

LEARNING DISABILITY EDUCATIONAL FRAMEWORK FOR HEALTHCARE STAFF IN WALES

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This framework is dedicated to the memory of Paul Ridd.



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INTRODUCTION

The Learning Disability Educational Framework for Healthcare Staff in Wales has been developed as an outcome of the Welsh Government Improving Lives Programme. Building knowledge, skills and competence across the workforce is a key action in reducing health inequalities for people with a learning disability.

FOREWORD

by the Chief Nursing Officer



I dedicate this education framework “The Learning Disability Educational Framework for Healthcare Staff in Wales” to the memory of Paul Ridd and to the work of his family who formed the Paul Ridd Foundation in Paul’s name. The family, through the Foundation, have worked tirelessly to support the health service in Wales to understand better the needs of people with a learning disability and consider how best to respond to those needs – often called making reasonable adjustments.

The Welsh Government has a long standing commitment to improving the quality of life for people with a learning disability. In 2018, we launched our cross-government Improving Lives Programme designed to secure responsive and appropriate services for people with a learning disability. The programme contains twenty-four actions; one of which is to ensure reasonable adjustments are made to support people with learning disabilities and their families to access good quality, mainstream NHS services.

Ensuring healthcare staff have the necessary knowledge and skills to identify and meet the health needs of people with learning disabilities is a crucial element to reducing the known health inequalities and preventing avoidable deaths. In November 2019, the Deputy Minister for Health and Social Services made a commitment to mandate awareness raising training for all NHS staff in response to a petition by the Paul Ridd Foundation. In addition, the Deputy Minister outlined plans to establish a national education programme to ensure that everyone working in a health care setting has the appropriate skills and training necessary for them to make the reasonable adjustments that ensures individuals with a learning disability are treated effectively and receive high quality care appropriate to their needs. This Learning Disability Educational Framework for Healthcare Staff in Wales provides a comprehensive and structured approach to ensuring that healthcare staff are supported to understand better the needs of people with a learning disability and achieve the appropriate level of knowledge, skill and competence relevant to their role in any healthcare setting – not just in hospitals.

An important element of this framework is the Foundation level which is the essential awareness raising training for all healthcare staff in a public/patient facing role. Tiers two and three of the framework describe more in-depth competency and knowledge targeted for staff in key roles. This will ensure staff are fully cognisant of the issues and able to deliver the best possible service for individual patients and their families.

The challenge of managing the pandemic has unfortunately delayed the introduction of the framework. However, as we return cautiously optimistic towards recovery we can begin implementation; ultimately, implementing the framework will foster confidence that the healthcare workforce has the right values, knowledge, skills and competence to provide the right care at the right time.

Jean White

Professor Jean White CBE
Chief Nursing Officer
Nurse Director NHS Wales



To read Paul's story and understand the work of the Paul Ridd Foundation visit: <https://paulriddfoundation.org/>

1. WHY IS THIS FRAMEWORK NEEDED?



The United Nations Convention on the Rights of Persons with Disabilities² states that disabled people have ‘the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability’ (Article 25). In addition, the Convention requires that health professionals provide care that is of the standard as that provided for non-disabled people.

However, numerous reports document the health inequalities experienced by people with learning disabilities^{3,4,5,6}. From such reports it appears that people with learning disabilities may be vulnerable to their health needs not being recognised and therefore not met, they may have increased difficulties with accessing healthcare services and where services are received, they may not be of an acceptable quality. Ultimately, such barriers impact negatively on the mental and physical health of people with learning disabilities and premature and avoidable mortality has been identified⁷. Nonetheless, such vulnerabilities should not be an inevitable consequence of having a learning disability: barriers to appropriate, and timely healthcare, can be identified and addressed.

A recurring theme within reports and within wider research^{8,9,10} is the need for all healthcare staff to possess the necessary knowledge and skills, to identify and meet the health needs of people with learning disabilities. Indeed, this is viewed as a key element of reducing the identified health inequalities.

This educational framework thus has a number of aims:

- To outline the knowledge, skills and competence required within the healthcare workforce.
- To improve timely access to, and the quality of, healthcare provision for people with learning disabilities.
- To promote confidence amongst people with learning disabilities and their families, ensuring that the workforce has the right values, knowledge, skills and competence to provide the right care at the right time.
- To support individual workers, managers, and organisations, to plan and support the right education, training, and continuing professional development, amongst healthcare staff.
- To guide the development of educational provision to support the knowledge, skills and competence of healthcare workers, to support people with a learning disability.

Whilst the document is aimed primarily at healthcare staff and organisations, it is recognised that staff from other backgrounds (such as social care) also play a key role in identifying and meeting the health needs of people with learning disabilities. Some of the areas of competence may, therefore, also be of relevance to them.

