

CONSULTATION DRAFT
February 2019

**Learning Disability
Capabilities Framework**

This is an updated version of the original 'Learning Disabilities Core Skills Education and Training Framework'.

Acknowledgements

To be completed

Contents

Foreword/s	4
Introduction and background	4
Structure of the framework	5
Scope of the framework	6
How to use this framework	8
Principles and values	12
Domain A. Understanding learning disabilities.....	14
Capability 1: Learning disability awareness	14
Capability 2: Identification and assessment of learning disabilities	18
Domain B. Person-centred collaborative working	20
Capability 3: Communication	20
Capability 4: Empowerment and person-centred care.....	23
Capability 5: Families and carers as partners in care and support.....	26
Capability 6: Supporting people at risk of behaviours that challenge	29
Domain C. Health and wellbeing.....	32
Capability 7: Physical health	32
Capability 8: Supporting people with mental health conditions	35
Capability 9: Health equality and reasonable adjustments	38
Capability 10: Nutrition, hydration and dysphagia	41
Capability 11: Epilepsy	44
Capability 12: Supporting people with Profound and Multiple Learning Disabilities (PMLD)	47
Capability 13: End of life care	50
Domain D. Personalised care and support.....	53
Capability 14: Supporting people with a learning disability and autism	53
Capability 15: Wellbeing and independence.....	56
Capability 16: Relationships, sexuality and sexual health	59
Capability 17: Supporting children and young people with a learning disability	62
Capability 18: Preparing young people with a learning disability for adulthood.....	66
Capability 19: Supporting older people with a learning disability.....	68
Capability 20: Forensic support	71
Domain E. Risk, legislation and safeguarding	74
Capability 21: Law, ethics and safeguarding	74
Capability 22: Equality, diversity and inclusion	78
Domain F. Leadership and management, education and research	80
Capability 23: Leadership and management	80
Capability 24: Education and personal development.....	83
Capability 25: Research and evidence-based practice.....	85

Appendix 1: How this framework was developed	87
Appendix 2: Related standards and frameworks	88
Appendix 3: Suggested standards for training delivery	89
Appendix 4: Sources of further guidance and information	90
Appendix 5: Bibliography	91

Foreword/s

To be completed...

Introduction and background

The original 'Learning Disabilities Core Skills Education and Training Framework' (2016) was commissioned and funded by the Department of Health and developed in collaboration by Skills for Health, Health Education England and Skills for Care. This updated framework is a joint commission by Health Education England and NHS England, ensuring it remains up to date with current guidance. The framework has also been extended to provide increased focus on improving health outcomes and avoiding premature mortality.

Since the original framework was published, the learning disabilities workforce has been the focus of much attention, not least as a result of the national Transforming Care Programme which aims to improve health and care services so that everyone can live in the community, with the right support, and close to home. More recently, the Learning Disabilities Mortality Review (LeDeR) Programme has highlighted the persistence of preventable health inequalities and that people with a learning disability die, on average, 15-20 years sooner than people without a learning disability. The LeDeR programme has highlighted the need for:

- healthcare coordination for people with complex or multiple health conditions
- assurance that effective reasonable adjustments are being provided for people with a learning disability and their families
- mandatory learning disability awareness training for all staff supporting people with a learning disability

The launch of the NHS Long Term Plan (2019) has provided additional focus on action the NHS will take to strengthen its contribution to prevention and health inequalities, including mechanisms to ensure that people with learning disability and/or autism get better support. It sets out actions to improve understanding of the needs of people with learning disability and autism, to improve their health and wellbeing and to tackle the causes of morbidity and preventable deaths.

Developing the workforce to meet these aims requires a review of roles and associated education and training. The purpose of this framework is therefore to support development and planning of the current and future workforce, to inform the design of curricula and the delivery of education and training programmes – working in partnership with people with a learning disability.

Structure of the framework

The framework describes **capabilities** i.e. the attributes (skills, knowledge and behaviours) which people bring to their work. This includes the ability to be competent and beyond this, to manage change, be flexible, deal with situations which may be unpredictable and continue to improve performance.

The framework begins with a description of the principles and values which underpin all capabilities in this framework.

The framework then comprises 25 capabilities, which are grouped in 6 domains:

Domain A. Understanding learning disabilities

Domain B. Person-centred collaborative working

Domain C. Health and wellbeing

Domain D. Personalised care and support

Domain E. Risk, legislation and safeguarding

Domain F. Leadership and management, education and research

Each capability comprises:

- an introduction
- suggested target audience
- key learning outcomes
- links to relevant guidance and/or legislation
- links to relevant national occupational standards, or other frameworks.

The capabilities are numbered (1 to 25) for ease of reference. This does not indicate a prescribed pathway, process or hierarchy. Full coverage of all capabilities may also be achieved by teams, in which case some team members may find that not all capabilities are relevant to their individual role.

The capabilities in this framework are those which are common and transferable across different types of service provision.

Capabilities for other areas of the workforce in learning disabilities and autism services are covered in related frameworks due to launch during 2019:

- Learning Disability, Autism or both: Advanced Clinical Practice Capabilities Framework: www.skillsforhealth.org.uk/ACPinLD
- Autism Capabilities Framework: www.skillsforhealth.org.uk/autism-framework
- Workforce Competency Framework for Providing Community Forensic Services for People with Learning Disabilities and/or Autistic Spectrum Conditions (Health Education England, due in 2019).

Scope of the framework

The successful delivery of health and social care services, both mainstream and learning disability specific, involves a workforce that is extensive and diverse, including many staff closely engaged in providing care as well as offering information, support and assistance. Learning disabilities services may be offered in a broad variety of settings including an individual's own home, community settings, schools, residential homes and acute hospitals. Support staff and other individuals outside the health and care sectors (e.g. justice, education, housing and employment) may interact with those affected by learning disabilities and therefore need to have awareness and understanding of learning disabilities issues.

The capabilities (i.e. skills, knowledge and behaviours) described in the framework are therefore defined at **3 tiers**:

Tier 1 Those that require general awareness of people with a learning disability and the support they need.

Relevant to those in working in any sector who may occasionally interact with those affected by learning disabilities but who do not have responsibility for making decisions about their care or support. For example, this may include those working in education, policing, custodial care, housing or indeed any organisation. This is also relevant to the entire health and social care workforce including ancillary and clerical staff.

Tier 1 is also relevant to the family, friends and carers of people with a learning disability, to ensure they are making the most of the support on offer and can plan effectively for current and future needs.

Capability 1: Learning Disability Awareness brings together the Tier 1 learning outcomes. For example, this would be relevant to an introductory learning disability awareness course.

Tiers 2 and 3 provide coverage of capabilities in greater breadth and depth.

Tier 2 Health and social care staff and others with responsibility for providing care and support for a person or people with a learning disability, but who would seek support from others for complex management or complex decision-making

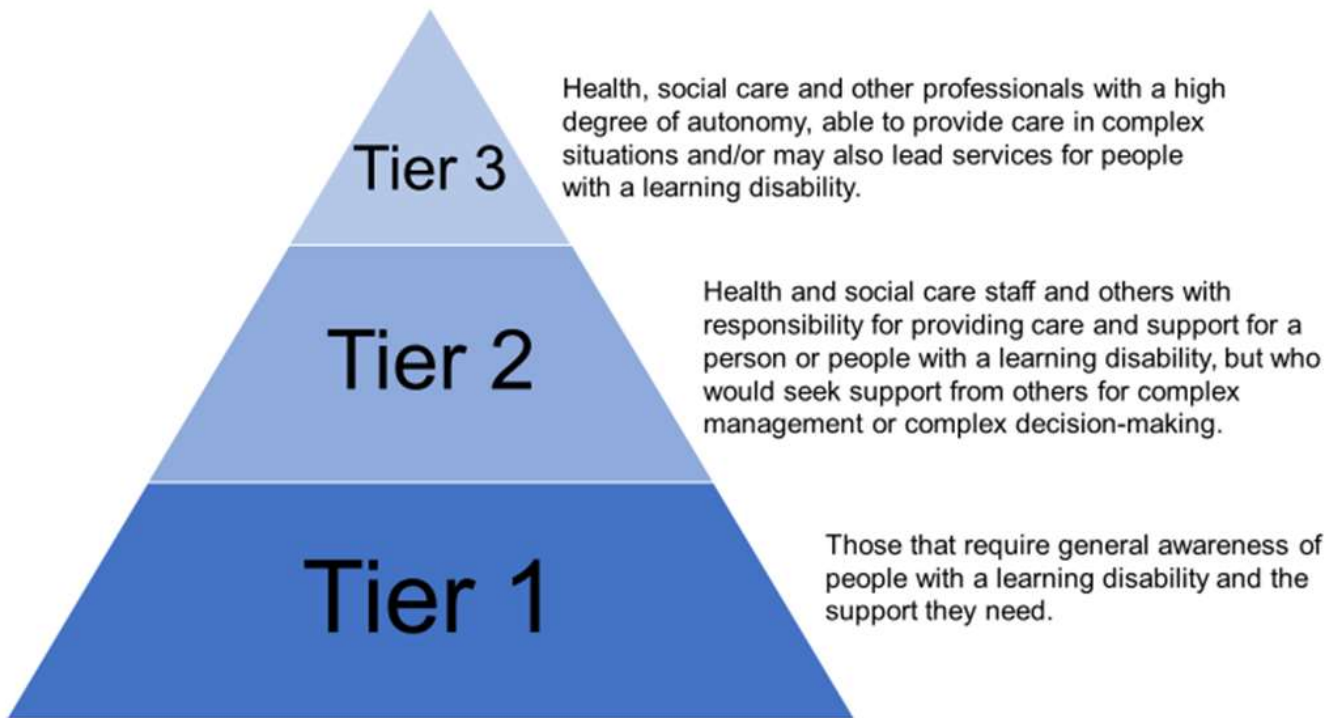
This is relevant to health and social care workers providing care and support, including care assistants working in residential or home care and also personal assistants.

Tier 2 may also be relevant to family and friends who are providing care and support.

Tier 2 also underpins the more specialist skills and knowledge required at tier 3.

Tier 3 Health, social care and other professionals with a high degree of autonomy, able to provide care in complex situations and/or may also lead services for people with a learning disability.

This is relevant to staff working intensively with people with a learning disability including those who take a lead in decision making and developing or disseminating good practice. For example, this may include learning disability nurses, clinical psychologists, psychiatrists, GPs with special interest in learning disability, social workers etc. It may also include registered managers and other social care leaders including operational managers who have responsibility for services which provide care and support to people with a learning disability



It is important to note that the level of knowledge and skill people require is not necessarily reflected by their job role or title e.g. a specialist practitioner may have a more in-depth level of knowledge and skill in some capabilities than a practitioner in another, but more senior role.

The framework is incremental i.e. tiers 2 and 3 assume that learners possess the skills and knowledge at preceding tiers (to minimise unnecessary repetition).

How to use this framework

The framework is particularly relevant to employers, their employees and also to educational organisations which train students who will be employed in the health, social care and other sectors. Use of the framework will support organisations to:

- standardise learning disabilities education and training
- guide the focus and aims of learning disabilities education and training delivery
- ensure the educational relevance of learning disabilities training
- improve the quality and consistency of education and training provision.

The framework also supports the development and planning of the current and future workforce. The capabilities can be used to support the commissioning of services, the design of roles and/or teams as well as assessment of competence, training needs analysis and provision of minimum standards of performance within performance management systems (e.g. as part of supervision or appraisal).

Learning outcomes

The learning outcomes aim to describe what the learner will know, understand or be able to do as a result of their learning or experience. This approach is derived from Bloom's Taxonomy¹

The person or practitioner will:

- Be aware of: General awareness of information
- Know: Remember previously learned information
- Understand: Demonstrate an understanding of the facts
- Be able to: Apply knowledge to actual situations
- Analyse: Break down objects or ideas into simpler parts and find evidence to support generalisations
- Synthesise: Compile component ideas into a new whole or propose alternative solutions
- Evaluate: Make and defend judgements based on internal evidence or external criteria.

The majority of learning outcomes at tiers 1 and 2 describe knowledge, comprehension/understanding and application, although there are some learning outcomes (particularly at tier 3) which may include analysis, synthesis and evaluation.

