



## Improving general hospital care of patients who have a learning disability

## Acknowledgements

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## The purpose of this guide

This improvement guide has been produced to enable healthcare organisations and their teams to successfully implement a series of interventions to improve the safety and quality of care that their patients receive.

It is recommended this guide is read in conjunction with the following:

- How to Improve - The guide for reliable and sustained improvement
- The 1000 Lives Improvement Quality Improvement Guide
- Learning to use Stories for Improvement

These are available from 1000 Lives Improvement.

## About 1000 Lives Improvement

1000 Lives Improvement wants to support NHS Wales staff and contractors in the work they are doing, to improve care and services.

The service offers help in a number of ways

- National programmes addressing issues at a strategic level.
- Bespoke improvement projects targeting specific issues identified by organisations.
- Improvement support services designed to equip and enable NHS Wales staff to make improvements, including publications and resources, events, advice and expertise.

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“The acid test of a national health service is not whether it works for people who are generally healthy but whether it benefits those with the shortest life expectancy, the greatest problems accessing services and the biggest risk that poor health will stop them taking part in society.” (Disability Rights Commission, 2006)

“The Confidential Inquiry’s findings show that people with learning disabilities continue to have poor experience and outcomes compared to people without learning disabilities.” (Department of Health, 2013)

## 1. Introduction

### Definitions and characteristics of learning disabilities

First and foremost, people with learning disabilities are people. They are unique individuals with their own likes and dislikes, history and opinions and they have the same rights as anyone else (GAIN, June 2010).

‘Learning disabilities’ is an umbrella term for persons who have varying degrees of ‘Impairment of intellectual and social functioning’. Learning disabilities affect about 1.5 million people in the UK and are common, lifelong conditions which are neither illness nor disease. In Wales there are some 11,000 adults with learning disabilities who are known to social services and in receipt of services. There are estimated to be at least a further 40,000 adults with milder learning disabilities who are not in receipt of services (Welsh Government, 2007).

‘Learning disability’ commonly refers to a history of developmental delay, a delay in or failure to acquire a level of adaptive behaviour and/or social functioning expected for a certain age, and evidence of significant intellectual impairment. Learning disability is nearly always present from birth, although some people do acquire a learning disability through trauma or infection. For them, their condition is the norm and it will always be there.

Learning disability is a lifelong condition, although with appropriate support many people can acquire practical and social skills, even if this may take them longer than usual. However, some people with a learning disability may also have other physical and emotional conditions and this may lead to the person having more than one diagnosis.

The nature of people’s learning disability varies widely and will affect the kind of support that they may require. Many people with a learning disability will have a significantly reduced ability to cope independently in a variety of situations (including health services), to understand new or complex information, to learn new skills (whether practical things like tying shoelaces, or social skills such as holding a conversation or self-care), and they may have difficulty with generalising any learning to new situations.

Some people with learning disability may not have any effective verbal

communication and need to find other ways of communicating with those around them. Some need help with everyday things like getting dressed or making a cup of tea, whilst others will live quite independently with minimal support.

It is expected that by 2020 the number of people with a learning disability in the UK will have grown by over 10 per cent as well as a growth in the complexities of learning disabilities (Michael, 2008). This is due to people with learning disabilities living longer and also due to young people with complex disabilities surviving into adulthood.

## 2. The general health of people with learning disabilities

People with learning disabilities have very diverse personalities and characteristics. Like the rest of the population, they acquire and develop other conditions and diseases which need to be treated. However, some conditions may occur more frequently.

Research evidence consistently suggests that people with a learning disability are at greater risk of physical and mental ill health than the general population. In 1998, Hollins et al reported that people with a learning disability are 58 times more likely to die aged under 50 than other people, and four times as many people with a learning disability die of preventable causes than do people in the general population. More recently, the Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) Final Report (Heslop et al, 2013) found that, on average, men with learning disabilities die 13 years younger than the general male population and women with learning disabilities die 20 years younger than the general population. Many of these deaths are considered avoidable and/or premature.

Michael (2008) reported that the general standard of health of people with learning disabilities is lower than for the general population. They have a greater risk of poorer health because they experience greater variety, complexity and range of health problems compared with the general population. Reviewing studies related to the health of people with learning disabilities and the inequalities in health that they experience, Emerson et al (2012) note the following:

- The prevalence rates of epilepsy are reported as being 20 per cent in the learning disability population, compared to less than one per cent in the general population, and seizures may be both multiple and treatment resistant.
- Dementia is said to occur in 22 per cent of adults with learning disabilities aged over 65 compared with a prevalence rate of 6 per cent for the general population. It may also occur earlier in certain groups, e.g. Down's syndrome, where people in their 30s and 40s may display symptoms.

- People with Down's syndrome are also at a specific risk of hypothyroidism with studies reporting prevalence rates of 9 - 19 per cent.
- Approximately 40 per cent of people with learning disabilities have some degree of hearing loss.
- Estimates of visual impairment vary widely and are given as being 8 - 200 times more likely in people with learning disabilities than the general population.
- Research is limited but there is some suggestion that people with learning disabilities may be at higher risk of osteoporosis than the general population.
- One in three adults with learning disabilities and four out of five people with Down's syndrome have unhealthy teeth and gums.

People with learning disabilities have a higher risk of coronary heart disease (second most common cause of death) and higher rates (roughly double) of gastrointestinal cancers, such as oesophageal, stomach and gall-bladder, and stomach disorders, and are more prone to developing diabetes than the general population. Respiratory disease is the main cause of death in people with learning disabilities. They are at risk of respiratory tract infections caused by aspiration or reflux if they have swallowing difficulties, and they are less likely to be immunised against infections and hence are three times more likely to die from respiratory disease than are the general population (RCN, 2006).

People with learning disabilities may experience multiple co-morbidities and chronic health problems. For example, in the Confidential Inquiry (Heslop et al, 2013), 17 per cent of the sample had four or more such conditions. Due to their experiences of both acute and chronic illness, people who are learning disabled have an increased attendance and admittance to acute general hospitals and the demand from people with learning disabilities, their families and carers on specialist and general health service is expected to increase significantly in the future (Gates, 2011).

Evidence shows that many physical, sensory and mental health needs of people with learning disabilities go unrecognised and unmet by services, with consequent negative impacts on the person's quality of life, life chances, life expectancy and experience of services (Scottish Government et al, 2012).

Language choice and language need are integral to good care and patient safety. The Strategic Framework for Welsh Language Services in Health, Social Services and Social Care (Welsh Government, 2012) states that organisations have a responsibility to recognise and accept responsibility to respond to language need as an integral element of care. This must include both choice of language and also the use of appropriate communication aids.