For examples of the lived experience of people with learning disabilities in Wales accessing healthcare please read the stories of Martha, Anita, Geraint & Gwnyfor (appendix 1.)



2. HOW HAS THE FRAMEWORK BEEN DEVELOPED?



A number of activities have been undertaken in order to develop this framework:

- A review of relevant research and existing educational frameworks was completed. Key themes were identified and documented from this review.
- A series of telephone interviews were undertaken with a range of key stakeholders (n=22) that included representatives of third sector organisations, family members, healthcare professionals, social care representatives, providers of healthcare education and healthcare managers. Staff working in both primary and secondary healthcare were included, and a range of healthcare professions participated. Participants in these interviews were asked their views regarding the values that should underpin the proposed framework, potential content, possible approaches to achieving competence and assessment of competence. A further 3 participants responded to the same questions via an email questionnaire. During the interviews, notes were taken and then reviewed in order to identify common themes and recurring issues.
- Consultation took place with the Teaching and Research Advisory Committee (TRAC) at the University of South Wales. TRAC are a group of men and women with learning disabilities who meet on a monthly basis at the university and who are actively involved in the development, delivery and assessment of learning for student nurses and other healthcare professionals.
- A stakeholder event and further email consultation were conducted in which feedback on a draft version of the framework was sought.

Information from each of these activities was synthesised in order to develop the framework presented in this document. It is thus based on both current research evidence and the views and experiences of key stakeholders within Wales.

3. WHAT ARE THE VALUES AND PRINCIPLES UPON WHICH THIS FRAMEWORK IS BASED?



In both the wider literature, and in discussions with key stakeholders, the importance of ensuring that this framework is based on a clear set of values was evident. The following are therefore those values that have informed development of the framework, and which should also inform its implementation:

- **Rights** - the rights of people with learning disabilities to healthcare of an equal quality are the starting point for the development of this framework. However, other rights such as the right to life, the right to accessibility, the right to freedom from cruel, inhuman or degrading treatment, or punishment, the right to freedom from abuse and torture, the right to living independently in the community, the right to respect for home and family, the right to education and work, and the right to an adequate standard of living and social protection² are also of relevance.
- **Equality** - this framework is based on the principle that people with learning disabilities should have access to healthcare of an equal standard, to that received by other citizens. However, this does not always mean providing care, which is the same but rather, that there is a need to anticipate and accommodate the need for reasonable adjustments to care and care processes so that differing needs can be met, and an equal standard of care be achieved.

- **Person centred** – the term ‘learning disability’ encompasses a wide range of personal experiences that include the nature and extent of learning disability, gender, age, sexual orientation, living circumstances and ethnicity. Each of these personal characteristics will impact on the life experience of individuals, and also on the way(s) in which they experience health inequalities. This means that healthcare professionals need to recognise that people with learning disabilities are a diverse group, with differing needs, and hence a person-centred approach to support is required.

In addition, there are a number of key principles that have informed the development of this framework and which should also inform its implementation.

- **Shared responsibility** – this framework is based on the principle that addressing the health needs of people with learning disabilities, and reducing health inequalities, is the responsibility of all healthcare staff. This means that whether staff are working in a clinical, administrative or managerial capacity, they all have a role to play.
- **Collaboration and partnership** – addressing health inequalities will only be achieved by healthcare staff and organisations working in partnership with people with learning disabilities, their families and carers. Also, they need to collaborate effectively with each other.
- **A lifespan approach** – as individuals grow and develop their needs change and hence support needs to be tailored appropriately. This framework thus recognises that healthcare staff need to be equipped to identify and respond to the health needs of people with learning disabilities across their lifespan. They also need to be able to work across age-related service boundaries in healthcare provision to reduce the potential for breakdown or fragmentation of support.

Finally, it is important to note that whilst the overall aim of this framework is to ensure that people with learning disabilities have access to skilled support from healthcare staff, such skills need to be underpinned by the appropriate values and knowledge. Therefore, Figure 1 sets out the structure that will be used to present the competencies in this framework.

It will be seen that the values staff need to demonstrate form the basis of competence. The framework thus includes a separate section that focuses on the values that all staff need to demonstrate. They then need to acquire appropriate knowledge, and to translate these values and knowledge into practice through the demonstration of the appropriate skills. Values, knowledge and skills are therefore inter-related and inter-dependent. Competence statements in relation to knowledge and skills are outlined in the framework.