The learning outcomes for each capability should together indicate the minimum content for the design and delivery of teaching and learning for each tier in that capability. However, it is important to reiterate that this is a *core* capabilities framework i.e. the scope of the framework is that which is common and applicable to all settings. Additional content may also be required for some roles and contexts.

The learning outcomes are written as broad statements e.g. 'The Learner will: be aware of / know / understand / be able to...' This provides scope for the framework to be applicable across a wide range of contexts and settings.

¹ Bloom B (1956), *Taxonomy of educational objectives*

Training and assessment

The framework does not prescribe a training/teaching method. This will be developed according to the particular context or setting. However, we do know that in order to produce good quality training, people with a learning disability should be involved in the design and the delivery.

Similarly, the framework does not seek to prescribe assessment methods, however assessment in many areas is important and should be factored into the design and delivery of training.

For application in a specific context, relevant learning objectives or assessment criteria may be developed to measure achievement of the learning outcomes. In a given context, more specific verbs may be applied to each learning outcome e.g. 'The learner will: explain / describe / demonstrate / discuss / identify / etc...'

For example, in different organisations or contexts learning outcomes may be assessed by a range of methods e.g. e-assessment, group discussion, observation of performance, products of work, testimony from witnesses, project/case study work etc. The learning outcomes in the framework are intended to be adaptable to this variety of assessment methods.

Who is this framework for?

The framework provides a focus on the skills, knowledge and behaviours expected for the delivery of learning disabilities services. This should be of particular value to:

People with a learning disability and their family, friends and carers

The framework can be used by people with a learning disability to better understand the capabilities they can expect from those providing services, how to make the most of the support on offer and to plan effectively for their own current and future care. In particular, the framework highlights that people with a learning disability and their family, friends and carers must be able to make informed choices about effective care and support alongside healthcare and other practitioners, i.e. to participate in shared decision-making.

Workers and teams

The framework sets out clear expectations for learners and in particular, the core learning outcomes that specific tiers of the workforce should be able to demonstrate. This supports individuals and teams to:

- be clear about the requirements of their roles and to recognise their own transferable skills
- conduct formal or informal training needs analysis, comparing current skills and knowledge with required skills and knowledge
- plan future education and training requirements to enable continuing professional development and career progression.

Subject matter experts / trainers

The framework helps those who design education and training opportunities to focus on the key outcomes that learners need to achieve, which in turn will guide the content to be included and the use of appropriate teaching strategies. This includes co-production of training with people with a learning disability and families and carers.

The specific learning outcomes also support the effective evaluation of education and training. Approaches to evaluation can include:

- evaluating whether learners have achieved the required learning outcomes immediately following a learning intervention (e.g. through assessment of knowledge and/or competence)
- evaluating whether the learning is being applied in the workplace (e.g. through longer-term evaluation of impact on practice, possibly as part of supervision or appraisal processes)

- evaluating the impact on quality of care (e.g. measuring patient outcomes and/or levels of satisfaction from individuals with a learning disability and their families). Such evaluation will require data collection to measure what changes.

Assessors of occupational standards

References to relevant national occupational standards and other skills frameworks indicate how the framework relates to national standards. For example, a learner working towards the requirements of a national occupational standard could use the framework as a guide to the skills and knowledge they would need to demonstrate in achieving the national occupational standard in the specific context of *learning disabilities*.

Managers in organisations / individual employers / commissioners of training

The framework enables managers and commissioners to be clear about the specific outcomes required from staff development interventions. Use of the framework within an organisation enables managers to demonstrate that core learning disabilities training has been planned and delivered in accordance with a nationally recognised framework. Similarly, commissioners can use the framework to provide education and training providers with a quality assurance specification for learning disability capabilities.

Education providers

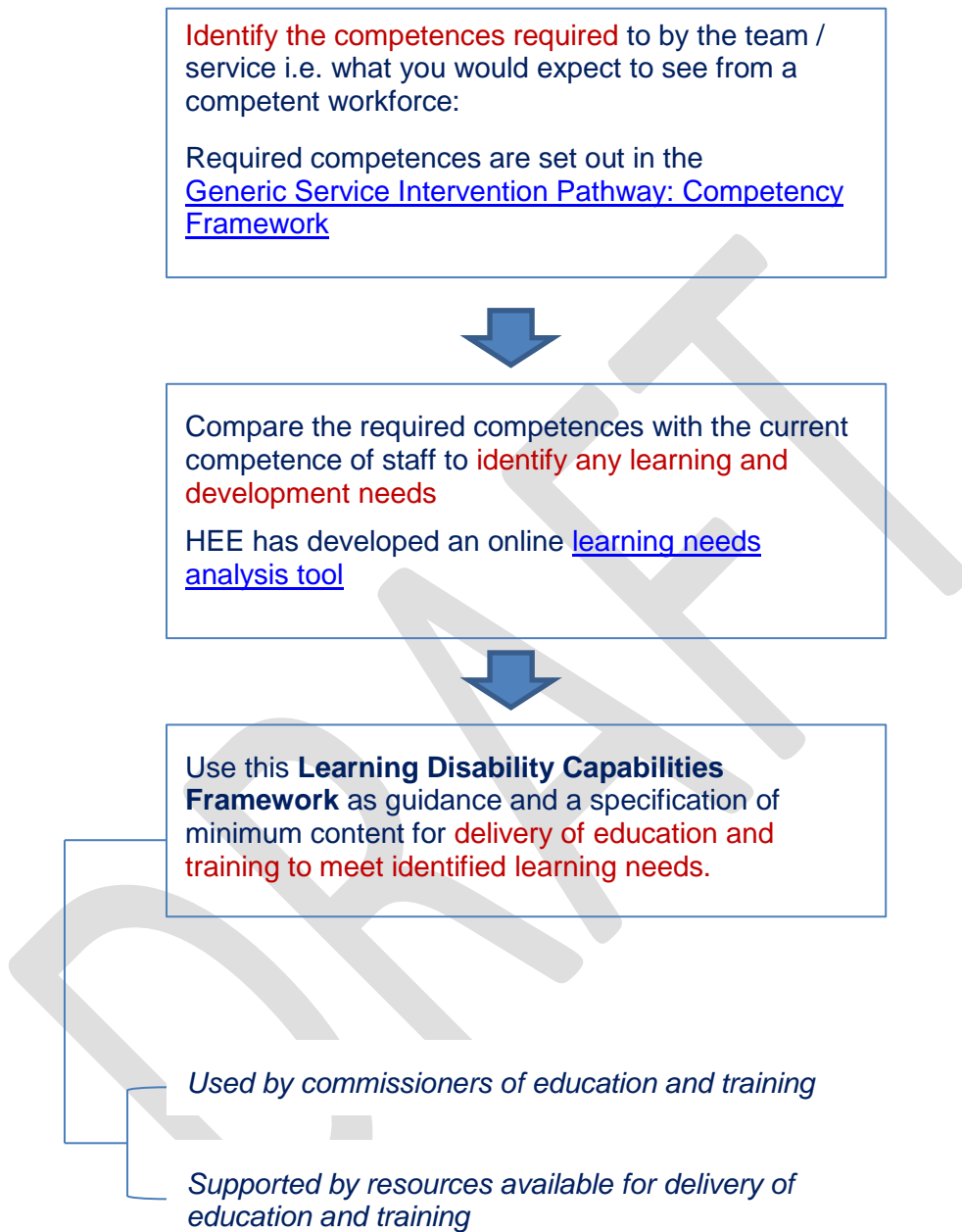
Universities, colleges and private training providers can use the framework to underpin the design of education and training curricula, ensuring that the required core learning outcomes are integrated appropriately and/or mapped to overall achievement of curriculum aims. This will help ensure that those learners undertaking health and care programmes are given the opportunity to acquire learning disabilities core knowledge and skills which are relevant to the requirements of employing organisations.

Regional and national implementation

A further aspiration in providing this framework is that organisations will be able to review their current arrangements for defining and delivering learning disabilities education and training and through the adoption of the framework align their approaches. Such alignment should then have benefits in ensuring consistent approaches, which, through the use of learning outcomes, should be more educationally focused and valued. This has the potential to promote organisational and system wide efficiencies by encouraging the adoption of education and training which meets recognised standards and in doing so help to prevent unnecessary duplication of education and training delivery.

The framework also supports the increasing integration between health and social care services and their respective workforces. In particular, a capabilities framework can help to improve communication, collaborative working and potentially provide opportunities for joint education and training.

Figure 1: Complementary frameworks / tools



Principles and values

Providing care and support for people (children, young people and adults) with a learning disability requires commitment to strong principles and a firm value base. These principles and values underpin all the capabilities in this framework.

Principles

Valuing People: A New Strategy for Learning Disability for the 21st Century² set out four key principles that should underpin all care and support for people (children, young people and adults) with a learning disability:

- **Rights:** People with learning disabilities and their families have the same human rights as everyone else.
- **Independent living:** This does not mean living on your own or having to do everything yourself. All disabled people should have greater choice and control over the support they need to go about their daily lives; greater access to housing, education, employment, leisure and transport opportunities and to participation in family and community life.
- **Control:** This is about being involved in and in control of decisions made about your life. This is not usually doing exactly what you want, but is about having information and support to understand the different options and their implications and consequences, so people can make informed decisions about their own lives.
- **Inclusion:** This means being able to participate in all the aspects of community – to work, learn, get about, meet people, be part of social networks and access goods and services – and to have the support to do so.

Valuing People Now: a New Three-Year Strategy for People with Learning Disabilities³ reaffirmed the four principles and promoted a human rights approach as a key underpinning principle. The strategy also re-emphasised that people with a learning disability and their families have the same rights as everyone else, as enshrined in the Human Rights Act (1998), the UN Convention on the Rights of Persons with Disabilities (**CRPD**) and Disability Discrimination Act (2005).

Commonly agreed 'human rights principles' sometimes referred to as the FREDA principles include: fairness, respect, equality, dignity, and autonomy (choice and control). These principles are considered to underpin all international human rights treaties. They are used, for example, in the Human Rights in Healthcare framework for local action.⁴

- **Fairness** – people who use services and people acting on their behalf have access to clear and fair processes for getting their views heard, for decision-making about care and treatment and to raise and resolve concerns or complaints.
- **Respect** – people who use services are valued as individuals and are listened to, and what is important to them is viewed as important by the service. People acting on behalf of others, such as family and friends are also valued and listened to.
- **Equality** – people who use services do not experience discrimination and have their needs met, including on the grounds of age¹⁶, disability, gender, race, religion and belief, sexual orientation, gender reassignment and pregnancy and maternity status. This includes looking at the needs of people who may experience multiple discrimination or disadvantage on more than one ground.
- **Dignity** – people who use services are always treated in a humanitarian way – with compassion and in a way that values them as a human being.

² *Valuing People: a new strategy for learning disability for the 21st century - a White Paper*. London: Department of Health 2001

³ *Valuing People Now: a new three-year strategy for people with learning disabilities*. London: Department of Health, 2009

⁴ British Institute for Human Rights and Department of Health, *Human Rights in Healthcare – a framework for local action*, 2007

- **Autonomy** – people who use services can exercise the maximum amount of choice and control possible – in care planning, in their individual care and treatment, in service development, in their relationships with others such as family and friends and as citizens beyond the health and social care services that they are using.
- **Right to life** – people who use services will have their right to life protected and respected by the health and social care services that they use.
- **Staff rights and empowerment** – staff working in health and social care have their human rights protected and respected, including being encouraged to freely speak up about concerns and have these considered, being free from unlawful workplace discrimination, harassment, bullying or violence and being supported and empowered to promote the human rights of people using their service.

Values

In addition to the above principles, care and support for people (children, young people and adults) with learning disabilities should be delivered in line with the value base of health and social care.

Values influence the way we work and guide our approach to those we support and can provide the foundations underpinning good care practice. In health and social care these values include the following:

- Individuality and identity
- Rights
- Choice
- Privacy
- Independence
- Dignity
- Respect
- Partnership

The Code of Conduct for Healthcare Support Workers and Adult Social Care Workers in England⁵ sets the standard of conduct expected of all adult social care workers and healthcare support workers in England. It helps workers provide high quality, safe and compassionate care and support and outlines the behaviours and attitudes that people who use care and support should rightly expect.