## Why do people with learning disabilities find it harder to access effective healthcare services?

People with learning disabilities can find it difficult to access services and often have a different experience of using services than do other patients, for a variety of reasons.

For example, if they have poor understanding, communication difficulties or sensory impairments, people will need to communicate with them in an appropriate and accessible manner. However, professional barriers can inhibit this. Professional barriers include:

- Lack of awareness of learning disabilities.
- Lack of training in learning disabilities.
- Assumptions and biases about people with learning disabilities.
- Diagnostic overshadowing - attributing symptoms and behaviour associated with illness to the learning disability rather than any other cause, and consequently appropriate investigations and treatments may not be undertaken and illness can be overlooked.

In addition, organisational barriers can also impede effective communication. Organisational barriers include:

- Rigid appointment systems.
- Reliance on written forms of communication.
- Poor signage, which people with low literacy skills and poor sensory abilities will find difficult to follow.
- Lack of awareness of the Mental Capacity Act, 2005.
- Inter-agency and inter-professional barriers.

## Risks and challenges

Several reports (for example, Mencap, 2007 and 2012, Michael, 2008) have highlighted the poor experience and poor health outcomes, including premature death, of learning disabled people of general hospital services. Reports also note the failure of organisations to make changes in the way they deliver services to take into account people's differing needs.

Michael (2008) found convincing evidence that people with learning disabilities have higher levels of unmet need and receive less effective treatment, despite the fact that the Disability Discrimination Act and Mental Capacity Act set out a clear legal framework for the delivery of equal treatment.

Whilst the Michael Report identified examples of good practice, some appalling examples of discrimination, abuse and neglect across the range of health services were also identified. It was found that health service staff, particularly those working in general healthcare, had very limited knowledge about learning disability and the health needs, communication problems, and cognitive impairment characteristic of learning disability, were unfamiliar with the legislative framework, and commonly did not understand that a right to equal treatment does not mean treatment should be the same.

Staff were also not familiar with what help they should provide or from whom to get expert advice. It was also found that partnership working and communication (between different agencies and tiers of services providing care, and between services for different age groups) was poor in relation to services for adults with learning disabilities.

Michael recognised that “addressing the difficulties faced by people with learning disabilities in accessing general healthcare services does not require specialist knowledge about learning disabilities; the issues they face are relevant to all members of society. What matters is that people with learning disabilities are included as equal citizens, with equal rights of access to equally effective treatment.”

The report set out ten recommendations which have clear links to the Disability Discrimination Act, 2005 (now addressed within the Equality Act, 2010) and the requirement that health service providers make ‘reasonable adjustments’ so that services can be accessed by all.

## Reasonable adjustments

People with learning disabilities have the right to the same level of medical and nursing care as that provided to the general population. ‘Reasonable adjustments’ mean that services must anticipate and be responsive and flexible so that any diagnosis or treatment takes into full account the learning disabilities and needs of the person, so that the best possible health outcome for that person can be achieved (NPHS, 2009).

However, ‘equality’ for a patient with a learning disability does not necessarily mean receiving the same service as patients without a learning disability, and may mean providing additional and alternative methods of support established with the patient and/or their families/carer in order to achieve a positive outcome (GAIN, June 2010).



## 3. General hospital care of patients who have a learning disability

### Care Bundle and Driver Diagram

The aim in NHS Wales is for a strategic, cultural long-term shift to achieve better experiences and outcomes for people with learning disabilities when they access general hospital services, with greater integration, communication and information sharing between general hospital and learning disability services as the norm.

The 'care bundle', which has been developed and trialed by 1000 Lives Improvement and Abertawe Bro Morgannwg University Health Board (ABMUHB), is a step in this direction. It will help NHS Wales health boards and trusts to be consistently alert to, and to respond to, the needs of people with learning disabilities, and their families and carers, when they access general hospital services.

The care bundle sets out key steps, which if taken consistently for all patients who have a learning disability, will ensure:

- Early recognition of patients with learning disabilities.
- Effective communication with patients, carers, family members and clinicians.
- Dignified, person-centred care and treatment.
- Effective review and discharge planning.

The bundle comprises several steps at various stages of the patient's stay.

#### ***Steps to be taken within 4 hours of attendance or admission of a patient who has a Learning Disability***

- Notify patient advocate/care co-ordinator/Care Manager/acute liaison nurses/specialist Learning Disability services to help liaison with investigating departments.
- Notify next of kin and/or primary carer of admission.
- Request hospital passport (e.g. traffic light assessment) for the person.

#### ***Steps to be taken daily (regardless of length of stay)***

- Patient-centred plan, developed with the patient, primary carers and/or family, reviewed and updated.
- Care plan communicated and shared with ward team members.
- Named nurse identified to patient/family and other staff throughout the duration of stay.