Figure 1: The relationship between values, knowledge and skills



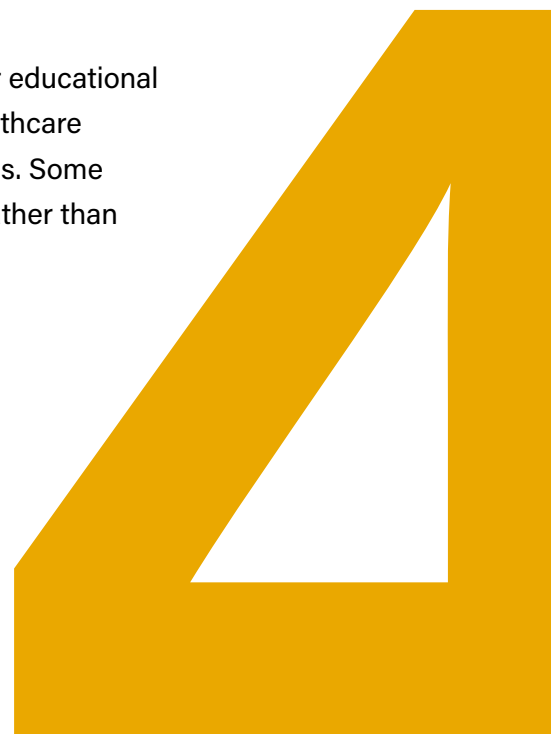
4. USING THE FRAMEWORK



It is intended that this framework will be used in a number of different ways including:

- By individual healthcare staff to identify their current level of competence and learning needs.
- By staff teams to identify their current level of competence and learning needs.
- By education and training departments within healthcare provider organisations to plan educational opportunities for staff. This may include both the development of new educational provision and the inclusion of these competencies in existing provision (for example within equalities training).
- By higher education providers to inform curriculum development and delivery.
- By healthcare organisations to audit current educational provision.
- By inspectors and commissioners of healthcare to benchmark educational provision and support within services.
- By professional bodies involved in the development of professional educational standards.

When using this framework, it is also important to cross refer to other educational and competence frameworks such as those relating to individual healthcare professions and those that have been developed on an All Wales basis. Some examples of these are provided in Box 1 below but these illustrative rather than exhaustive.



Box 1: Examples of other relevant educational frameworks




- **The All Wales Induction Framework for Health and Social Care**
<https://socialcare.wales/learning-and-development/induction-for-health-and-social-care>
- **The Health and Care Learning Wales Qualification Framework**
<https://www.healthandcarelearning.wales/qualifications/>
- **The NHS Wales Learning and Development Framework**
(currently under development)



5. THE COMPETENCY FRAMEWORK



Within this framework a tiered approach to competence is taken in which there is a focus on three tiers or levels of competence:

-  **Foundation** - the values, knowledge and skills required of all healthcare staff.
-  **Enhanced** - the values, knowledge and skills required of those healthcare staff whose role brings them into regular contact with people with learning disabilities.
-  **Advanced** - the values, knowledge and skills required of those healthcare professionals who specialise in working with people with learning disabilities.

It should be stressed that the Foundation level applies to all staff involved in healthcare including reception and administrative staff, portering and housekeeping staff, clinical staff, managers and board members. Staff working at the Enhanced level need to be able to demonstrate those additional competencies identified for that level in addition to those at the Foundation level. Similarly, staff working at an Advanced level need to be able to demonstrate the additional competencies at that level in addition to those at Foundation and Enhanced levels.

Figure 2: The key areas within the educational framework



Figure 2 above provides an overview of the framework. At the centre of the framework are the values that staff should be expected to demonstrate. These values inform and underpin seven key areas, each of which have competences relating to the associated knowledge and skills. They are presented here as a cycle to reflect the fact that each area impacts on and is related to the others. For example, in order to understand and respond to behaviours it is necessary to have knowledge and skills in relation to communication.

5.1 Values

The following are key values that are universally important in all healthcare settings but are identified here as being particularly important when seeking to ensure that people with learning disabilities are able to access healthcare. Unlike the other areas of competence detailed in this document these values are not specified at different levels / tiers since they are viewed as being required by all staff at all levels.

All healthcare staff should:

- Be aware of their own personal values and biases and how these may impact on their interactions with people with learning disabilities, their families and their supporters.
- Value people with learning disabilities as individuals with differing abilities, strengths and needs.
- Respect the right of people with learning disabilities to equality, autonomy, dignity, compassion and inclusion.
- Recognise the importance of adjusting the way in which care and services are provided in order to ensure high quality, person-centred and age appropriate care.

Whilst these values are identified separately here to highlight their significance, it should be noted that they are inherent to, and underpin, each of the seven areas detailed below. All staff, working at all levels are therefore expected to demonstrate these values in all aspects of their work with people with learning disabilities.