The '6Cs', which underpin the Compassion in Practice strategy, were developed as a way of articulating the values which need to underpin the culture and practise of organisations delivering care and support. These are immediately identifiable as values which also underpin quality social care provision.⁶

⁵ Code of Conduct for Healthcare Support Workers and Adult Social Care Workers in England, Skills for Care & Skills for Health 2013

⁶ Compassion in Practice Nursing, Midwifery and Care Staff Our Vision and Strategy, Commissioning Board Chief Nursing Officer and DH Chief Nursing Adviser December 2012

Domain A. Understanding learning disabilities

Insert image

Capability 1: Learning disability awareness

Introduction

Children, young people and adults with a learning disability and/or autism have the right to the same opportunities as anyone else to live satisfying and valued lives, and to be treated with dignity and respect. They should have a home within their community, be able to develop and maintain relationships, and get the support they need to live healthy, safe and rewarding lives.⁷

Department of Health figures suggest that about 1.5 million people (children, young people and adults) (around 2.5 per cent of the UK population) in the UK has a learning disability. The prevalence of learning disability in the general population is expected to rise by around one per cent per annum for the next 10 years and to grow overall by over ten per cent by 2020.⁸

The services and support commissioned by health and social care for people with a learning disability are shaped by key government policies and strategies. *Valuing People: A New Strategy for Learning Disability for the 21st Century* set out the Government's proposals for improving the lives of people with a learning disability and their families and carers, based on recognition of their rights as citizens, social inclusion in local communities, choice in their daily lives and real opportunities to be independent.⁹

The cross-government concordat, *Putting People First* (2007)¹⁰ set out a vision for social care services that support people to live independently, stay healthy and have the best possible quality of life, irrespective of illness and disability. It confirmed a shift in emphasis towards greater personalisation.

The three-year strategy, *Valuing People Now* (2009)¹¹ reaffirmed the principles of the original *Valuing People* strategy and introduced a stronger emphasis on:

- Improving opportunities for people with learning disabilities to make an informed choice about where, and with whom, they live;
- Addressing social exclusion;
- Increasing the number of people with learning disabilities in paid employment;
- Improving support for people with complex needs;
- Improving healthcare outcomes; and
- Improving support for family carers.

More recently, the Learning Disabilities Mortality Review (LeDeR) Programme has highlighted the persistence of health inequalities and that people with a learning disability die, on average, 15-20 years sooner than people without a learning disability. Key recommendations of the LeDeR programme include the provision of reasonable

⁷ Building the right support: A national plan to build community services and close inpatient facilities for people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition, LGA/ADASS/NHS England (October 2015).

⁸ Emerson E, Hatton C. Estimating the current need/demand for support for people with learning disabilities in England. Lancaster University. 2004.

⁹ Valuing People - A New Strategy for Learning Disability for the 21st Century 2001 DH

¹⁰ Putting People First A shared vision and commitment to the transformation of Adult Social Care 2009 HM.Gov

¹¹ Valuing People Now - A summary.2009-2010

adjustments, greater awareness of the health problems that are more common for people with a learning disability and that mandatory learning disability awareness training should be provided to all staff and be delivered in conjunction with people with a learning disability and their families.

The launch of the NHS Long Term Plan (2019) has provided additional focus on action the NHS will take to strengthen its contribution to prevention and health inequalities, including mechanisms to ensure that people with learning disability and/or autism get better support. In addition to those providing health and social care, others who come into contact with people with a learning disability need to have an awareness and understanding of their specific needs and those of their families and carers.

Target audience

Tier 1 – Those that require general awareness of people with a learning disability and the support they need.

This tier 1 capability brings together the learning outcomes required for a basic awareness of other capabilities in the framework. The outcomes at tier 1 (below) are therefore grouped according to the domains for tiers 2 and 3.

Key learning outcomes

Understanding learning disabilities (Domain A)

The person or practitioner will:

- a) know what is meant by the term learning disability
- b) know the common types of conditions that may lead to a learning disability
- c) know the importance of timely identification and assessment of learning disabilities and support needs
- d) be aware of the key legislation, policy and guidelines relating to people with a learning disability, including their own responsibilities under the Mental Capacity Act 2005, the Equality Act 2010, the Care Act 2014 and the Accessible Information Standard.
- e) be aware of the socio-political background and context of learning disability services including the development of approaches which recognise the strengths and potential of people with a learning disability

Person-centred collaborative working (Domain B)

- f) know the importance of a person-centred approach when working with people with a learning disability
- g) be able to make simple adaptations to communication methods to meet the needs and preferences of persons with a learning disability and understand how to access further support to ensure people's communication needs are met
- h) understand the purpose and scope of the Accessible Information Standard for health and social care organisations
- i) be aware of the key barriers faced by people with a learning disability and their families and carers
- j) be aware of the roles family carers and paid supporters may play in the lives of people with a learning disability

Health and wellbeing (Domain C)

- k) be aware of the prevalence and potential impact on the lives of people with a learning disability of the following conditions:
 - i. epilepsy
 - ii. dysphagia
 - iii. diabetes
 - iv. heart disease
 - v. constipation
 - vi. colorectal cancer
 - vii. sepsis
 - viii. trauma

- l) know the common signs and symptoms of the above conditions and that a person with a learning disability may present different signs or no signs at all
- m) understand that adults with a learning disability should be considered a high-risk group for deaths from respiratory problems and choking
- n) understand that any change in a person's presentation or behaviour may be a sign of a health or emotional problem even if it presents differently than in other people
- o) be aware of the main causes of health inequality for people with a learning disability
- p) be aware of the common adjustments which may be necessary when supporting people with a learning disability and the purpose of health action plans / health passports in signposting critical adjustments

Personalised care and support (Domain D)

- q) be aware of the kinds of support people with a learning disability may need when experiencing significant changes in their lives
- r) know how views and attitudes of others impact on the lives of people with a learning disability and their families and carers
- s) understand the key sources of support and know when and how to signpost people with a learning disability and their families and carers to those other services and support
- t) understand the key mechanisms and sources of support within one's own organisation and know when and how to safely refer people with a learning disability when extra support is needed to manage their care
- u) understand the importance of care co-ordination for people with complex needs

Risk, legislation and safeguarding (Domain E)

- v) be aware of the importance of addressing inequalities for people with a learning disability
- w) be aware of the basic principles and practice of advocacy in supporting people with a learning disability
- x) be aware of how individuals and organisations should work together to prevent abuse and neglect and to ensure the safety and wellbeing people with a learning disability
- y) be aware of disability hate crime and how to report such incidents.

NB. These core learning outcomes for learning disability awareness may be supplemented by additional outcomes to take account of factors such as type of role, location, service need and risk analysis. Learning disability awareness also needs to be understood in conjunction with related statutory and mandatory capabilities as appropriate to role.

Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to learning disabilities awareness are shown below:

Guidance

- [Generic Service Interventions Pathway: A competency framework to support development of the learning disability workforce, Health Education England \(2015\)](#)
- [Care and Support statutory guidance \(2016\)](#)
- [Mental Capacity Act 2005 Code of Practice](#)

- [Improving healthcare access for people with learning disabilities: Guidance for social care staff on how to help people with learning disabilities get better access to medical services to improve their health, Public Health England \(2017\)](#)
- [Reasonable adjustments for people with a learning disability Guides on how reasonable adjustments to health services and adjustments to help people with learning disabilities to access services, Public Health England \(2018\)](#)
- [Learning Disabilities Mortality Review \(LeDeR\) Programme, University of Bristol \(2017\)](#)

Legislation

- [Care Act \(2014\)](#)
- [Children and Families Act 2014](#)
- [Equality Act 2010](#)
- [Disability Discrimination Act 1995](#)
- [Human Rights Act 1998](#)
- [Mental Capacity Act 2005](#)

Indicative mapping to relevant national standards or frameworks

Mapping to be completed...

[Return to contents page](#)

Capability 2: Identification and assessment of learning disabilities

Introduction

Having a learning disability identified can be difficult; some learning disabilities are known about or suspected during the mother's pregnancy or discovered at birth, while others are not identified until much later. When a learning disability is not identified at birth, finding out a child has a learning disability can take time. However, most learning disabilities are apparent by the age of five, although moderate learning disabilities may only become apparent later in life and some older adults may never have been diagnosed with a learning disability.

Timely identification of learning disabilities is crucial to people with a learning disability getting the support they need to live full and independent lives. Knowing the indicators of a learning disability and effective working with the child's family helps with early identification and assessment.

Target audience

Tier 2 – Health and social care staff and others with responsibility for providing care and support for a person or people with a learning disability, but who would seek support from others for complex management or complex decision-making

Tier 3 – Health, social care and other professionals with a high degree of autonomy, able to provide care in complex situations and/or may also lead services for people with a learning disability..

Key learning outcomes

Tier 2

The person or practitioner will:

- a) know that learning disability ranges in severity and is sometimes called 'mild', 'moderate' or 'severe' and that 'profound and multiple learning disabilities' means a person has a severe learning disability and other disabilities that significantly affect their ability to communicate and be independent.
- b) understand why the term 'intellectual disability' / intellectual impairment' might be used
- c) be aware of the indicators of learning disabilities that would signal the need for further assessment
- d) know why timely identification of learning disabilities is important and the likely outcomes if assessment is delayed
- e) be aware of the process to be used to identify and assess learning disabilities
- f) be able to explain the benefits of an assessment of a learning disability with sensitivity and in a way that is appropriate to the person with a learning disability
- g) be able to appropriately refer people with a learning disability to access specialist services and support networks
- h) be able to promote equal access to universal services and facilities for people with a learning
- i) understand the contribution that families and carers make to care and support for people with a learning disability
- j) be able to engage with families and carers providing care and support for a person with a learning disability.

Tier 3

Tier 2 learning outcomes plus the following

The person or practitioner will:

- a) be able to work in partnership with a person with a learning disability (and their family where appropriate) and others to facilitate person centred assessment
- b) be able to carry out person centred assessment that promotes social, emotional, cultural, spiritual and physical wellbeing
- c) be able to undertake a comprehensive assessment for learning disability utilising appropriate assessment tools
- d) be able to assess the needs of families and carers providing care and support for a person with a learning disability
- e) be able to develop a plan to support families and carers providing care and support for a person with a learning disability
- f) be aware of the potential impact of assessment errors for people (children, young people and adults)
- g) be able to communicate with sensitivity about the identification of a learning disability and related implications
- h) know how to support people with a learning disability to access post-assessment support services and advanced care and support planning
- i) understand the differing needs of people with mild, moderate and severe learning disability and those with profound and multiple learning disabilities (PMLD)
- j) understand the importance of equal access to learning disabilities assessment for people from diverse communities and how cultural and language differences may affect this access.

Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to identification, assessment and identification of learning disabilities are shown below:

Guidance

- [Generic Service Interventions Pathway: A competency framework to support development of the learning disability workforce, Health Education England \(2015\)](#)

Legislation

- [Care Act \(2014\)](#)
- [Children and Families Act 2014](#)
- [Equality Act 2010](#)
- [Disability Discrimination Act 1995](#)
- [Human Rights Act 1998](#)
- [Mental Capacity Act 2005](#)

Indicative mapping to relevant national standards or frameworks

Mapping to be completed...

[Return to contents page](#)

Domain B. Person-centred collaborative working

Insert image

Capability 3: Communication

Introduction

People (children, young people and adults) with a learning disability can face particular challenges with communication. A learning disability can affect both the way a person understands and conveys information. In addition, most people with a learning disability have some difficulties with speech, language, communication and/or sensory impairment which can be hidden, masked or overlooked. It is therefore important to know what good communication support 'looks like', how organisations can inadvertently contribute to communication difficulties and what reasonable adjustments may be needed.

In order to communicate effectively it is essential to understand and value the way a person communicates, taking account of an individual's communication, speech, language and sensory needs and preferences.

Target audience

Tier 2 – Health and social care staff and others with responsibility for providing care and support for a person or people with a learning disability, but who would seek support from others for complex management or complex decision-making

Tier 3 – Health, social care and other professionals with a high degree of autonomy, able to provide care in complex situations and/or may also lead services for people with a learning disability..