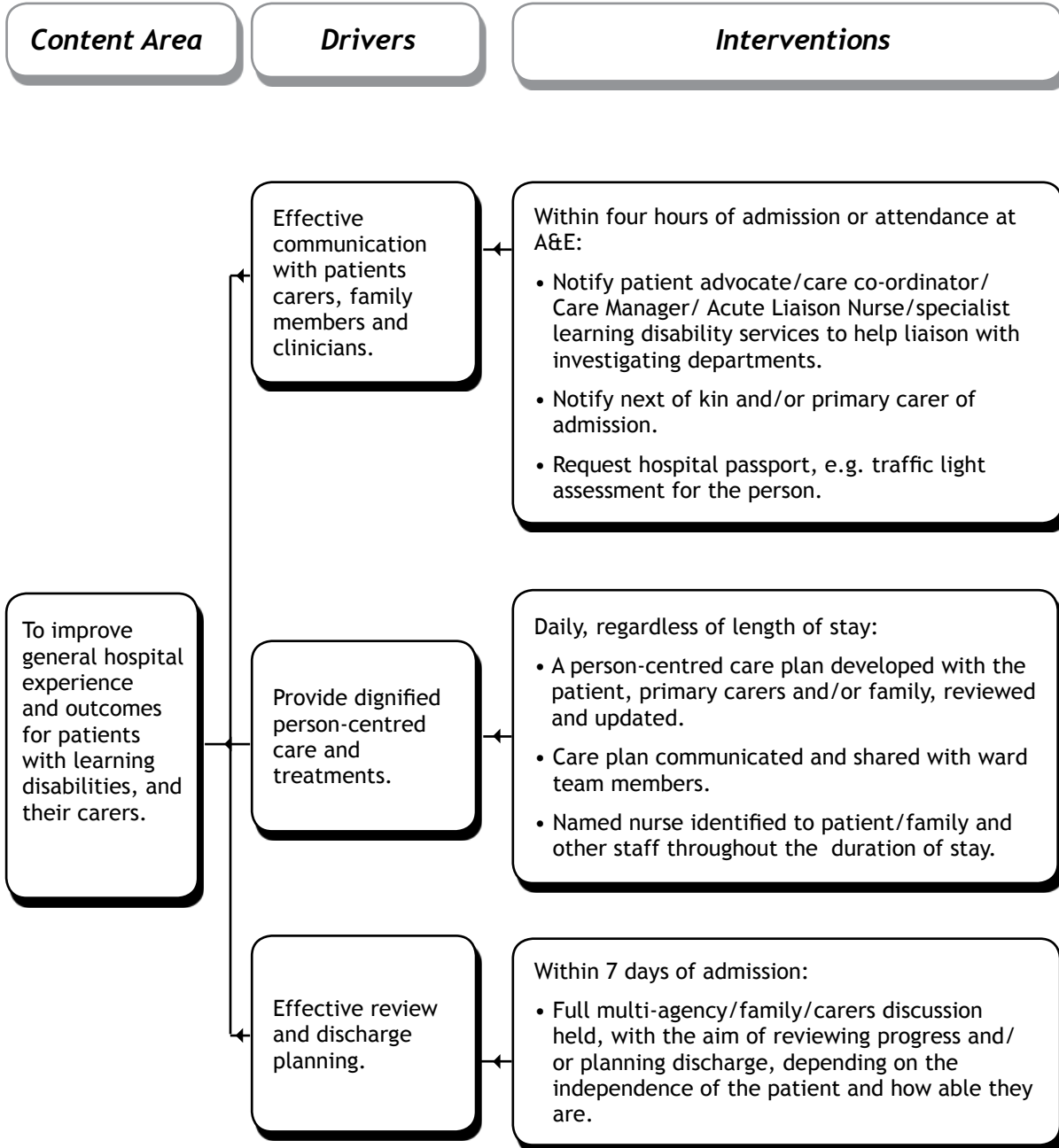
***Steps to be taken within 7 days of admission of a patient with a Learning Disability***

- Full multi-agency/family/carers discussion held, with the aim of reviewing progress and/or planning discharge.

The bundles are incorporated into the following driver diagram.

Note: All parts of the bundle must be delivered, otherwise the bundle should not be recorded as delivered.

## General hospital care of patients who have a Learning Disability Driver Diagram



## The Model for Improvement

1000 Lives Improvement uses the Model for Improvement as the basis for all its improvement programmes. It requires you to address three key questions and then use Plan-Do-Study-Act (PDSA) cycles to test a change idea. By doing repeated small-scale tests, you will be able to adapt change ideas until they result in the reliable process improvement you require. Only then are you ready to implement and spread the change more widely.

It is recommended that all staff involved in improvement efforts are introduced to the methodology through completing the bronze level of Improving Quality Together, the national learning programme of improvement skills for NHS Wales staff and contractors. The bronze level can be accessed online at [www.IQT.wales.nhs.uk](http://www.IQT.wales.nhs.uk) and takes a maximum of two hours to complete.

The Model for Improvement is also explained in two publications available online at [www.1000livesi.wales.nhs.uk](http://www.1000livesi.wales.nhs.uk)

- How to Improve
- The Quality Improvement Guide

## Making improvement happen

Successful improvement initiatives don't just happen - they need careful planning and execution. There are many things to consider and techniques to employ.

In any improvement initiative you need to succeed in three areas. You need to generate the **Will** to pursue the changes, despite difficulties and competing demands on time and resources. You need the good **Ideas** that will transform your service. Finally you need to **Execute** those ideas effectively to get the change required.

### Will

The interventions you need to build Will are explained in the 'Leading the Way to Safety and Quality Improvement' and 'How to Improve' guides available from 1000 Lives Improvement ([www.1000livesi.wales.nhs.uk](http://www.1000livesi.wales.nhs.uk)). They concentrate on raising the commitment levels for change and then providing the project structure to underpin improvement approaches. Spreading changes to achieve transformative change across the whole health system requires strong leadership.

We need to create an environment where there is an unstoppable will for improvement and a commitment to challenge and support teams to remove any obstacles to progress.

### Ideas

The interventions in this guide describe ideas which evidence shows to be effective for achieving changes that result in improvements. It gives examples from organisations that have achieved them and also advice based on their experience. Methods and techniques for generating new ideas or innovative ways to implement the evidence can be found in the 'How to Improve' guide and other improvement literature.

## Execution

However, to bring these ideas into routine practice in your organisation, it is essential that you test the interventions and ensure that you have achieved a reliable change in your processes before attempting to spread the change more widely.

### The three key questions

#### *What are we trying to accomplish?*

You will need to set an aim that is Specific, Measurable, Achievable, Realistic and Time-bound (SMART). Everyone involved in the change needs to understand what this is and be able to communicate it to others.

#### *How will we know that change is an improvement?*

It is essential to identify what data you need to answer this question and how to interpret what the data is telling you. 'How to Improve' - available from [www.1000livesi.wales.nhs.uk](http://www.1000livesi.wales.nhs.uk) - provides detailed information on the tools, tips and information you need to achieve this, and includes the following advice:

- **Plot data over time.** Tracking a few key measures over time is the single most powerful tool a team can use.
- **Seek usefulness, not perfection.** Remember, measurement is not the goal; improvement is the goal. In order to move forward to the next step, a team needs just enough data to know whether changes are leading to improvement.
- **Use sampling.** Sampling is a simple, efficient way to help a team understand how a system is performing.
- **Integrate measurement into the daily routine.** Useful data is often easy to obtain without relying on information systems.
- **Use qualitative and quantitative data.** In addition to collecting quantitative data, be sure to collect qualitative data, which is often easier to access and highly informative.
- **Understand the variation that lives within your data.** Don't over-react to a special cause and don't think that random movement of your data up and down is a signal of improvement.

#### *What change can we make that will result in improvement?*

The interventions in this guide describe a range of change ideas that are known to be effective. However, you need to think about your current local systems and processes and use the guide as a starting point to think creatively about ideas to test. The improvement methodology guide gives more advice to support you in generating ideas.