5.2 Key area 1: Understanding learning disability

Knowledge



Foundation level

All staff will:

- Understand what is meant by the term 'learning disability'.
- Know that the term 'learning disability' is applied to people with wide ranging and diverse strengths and needs.
- Recognise that learning disability impacts in different ways on individuals.
- Understand the importance of a person-centred approach.
- Know that sometimes people with learning disabilities may also have co-occurring conditions such as autism spectrum disorder.
- Understand that people with learning disabilities are disabled by a range of social, physical, economic and psychological barriers (the social model of disability).

Enhanced level

In addition, staff working at this level will:

- Understand that the impact of learning disabilities on the individual may vary over time and context.
- Be aware of stigma and the effect this can have on the lives of people with learning disabilities.
- Know that the barriers they experience are not an inevitable part of having a learning disability – they can be removed or reduced.
- Recognise that they have a role to play in recognising and reducing these barriers.

Advanced level

In addition, staff working at this level will:

- Understand specific genetic conditions (for example Down's Syndrome and Fragile X Syndrome) and the ways in which these can impact on individuals.
- Understand the histories of people with learning disabilities that they support and how such history impacts on their current situation.





Foundation level

All staff will be able to:

- Recognise when someone may have a learning disability.
- Adjust their support according to the needs of people with learning disabilities.

Enhanced level

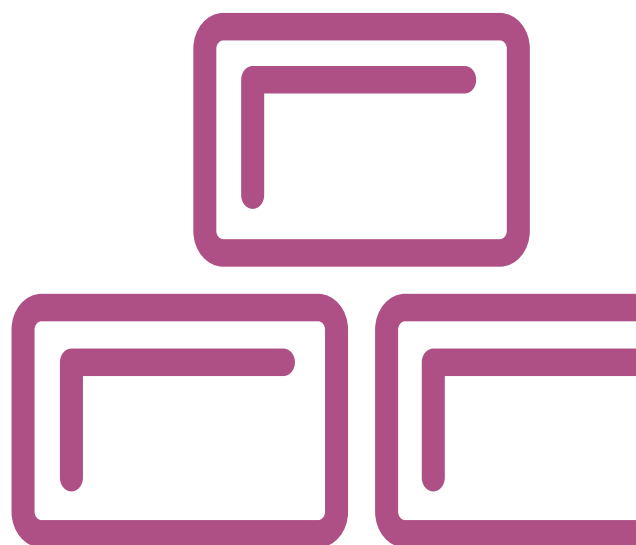
In addition, staff working at this level will be able to:

- Challenge stigma and discrimination experienced by people with learning disabilities.
- Support others to understand the impact that learning disabilities may have on an individual.

Advanced level

In addition, staff working at this level will be able to:

- Act as a source of specialist advice regarding learning disabilities including specific genetic conditions.
- Use their understanding of an individual's history to develop appropriate packages of support.



Key area 2: The Health Needs of People with Learning Disability

Knowledge



Foundation level

All staff will:

- Know that people with learning disabilities experience the same range of physical and mental health problems as their non learning-disabled peers.
- Understand that sometimes these health problems may present differently amongst people with learning disabilities.
- Recognise that sometimes people with learning disabilities may experience a number of co-occurring health problems.

Enhanced level

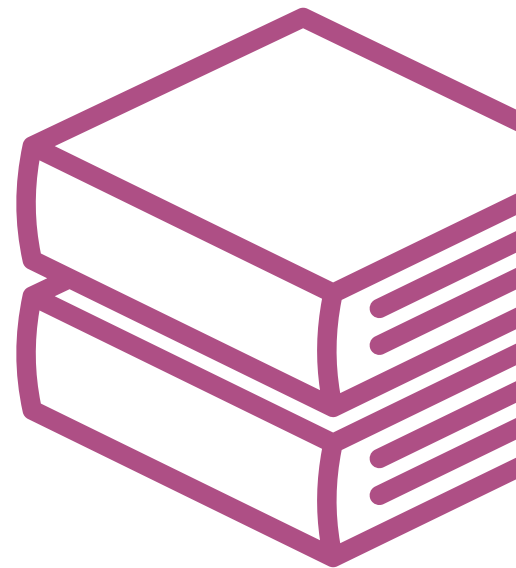
In addition, staff working at this level will:

- Understand the concept of diagnostic overshadowing.
- Be aware of the specific health needs of people with certain syndromes such as Down's Syndrome.
- Be aware of the annual health checks available for people with learning disabilities.
- Understand the impact of the ageing process on the health needs of people with learning disabilities.
- Be aware of specific tools that can be used with people with learning disabilities to assess pain and distress (for example Abbey Pain Scale).
- Be aware of specific risk factors that people with learning disabilities may experience (for example dysphagia and epilepsy).
- Understand the importance of health promotion for people with learning disabilities.