Key learning outcomes

Tier 2

The person or practitioner will:

- a) know that maximising an individual's opportunity for communication, in all areas of life, is critical for supporting the autonomy, wellbeing and quality of life of people with a learning disability
- b) understand that each person with a learning disability may have a unique way of communicating
- c) understand the importance of non-verbal communication e.g. body language, signing, visual images and the appropriate use of touch
- d) understand how behaviour is a form of communication, and the meanings that can be attached to behaviour
- e) understand that behaviours that challenge will usually function as communication for people with a learning disability

- f) be able to use a range of communication techniques to convey information, according to the different abilities and preferences of people with learning disabilities
- g) understand the importance of listening to and understanding people with learning disabilities, with the ability to adapt how they listen and understand information presented nonverbally
- h) understand the importance of confidentiality in interactions with people with a learning disability, including recognising the nuances and limitations of confidentiality.
- i) know why individualised communication plans should be developed, implemented and reviewed with people with a learning disability
- j) understand a person's communication plan or passport and use it to adapt communication with that individual
- k) be aware of the impact of the environment on communication – knowing how to find the right time and place and situation for important communications
- l) know the importance of ensuring that people with a learning disability have any required sensory support (e.g. spectacles, hearing aids and / or communication systems) to enable successful communication
- m) understand the importance of effective communication with families and carers and the expertise that families and carers may be able to offer to support effective communication with the person with a learning disability
- n) understand the legal requirements (Public Equality Duty, Equality Act, Mental Capacity Act and Accessible Information Standard) to make adjustments to all forms of communication and information.

Tier 3

Tier 2 learning outcomes plus the following

The person or practitioner will:

- a) understand why communication is critical for supporting autonomy, wellbeing and quality of life
- b) understand how to use assistive technology to enhance communication
- c) be able to improve communication systems and practices that support positive outcomes for people with a learning disability
- d) be able to actively support, develop and change communication systems for each person with a learning disability
- e) be able to support staff in the understanding of more complex communication needs
- f) be able to support assessment and intervention components that address alternate functional communication
- g) be able to utilise a range of augmentative and alternative communication methods and services that meet the communication needs of people with a learning disability
- h) understand how service systems and processes can sometimes put barriers in the way of effective communication with people with a learning disability and families and carers

Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to communication in learning disability care and support are shown below:

Guidance

- [Accessible Information Standard - NHS England \(2017\)](#)

- [Generic Service Interventions Pathway: A competency framework to support development of the learning disability workforce, Health Education England \(2015\)](#)
- [Positive Behavioural Support: A Competence Framework - Positive Behavioural Support \(PBS\) Academy \(May 2015\)](#)
- [Five good communication standards: Reasonable adjustments to communication that individuals with learning disability and/or autism should expect in specialist hospital and residential settings - Royal College of Speech and Language Therapists \(2013\)](#)
- [Career & Development Framework for Learning Disability Nursing in Scotland, March 2013](#)

Legislation

- [Care Act \(2014\)](#)
- [Children and Families Act 2014](#)
- [Mental Capacity Act 2005](#)
- [Equality Act 2010](#)
- [Disability Discrimination Act 1995](#)
- [Human Rights Act 1998](#)

Indicative mapping to relevant national standards or frameworks

Core Skills/Capabilities Frameworks (at: www.skillsforhealth.org.uk/cstf)

- Person-Centred Approaches: A Core Skills Education and Training Framework

Mapping to be completed...

[Return to contents page](#)

Capability 4: Empowerment and person-centred care

Introduction

Person-centred thinking and planning in learning disability care and support is about understanding and responding to the person with a learning disability as an individual. It involves considering the whole person, taking into account each individual's life history, unique abilities, interests, preferences and needs. It is about building relationships with people with a learning disability and their family and carers, putting them in the driving seat of decision making and empowering them to be in control of their lives.

Empowerment and person-centred thinking and planning is at the heart of all recent policy relating to the care and support for people (children, young people and adults) with a learning disability. It refers to a family of approaches aimed at enabling people who use care and support to plan their own futures and to get the support they need. While the terminology varies between different user groups, the fundamental values of the concept are the same – embracing the principles of independence, choice, inclusion, equality and empowerment as the foundations of care and support.

Target audience

Tier 2 – Health and social care staff and others with responsibility for providing care and support for a person or people with a learning disability, but who would seek support from others for complex management or complex decision-making

Tier 3 – Health, social care and other professionals with a high degree of autonomy, able to provide care in complex situations and/or may also lead services for people with a learning disability..

Key learning outcomes

Tier 2

The person or practitioner will:

- a) practice person-centred thinking and planning in care and support for people with a learning disability
- b) know how to involve people with a learning disability who don't use verbal language to communicate their needs
- c) understand the significance of a person with a learning disability's background, culture and experiences when providing care and support
- d) understand how person-centred thinking and planning can provide insights into care and support approaches and solutions to meeting the needs of people with a learning disability
- e) understand the important role of family and carers in person-centred thinking and planning with people with a learning disability
- f) understand the importance of clear processes to communicate the care and support needs of people with a learning disability
- g) understand own role in person-centred thinking and planning with people with a learning disability
- h) be able to contribute to the gathering of information about a person with a learning disability's strengths, needs, preferences, hopes, dreams and desires for their person-centred plan
- i) be able to schedule and measure progress towards goals important to the person with a learning disability
- j) be able to participate in person-centred planning meetings
- k) understand the principles and practices of co-production

- l) understand the roles that advocacy can play in person centred support, including the different types of advocacy and how to refer/signpost an individual for advocacy support.

Tier 3

Tier 2 learning outcomes plus the following

The person or practitioner will:

- a) understand the theory and principles that underpin person centred thinking and planning in care and support for people with a learning disability
- b) understand the value of person-centred care and support in therapeutic relationships and communication
- c) lead person-centred practice for people with a learning disability
- d) understand the importance of establishing consent when providing care or support for people with a learning disability
- e) understand how to ensure a person with a learning disability can exercise their right to make choices
- f) understand the role of positive risk taking in enabling a person-centred approach
- g) understand duty of care and mental capacity legislation in relation to supporting positive risk-taking
- h) be able to work in partnership with a person with a learning disability and others to facilitate person-centred assessment
- i) be able to carry out person-centred assessment that promotes social, emotional, cultural, spiritual, intellectual, financial and physical wellbeing
- j) be able to implement personalised systems for goal-based person-centred outcome planning, implementing plans, and monitoring their impact
- k) be able to incorporate person-centred thinking and planning in the management and development of services
- l) be able to incorporate co-production in the management and development of services

Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to person-centred care and support for people with a learning disability are shown below:

Guidance

- [Generic Service Interventions Pathway: A competency framework to support development of the learning disability workforce, Health Education England \(2015\)](#)
- [Positive Behavioural Support: A Competence Framework - Positive Behavioural Support \(PBS\) Academy \(May 2015\)](#)
- [Accessible Information Standard - NHS England \(2017\)](#)

Legislation

- [Care Act \(2014\)](#)
- [Children and Families Act 2014](#)
- [Human Rights Act 1998](#)
- [Equality Act 2010](#)

- [Disability Discrimination Act 1995](#)
- [Mental Capacity Act 2005](#)

Indicative mapping to relevant national standards or frameworks

Core Skills/Capabilities Frameworks (at: www.skillsforhealth.org.uk/cstf)

- Person-Centred Approaches: A Core Skills Education and Training Framework

Mapping to be completed...

[Return to contents page](#)

DRAFT

Capability 5: Families and carers as partners in care and support

Introduction

The support and commitment of families and carers can be critical in enabling people (children, young people and adults) with a learning disability to achieve independence, choice and inclusion. Families and carers are usually central to the lives of people with a learning disability, providing care, support and advocating for new opportunities.

Where peoples' families and/or carers are involved in their lives, working with them as partners and promoting their wellbeing can be key to successful outcomes for people with a learning disability.

Target audience

Tier 2 – Health and social care staff and others with responsibility for providing care and support for a person or people with a learning disability, but who would seek support from others for complex management or complex decision-making

Tier 3 – Health, social care and other professionals with a high degree of autonomy, able to provide care in complex situations and/or may also lead services for people with a learning disability..

Key learning outcomes

Tier 2

The person or practitioner will:

- a) understand the significance and value of families, carers and social networks in planning and providing care and support for people with a learning disability
- b) be aware of the potential benefit of a person with a learning disability having a circle of support
- c) know the key people in the person with a learning disability's circle of support and the role that they play in that person's life
- d) know the importance of engaging with, and supporting family members and others in the person's social network
- e) understand the importance of developing partnerships with families and carers and discussing when and how they would like to be involved in the person's care
- f) be able to establish and maintain positive relationships with families and carers
- g) be able to plan shared approaches to the care and support of people with a learning disability with their families and carers
- h) understand the right of families to be involved in decisions, where the person lacks capacity and a best interests decision is being made
- i) be able to gather information about a person with a learning disability's history and preferences from their families and carers
- j) be able to work with families to access support in their role as carers
- k) be able to exchange and record information about partnership work with families and carers appropriately in each situation whilst understanding a person with a learning disability's right to confidentiality and to make informed choice or have best interest decisions made about sharing information

- l) be able to contribute to reviewing partnership work with families and carers
- m) understand the positive and negative impact that caring for a person with a learning disability in the family may have on relationships and family members' own wellbeing
- n) understand the importance of providing information and advice and where appropriate, training, to families and carers and utilising their expertise in developing training
- o) understand the importance of recognising and assessing a carer's own needs and be able to signpost carers for an assessment of their needs
- p) be aware that the needs of different families and carers and the person with a learning disability will not be the same
- q) be aware of the importance of social interactions and relationships for families of people with a learning disability and accepting of each families' own culture, traditions and style of interaction.

Tier 3

Tier 2 learning outcomes plus the following

The person or practitioner will:

- a) understand the contribution that families and carers make in supporting people with a learning disability
- b) be able to assess the needs of families and carers providing care for a person with a learning disability
- c) be able to co-produce a plan to support families and carers providing care for a person with a learning disability
- d) understand family and carer interventions and how to undertake them
- e) understand the value of short breaks and other forms of 'respite' or carer support, and how to access them
- f) be able to support access to carers' personal budgets, parental support groups, family support groups, and community groups
- g) be able to implement recommendations that take into account communication needs of families and carers
- h) be able to help create healthy psychological environments for people with a learning disability by giving support and advice to carers and families
- i) be able to contribute to the development of practices and services that meet the needs of families and carers
- j) understand the potential for dilemmas arising where there are differing needs between people with a learning disability and their families and carers
- k) understand legislation relevant to families' and carers' rights
- l) be able to signpost families and carers for further support around legal issues (e.g. deputyship, appointeeship or lasting power of attorney)
- m) understand the needs of the ageing family carer, and how to signpost them to sources of support
- n) be able to share knowledge and train carers in the care of a particular person with a learning disability

Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to families and carers as partners in learning disability care and support settings are shown below:

Guidance

- [Generic Service Interventions Pathway: A competency framework to support development of the learning disability workforce, Health Education England \(2015\)](#)
-
- [Department of Health \(2010\), Recognised, valued and supported: Next steps for the Carers Strategy](#)
- [Department of Health \(2014\), Care and Support Statutory Guidance: Issued under the Care Act 2014](#)
- [Department of Health \(2014\), Care Act Factsheets, Factsheet 8: The law for carers](#)
- NICE guideline - Carers: provision of support for adult carers (expected publication January 2020)
- Skills for care with Avenues, guide to working with families;

Legislation

- [Children and Families Act 2014](#)
- [Care Act 2014](#)
- [Mental Capacity Act 2005](#)

Indicative mapping to relevant national standards or frameworks

Mapping to be completed...

[Return to contents page](#)

Capability 6: Supporting people at risk of behaviours that challenge

Introduction

Some people with a learning disability (as with many people without one) may sometimes display behaviours that challenge. This behaviour often results from the interaction between personal and environmental factors and can include self-injury, stereotypic behaviour, withdrawal, aggression and disruptive or destructive behaviour. This can be frightening for the person and those around them and this can lead to unhelpful responses and inappropriate use of restraint and psychotropic medication.

Positive behavioural support (PBS) is a recognised framework with which to understand and develop ways of supporting people who display, or are at risk of displaying, behaviours that challenge.