## 4. Drivers and interventions

### Driver 1: Effective communication with patients, carers, family members and clinicians

People with learning disabilities are likely to have communication difficulties which may impact upon their ability to report symptoms and to receive information. People with a learning disability may also present with unusual or challenging behaviour, which may be indicative of pain or ill-health and can impact on the process of providing health care.

Communication is key to good health outcomes. Healthcare professionals need to communicate effectively with the person with a learning disability and also with their families, carers and any other service providers working with the person, as they will know the person and what support he or she needs.

Effective communication also means communicating with the person with learning disability and their families/carers in their choice of language. The Equality Act, 2010 sets out legal requirements to provide information that is accessible to all patients regardless of any disability (reasonable adjustment).

The benefits of achieving effective communication with patients, carers, family members and clinicians include:

- People with learning disabilities are identified early at the first point of contact with general hospital services to ensure reasonable adjustments are put in place promptly.
- Patients, family members and carers are involved as a matter of course in the provision of treatment and care in decision-making (Michael, 2008).
- Health professionals can access the essential information which carers possess, especially important in relation to communication with someone who may have no speech or no sight, special needs or fears and/or challenging behavior (Michael, 2008). This can help to establish whether behaviours are unusual or indicative of pain, and can help professional staff to avoid diagnostic overshadowing - assumptions that certain behaviours are part of having a learning disability (Welsh Government, 2011).
- Professional staff can be proactive and prompt in intervening and assessing the needs of a person with a learning disability (Mencap, 2007) and additional care needs are identified at an early stage.
- Other professionals, e.g. the Learning Disability Support Team can assist with patient assessment, communication and liaison with other services
- Informed decision-making involving all parties.
- A positive and constructive relationship between patients, families, carers and staff.
- Understanding quality of life from the patient's perspective rather than the professional's opinion (Mencap, 2007).
- A better experience of general hospital services and better outcomes for people with learning disability.

## **Context**

This driver applies to all general hospital in-patient and day case areas.

## **Timing**

The interventions which relate to this driver are completed within four hours of admission or attendance at the Emergency Department.

## **Intervention 1:**

### **Notify patient advocate/care co-ordinator/ care manager to help liaison with investigating departments**

The rationale for this intervention is that notifying the person's advocate, care coordinator or care manager can help liaison with investigating departments, and speed up investigations, diagnosis and treatment - this is good practice. This familiar support will also help the person with learning disabilities to settle into the new environment, understand what is happening and reduce their anxiety.

### ***Examples of local practices***

**Aneurin Bevan University Health Board** Health Liaison Team for people with a learning disability undertakes assessment via a Learning Disability Screening Questionnaire (LDSQ) to identify if the person has a learning disability, if the person is not already known to the service.

**Abertawe Bro Morgannwg University Health Board**, together with some of its local authority partners, has appointed a Consultant Nurse for Learning Disabilities, with a specific role of improving access to and quality of primary and secondary care services. The Consultant Nurse works very closely with staff from the acute service and promotes learning disability issues and awareness in the general hospitals. The role also involves strategic planning and policy development.

The health board has an executive-led Learning Disabilities Steering Group that provides strategic direction in relation to acute hospital services. This strategic direction is implemented through a multi-professional/agency operational 'Pathway' group which has representation from service user and carer groups and third sector providers.

**Betsi Cadwaladr University Health Board** Acute Liaison Nurses ensure that all people involved with the person's care are informed of the admission and are kept up to date with their care in the general hospital

The Health Liaison Team support GPs to ensure that their Learning Disability registers are accurate. Discussions are being held with IT leads to "flag" people with learning disability, sharing GP information: some people with very complex needs are already 'flagged' on the Health Board systems, in line with a similar model used by NHS Lothian

**Powys Teaching Health Board** Community Learning Disability Team links with the hospital liaison team as a point of contact between the services. This ensures smooth transition prior to admission and on discharge.





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## Top tips

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- Acute liaison nurses help to bridge community and hospital services and to ensure continuity for patients with a learning disability when they access general hospital services. This value of this role is endorsed by research: the Michael report (2008) states that “there is preliminary qualitative support for the value of appointing staff, commonly called ‘acute liaison nurses’ to provide health facilitation or link working (Caan, 2005 and Taylor, 2007, both cited in Michael, 2008) between and across primary and secondary specialised (acute hospital) care”.
- Hospital patient administration systems should ‘flag’ all people with learning disabilities. This will help to ensure that reasonable adjustments are made, e.g. information sent out is in easy read/ accessible format or bilingually as required, and that support staff are utilised as appropriate. The first recommendation of the Michael Report (2008) is that “all health care organisations should ensure that they collect the data and information necessary to allow people with learning disability to be identified by the health service and their pathways of care tracked”.
- Establish systems (e.g. automatic e-mail) for alerting the Acute Liaison Nurses, where they are in post, of each admission to hospital of a person who has a learning disability.

## Intervention 2:

### Notify next of kin and/or primary carer of admission

The rationale for this intervention is that notifying the person’s next of kin and/or primary carer is good practice which should be routine:

“Family and other carers should be involved as a matter of course as partners in the provision of treatment and care, unless good reason is given, and (Trust) Boards should ensure that reasonable adjustments are made to enable and support carers to do this effectively. This will include the provision of information, but may also involve practical support and service co-ordination”. (Recommendation 3, Michael, 2008)

This approach will ensure that key carers are aware of the admission and are able to support the person, and to provide valuable information that will support both the person and the clinical process, and to make informed decisions.

Involving families and carers increases opportunities for hospital staff to exchange information, to provide emotional support and to check that their explanations about procedures, medication and changes in condition or treatment are fully understood by the patient and carers.

This may also assist with decision making if the individual lacks capacity to make decisions associated with treatment and a 'best interests' decision is required. (For more information on 'best interests' decision see the Code of Practice to the Mental Capacity Act 2005 <http://www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act>).

### ***Examples of local practices***

**Abertawe Bro Morgannwg University Health Board** has introduced the use of Hospital Communication Boards in the Princess of Wales Hospital. These boards have been developed in partnership with people with a learning disability and key staff in each of the clinical areas have received training in their use from the specialist learning disabilities Speech and Language therapy team.

There are ongoing training programmes for acute staff across the Health Board in relation to learning disabilities. Significant numbers of acute staff have been trained through both mandatory/statutory training programmes and also bespoke training to key staff groups. Training is delivered by specialist learning disabilities staff. General Hospital staff from the HB's Learning Disabilities Pathway group have also cascaded training in relation to the Care Pathway in their clinical areas.

