Nurse training objectives incorporate:

Core Element	Included
a) A greater awareness of the needs of patients with a learning disability;	
b) An understanding of the risks of harm posed by being in the hospital environment and knowledge of how these risks can be managed;	
c) An understanding of the difficulties facing patients with a learning disability and their carers when using hospital services;	
d) Knowledge and skills in caring for patients who have a learning disability and the promotion of person centred care processes at ward level;	
e) The development of local action plans to improve practice.	

SECTION 5: Legal Issues

Q.1 Have trust staff working in general hospitals received specific training on relevant equality and disability legislation, with particular emphasis given to the requirement for reasonable adjustments at a practice, policy and organisational level?

Q.2 If Yes, please describe this training.

Q.3 Does the trust make any of the following adjustments?

Reasonable adjustments	Yes/No
Providing information in a format that is most likely to aid understanding;	
The provision of longer appointments (e.g. in outpatients);	
Effective communication with the individual and/or carers;	
Appropriate mechanisms in place to identify pain and/or distress;	
Appropriate complaint handling;	
The level and extent of involvement of others such as family/carers/ advocate;	
Identifying the reasonable adjustments that are required within the individual care/treatment plans.	
Please outline any others (below…)	

SECTION 5: Legal Issues

Q.4 Please outline how the trust ensures the principle of presumed capacity in general hospital settings

Q.5 What action is taken in respect of i) Capacity assessment of individuals who are suspected to be incapacitious?

and ii) Best interest decisions

Q.6 Does every hospital ward/clinical setting have access to the document “Seeking Consent: Working with People with Learning Disabilities” (DHSSPS 2003)?

SECTION 5: Legal Issues

Q.7 For staff who work with children who have a learning disability, does the ward/clinical setting have access to the document "Seeking Consent: Working with Children" (DHSSPS 2003)?

Q.8 How does the trust seek the agreement of the person with a learning disability, to enable staff to inform and involve carers (both paid and unpaid) fully in any discussions or decisions about care or treatment?

Q.9 How does the trust apply Do Not Resuscitate decisions involving people with a learning disability"

SECTION 6: Outpatients

Q.1 What is the process in place for people making a referral to provide an indication of any additional support needs a person with learning disability may require at an outpatient appointment?

Q.2 What is the process for trust staff contacting people identified as having learning disability in advance of / after their planned appointment to discuss possible reasonable adjustments required?

Q.3 Please outline the structured approach used within the Out Patients Department (OPD) across the trust to gather key information on the person's abilities and needs and any reasonable adjustments required?

SECTION 6: Outpatients

Q.4 What types of accessible information are used within the OPD to explain the appointment process and any related investigations to person with learning disability? (Provide examples of types used.)

Q.5 Who is responsible for liaison with learning disability services after an OPD appointment when required?

Q.6 How do OPD's access to the telephone numbers of Community learning disability services?

SECTION 7: The admission process and support during the hospital stay

Q.1 What are the arrangements for a pre admission and / or ward visit prior to a planned admission to all wards in the hospital?

Q.2 What types of accessible resources are available / used to explain examination, treatment and care to a person with learning disabilities?

Q.3 Please outline the key contact details for learning disability services held at ward level and who is responsible for contacting learning disability services when required.

SECTION 7: The admission process and support during the hospital stay

Q.4 How many link nurses / learning disability champions exist within the general hospitals across the trust and what is their role?

Role / Description (ie LD Champion)	**Number of Staff** (ie 2)	**Base Location** (ie Ward 2 & 6, Any Hospital)

Q.5 What are the arrangements for the orientation of the person with learning disability and their carers to the ward layout, facilities and how to summon help?

Q.6 What are the arrangements in place for pre operative visit by theatre / recovery nursing staff and how do they establish if reasonable adjustments are necessary for people with learning disability coming to their department?

SECTION 7: The admission process and support during the hospital stay

Q.7 What are the arrangements in place for determining if increased clinical observations or additional staff support / supervision are required during a hospital stay?

SECTION 8: Discharge planning

Q.1 What types of accessible information are used to explain the discharge process and any follow up required to a person with learning disability?

Q.2 What are the arrangements included in a discharge planning meeting that actively involves the person with learning disability?

Q.3 Who is normally involved in discharge planning meetings?

Q.4 What contact numbers are provided to people with learning disability in case they may require further advice or information regarding their care following discharge?

SECTION 8: Discharge planning

Q.5 Outline the process for inviting the person with learning disability and their carers to provide feedback from their experiences about their hospital stay.