It's important that health and social care workers have the right skills and knowledge to support people with a learning disability and behaviours that challenge or who may be at risk of behaviour that challenges. Skills and knowledge in the areas of learning disability awareness, communication, person-centred planning and supporting independence and choice will all help in preventing and managing behaviours that challenge and are covered elsewhere in this framework.

It is important to note that all of the capabilities in this framework include learning outcomes that are relevant to people with a learning disability and at risk of behaviours that challenge. This capability includes specific learning outcomes that relate to care and support for people with a learning disability at risk of behaviours that challenge that are not covered elsewhere in the framework.

Target audience

Tier 2 – Health and social care staff and others with responsibility for providing care and support for a person or people with a learning disability, but who would seek support from others for complex management or complex decision-making

Tier 3 – Health, social care and other professionals with a high degree of autonomy, able to provide care in complex situations and/or may also lead services for people with a learning disability..

Key learning outcomes

Tier 2

The person or practitioner will:

- a) understand the term 'behaviours that challenge' and any other terms that may be used, e.g. behaviours of concern
- b) understand behaviour as a form of communication
- c) understand the relationship between the quality of someone's life and behaviours that challenge
- d) understand the relationship between physical and emotional wellbeing and behaviours that challenge
- e) understand the interactions between physical health problems/pain and behaviours that may be interpreted as 'behaviours that challenge'
- f) Understand the principles of Positive Behaviour Support (PBS) and its approach to:
 - o Creating high quality care and support environments
 - o Functional, contextual and skills-based assessments

- Developing and implementing a Behaviour Support Plan (BSP)
 - Evaluating intervention effects and on-going monitoring.
- g) be able to contribute to a functional assessment of a person with a learning disability and at risk of behaviours that challenge
- h) be able to follow a behaviour support plan; according to specified responsibilities and timeframes
- i) understand the important role families and carers have in supporting people with a learning disability and at risk of behaviours that challenge in addition to the full involvement of the person themselves
- j) understand when the support of a 'specialist' might be needed and how to access them

Tier 3

The person or practitioner will:

- a) be able to fully involve the person with a learning disability and at risk of behaviours that challenge (and where relevant, their family) in the process of understanding and devising supports relating to behaviours that challenge
- b) understand the context and common causes of behaviours that challenge
- c) be able to synthesise data to create an overview of a person with a learning disability and at risk of behaviours that challenge's skills and needs
- d) be able to construct a model that explains the functions of behaviour and how behaviour is maintained
- e) be able to teach people with a learning disability and at risk of behaviours that challenge new skills based on an understanding of how different people learn
- f) be able to understand and implement behaviour support plans
- g) be able to teach colleagues and others new skills so they can implement a behaviour support plan
- h) be able to implement multi-element evidence-based support strategies based on the overview and model
- i) be able to implement a least restrictive crisis management strategy
- j) be able to monitor the delivery of a behaviour support plan (procedural / treatment / fidelity / integrity)
- k) be able to contribute to an evaluation/review of the effectiveness of a behaviour support plan.

Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to supporting people (children, young people and adults) with a learning disability at risk of behaviour that challenges are shown below:

Guidance

- [Positive Behavioural Support: A Competence Framework - Positive Behavioural Support \(PBS Coalition UKAcademy, May 2015\)](#)
- [Learning disabilities: challenging behaviour NICE Quality Standard Published: 8 October 2015](#)
- [NICE Challenging behaviour and learning disabilities pathway \(2015\)](#)
- [HSC 3065 – Implement the Positive Behavioural Support model \(level 4, ref: T/601/9738\)](#)

- [Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges.](#)
- [Stopping over medication of people with a learning disability, autism or both \(STOMP\)](#)
- Care roles to deliver the Transforming Care programme - building the right support (Skills for Care 2016)
<https://www.skillsforcare.org.uk/Learning-development/ongoing-learning-and-development/learning-disability/transforming-care/Transforming-Care.aspx>

Legislation

- [Care Act \(2014\)](#)
- [Children and Families Act 2014](#)
- [Equality Act 2010](#)
- [Disability Discrimination Act 1995](#)
- [Human Rights Act 1998](#)
- [Mental Capacity Act 2005](#)

Indicative mapping to relevant national standards or frameworks

Mapping to be completed...

[Return to contents page](#)

Domain C. Health and wellbeing

Insert image

Capability 7: Physical health

Introduction

People (children, young people and adults) with a learning disability have a right to access good quality healthcare. Their health needs are often greater and more complex and often present differently from those of the general population.

This capability is focussed on awareness of the prevalence, impact and management of a range of common health conditions. In addition, some conditions such as dysphagia and epilepsy are more common for people with a learning disability and these conditions are therefore covered in greater details in other capabilities.

Target audience

Tier 2 – Health and social care staff and others with responsibility for providing care and support for a person or people with a learning disability, but who would seek support from others for complex management or complex decision-making

Tier 3 – Health, social care and other professionals with a high degree of autonomy, able to provide care in complex situations and/or may also lead services for people with a learning disability..

Key learning outcomes

Tier 2

The person or practitioner will:

- a) understand the importance for people with a learning disability to maintain good physical and mental health through nutrition, exercise and a healthy life style that includes social engagement
- b) be aware of the prevalence and potential impact on the lives of people with a learning disability of the following conditions:
 - o epilepsy
 - o dysphagia
 - o diabetes
 - o heart disease
 - o constipation
 - o colorectal cancer

- sepsis
 - trauma
- c) know the common signs and symptoms of the above conditions and that a person with a learning disability may present different signs or no signs at all
 - d) know the function of different healthcare services that people with a learning disability may need to access, in particular physiotherapists, speech and language therapists, occupational therapists, community dentists, and learning disability nurses
 - e) be able to contribute to health action plans with people with a learning disability
 - f) understand the role of families and carers in supporting the health and wellbeing of people with a learning disability
 - g) be able to prompt and/or administer medication safely where appropriate
 - h) be aware of the consequences (including short-term and long-term side effects) of psychotropic medication and their potential impact on the lives of people with a learning disability
 - i) be able to refer people with a learning disability to specialist healthcare services for assessment and diagnosis and support and encourage them and persist in liaison with specialist services
 - j) be able to suggest, encourage, support and promote healthy lifestyle options and make referral to services providing healthy lifestyle advice and options
 - k) understand the importance of good eye care and dental care and the impact for people with a learning disability when these are neglected
 - l) be able to support women with a learning disability with understanding and decision-making around menstruation, pregnancy and the menopause
 - m) be able to support people with a learning disability to make decisions and take up offers of general health screening.

Tier 3

Tier 2 learning outcomes plus the following

The person or practitioner will:

- a) understand the complexity of ageing and co-morbidity in people with a learning disability
- b) understand the healthcare needs that may affect the right to make choices for people with a learning disability
- c) understand good practice in supporting people with a learning disability to access healthcare services
- d) understand how to support others to develop, implement, monitor and review plans for healthcare
- e) be able to develop processes to support others to meet the healthcare needs of people with a learning disability
- f) be able to promote good practice to others in their support of people with a learning disability accessing healthcare
- g) be able to develop and disseminate health promotion information and advice
- h) be able to encourage behavioural change in individuals and organisations to promote health and wellbeing
- i) be able to monitor, evaluate and improve the effectiveness of health promotion activities
- j) be robust and effective in advocating on behalf of people when dealing with other services.

Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to health and wellbeing for people with a learning disability are shown below:

Guidance

- [Generic Service Interventions Pathway: A competency framework to support development of the learning disability workforce, Health Education England \(2015\)](#)
- [Meeting the health needs of people with learning disabilities - Royal of College of Nursing \(2013\)](#)
- [Promoting access to healthcare for people with a learning disability – a guide for frontline NHS staff - NHS Quality Improvement Scotland \(2006\)](#)
- [Improving healthcare access for people with learning disabilities: Guidance for social care staff on how to help people with learning disabilities get better access to medical services to improve their health, Public Health England \(2017\)](#)

Legislation

- [Care Act \(2014\)](#)
- [Children and Families Act 2014](#)
- [Equality Act 2010](#)
- [Disability Discrimination Act 1995](#)
- [Human Rights Act 1998](#)
- [Mental Capacity Act 2005](#)

Indicative mapping to relevant national standards or frameworks

Mapping to be completed...

[Return to contents page](#)

Capability 8: Supporting people with mental health conditions

Introduction

Research evidence suggests that children and young people with a learning disability are 4-5 times more likely to have mental health problems than other children, and adults with a learning disability are also more likely (at least twice as likely) to experience some kind of mental health problem¹².

Lack of early recognition of mental health problems in people with a learning disability can lead to negative consequences for the person affected, and for their family and carers. Factors that influence poor recognition include: a lack of knowledge in health and social care staff, and families of carers, about the signs and symptoms of mental health conditions; diagnostic overshadowing by the learning disability or physical illness (assuming that differences are due to the person's learning disability); how well people providing care and support know the person and how well information is shared; and difficulties the person with a learning disability may have communicating their mental health problems. This lack of recognition can lead to no or ineffective treatment or inappropriate resource-use. Effective treatment requires an assessment and the development of a care plan to ensure that the best available interventions are provided.

It is important to note that all of the capabilities in this framework include learning outcomes that are relevant to people with a learning disability and a mental health condition. This capability area includes specific learning outcomes that relate to care and support for people with a learning disability and a mental health condition that are not covered elsewhere in the framework.

Target audience

Tier 2 – Health and social care staff and others with responsibility for providing care and support for a person or people with a learning disability, but who would seek support from others for complex management or complex decision-making

Tier 3 – Health, social care and other professionals with a high degree of autonomy, able to provide care in complex situations and/or may also lead services for people with a learning disability..

Key learning outcomes

Tier 2

The person or practitioner will:

- a) understand that people with a learning disability can experience similar mental health conditions as people without a learning disability
- b) understand that mental health conditions may develop and present in different ways from people without learning disabilities, and the usual signs or symptoms may not be observable or reportable
- c) understand that mental health conditions are commonly overlooked in people with a learning disability
- d) know the main types of mental health conditions which may impact on the lives of people with a learning disability. including (but not limited to):
 - i. psychoses
 - ii. neuroses and stress related disorders
 - iii. personality disorders

¹² <https://hee.nhs.uk/our-work/hospitals-primary-communitycare/mental-health-learning-disability>

- iv. other developmental conditions such as ADHD
 - v. mood disorders (including suicidality)
 - vi. substance misuse
 - vii. dementia and confusional states
 - viii. eating disorders
 - ix. sexual and gender identity disorders
- e) understand the reasons why people with a learning disability are at increased risk of mental health conditions
 - f) understand that people with a learning disability are at greater risk than the general population of developing dementia as they get older
 - g) know the function of different mental health services that people with a learning disability may need to access - in particular, occupational therapists, counsellors, psychologists, psychiatrists, and mental health and learning disability nurses
 - h) know the things that promote good mental health for everyone and be able to support people with a learning disability to adopt these actions
 - i) be able to create opportunities for people with a learning disability to express their feelings and talk about loss, grief and bereavement
 - j) understand how the past experiences of people with a learning disability may often cause stress, anxiety and trauma
 - k) know where to refer a person with a learning disability and a suspected mental health condition.

Tier 3

Tier 2 learning outcomes plus the following

The person or practitioner will:

- a) understand how specialist and personalised assessment, and care, treatment and support is provided for people with a learning disability and a mental health condition
- b) be able to support a person with a learning disability and mental health condition to access and use specialist and personalised assessment, and care, treatment and support
- c) know how to coordinate and communicate with key people and services in the life of the person with a learning disability and a mental health condition
- d) recognise the issue of overmedication of people with a learning disability and know how to address this
- e) know how to arrange and manage services so that people are supported with the things that are important to their mental wellbeing.

Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to supporting people (children, young people and adults) with a learning disability and a mental health condition shown below:

Guidance

- [NICE Guidance: Mental health problems in people with learning disabilities: prevention, assessment and management \[NG54\] \(2016\)](#)
- ["Feeling Down" https://www.mentalhealth.org.uk/learning-disabilities/publications/feeling-down-looking-after-my-mental-health](https://www.mentalhealth.org.uk/learning-disabilities/publications/feeling-down-looking-after-my-mental-health)

- Stopping over medication of people with a learning disability, autism or both (STOMP)
- [new resource under co-production by Skills for Care, CHAGE and the Judith trust expected early 2019](#)

Legislation

- [Care Act \(2014\)](#)
- [Children and Families Act 2014](#)
- [Equality Act 2010](#)
- [Disability Discrimination Act 1995](#)
- [Human Rights Act 1998](#)
- [Mental Capacity Act 2005](#)
- Mental Health Act 1983

Indicative mapping to relevant national standards or frameworks

Core Skills/Capabilities Frameworks (at: www.skillsforhealth.org.uk/cstf)

- Mental Health Core Skills Education and Training Framework
- Dementia Training Standards Framework

Mapping to be completed...

[Return to contents page](#)

Capability 9: Health equality and reasonable adjustments

Introduction

People (children, young people and adults) with a learning disability have a right to access good quality healthcare. Their health needs are often greater and more complex and often present differently from those without a learning disability. There is evidence that people with a learning disability experience poorer healthcare and worse health outcomes. One of the starkest inequalities is that people with a learning disability experience very high rates of premature mortality. The Learning Disabilities Mortality Review (LeDeR) Programme has highlighted the persistence of health inequalities and that people with a learning disability die, on average, 15-20 years sooner than people in the general population¹³. There are frequent examples of these deaths being preventable or premature in that the conditions which caused the person's death should have been identified and treated sooner.

Annual Health Checks are a crucial element in improving health outcomes for people with a learning disability, screening for specific syndrome conditions and providing the vital link into national screening prevention programmes.

The Independent Inquiry chaired by Sir Jonathan Michael following publication of the Mencap report *Death by Indifference*¹⁴, found convincing evidence that people with a learning disability 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.¹⁵

It is vital therefore that access is widened and that the necessary adjustments are made to enable people with a learning disability to access high quality healthcare that meets their needs. It is also essential that people have the support they need to make informed choices about a lifestyle which maintains or improves their mental and physical health.

Target audience

Tier 2 – Health and social care staff and others with responsibility for providing care and support for a person or people with a learning disability, but who would seek support from others for complex management or complex decision-making

Tier 3 – Health, social care and other professionals with a high degree of autonomy, able to provide care in complex situations and/or may also lead services for people with a learning disability..

Key learning outcomes

Tier 2

The person or practitioner will:

- a) understand the health inequalities commonly experienced by people with a learning disability
- b) understand the importance of access to appropriate healthcare for people with a learning disability
- c) understand the key barriers that may prevent people with a learning disability accessing appropriate healthcare, including diagnostic overshadowing, failure to follow legal duties in the Mental Capacity Act, inappropriate decisions not to treat or withhold lifesaving care, inaccessible information, lack of co-ordination of care and failure to make reasonable adjustments

¹³ The Learning Disabilities Mortality Review (LeDeR) Programme Annual Report, University of Bristol 2017

¹⁴ Op cit.

¹⁵ Healthcare for All: Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities, Sir Jonathan Michael, 2008

- d) be aware of current legislation, policies and guidance relevant to people with a learning disability accessing healthcare
- e) understand how annual health checks and health action plans can underpin long term health and wellbeing for people with a learning disability
- f) know the importance of health passports, health action plans, hospital traffic lights or hospital passports and books and how these can provide important information about a person's communication and care needs and any potential hazards such as a risk of choking, known allergies and epilepsy – and how to interpret and use the information within them
- g) encourage people to be registered with their GP as having a learning disability
- h) support people with a learning disability to access and use healthcare services, addressing any barriers and able to seek specialist support
- i) be able to identify the need for, and action, common reasonable adjustments to enable the health needs of people with learning disabilities to be met, which may include consideration around appointment times, duration and support required
- j) understand how limited communication and health literacy may reduce the capacity for people with a learning disability and/or autism to convey health needs effectively to others
- k) understand how to identify the need for, and provide accessible information, as required by the Accessible Information Standard, tailored to the communication needs of people with a learning disability including:
 1. know how to find out if people have any information or communication needs and how to meet their needs.
 2. understand how to seek out information around communication needs and respond to flags or additional information provided within a person's records or correspondence.
 3. understand how to share information about people's information and communication needs with other providers of NHS and adult social care, when they have given consent or permission to do so.

Tier 3

Tier 2 learning outcomes plus the following

The person or practitioner will:

- a) understand the health inequalities experienced by people with learning disabilities
- b) understand how reasonable adjustment to meet people's inclusive communication support needs can lead to better outcomes for people, enabling greater independence and participation
- c) be able to provide and support people to populate health passports, health action plans, hospital traffic lights or hospital passports and books and how these can provide important information about a person's communication and care needs and any potential hazards such as a risk of choking, known allergies and epilepsy
- d) understand the guidelines and principles aimed at stopping the over-medication of people with a learning disability
- e) be able to advise on and implement reasonable adjustments to enable the health needs of people with a learning disability to be met
- f) understand the importance of inter-agency collaboration and communication
- g) be able to lead person-centred practice for people with a learning disability
- h) understand the scope of the Accessible Information Standard for health and social care organisations as a whole, including requirements for policy, procedures, human behaviour and where applicable, electronic systems. This includes the five-step process for:

1. Identification of needs
 2. Recording of needs
 3. Flagging of needs
 4. Sharing of needs
 5. Meeting of needs.
- i) understand the interactions of mental capacity legislation, and the appropriate use of DoLs and best interest decisions as it relates to consent for treatment and investigations.

Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to health equality and reasonable adjustments are shown below:

Guidance

- [Accessible Information Standard - NHS England \(2017\)](#)
- [Generic Service Interventions Pathway: A competency framework to support development of the learning disability workforce, Health Education England \(2015\)](#)
- [Improving healthcare access for people with learning disabilities: Guidance for social care staff on how to help people with learning disabilities get better access to medical services to improve their health, Public Health England \(2017\)](#)
- [Reasonable adjustments for people with a learning disability Guides on how reasonable adjustments to health services and adjustments to help people with learning disabilities to access services, Public Health England \(2018\)](#)
- [Learning Disabilities Mortality Review \(LeDeR\) Programme, University of Bristol \(2017\)](#)

Legislation

- [Care Act \(2014\)](#)
- [Children and Families Act 2014](#)
- [Human Rights Act 1998](#)
- [Equality Act 2010](#)
- [Disability Discrimination Act 1995](#)
- [Mental Capacity Act 2005](#)

Indicative mapping to relevant national standards or frameworks

Mapping to be completed...

[Return to contents page](#)

Capability 10: Nutrition, hydration and dysphagia

Introduction

The provision of good nutrition and hydration, including information about food and drink is important for people with a learning disability. In addition, people with a learning disability are more likely to experience eating, drinking or swallowing difficulties than people without a learning disability, and even more so if they have severe cognitive impairment.

Dysphagia is the term to describe eating, drinking or swallowing difficulties, the consequences of which can include coughing and distress when eating or drinking, choking, recurrent chest infections, aspiration pneumonia, weight loss, dehydration, malnutrition, social isolation and distress. In the worst cases it can contribute to an individual's death. Because dysphagia is a key risk issue for people with a learning disability it is important that people with a learning disability who are at a particularly high risk for dysphagia are identified and management approaches adopted to support their eating and drinking.

Target audience

Tier 2 – Health and social care staff and others with responsibility for providing care and support for a person or people with a learning disability, but who would seek support from others for complex management or complex decision-making

Tier 3 – Health, social care and other professionals with a high degree of autonomy, able to provide care in complex situations and/or may also lead services for people with a learning disability..

Key learning outcomes

Tier 2

The person or practitioner will:

- a) understand the need for a balance between a nutritionally balanced diet and providing the opportunity for people with a learning disability to enjoy the food and drink of their choice
- b) know how to improve the provision of good nutrition and hydration through monitoring food and drink intake appropriately and help people understand information about food and drink so they can make informed choices
- c) understand the factors that influence mealtimes to provide a positive mealtime experience and support people to make healthy choices
- d) know where to find evidence-based information and resources on nutrition and hydration and when to refer for more specialist advice from other health professionals such as a dietitian, nutritionist or speech and language therapist
- e) be aware of the signs, symptoms and consequences of having dysphagia which may include coughing and distress when eating or drinking, choking, recurrent chest infections, aspiration pneumonia, weight loss, dehydration, malnutrition, social isolation and distress
- f) understand that people with a learning disability are more likely to have dysphagia than the general population, and even more so if they have severe cognitive impairment
- g) understand there may be exercises or techniques people can try that may help them eat and drink more successfully
- h) be able to reduce distress for people with a learning disability and dysphagia
- i) know the importance of good oral hygiene for people with dysphagia

- j) be able to involve a person's family and/or care staff if the person lacks capacity to work with professionals to make decisions about eating and drinking
- k) be able to refer people with a learning disability and dysphagia to specialised multi-disciplinary assessment to ensure their needs are fully addressed in a timely manner
- l) understand the mental capacity act and the need for best interest decisions when needed in relation to eating and drinking
- m) understand the impact of tooth decay and/or absent teeth on eating and drinking.

Tier 3

Tier 2 learning outcomes plus the following

The person or practitioner will:

- a) be able to identify groups of people with a learning disability who are at a particularly high risk for dysphagia including people who are getting older as well as people who use particular medications or who are unwell and people with dementia
- b) understand the main clinical causes of dysphagia
- c) understand that other health conditions have been associated with dysphagia e.g. urinary tract infections, headaches, constipation, oesophagitis and reduced ability to fight infections
- d) understand that adults with a learning disability should be considered a high-risk group for deaths from respiratory problems
- e) understand the anatomy and physiology relevant to maintaining a safe swallow
- f) be able to conduct protocol guided swallow screening/assessment according to locally agreed protocols using standardised documentation
- g) be able to develop management approaches together with the individual with a learning disability to ensure they are person centred. Recommendations may include advice about:
 - i. food textures
 - ii. high risk foods
 - iii. the best posture or positioning
 - iv. utensils
 - v. pace of eating
 - vi. how to support people with a learning disability and dysphagia to eat and drink
 - vii. the best environment in which to eat and drink.

Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to supporting people with a learning disability and nutrition, hydration and dysphagia are shown below:

Guidance

- [Dysphagia and people with learning disabilities, Public Health England \(2016\)](#)

Legislation

- [Care Act \(2014\)](#)
- [Children and Families Act 2014](#)
- [Equality Act 2010](#)
- [Disability Discrimination Act 1995](#)
- [Human Rights Act 1998](#)
- [Mental Capacity Act 2005](#)

Indicative mapping to relevant national standards or frameworks

Mapping to be completed...

[Return to contents page](#)

DRAFT

Capability 11: Epilepsy

Introduction

Epilepsy is much more common in people with a learning disability or autism and it is much more likely to be more difficult to control. Seizures can have a profound impact on a person's ability to live and enjoy their life as well as impacting on their level of learning disability and functional interaction with others.

Poorly controlled epilepsy can also present a huge burden of care and anxiety to family members and carers. Seizures are often distressing to witness, can require urgent intervention and can lead to injury or sudden and premature death. The recently published LeDeR report highlights that too often people with learning disability die many years sooner than they should and epilepsy is a frequently named cause of this. With good seizure control people's lives, both in terms of quality of life and length of life, can be transformed (NHS 2018).

Target audience

Tier 2 – Health and social care staff and others with responsibility for providing care and support for a person or people with a learning disability, but who would seek support from others for complex management or complex decision-making

Tier 3 – Health, social care and other professionals with a high degree of autonomy, able to provide care in complex situations and/or may also lead services for people with a learning disability..