**Betsi Cadwaladr University Health Board** Health Liaison team have ensured that wards within the Health Board have access to the hospital communication book, which supports communication with people which has been developed in partnership with people with learning disabilities and learning disability nurses and includes numerous colour illustrations to support communication on basic needs, food and drink, pain, signs and symptoms, tests and treatment and maternity (<http://www.communicationpeople.co.uk/wp-content/uploads/2013/11/Hospital-Communication-Book-Flyer-version-3-Nov-13.pdf>)

**Hywel Dda University Health Board** won an NHS award in 2013 for their initiative to introduce new hospital signage at Withybush Hospital which was developed and evaluated by a group of adults with learning disabilities. Their learning has been captured on video and can be viewed online at <http://bit.ly/hdhnhs>

**Velindre NHS Trust** has developed fully accessible books for people with learning disabilities, with easy words and pictures. The books are available on each ward and in the outpatients and palliative medicine departments, and explain screening and staying healthy, diagnosis and treatment, and palliative and end of life care and bereavement. Versions of all three books are available for carers and easy read leaflets which explain radiotherapy and the equipment used are also available.



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## Top tips

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- Engage with and listen to carers, formal or informal. There are a variety of ways to do this and advice can be sought from 1000 lives improvement.
- Wherever possible include family carers and/or paid support staff in the nursing handover and, if not possible, seek current information from them for inclusion in the handover (Welsh Government, 2011).
- Introduce user-friendly information/booklets around all aspects of the patient's journey within the service (e.g. Going to Hospital, Going to A&E) (Loughran et al, 2013).
- Develop user-friendly guidelines/tools/communication systems in partnership with service users (Loughran et al, 2013).
- Always write and present information in ways which make it easier for everyone to understand (Loughran et al, 2013).
- Recognise and respond to language of choice and language of need.
- Consult people who have learning disabilities and their carers/families at all levels of service development (Loughran et al, 2013).
- Provide training to ensure that staff understand the communication needs of people who are learning disabled.

## Intervention 3:

### Request hospital passport for the person

A hospital passport (e.g. traffic light assessment) is a statement that has already been prepared for a person with learning disabilities which accompanies the person to hospital. Its primary purpose is to provide important information about the individual, their needs and how best their needs can be met. It sets out:

- Information the service must know about the person, including personal details, contact information and health profile (red).
- Information which the person would like the service to know about them such as communication and understanding, personal care, mobility, sight and hearing (amber).
- Information and preferences the person would like to happen to them to make their hospital stay more enjoyable, including likes and dislikes (green). (See example in Appendix A).

Using this tool ensures that key information to inform and improve communication, diagnosis and treatment can travel with the person to different departments around the hospital. Every healthcare professional in contact with the patient can access it and use the information it contains to inform their practice.

The hospital passport can improve communication and care between professionals and between healthcare staff and the person. It can reduce risk and improve the quality of the individual's experience of general hospital services. Also, there should be liaison with those who are named as significant contacts on the assessment regarding the patient's hospital stay.

### ***Examples of local practices***

In **Abertawe Bro Morgannwg University Health Board** a laminated poster is available for all general hospital wards and departments which explains the traffic light system and how general hospital services for people with learning disabilities can be improved (see Appendix B).

In **Aneurin Bevan University Health Board** the traffic light assessment is available to all staff on the intranet.

In **Betsi Cadwaladr University Health Board**

- The Health Liaison Team is working with Conwy Connect to develop a 'model' by which all people with Learning Disability will have a Traffic Light Assessment.
- The Health Liaison Team are developing an e-learning package which will include the Traffic Light Assessment.
- There is active monitoring of the numbers of Traffic Light Assessments brought into hospital when people who have a learning disability are admitted. The data shows that since the introduction of Acute Liaison Nurses the number of people with learning disabilities admitted to general hospitals with hospital passport systems has increased from 20 per cent to 50 per cent. Copies are available to be completed (usually by the carer or family member) for those who attend without a passport.
- Traffic Light Assessments will be available to all people with learning disabilities and hospital staff will be trained to recognise and ask for these.



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### **Top tips**

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- Community learning disability teams should ensure that hospital passports are available and include up-to-date contact details.
- Train hospital staff to recognise and use the hospital passports from first year student nurses in all fields, upwards.
- Ensure hospital staff who will be involved of the care of the person with learning disability are familiar with the person's hospital passport as soon as it is available.

## **Driver 2: Provide person-centred care**

The rationale for this driver is to ensure that all general hospital care for people who have learning disabilities is planned and delivered on the basis of the needs and preferences of each individual person and their circumstances.

### **Context**

The principle of this driver applies to all general hospital in-patient and day case areas and to Accident and Emergency (A&E) departments. However, the interventions will be used in general hospital in-patient and day case areas, not accident and emergency departments.

### **Timing**

The interventions relating to this driver are completed on a daily basis, for the duration of the hospital stay, regardless of the length of that stay.

### **Intervention 1:**

#### **Patient-centred plan, developed with patient, primary carers and/or family, reviewed and updated.**

Each person with learning disabilities will have different needs and will benefit from different levels of support to help them cope and to achieve the best health outcomes for their stay in hospital. It is crucial to carefully assess each person's need for support and who is best placed to provide that support (Welsh Government, 2011). Having a patient-centred plan, which is developed with patient, primary carers and/or family and which is reviewed and updated daily, with their input, will help to ensure that:

- Care and treatment is provided as prescribed.
- Care is co-ordinated between professional groups.
- Communication between families and carers and hospital staff is maintained.
- The emotional support needs of the person are recognised and can be addressed.
- Hospital staff are aware of how best to support the person, e.g. sufficient support and time can be identified to prepare the person for investigations or interventions and for health professionals to conduct complex consultation, investigations or interventions.
- There is appropriate liaison with relevant others over capacity to consent and best interests as appropriate within the context of the Mental Capacity Act, 2005.

- Learning disability professionals are consulted and/or attend relevant reviews.
- The knowledge professional staff have of health issues for people with learning disabilities is increased.
- There is less risk of 'diagnostic overshadowing'.

### ***Examples of local practices***

#### **Betsi Cadwaladr University Health Board**

A part time Health Care Support Worker (HCSW), who has a learning disability, works within the Health Liaison Team. He contributes to all operational planning for the team, assists in the development of accessible information, and participates in the training of student nurses, psychology students, out-patient department technicians, and ward staff.

The HCSW also delivers Health Action Planning and group work with members of the Health Liaison Team and Community Learning Disability Teams and he has completed an audit into service users' perceptions of Health Action Planning.