SECTION 9: Emergency care

Q.1 Outline the pathway of care when a person with learning disability is in contact with an Emergency Department.

Q.2 What arrangements are in place to prioritise the needs of a person with learning disability when they attend an Emergency Department?

Q.3 What arrangements are in place for the Triage nurse to establish the communication needs and reasonable adjustments necessary when a person with learning disability attends an Emergency Department?

Q.4 What types of accessible information are available and used to explain to a person with learning disability the examination, treatment, care and discharge process that will be required in an Emergency Department?

SECTION 9: Emergency care

Q.5 What types of accessible information are available and used to explain to a person with learning disability the examination, treatment, care and discharge process that will be required in an Emergency Department?

Q.6 What is the process involved in ensuring that the person with learning disability understands the discharge advice and any follow up arrangements?

Q.7 What specific contact information for local Community Learning Disability services is available within Emergency Departments to enable staff to be contacted or a referral to be made?

SECTION 10: Support for Carers

Q.1 For both children and adults with a learning disability, what are the arrangements with regard to family/carers providing direct care and support to the individual when using General Hospital Services?

Q.2 If family members or carers are involved in providing direct support, what arrangements are in place to provide breaks, refreshments and additional support to them?

Q.3 Are people with learning disabilities and/or their family carers involved in education/training activities delivered to general hospital staff?

SECTION 11: Nutrition and Hydration

Q.1 Please outline the process of nutritional assessment of people with learning disabilities when they use general hospital services?

Q.2 Please provide an overview of the reasonable adjustments that are put in place for people with learning disabilities to address nutritional needs while in receipt of general hospital services?

Q.3 What arrangements are in place to help people with learning disabilities with menu choice?

Q.4 What supports are provided for people with a learning disability who are unable to feed themselves?

Q.5 What arrangements are available for people with learning disabilities who have complex nutritional needs?

SECTION 12: Pain

Q.1 For those patients with a learning disability, who have difficulty with communication, what processes are in place to effectively assess and manage pain?

Q.2 Are there any specific tools or communication aids used with people with a learning disability to assess the use and effect of medication on pain? If so, please elaborate.

SECTION 13: Children in Hospital

Q.1 At what age does a child with learning disability transfer from childrens to adult wards within your service?

Q.2 What are the transition arrangements in place when such a circumstance occurs?

Q.3 Please outline any pre-admission processes that are in place to support children with learning disability being admitted to a general hospital?

Q.4 Are there any processes in place to facilitate prioritising access for children with learning disabilities into general hospitals?

SECTION 13: Children in Hospital

Q.5 Please outline the contact arrangements between hospital and community services during the admission of a child with learning disabilities?

Q.6 What arrangements are in place within childrens wards, to facilitate in-reach from relevant community staff?

Q.7 Do childrens wards have the contact numbers of local community learning disability services?

Q.8 If the child with learning disabilities also has complex physical healthcare needs, are there any additional supports or systems of care delivery utilised? If so, please elaborate.

SECTION 13: Children in Hospital

Q.9 Is the regional integrated pathway for children and young people with complex physical healthcare needs routinely used with children with learning disabilities who also have complex physical healthcare needs and explain how this is recorded?

Q.10 Please outline the discharge planning process for children with a learning disability including details of those that are routinely involved in this process?

Q.11 Please provide an overview of the education and training provided to all staff working within children's wards in the context of learning disability?

Q.12 What is the process for educating/training family members and/or carers who are required to deliver certain aspects of care when the child returns to their home environment?

SECTION 13: Children in Hospital

Q.13 What supports are in place to allow family members/carers to maintain contact with the child during their stay in hospital?

Q.14 For children requiring extended stays in hospital, please outline any additional support that is made available in the context of education, play activities and any other social activities?

Q.15 Is any specific easy read information available to aid communication processes when a child with learning disability accesses general hospital services?

Profiling Assessment for Review of GAIN Guidelines: Caring for People with a Learning Disability in General Hospital Settings

Organisation's Declaration			
Name of Organisation:			
Address:			
Chief Executive's Name:			
Affiliate's Name:			
Affiliate's Contact Details:	**Email:**		
	Telephone:		
Date Self-Assessment Form was Completed:			
In accordance with Article 34 of The Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003, I confirm that the information provided in this pro-forma and the accompanying evidence is a true reflection of this organisation.			
Signature of Chief Executive:		**Date:**	

Check list of Submissions

Section 1 Questions 4 & 6

Section 3 Questions 4 & 5

Section 6 Question 4

Appendix 2 - Audit Tool

RQIA – Review of implementation of GAIN Guideline: Caring for people with a Learning Disability in general hospital settings (June 2010) – Audit / file review of care provided

Complete one form for each patient.