Key learning outcomes

Tier 2

The person or practitioner will:

- a) know what is meant by the term 'epilepsy'; common types and causes
- b) be aware that epilepsy is more common in people with a learning disability than for people without a learning disability
- c) understand that people with a learning disability and epilepsy have greater health needs than people without a learning disability and are more likely to have respiratory disease, gastrointestinal reflux or osteoporosis which affects their epilepsy and treatment
- d) understand how epilepsy affects people with a learning disability and how to follow plans and risk assessments in relation to issues such as freedom of choice and activities that may trigger a seizure
- e) know common triggers for seizures and how to reduce or manage these triggers
- f) recognise any indications that people may be about to experience a seizure and know what to do in response
- g) be able to utilise appropriate assessment tools to gather information on:
 - i. seizure type
 - ii. triggers for seizures
 - iii. seizure severity (type, pre/post ictal)
 - iv. seizure frequency
 - v. seizure pattern
 - vi. injuries

- h) understand how individuals with a learning disability may respond differently to treatment and may be unable to articulate side-effects
- i) understand the important role families and carers have in supporting people with a learning disability and epilepsy and involve them appropriately in the care of the person
- j) understand when and how to make a referral when the support of a 'specialist in epilepsy' might be needed
- k) be aware of the key legislation, policy and guidelines when working with people with a learning disability and epilepsy.

Tier 3

Tier 2 learning outcomes plus the following

The person or practitioner will:

- a) know the classification of seizures and be able to differentiate, through appropriate use of history taking and assessment tools, the type of seizure and syndrome
- b) know of current national guidelines in relation to assessment and treatment of epilepsy
- c) understand the complexity and comorbidity of epilepsy in people with a learning disability and support them to reduce health inequalities as a result of this complexity and comorbidity
- d) understand that epilepsy may develop and present in different ways in people with a learning disability, and that the usual signs or symptoms may not be observable or reportable
- e) assess and manage risk related to epilepsy in people with a learning disability
- f) be able to initiate and evaluate appropriate rescue medication
- g) understand the effect of a learning disability on how individuals may respond to medication
- h) know and be able to consider the link between the epilepsy syndrome and the aetiology of learning disabilities in order to more effectively manage the person's condition to improve their quality of life
- i) be able to synthesise data to create a formulation for a person with a learning disability and epilepsy and devise appropriate care and support plans
- j) be able to fully involve the person with a learning disability and epilepsy (and if relevant their family and carers) in the process of understanding and devising supports relating to their epilepsy
- k) know what health services are available and how to refer people with a learning disability to improve their biopsychosocial outcomes in relation to the epilepsy
- l) be able to initiate, monitor and evaluate epilepsy treatment, including knowing the specific idiosyncratic effects in people with a learning disability and the need to take into account potential comorbidities such as dysphagia
- m) develop and disseminate health promotion advice to people with a learning disability, their families and carers in relation to epilepsy.

Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to supporting people with a learning disability and epilepsy are shown below:

Guidance

[Management of epilepsy in adults with intellectual disability, Royal College of Psychiatrists \(2017\), Good Practice Guide CR203](#)

Legislation

- [Care Act \(2014\)](#)
- [Children and Families Act 2014](#)
- [Equality Act 2010](#)
- [Disability Discrimination Act 1995](#)
- [Human Rights Act 1998](#)
- [Mental Capacity Act 2005](#)

Indicative mapping to relevant national standards or frameworks

Mapping to be completed...

[Return to contents page](#)

DRAFT

Capability 12: Supporting people with Profound and Multiple Learning Disabilities (PMLD)

Introduction

A diagnosis of a profound and multiple learning disability (PMLD) is used when a person (child, young person and adult) has more than one disability, with the most significant being a severe or profound learning disability. People with profound and multiple learning disabilities will have significant challenges with communication and many will have additional sensory or physical disabilities, complex health needs or mental health conditions. The combination of these needs and/or the lack of the right care and support may also affect behaviour.

Despite such serious challenges, with the right support, people with PMLD can form relationships, make choices and enjoy activities. The people who love and care for them can often understand their personality, their mood and their preferences. All people with profound and multiple learning disabilities will need high levels of support to live full and rewarding lives.

It is important to note that all of the capabilities in this framework include learning outcomes that are relevant to people with profound and multiple learning disabilities. This capability area includes specific learning outcomes that relate to care and support for people with profound and multiple learning disabilities that are not covered elsewhere in the framework.

Target audience

Tier 2 – Health and social care staff and others with responsibility for providing care and support for a person or people with a learning disability, but who would seek support from others for complex management or complex decision-making

Tier 3 – Health, social care and other professionals with a high degree of autonomy, able to provide care in complex situations and/or may also lead services for people with a learning disability..

Key learning outcomes

Tier 2

The person or practitioner will:

- a) understand the meaning of Profound and Multiple Learning Disabilities (PMLD)
- b) be aware of the range of needs of people with PMLD
- c) be aware of good practice in communication with people with PMLD
- d) understand why it is important to recognise when someone with PMLD is in pain and to manage this effectively
- e) understand the importance of consistently supporting posture throughout the day and night in order to reduce the risk of complications associated with severe physical disability e.g. pain, pressure sores, spinal deformity, joint contractures and respiratory infection.

Tier 3

The person or practitioner will:

- a) understand that people with PMLD have greater health needs than people without a learning disability and are more likely to have the following conditions; Respiratory Disease, Epilepsy, Coronary heart disease, Gastrointestinal reflux, Diabetes, Helicobacter pylori, Osteoporosis

- b) be able to involve professionals who can offer support and advice to people with PMLD and their families and carers
- c) know the adjustments that should be made to ensure that people with PMLD can access support and services
- d) be aware of the resources available to help people with PMLD have a positive experience in hospital and community settings
- e) understand the effects of communication needs on people with PMLD and their families and carers
- f) understand how sensory differences affect people with PMLD
- g) know that the details of local specialist postural-care therapists and other professionals involved in care should be identified in the person's Health Action Plan (HAP)
- h) understand that people with PMLD and their family and carers should be involved with assessment, selection and issue of equipment and review to ensure equipment and guidelines are acceptable and 'fit' with family life
- i) understand that postural-care guidelines and equipment need to be reviewed as part of an annual review of health needs
- j) understand that any prescribed postural-care equipment should improve quality of life
- k) understand the mental capacity act and the need for best interest decisions when needed in relation to using 'clinical holding', postural care equipment, including wheelchairs, splints and straps.

Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to Profound and Multiple Learning Disabilities (PMLD) are shown below:

Guidance

- [Communication and people with the most complex needs: What works and why this is essential, Mencap \(July 2010\)](#)
- [See What I Mean: Guidelines to Aid Understanding of Communication by People with Severe and Profound Learning Disabilities by Grove N., Bunning K., Porter J., Morgan M. \(2000\). Kidderminster: BILD/Mencap.](#)
- Involve Me: increasing the involvement of people with profound and multiple learning disabilities in decision-making and consultation, Mencap and BILD (2011)
- [Top tips for supporting people with profound & multiple learning disabilities, published by NHS Midlands and East](#)
- [Department of Health \(2010\), Raising our sights: services for adults with profound intellectual and multiple disabilities](#)
- Raising our sights: How-to guides (2012). Mencap and the PMLD Network.
- Supporting people with profound and multiple learning disabilities: Core and essential standards. (2017) Doukas T., Fergusson, A., Fullerton, M., Grace, J.
- Postural care services and people with a learning disability. Public Health England (2018)

Legislation

- [Care Act 2014](#)
- [Children and Families Act 2014](#)
- [Equality Act 2010](#)
- [Human Rights Act 1998](#)

- [Mental Capacity Act 2005](#)
- [Safeguarding Vulnerable Groups Act 2006](#)
- [Disability Discrimination Act 1995](#)

Indicative mapping to relevant national standards or frameworks

Mapping to be completed...

[Return to contents page](#)

DRAFT

Capability 13: End of life care

Introduction

It may often be difficult to recognise when a person with a learning disability is coming to the end of life. This can result in a lack of forward planning and end-of-life care which may be uncoordinated. People with a learning disability are less likely than others to have access to specialist palliative care services, like hospices. Often pain management for them is neglected or ineffective.

Just as for people without a learning disability, there are things that can be done to improve end of life care and the support given at this time. This includes treating the person as an individual, ensuring access to care (including reasonable adjustments where needed), maximising comfort and well-being, ensuring care is coordinated and accessing services and support in the community.

Target audience

Tier 2 – Health and social care staff and others with responsibility for providing care and support for a person or people with a learning disability, but who would seek support from others for complex management or complex decision-making

Tier 3 – Health, social care and other professionals with a high degree of autonomy, able to provide care in complex situations and/or may also lead services for people with a learning disability..

Key learning outcomes

Tier 2

The person or practitioner will:

- a) be able to engage in conversation with people with a learning disability to talk about death and dying, grief and loss and their own end of life preferences
- b) be able to provide information to a people with a learning disability about their illness and symptoms in ways they are able to understand e.g. how to access and use information and easy-read resources to help support a person at end of life
- c) understand the different barriers to communication at end of life, including where someone has additional care, support or communication needs
- d) understand the use of end of life care pathways and individualised care plans and the impact this has on care and support offered
- e) understand the importance of access to palliative care and how advance planning can avoid crisis driven changes or decisions
- f) understand how best interest decision and advance decisions/directives will affect caring activities
- g) be able to identify symptoms associated with end of life and how these symptoms can be managed with care and compassion
- h) know how to recognise and manage pain and address the broader physical needs (e.g. hydration, reduced appetite) in people at end of life and how different factors can alleviate or exacerbate pain and discomfort
- i) be aware of the needs of bereaved families and friends including the potential for conflicting emotions
- j) be aware of cultural and religious differences associated with death, care of the dying and the deceased person
- k) be able to advocate for a person with a learning disability around end of life and funeral arrangements.

Tier 3

Tier 2 learning outcomes plus the following

The person or practitioner will:

- a) be able to work with people with a learning disability and others to develop a person-centred end of life care plan that balances treatment with care and support needs and preferences
- b) understand the processes involved in deciding when a person with a learning disability is deemed to be at end of life
- c) understand guidance, risks and benefits, and ethical considerations associated individual's food and drink related needs, including that related to clinically assisted nutrition and hydration
- d) be able to support end of life services to make reasonable adjustments for people with a learning disability
- e) understand referral criteria and processes for referral to specialist services to meet the needs of people with a learning disability and those important to them, and if necessary, support these services to make reasonable adjustments
- f) be able to recognise and suggest ways to overcome potential barriers people with a learning disability may face in accessing end of life care
- g) understand the purpose of reviews of death of people with a learning disability and which organisations should be contacted following the death of a person with a learning disability
- h) be able to contribute to the development of practices and services that meet the end of life needs of people with a learning disability.

Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to end of life care are shown below:

Guidance

- [Care and support of people growing older with learning disabilities, NICE Guideline \[NG96\] \(2018\)](#)
- [How social care staff can support palliative and end of life care for people with learning disabilities, Public Health England \(2017\)](#)

Legislation

- [Care Act 2014](#)
- [Children and Families Act 2014](#)
- [Equality Act 2010](#)
- [Human Rights Act 1998](#)
- [Mental Capacity Act 2005](#)
- [Safeguarding Vulnerable Groups Act 2006](#)
- [Disability Discrimination Act 1995](#)

Indicative mapping to relevant national standards or frameworks

Core Skills/Capabilities Frameworks (at: www.skillsforhealth.org.uk/cstf)

- End of Life Care Core Skills Education and Training Framework

Mapping to be completed...

[Return to contents page](#)

DRAFT

Domain D. Personalised care and support

Insert image

Capability 14: Supporting people with a learning disability and autism

Introduction

Autism is not a learning disability, but research suggests that around half of people with autism may also have a learning disability, which will affect the level of care and support they need to live fulfilling and rewarding lives. Recent research by the Learning Disabilities Observatory indicates that around 20-30% of people (children, young people and adults) with a learning disability also have an autistic spectrum condition¹⁶, and approximately 50% of children with autism also have a learning disability.¹⁷ People working in health and social care therefore require the knowledge and skills to recognise and provide appropriate care and support for people with a learning disability and autism.

It is important to note that all of the capabilities in this framework include learning outcomes that are relevant to people with a learning disability and autism. This capability area includes specific learning outcomes that relate to care and support for people with a learning disability and autism that are not covered elsewhere in the framework.

Target audience

Tier 2 – Health and social care staff and others with responsibility for providing care and support for a person or people with a learning disability, but who would seek support from others for complex management or complex decision-making

Tier 3 – Health, social care and other professionals with a high degree of autonomy, able to provide care in complex situations and/or may also lead services for people with a learning disability..

¹⁶ The Estimated Prevalence of Autism among Adults with Learning Disabilities in England, Eric Emerson & Susannah Baines, 2010.