**Abertawe Bro Morgannwg University Health Board** has developed a Care Pathway that clearly defines the roles of staff from both acute and specialist learning disabilities services when patients with learning disabilities are admitted to acute settings. The Pathway is available to all staff from the Health Board's intranet homepage

**Abertawe Bro Morgannwg University Health Board, Aneurin Bevan University Health Board and Powys Teaching Health Board** have signed up to Mencap's Getting it Right Charter (<http://www.mencap.org.uk/campaigns/take-action/getting-it-right>) to show their commitment to ensuring that people with a learning disability get the healthcare they are entitled to.

The Charter sets out the key activities that all healthcare professionals should undertake to ensure that there is equal access to health.

Key priorities for the health boards are:

- Make sure that hospital passports are available and used.
- Promote the Mental Capacity Act 2005 and make sure that all staff understand and apply the principles of this Act.

- Provide on-going learning disability awareness training for all staff.
- Listen to, respect and involve families and carers.
- Provide practical support and information to families and carers.
- Provide information that is accessible to people with a learning disability.

Alongside this, other initiatives which the Health Boards are pursuing include:

- Ensuring the same right of access to primary, secondary and specialist health services as for other people.
- Supporting staff in general healthcare to understand the needs of the learning disabled.
- Improving dementia care for the learning disabled.

**Velindre NHS Trust** has developed a care pathway for people with a learning disability attending the Velindre Cancer Centre.

A pilot initiated between the Flintshire and Wrexham Community Learning Disability Teams, Cervical Screening Wales and Breast Test Wales, aimed to support women with a Learning Disability to make an informed choice with regard to accessing screening services and to train nurses regarding provision of services to women with learning disabilities. Two volunteers who were known to the Learning Disability services contributed to the development of a clinical pathway, photographic teaching aids and examples of the equipment used during the screening procedures. The initiative proved so successful that it was subsequently rolled out across Wales.





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## Top tips

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- Highlight key contacts in the care plan.
- Involve people with learning disability and their family and carers wherever possible, e.g. through carers' groups, team awareness days, focus groups, and involvement in ongoing developments.
- Where someone lacks capacity to make a specific decision, ensure all the key people who know the person well are involved in Best Interest decision making, multi-disciplinary team meetings and discharge planning, and planning groups should invite people with learning disability, their carers and family to inform service development plans.
- Whenever there is an indication that the patient requires more or less support undertake an assessment of risk, dependency and support needs. (Welsh Government, 2011).
- Monitor and evaluate the effectiveness of the hospital Learning Disability care pathway and involve people with Learning Disabilities and their carers. (Welsh Government, 2011).
- Develop collaborative approaches to designing tools, care pathways and procedures and factor learning disability into these to ensure that people with learning disabilities are afforded the same services as the rest of the population, with reasonable adjustments where necessary (Loughran et al, 2013).
- Liaise with the patient, carers and the Community Support Team in developing a person-centred Care Plan using tools described in the care pathway.
- Utilise appropriate methods of communication, taking into consideration the language needs of the person, family and carers.
- Where Acute Liaison Nurses are in post, referral to and negotiation regarding involvement should take place. Liaison Nurses should be kept informed of changes to the person's health.
- The responsibility for providing care to the person with a Learning Disability lies with the clinical area to which the person has been admitted, however the usual support that the person has may be available through negotiation with the family/ local authority / care provider.

## Intervention 2:

### Person-centred care plan communicated and shared with ward team members

The objective of this intervention is to ensure that all ward team members are aware of the care plan for the individual so that this can be followed and the person receives care delivered in accordance with the plan, enjoys a positive hospital experience and achieves the best possible outcome.

#### *Examples of local practices*

**Aneurin Bevan University Health Board** has developed a Health Liaison Team who facilitate co-ordination of general hospital services for the person with a learning disability to ensure that person-centred reasonable adjustments are made, e.g. liaison with outpatient departments and anaesthetists to consolidate visits, to minimize disruption and distress to the person.

#### **Betsi Cadwaladr University Health Board**

The Acute Liaison Nurse is the point of contact for family and carers and provides liaison between them and the ward. The Acute Liaison Nurses link with ward staff to keep them up to date with any progress or issues; this is a very informal approach at present but it is proving successful.

The Acute Liaison Nurses ensure that any protocols or care plans such as for Epilepsy, Dysphagia or PEG are available to hospital staff and work alongside these staff so that the plans can be better understood and adhered to.

#### **Powys Teaching Health Board**

The Community Learning Disability Team use the Acute Liaison Nurse as a point of contact between the services to ensure that all information, e.g. epilepsy profiles, risk assessments, dysphagia plans, traffic light assessments, has been shared to promote better outcomes for the person.



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## Top tips

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- Ensure all hospitals have a care pathway in place which details good practice at each stage of the admission process through to discharge and individual responsibilities in ensuring patients with learning disabilities have appropriate care (Welsh Government 2011).
- Ensure that people with learning disabilities have access to the same investigations and treatments as anyone else, but acknowledge and accommodate if they need to be delivered differently to achieve the same outcome (Heslop et al, 2013).

## Intervention 3:

### Named nurse identified to patient/family and other staff throughout the duration of stay

Ensuring that a named nurse is identified throughout the duration of the patient's stay and that the patient, family and carers and other staff know who this named nurse is will help to reduce anxiety and to improve understanding between all concerned and will help towards a more personal and less stressful experience.

The CIPOLD Report (2013) recommends that, "A named healthcare coordinator to be allocated to people with complex or multiple health needs, or two or more long-term conditions."

#### *Examples of local practices*

##### **Betsi Cadwaladr University Health Board**

The Acute Liaison Nurses identify a small number of ward staff to work with, to overcome discontinuity due to staff rotation and shifts, to link with and to clarify any issues. They also attend ward rounds, if appropriate, to get up to date information from the medical staff and they also have access to the hospital IT systems.

##### **Powys Teaching Health Board**

The policy is to ensure that all relevant information from the Community Learning Disability Team is shared with hospital staff, and to ensure that a person who has learning disabilities is appropriately supported throughout their admission.



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## Top tips

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- Acute liaison nurses on the general hospital site can access the same documentation that hospital staff can, and identify the person who is best placed to provide them with any clarity needed in relation to a person's care.
- Identify an experienced member of health care staff for each ward or department to take a lead on support for people with Learning Disabilities in their clinical areas (Welsh Government, 2011).
- Make arrangements for someone who knows the individual and their issues to be present during ward rounds (Welsh Government, 2011).