Q1. Health and Social Care Trust:

Belfast/ Northern/ Southern/ Western/ South Eastern

Q2. Patient coding reference: | | | |

Q3. Sex: Male / Female

Q4. Age: 0 -12 years

13 -17 years

18 - 24 years

25 - 34 years

35 - 44 years

45 - 54 years

55 - 64 years

65 - 74 years

75 + years

Q5. General hospital setting:

Outpatient/ Emergency Department/ Inpatient Surgical/

Inpatient Medical/ Children

Ref	Question	Yes/ No/ n/a	Comments
Theme 1: Documentation on Learning disability status and other related conditions such as epilepsy, autism, challenging behavior			
6	Were the casenotes labelled that the patient had a Learning Disability?	Yes / No	
7	If appropriate, was it documented that patient had additional support needs/ co-morbidities? If yes - what conditions were identified?	n/a	Conditions identified:
Theme 2: Effective communication with the patient/ family/ carers and provision of easy read information			
8	Was an assessment of the patient's preferred method of communication recorded in casenotes?	Yes / No	
9	Did the casenotes refer to a document that highlights how the patient communicates? e.g. health action plan, patient passport, hospital support plan	Yes / No	
10	What measures were recorded in casenotes that indicated the patient had been helped to understand of the care they required? e.g. Straight forward language, picture cards, easy read literature, allowing extra time to facilitate understanding	n/a	Measures recorded:
11	Is there evidence that there was an explanation of the process of the appointment / sequence of events, using the patients preferred method of communication?	Yes / No	

Ref	Question	Yes/ No/ n/a	Comments
Theme 3: Inclusion of and support to family/carers			
12	Was there a record of discussion in relation to the involvement of family/carers during the episode of care? e.g. Involvement in direct care delivery. Involvement in discussions with regard to treatment options; in discussions to clarify assessment and care planning processes.	Yes / No	
13	Was there a record in casenotes of facilitation of family/carers to assist them to provide support to patient (including overnight provision if required)?	Yes / No / n/a	
Theme 4: Consent and best interests processes			
14	Was there any evidence of the person's capacity to make healthcare decisions recorded in casenotes?	Yes / No	
15	For individuals who were deemed not to have capacity, is there evidence of best interests processes and documentation?	Yes / No / n/a	
Theme 5: Reasonable adjustments reflected within the care plan			
16	Did the care plan include how the patient communicates their specific needs/ problems? e.g. In relation to hunger, thirst, toileting needs, pain/distress	Yes / No	
17	Is there evidence of other and appropriate reasonable adjustments within the casenotes? e.g. Adjustments in relation to waiting times, communication, meeting nutritional needs, level of support/observation, provision of aids/equipment	Yes / No	
18	Where pain was identified as a care issue, how was pain assessment carried out? e.g. Using pain assessment tools (observational reports, DISDAT), careful history taking, close observation of the individual, accurate interpretation of the communicative behaviour, clinical judgement	n/a	Method of pain assessment:
19	For learning disabled children patients, was provision made for entertainment/ social programme where appropriate?	Yes / No / n/a	

Ref	Question	Yes/ No/ n/a	Comments
Theme 6: Pre-admission contacts/visits			
20	Is there evidence within the casenotes of contact with the patient prior to the appointment/admission?	Yes / No	
Theme 7: Effective discharge planning/ transition			
21	Is a partnership approach (between hospital staff, relevant community staff and services, the patient and family/carers) to the discharge process reflected in casenotes? e.g. Sharing of information, potential discharge date notified, continued care needs of patient, role of staff in community setting, additional support for parent/carers	Yes / No	
22	Where appropriate, is there evidence of training provided for families/other essential carers to support effective discharge?	Yes / No / n/a	
23	For learning disabled children with complex health care needs, does the casenotes reflect the use of the regional integrated care pathway?	Yes / No / n/a	
24	Where required did follow up liaison with patient & family/carer occur?	Yes / No / n/a	
Theme 8: Communication between staff and with other relevant services (e.g. local learning disability services)			
25	Is there evidence within the casenotes of effective communication with other relevant services? e.g. Community learning disability team, community key worker, community children's nurse etc.	Yes / No	
26	Did referral information provided on discharge provide an indication of any additional support required?	Yes / No / n/a	

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ISBN 978-1-908660-48-0