Advanced level

In addition, staff working at this level will:

- Have advanced knowledge of the health needs of people with learning disabilities.
- Have advanced understanding of how these health needs may impact on people with learning disabilities.
- Have knowledge of complex health conditions.
- Have knowledge of a range of strategies that can be used to promote health amongst people with learning disabilities.





Foundation level

All staff will be able to:

- Identify when people with learning disabilities are unwell, experiencing pain or distress.
- Seek appropriate support to ensure that such needs are met.

Enhanced level

In addition, staff working at this level will be able to:

- Respond appropriately to signs of ill health (mental and physical) amongst people with learning disabilities.
- Deliver physical and mental first aid.
- Manage epileptic seizures.
- Seek appropriate specialist support when required.
- Promote uptake of the annual health check.
- Provide health promotion advice for people with learning disabilities and their families / carers.

Advanced level

In addition, staff working at this level will be able to:

- Manage complex health conditions.
- Act as source of specialist advice.
- Educate others regarding the health needs of people with learning disabilities.
- Plan and deliver programmes of health promotion for people with learning disabilities and their families.

Key area 3: Recognising and Removing Barriers to Healthcare

Knowledge



Foundation level

All staff will:

- Be aware of the health inequalities experienced by people with learning disabilities.
- Recognise that achieving equality of healthcare may mean providing services in a different way.
- Understand the concept of reasonable adjustments.
- Recognise and understand the importance of the Health Profile to promoting access to appropriate healthcare for people with learning disabilities.
- Be aware of the learning disability care bundle.

Enhanced level

In addition, staff working at this level will:

- Understand their role in ensuring that the Care Bundle¹¹ is implemented.
- Be aware of key barriers that can limit access to healthcare by people with learning disabilities.
- Be aware of the need for anticipatory reasonable adjustments.
- Understand the concept of risk assessment and its importance to the provision of appropriate support.

Advanced level

In addition, staff working at this level will:

- Understand the evidence base regarding health inequalities experienced by people with learning disabilities.
- Understand their role in identifying and removing barriers to healthcare.
- Have advanced knowledge of risk assessment including in the context of complex needs.





Foundation level

All staff will be able to:

- Adjust the way they deliver their service in order to promote equality of access for people with learning disabilities.
- Use the Health Profile to support delivery of person-centred care appropriate to individual needs.
- Contribute to implementation of the Care Bundle10 as appropriate.

Enhanced level

In addition, staff working at this level will be able to:

- Complete the risk dependency assessment10.
- Support the completion of Health Profiles.
- Monitor implementation of the Care Bundle10.
- Assess their place of work to identify where anticipatory reasonable adjustments may be required.
- Implement reasonable adjustments.

Advanced level

In addition, staff working at this level will be able to:

- Educate other healthcare staff regarding Health Profiles and the Care Bundle10.
- Use available evidence to identify and remove barriers to healthcare for people with learning disabilities.
- Undertake complex risk assessments.

Key area 4: Understanding and Responding to Behaviour

Knowledge



Foundation level

All staff will:

- Understand that all behaviour has meaning, and that behaviour is a means of communication.
- Be aware that sometimes people with learning disabilities may communicate pain, illness and distress through changes in their behaviour rather than through words.
- Recognise that how they interact with individuals with learning disabilities will impact on their behaviour.
- Be aware that family members and/ or other supporters can provide essential information regarding what is normal for an individual (and hence when changes may mean that action is required).

Enhanced level

In addition, staff working at this level will:

- Understand the basic principles of positive behavioural support.
- Be aware of how anxiety and distress can impact on decision making.
- Recognise that certain behaviours and/ or environments may trigger anxiety and distress.

Advanced level

In addition, staff working at this level will:

- Have a good knowledge of positive behavioural support.
- Have a good knowledge of how the principles of positive behavioural support can be used to enhance access to healthcare for people with learning disabilities.
- Have a knowledge of advanced behavioural assessment skills.
- Have advanced understanding of the links between behaviour and health.
- Have a good understanding of approaches that seek to minimise the use of medication to manage behaviours that challenge in healthcare settings.





Foundation level

All staff will be able to:

- Adapt personal behaviour to meet the needs of people with learning disabilities.
- Respond appropriately to signs of anxiety and distress.
- Gather information from family/ supporters as appropriate.
- Use this information to adjust support and/ or to seek additional support.

Enhanced level

In addition, staff working at this level will be able to:

- De-escalate / defuse potentially difficult situations.
- Refer to specialist services for additional support when required.
- Make adjustments to the care provided in order to reduce anxiety and distress.