### Driver 3:

#### Effective review and discharge planning

##### ***Intervention 1: Full multi-agency/family/carers discussion held, with the aim of reviewing progress and/or planning discharge***

This driver aims to ensure that the person's condition, care and treatment are effectively reviewed so that progress is assessed and discharge planning can take place sufficiently early to ensure that the length of stay in the general hospital is appropriate to need.

Consideration can be given of any change in the person's needs since their admission, for example, as a consequence of surgery, and if so then the Local Authority Care Manager or Hospital Social Worker can be asked to carry out an assessment of changed needs or a continuing health care assessment. This will ensure that the allocation of additional funding for extra support will be agreed in plenty of time before the patient is discharged home.

Involving the patient, family and carers, the ward staff, Acute Liaison Nurses, social worker, care co-ordinator, the Community Learning Disability Team and the Local Authority Care Manager and support staff will help to keep all parties fully informed and all relevant information and concerns can be considered. The necessary arrangements can be put in place to facilitate a timely discharge and consideration can be given to what will be needed at home, any future requirements following the hospital stay and any possible side effects of new medication.

Staff can establish what to do and who to contact if any complications arise or if there are any concerns about the person's health after they have been discharged. Carers and families can use this session to give their views about the hospital stay and what worked well and what could be improved.

Everyone who needs to know when the person will be leaving hospital should be informed. Arrangements for any outstanding follow up appointments or specialist assessments such as occupational therapy can be confirmed and transport home organised if needed.

## Context

This driver and intervention applies to all general hospital inpatient and day case areas.

## Timing

Within seven days of admission.

### *Examples of local practices*

#### **Abertawe Bro Morgannwg University Health Board**

The health board hospital pathway for adults with a learning disability provides clear guidance on multi-professional care planning and effective discharge planning.

#### **Betsi Cadwaladr University Health Board**

Because of the input of the Acute Liaison Nurses and their relationships and contacts with the wards, they are invited to any discharge planning and Best Interest meetings and on many occasions instigate these meetings. The Acute Liaison Nurses all have close relationships with the discharge teams in the three general hospitals. In one of the hospitals the Acute Liaison Nurse is based with the discharge nurses and patient flow team and this has greatly improved communication and significantly reduced delayed transfers of care.

#### **Powys Teaching Health Board**

The health board ensures that wherever possible carers are involved with discharge planning to support the individual to experience a positive transition back into community living.



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## Top tips

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- Acute Liaison Nurses ‘shadowing’ the discharge support nurses is a very worthwhile activity as it gives a clear picture of the patient journey, allows observation of all elements of the discharge process and allows the Acute Liaison Nurses to make the discharge nurses aware of the issues that may arise when a person is discharged.
- The Discharge Planning process should begin in initial assessment when person is admitted.
- Ensure that the person and their family/carers are involved in the process and are invited to attend or contribute as they are able.
- Treat discharge of a person with learning disability as ‘complex discharge’.
- Refer to local discharge policies.
- Inform the Community Support Team of planned discharge.
- Provide discharge information in ‘easy read’ format.
- Recognise and respond to language of choice and language of need.
- Provide a comprehensive discharge summary with post-discharge action.
- Establish guidelines for post-discharge care requirements.
- Relevant senior personnel from both hospital and Learning Disability Team confer after each discharge to identify any problems or aspects that went particularly well.
- Encourage the patient, their family and paid support staff to give feedback on the whole hospital experience to support audit and further improvements.


## How will we know that change has been an improvement?

The only way to know whether a change has been an improvement is through measurement. The measures for the care bundle are listed below:

<b>Measure</b>	<b>Operational Definition</b>
Percentage compliance with 4 hour bundle	<p>All patients assessed with learning difficulties admitted to hospital who receive all three components of the 4 hour bundle</p> <p>÷</p> <p>All patients assessed with learning difficulties and admitted to hospital</p>
Percentage compliance with daily bundle	<p>All patients assessed with learning difficulties in hospital receiving daily bundle</p> <p>÷</p> <p>All patients assessed with learning difficulties in hospital</p> <p>NB - this measure can be made daily</p>
Percentage compliance with 7 days bundle	<p>All patients assessed with learning difficulties who are admitted to hospital and are the subject of a full multi-agency/family/carers discussion within their first 7 days in hospital</p> <p>÷</p> <p>All patients assessed with learning difficulties who have been in hospital for 7 days or more</p> <p>NB - discussions may be had before a patient has been in hospital for a full 7 days</p>

## 5. Appendices

### Appendix A - Example of a hospital passport



**GIG  
CYMRU  
NHS  
WALES**

Bwrdd Iechyd Prifysgol  
Abertawe Bro Morgannwg  
University Health Board

**Directorate of Learning Disabilities Services**

Staff Guidance

### HOSPITAL INFORMATION

**RED**

↓

Things you must know

**AMBER**

↓

Things which you should know about me

**GREEN**

↓

Things I would like to happen

Name:.....



<b>RED</b>		
<b>Important Information about Me</b>		
Name:	GP:	
Know as:		
Address:	Address:	
Tel No:	Tel No:	
Date of Birth:		
Next of Kin:	Relationship:	Tel No:
Carer:	Relationship:	Tel No:
Professionals Involved:	Relationship:	Tel No:
	Relationship:	Tel No:
Care Manager:		Tel No:
Religion:	Religious Requests:	
Current Medical Conditions:		
Current Medication:		
Brief Medical History:		
Allergies:		
Medical interventions:		
Level of understanding:		
Behaviours which may challenge or cause risk:		
Completed by .....		Date .....
Relationship .....		

**AMBER**

Things that you should know about me

Communication:

Understanding:

Eating and Drinking:

Medication:

Going to the toilet:

Seeing / hearing:


Moving around:

Personal care:

Oral Health & Hygiene:
Level of support:
Keeping safe:
Sleeping:
Pain:
Completed by: ..... Date: .....
Relationship: .....

<b>GREEN</b>	
<b>Things that would make my stay more enjoyable</b>	
Things I like	
Things I don't like	
Completed by: .....	Date: .....
Relationship: .....	
<small>Adapted from the Red, Amber, Green Hospital Assessment: Gloucestershire Partnership NHS Trust (Elliot &amp; Dean 2004)</small>	

## Appendix B - Example of educational posters



**GIG  
CYMRU  
NHS  
WALES**

Bwrdd Iechyd Prifysgol  
Abertawe Bro Morgannwg  
University Health Board

**Health and Health Needs of People  
with Learning Disabilities**

Directorate of Learning  
Disabilities Services

- Learning Disabilities can be described as an umbrella term under which all affected individuals are described as having varying degrees of "impairment of intellectual and social functioning."
- People with Learning Disability can have difficulty with communication and understanding. They may find it difficult to cope independently in a variety of situations. This includes health services.
- Learning disability usually occurs before, during or shortly after birth. However, it can occur at any time during childhood or adolescence.
- The term learning disability is a label. Labels help us describe one aspect of a person but do not capture the whole individual. Every person described as having a learning disability is a person first.