Advanced level

In addition, staff working at this level will be able to:

- Act as a source of specialist advice for other staff in relation to understanding and responding to behaviour.
- Develop care plans that recognise and address behavioural needs.
- Provide advice (where appropriate) in relation to therapeutic holding.
- Develop programmes to support desensitisation.

Key area 5: Communication

Knowledge



Foundation level

All staff will:

- Be aware of the range of ways in which people with learning disabilities may communicate.
- Understand the importance of adapting personal communication to meet individual needs.
- Understand how sensory impairments can impact on communication.
- Understand that communication barriers can impact on people with learning disabilities.
- Be aware of the need to avoid using 'jargon' and instead to use clear language.
- Be aware of the need to check for understanding.
- Be aware of how people who know an individual well (such as family and support workers) can provide important information about how an individual usually communicates their need.
- Be aware of the need to establish trust.
- Be aware of the need to communicate in an age appropriate manner.
- Understand that it may take longer for people with learning disabilities to process information.

Enhanced level

In addition, staff working at this level will:

- Be aware of the need to assess communication needs.
- Understand the importance of consulting with others to determine usual patterns and means of communication.
- Be aware of sources of specialist support to assist with communication and how to access such support.
- Understand how communication barriers can impact on people with learning disabilities.
- Understand how individuals usually communicate pain and distress.
- Be aware of alternative and augmentative communication approaches.
- Be aware of factors that can impact on communication (for example anxiety, pain, distress and the physical environment).
- Understand the need to adapt their communication to meet the needs of individuals who may have limited health literacy.
- Be aware of the need to adapt their personal communication approach to facilitate assessment.
- Understand the importance of easy read information.
- Understand the role of advocates.

Advanced level

In addition, staff working at this level will:

- Be aware of the need to adapt their personal communication to facilitate accurate assessment and identification of need.
- Understand complex communication needs.
- Have good knowledge of key communication approaches such as Makaton, Bliss symbols etc.
- Have a good knowledge of assistive technology.





Foundation level

All staff will be able to:

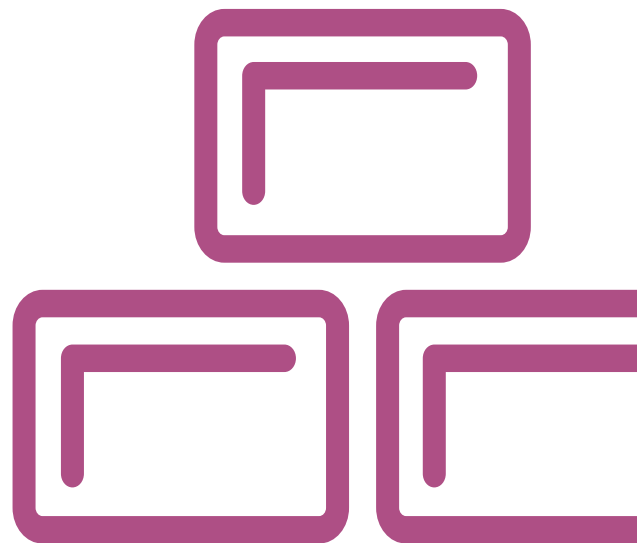
- Communicate effectively and in a person-centred, age appropriate manner with individuals with learning disabilities.
- Communicate effectively with the families and supporters of people with learning disabilities.
- Demonstrate effective listening skills.
- Demonstrate the ability to develop trusting relationships.
- Demonstrate patience when communicating with people with learning disabilities.
- Communicate effectively both orally and in writing with others.

Enhanced level

- In addition, staff working at this level will be able to:
- Demonstrate the ability to adjust personal communication to ensure that individual needs are identified and met.
- Demonstrate the ability to develop easy read information.
- Demonstrate the ability to check understanding.
- Demonstrate the ability to explain information in ways appropriate to individual needs.
- Demonstrate the ability to access specialist support when required.

Advanced level

- In addition, staff working at this level will be able to:
- Demonstrate the ability to communicate across organisational boundaries.
- Demonstrate effective negotiation skills.
- Demonstrate the ability to develop information tailored to meet individual needs.
- Demonstrate the ability to have 'difficult' conversations.
- Act as an effective advocate at individual, group and organisational levels.
- Demonstrate advanced skills in history taking including the ability to gather and synthesise information from a range of sources.



Key area 6: Coordination and Collaboration

Knowledge



Foundation level

All staff will:

- Understand the key role that families and other carers play in supporting people with learning disabilities.
- Understand the importance of working in partnership with people with learning disabilities, their families and other carers / supporters.
- Know when and where to seek specialist support if required.