Is the Health of People with learning disabilities different to that of the general population?

- People with learning disabilities have the same health needs as the rest of the population.
- Many also have additional health care needs and some will have a number of co-morbidities.
- Often these needs go undiagnosed and untreated.
- When diagnosis is made it is often late and treatment is delayed.
- People with a learning disability are likely to die younger.

Why do people with learning disabilities find it harder to access effective healthcare services?

- There are a number of reasons why people with learning disabilities find it difficult to access health services. These may be due to the individual, the healthcare professional or the way in which services are organised. These include:
  - Individual barriers:
    - Poor understanding
    - Communication difficulties
    - Sensory impairments
  - Professional barriers:
    - Lack of awareness of learning disabilities
    - Lack of training in learning disabilities
    - Biases and assumptions about people with learning disabilities
    - Diagnostic overshadowing
  - Organisational barriers:
    - Rigid appointment systems
    - Reliance on written forms of communication
    - Poor signage, relying on literacy skills and good sensory abilities

How you can improve services to people with Learning Disabilities

<p><b>Communication</b></p> <p>Make sure your communication is clear and easy to understand. Do not use "jargon" and explain any words that are difficult to understand.</p> <p>People with learning disabilities may find it difficult to take in too much information in one go. Break information down in to 'chunks' so the person is not overloaded.</p> <p>Give the person time to think about what you have told them and give them time to respond.</p> <p>Check that the individual has understood what you have said by asking them to repeat it.</p>	<p><b>Reduce Anxiety and Improve Understanding</b></p> <p>Find out the persons name and use it when addressing them.</p> <p>Tell them your name and the job that you do.</p> <p>Try and talk to the individual not the carer.</p> <p>With the persons permission, use the carer to facilitate understanding and communication</p> <p>Hospital routines can be stressful. Try and keep the number of procedures to a minimum.</p> <p>Explain any procedures before you carry them out.</p>	<p><b>Check out the persons Capacity to Consent</b></p> <p>There are 5 statutory principles governing decision making.</p> <p>Presumption of capacity</p> <p>Practical steps to assist capacity</p> <p>Unwise decisions</p> <p>Best interest</p> <p>Least restrictive option</p> <p>A person is unable to make a decision for himself if he is unable:</p> <ul style="list-style-type: none"> <li>to understand the information relevant to the decision</li> <li>to retain that information</li> <li>to use or weigh that information as part of the process of making the decision, or</li> <li>to communicate the decision (whether by talking, using sign language or any other means)</li> </ul>
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**For further information or to arrange training on Learning Disabilities contact:**  
 Christopher Griffiths, Consultant Nurse Learning Disabilities  
 Telephone: 01656 753930 or e-mail: Christopher.Griffiths2@wales.nhs.uk

Developed by Abertawe Bro Morgannwg University Health Board



## Appendix C - Glossary of terms

Annual health check	Primary Care based Annual Health Checks for adults with a learning disability on local authority registers, were introduced into Wales as a directed enhanced service (DES) in 2006, to address the inequalities in health care experienced by people with a learning disability. Such annual health checks were widely supported by patient and carer groups and research evidence. Health Checks involve a physical examination conducted by the doctor or nurse following a standard format which includes a structured interview to cover health promotion and specific issues relevant to people with an intellectual disability.
Acute liaison nurses	Part of the Health Liaison Team, act as ‘clinical advocates’ for people with a learning disability, and support the service user/patient to ensure accuracy of health care delivery with support from key health professionals, community services, carers and families
Care pathway	<p>Care pathways are described variously as integrated care pathways, clinical pathways, critical pathways, care maps, or anticipated recovery pathways. The National Leadership and Innovation Agency for Healthcare (2005) defined a care pathway as:</p> <p>“Anticipated care placed in an appropriate time frame, written and agreed by a multidisciplinary team. It has locally agreed standards based on evidence where available to help a patient with a specific condition or diagnosis move progressively through the clinical experience. It forms part or all of the clinical record, documenting the care given. It facilitates and demonstrates continuous quality improvement. It includes patient milestones and clinical interventions noted on the day or stage that they are expected to occur. It will include all of the following standards or show evidence that it is working towards meeting these standards:</p> <ul style="list-style-type: none"> <li>■ multi-disciplinary</li> <li>■ single documentation</li> <li>■ use exception reporting</li> <li>■ variance analysis</li> <li>■ patient/user involvement</li> <li>■ monitoring of utilisation</li> <li>■ cross boundaries</li> <li>■ standard format</li> <li>■ outcome orientated</li> <li>■ built in audit</li> <li>■ evidence based.”</li> </ul>

Community Support Team/Community Learning Disability Team	A social Services -led team comprising a care manager and specialist healthcare learning disability staff who undertake assessment and care planning for people with learning disabilities living in the community
Conwy Connect	A Third Sector independent organisation which helps promote the rights of people with a learning disability living within the County of Conwy in North Wales and which aims to ensure that people have equality of choice and opportunity in the community in which they live.
Health Liaison Team	The Health Liaison Team aims to initiate a positive impact on developing and improving the overall delivery of the health service to adults (18+) who have a learning disability. Their focus is on ensuring that the physical (medical) health needs of the population are being addressed.
Multi-disciplinary team (MDT)	A team comprising different health and social care professionals with specialised skills and expertise. The members collaborate together to make treatment recommendations that facilitate quality patient care. MDTs form one aspect of the provision of a streamlined patient journey by developing person-centred care plans that are based on 'best practice'. They aim to address treatment that is focused on the holistic needs of the person.
PEG	Percutaneous endoscopic gastrostomy.
Person-centred care plan	<p>Care planning that starts with the individual (not with services) and takes account of their wishes and aspirations. Person-centred planning is a mechanism for reflecting the needs and preferences of a person with a learning disability. (Department of Health, 2001)</p> <p>Key features of a person-centred plan are:</p> <ol style="list-style-type: none"> <li>1. The person is at the centre</li> <li>2. Family and carers are full partners</li> <li>3. It reflects the person's capacities, what is important to them and the support they need to make a valued contribution to their care.</li> </ol> <p>(Adapted from Department of Health, 2002)</p>



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## Appendix D - Contacts

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