Enhanced level

In addition, staff working at this level will:

- Be aware of different procedures and processes that are in place to support people with learning disabilities in healthcare settings (for example flagging systems and care pathways).
- Understand the need for effective and appropriate transfer of information between individuals and agencies.
- Know how to contact their local community support team.
- Understand the services offered by community support teams.
- Know who to contact to secure specialist support.

Advanced level

In addition, staff working at this level will:

- Know how to develop individual management plans and care pathways.
- Understand specialist assessment pathways.
- Understand wider (non-learning disability specialist) support systems and the importance of accessing these to ensure appropriate and coordinated support is provided.





Foundation level

All staff will be able to:

- Secure additional support to meet the needs of people with learning disabilities and their families when required.
- Work in partnership with individuals with learning disabilities, their families and carers to ensure timely and appropriate person-centred support.

Enhanced level

In addition, staff working at this level will be able to:

- Triangulate information from different sources in order to develop an appropriate plan of care and support.
- Escalate concerns as appropriate.
- Secure input from, and work effectively with, learning disability support services.

Advanced level

In addition, staff working at this level will be able to:

- Work effectively with a wide range of non-learning disability support services in order to secure effective packages of support for individuals.
- Develop, coordinate and monitor of packages of support for those with complex health needs.
- Demonstrate leadership skills.
- Demonstrate the ability to work across organisational boundaries both within and between organisations.

Key area 7: Legal and Policy Issues

Knowledge



Foundation level

All staff will:

- Be aware that people with learning disabilities have the same rights as other citizens.
- Be aware of their personal responsibilities in relation to safeguarding.
- Be aware of the importance of confidentiality and the limits to confidentiality.

Enhanced level

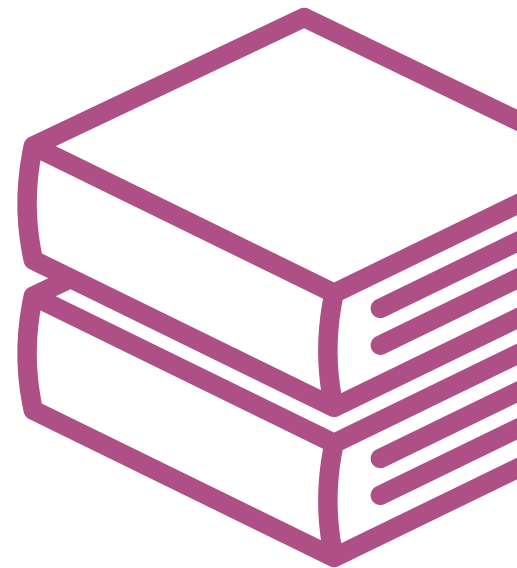
In addition, staff working at this level will:

- Be aware of the UN Convention on the Rights of Persons with Disabilities (UN 2006).
- Be aware of the key provisions of the Human Rights Act (1998).
- Be aware of the Equality Act (2010) and protected characteristics.
- Be aware of the legal basis for reasonable adjustments.
- Be aware of key provisions of the Mental Capacity Act (2005).
- Understand procedures for the assessment of capacity under the Mental Capacity Act.
- Understand best interests procedures.
- Understand organisational duties in relation to making reasonable adjustments and the anticipatory nature of these duties.
- Understand the legal rights of people with learning disabilities.
- Be aware of procedures relating to Deprivation of Liberties.
- Be aware of the provisions of the Mental Health Act (1983).
- Understand the importance of confidentiality and the limits to confidentiality.

Advanced level

In addition, staff working at this level will:

- Understand the Mental Health (Wales) Measure (2010) and its implications for people with learning disabilities.
- Possess in depth knowledge of human rights legislation and its relevance to the lives of people with learning disabilities.
- Know how to support and assess capacity in the context of the Mental Capacity Act (2005).
- Be aware of strategies that can be used to increase the awareness of others regarding the human and legal rights of people with learning disabilities.





Foundation level

All staff will be able to:

- Take appropriate action when the human rights of people with learning disabilities are compromised.
- Act appropriately when safeguarding concerns are noted.
- Seek appropriate support in relation to capacity and consent issues.

Enhanced level

In addition, staff working at this level will be able to:

- Identify the need for assessment of capacity.
- Seek appropriate support when best interests decisions may be required.
- Act within legal frameworks in relation to deprivation of liberties.
- Act within legal frameworks in relation to consent processes.
- Act within relevant policy and professional frameworks relating to confidentiality.

Advanced level

In addition, staff working at this level will be able to:

- Support others to understand and use relevant legislation to support the rights of people with learning disabilities and facilitate their access to healthcare.
- Fulfil their responsibilities in relation to the Mental Health (Wales) Measure.
- Undertake assessment of capacity and support consent procedures.
- Use the framework of the Mental Health Act to ensure the safety of individuals with learning disabilities and others.

6. ACHIEVING COMPETENCE



The aim of this framework is to set out what healthcare staff need to know, and do, in order to effectively identify and meet the health needs of people with learning disabilities: it does not seek to prescribe how such competence should be achieved. Nonetheless, it is relevant to highlight some suggested educational approaches that may be helpful.

The following are therefore offered as examples rather than as a comprehensive list of approaches:

- Classroom
- E-learning
- Simulation
- Workshops
- Coaching and mentorship
- Problem solving exercises
- Case discussion
- Patient stories

A number of factors are likely to influence the nature of any educational support required / provided such as staff time and availability, the nature of individual work roles, the context(s) in which they work, and competing workload pressures. Whilst classroom learning and workshops (for example) may be possible within the context of pre and post qualifying educational programmes, a more flexible approach may be needed to enable continuing professional development for those whose roles mean that time away from the workplace is difficult to arrange. In



such circumstances the provision of on-line educational materials in 'bite-sized' chunks may be more feasible.

Whatever the approach adopted however, it is important that the focus remains on the healthcare experience of people with learning disabilities and their families. To this end, wherever possible, there should be the opportunity for the voices and experiences of people with learning disabilities to be included whether through direct contact or through the use of recordings/ video clips.

In addition, it should be remembered that whilst some learning disability specific educational support may be required to assist staff in achieving the specified levels of competence, it is also possible to adjust existing mandatory training to ensure that the key areas of knowledge and skills are included. For example, the legal basis for ensuring equality and making reasonable adjustments for people with learning disabilities, could and should be reflected within the general equalities training that is provided.

It is not within the remit of this framework to prescribe if, and how, assessment of competence could or should be undertaken. However, during the consultation process that informed development of this framework, a number of suggestions were proposed which are offered for consideration. These include:

- Ensuring that knowledge, skills and the underpinning values relating to identifying and meeting the health needs of people with learning disability are reflected in assessments within pre and post qualifying programmes for health professionals.
- Use of self and peer assessment.
- Encouragement of reflection on practice.
- Clinical supervision.
- Encouraging the use of this framework in the context of professional revalidation.
- Discussion focused on the elements of this framework within appraisals/ development and performance reviews.
- Assessment at an organisational level of the extent to which staff are supported to develop and maintain these areas of competence.



7. CONCLUDING COMMENTS



This document has set out a framework that can be used to support healthcare staff in developing the competence and confidence to ensure that people with learning disabilities have access to appropriate and timely healthcare. It is therefore hoped that it will make a contribution to reducing the health inequalities that they continue to experience. However, just producing a document will not achieve this goal and hence it must be seen as an important first step. The key to success will lie in careful implementation and evaluation and it is important that we all recognise we have a role to play in this process and that by working together we can bring about positive change.

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APPENDIX

Lived experience examples:

1.

Martha is a lady with a mild learning disability she lives independently with her boyfriend and receives no formal support from statutory services. She is an active member of a self-advocacy group and stands up for the needs of people with a learning disability. However when Martha was suffering from constipation she was not able to describe her symptoms to the GP. The health care staff had little experience of learning disabilities and did not explore options to support communication, such as easy read and targeted questioning. Martha did not receive adequate care and she became seriously ill having to have a major operation, part of her bowel removed and lasting health needs as a result.

2.

Anita is a lady with profound and multiple learning disabilities, she is reliant on carers to meet all her needs. Her carers were concerned that she was in pain as she was not her 'usual self'. They visited the GP on several occasions and were advised to keep an eye as there were no obvious signs of illness. Staff insisted on a referral to hospital following completion of a pain assessment tool which they believed showed Anita to be in pain. On investigation in hospital Anita was found to have a serious hip complaint which would cause serious pain. She now has ongoing pain relief and appears much happier.

3.

Geraint is a man with moderate learning disabilities he appeared unwell one morning and was taken to hospital, staff felt that his presentation could be accounted for by his history of epilepsy. But his sister complained, making it repeatedly clear that she had experienced his seizure activity and this was not his usual presentation. Geraint was later diagnosed with brain haemorrhage and passed away.

4.

Gwynfor is a man with moderate learning disabilities with significant communication needs, he was supported to attend the emergency department on a weekend as carers felt he was unwell and chesty. He received an ECG but no chest X-ray or blood tests and was then sent home. He continued to have respiratory problems and was seen twice over the weekend by the out-of-hours doctors and prescribed antibiotics. On the Monday morning, Gwynfor was given a more thorough assessment, he was admitted to hospital, with pneumonia, described as 'severe' with a complete 'white out' of 1 lung. His condition deteriorated and he passed away. It is possible that an earlier diagnosis of his pneumonia might have prevented his premature death