¹⁷ Totsika, V., Hastings, R. P., Emerson, E., Lancaster, G. A., & Berridge, D. M. (2011). A population-based investigation of behavioural and emotional problems and maternal mental health: Associations with autism and intellectual disability. *Journal of Child Psychology and Psychiatry*, **52**, 91-99.

Key learning outcomes

Tier 2

The person or practitioner will:

- a) understand the main characteristics of autism
- b) understand how autism can impact on the lives of people with a learning disability and those around them
- c) understand how to achieve effective communication with people with a learning disability and autism
- d) understand the concept of a 'spiky profile' in autism; for example, that people may have good verbal abilities which mask difficulties in understanding or vice versa, may be very skilled in one area of life but need lots of support with another.

Tier 3

The person or practitioner will:

- a) understand how to support people with a learning disability and autism
- b) understand the implications of the legal and policy framework underpinning the support of people with a learning disability and autism
- c) be able to promote good practice in the support of people with a learning disability and autism
- d) be able to promote to others positive communication strategies for people with a learning disability and autism
- e) be able to pro-actively and reactively address any sensory issues that may affect a person with a learning disability and autism
- f) be able to implement strategies to support individuals with people with a learning disability and autism to support their sensory differences.

Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to supporting people (children, young people and adults) with a learning disability and autism are shown below:

Guidance

- [Think Autism: fulfilling and rewarding lives, the strategy for adults with autism in England: an update: HM Government \(2014\)](#)
- [NHS England, LGA, ADASS \(2015\), Building the right support](#)
- [Autism skills and knowledge list, for workers in generic social care and health services, Skills for Care and Skills for Health 2011](#)
- [Implementing the 'autism skills and knowledge list' through staff training and development, Skills for Care and Skills for Health 2011](#)
- [Getting it right for people with autism – the research behind the 'autism skills and knowledge list', Skills for Care and Skills for Health 2011](#)
- Increasing awareness and understanding of autism (SFC and SFH) <https://www.skillsforcare.org.uk/Learning-development/ongoing-learning-and-development/autism/Autism.aspx>

Legislation

- [Autism Act 2009](#)
- [Equality Act 2010](#)

Indicative mapping to relevant national standards or frameworks

Mapping to be completed...

[Return to contents page](#)

DRAFT

Capability 15: Wellbeing and independence

Introduction

People (children, young people and adults) with a learning disability have a right to live independent and fulfilling lives, including choice and control over any care and support they may need; access to housing, education, employment, leisure, transport opportunities; and, participation in family and community life.

This capability is about supporting people with a learning disability to have the same choice and control in their lives as other people, including maintaining and developing community links and opportunities to engage in everyday activities including education, employment, housing, and transport and leisure services.

Whilst it is important to understand duty of care in relation to risk-taking the focus should always be on a person's right to take positive risks so they can engage in meaningful occupations and activities. It is important for people with a learning disability to be active in daily life as it affects their health, wellbeing and quality of life and that of their communities.

Target audience

Tier 2 – Health and social care staff and others with responsibility for providing care and support for a person or people with a learning disability, but who would seek support from others for complex management or complex decision-making

Tier 3 – Health, social care and other professionals with a high degree of autonomy, able to provide care in complex situations and/or may also lead services for people with a learning disability..

Key learning outcomes

Tier 2

The person or practitioner will:

- a) know the principles for supporting independence in the activities of daily living for people with a learning disability
- b) know how to support people with a learning disability to develop and continue their interests, social life and community involvement and know why this is important
- c) be able to support people with a learning disability to retain, regain or develop skills for everyday life
- d) know how to support a person with a learning disability with their personal hygiene; including; washing, dressing, using the toilet, doing laundry and keeping their home habitable
- e) be able to provide support for people with a learning disability to manage their finances as appropriate
- f) know how to support people with a learning disability to use a personal budget to help them live well and take part in meaningful occupations and activities
- g) understand how to signpost and refer to professional advice services for people with a learning disability
- h) be able to support people with a learning disability to choose and use services and facilities and decide how long to use them for (for example, housing, transport and leisure services)
- i) understand a person with a learning disability's rights in relation to reasonable adjustments when accessing and using services
- j) understand the value of engagement in training, education, employment or meaningful occupation for people with a learning disability

- k) be aware of the support available to people with a learning disability to access education, training and employment
- l) know how to support people with a learning disability with an outcome-focused review
- m) understand the factors that impact on a person with a learning disability being able to get around their physical and social environment, including discrimination, bullying and hate crime
- n) be able to use everyday technology such as google maps, skype and apps for task planning, calendars online shopping etc. to enable people with a learning disability to choose and use the full range of social interaction available to other people
- o) be aware of the benefits of supporting people with a learning disability to choose to develop and maintain their relationships with family and friends
- p) be aware of the role of families and carers in enabling people with a learning disability to live well
- q) know how to recognise and respond to the cultural, religious and spiritual needs of a person with a learning disability
- r) know how to recognise and respond to the sexual and emotional needs of a person with a learning disability
- s) know how to support people with a learning disability to manage setbacks and personal difficulties by drawing on their strengths and assets
- t) understand the importance of a positive, person-centred approach to risk
- u) be able to support people with a learning disability to exercise their right to vote.

Tier 3

Tier 2 learning outcomes plus the following

The person or practitioner will:

- a) know how to promote personalisation in learning disability care and support
- b) understand the theories and principles that underpin outcome-based practice for people with a learning disability
- c) be able to assist a person to develop a support plan to meet their identified needs and right to make choices
- d) be able to facilitate the implementation and review of support plans led by the person with a learning disability and others
- e) be able to contribute to the review of housing, transport and leisure services for people with a learning disability
- f) be able to contribute to the development of practices and services that meet the individual needs of people with a learning disability.

Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to living well with a learning disability and promoting independence are shown below:

Guidance

- [Generic Service Interventions Pathway: A competency framework to support development of the learning disability workforce, Health Education England \(2015\)](#)
-

Legislation

- [Care Act \(2014\)](#)
- [Children and Families Act 2014](#)
- [Equality Act 2010](#)
- [Disability Discrimination Act 1995](#)
- [Human Rights Act 1998](#)
- [Mental Capacity Act 2005](#)

Indicative mapping to relevant national standards or frameworks

Mapping to be completed...

[Return to contents page](#)

DRAFT

Capability 16: Relationships, sexuality and sexual health

Introduction

The relationships and sexual rights of people with a learning disability have often been overlooked or ignored. Often, sexuality only becomes an area of life to be discussed when staff or family members feel there is a problem.

This capability is about the importance of relationships, friendships, marriages, partnerships, sexuality and sexual health to the lives of people with a learning disability. It is also about providing the right support to help to ensure that a balance can be struck between the positive outcomes associated with exploring and developing wider personal and social relationships and potential risks such as sexual exploitation, abuse, pregnancy, HIV and AIDS.

Target audience

Tier 2 – Health and social care staff and others with responsibility for providing care and support for a person or people with a learning disability, but who would seek support from others for complex management or complex decision-making

Tier 3 – Health, social care and other professionals with a high degree of autonomy, able to provide care in complex situations and/or may also lead services for people with a learning disability..

Key learning outcomes

Tier 2

The person or practitioner will:

- a) know the importance of offering each person with a learning disability support with their relationship with family members and other people in his or her social network
- b) be aware of factors affecting the capacity of people with a learning disability to develop and/or maintain relationships.
- c) know how to support people with a learning disability to choose relationships
- d) know how to support people with a learning disability to develop new relationships and maintain existing relationships
- e) understand how to support people to say no to unwanted relationships including when they may be at risk of 'mate crime; or 'cuckooing'
- f) understand the basic development of human sexuality
- g) be aware of the issues of sexual health and how these can be supported
- h) be aware of the potential that adults with a learning disability may be at risk of entering the criminal justice system due to perceived inappropriate sexual behaviour
- i) be aware of relevant legislation influencing the support of sexuality and sexual health for adults with a learning disability
- j) know how to support an adult with a learning disability to identify, access and use services to meet their sexual and sexual health needs if necessary
- k) be aware of the social context affecting the sexual and sexual health needs of adults with a learning disability
- l) be aware of LGBTQ+ issues as they may affect a person with a learning disability.

Tier 3

Tier 2 learning outcomes plus the following

The person or practitioner will:

- a) understand the relevance of relationship theories to learning disability care and support
- b) understand the impact of relationships and social networks on wellbeing and self-esteem
- c) understand factors that can influence the process of a relationship
- d) understand the impact of social and family contextual factors on the sexual and sexual health needs of adults with a learning disability
- e) understand relevant legislation influencing the support of sexuality and sexual health for adults with a learning disability
- f) know how to support the sexual expression of an adult with a learning disability
- g) be able to support an adult with a learning disability to identify, access and use services to meet their sexual and sexual health needs
- h) know how to support adults with a learning disability to consent to sex, marriage and civil partnerships
- i) be able to help people with a learning disability negotiate shared living space, lifestyles and financial commitments within partnerships
- j) be able to work in partnership with individuals, their families and other agencies to create support so that people with a learning disability can be good parents
- k) be able to support parents with a learning disability through child protection processes including assessments of parenting abilities (where appropriate).

Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to relationships, sexuality and sexual health are shown below:

Guidance

- [Generic Service Interventions Pathway: A competency framework to support development of the learning disability workforce, Health Education England \(2015\)](#)
- [Family Planning Association \(2017\), Learning disabilities, sex and the law; a practical guide](#)
- [Relationships and sex, Mencap at: <https://www.mencap.org.uk/advice-and-support/relationships-and-sex>](#)
- <https://www.communitycare.co.uk/2016/12/06/attachment-theory-social-work-adults/>
- <https://www.lgbthealth.org.uk/category/learning-disabilities/>
- <https://www.changepeople.org/projects/parenting-projects>
- [Integrated Maternity Care Pathway for women with LD: Learning Disability/Learning Difficulty/Hidden Disability/Autism \[www.easyonthei.nhs.uk\]\(http://www.easyonthei.nhs.uk\)](#)
- <https://www.disabledparent.org.uk/>

Legislation

- [Care Act \(2014\)](#)
- [Children and Families Act 2014](#)
- [Equality Act 2010](#)

- [Disability Discrimination Act 1995](#)
- [Human Rights Act 1998](#)
- [Mental Capacity Act 2005](#)
- [Sexual Offences Act 2003](#)

Indicative mapping to relevant national standards or frameworks

Mapping to be completed...

[Return to contents page](#)

DRAFT

Capability 17: Supporting children and young people with a learning disability

Introduction

Children and young people with a learning disability have a right to have their needs met. The Children and Families Act creates a new 'birth-to-25 years' Education, Health and Care (EHC) plan for children and young people with special educational needs and offers families personal budgets which aim to give more control over the type of support they get. In some cases, where a person is over 18, the "Care" part of the EHC plan will be provided for by adult care and support, under the Care Act.

The quality of life of every child improves when they are given a voice and real choices. The quality of life for a child or young person with a learning disability affects and is affected by many areas of their well-being, including:

- Physical well-being
- Emotional well-being
- Self-determination (making choices and determining the course of events)
- Interpersonal relationships
- Social inclusion
- Personal development
- Material well-being, and
- Rights and privacy

It is important to note that all of the capabilities in this framework include learning outcomes that are relevant to children and young people with a learning disability. This capability area includes specific learning outcomes that relate to care and support for children and young people (age range 0 – 25) with a learning disability that are not fully covered elsewhere in the framework.

Target audience

Tier 2 – Health and social care staff and others with responsibility for providing care and support for a person or people with a learning disability, but who would seek support from others for complex management or complex decision-making

Tier 3 – Health, social care and other professionals with a high degree of autonomy, able to provide care in complex situations and/or may also lead services for people with a learning disability..

Key learning outcomes

Tier 2

The person or practitioner will:

- a) be aware of the usual ages for developmental milestones in different areas (social, emotional, communication, cognitive, perceptual, and physical)
- b) know how children and young people's development may be affected by a learning disability
- c) know how to identify the risk factors that might help with early diagnosis of a learning disability

- d) be aware of the support available to children with a learning disability and their families and help to signpost families towards this
- e) understand the importance of timely intervention to support the development of children and young people with a learning disability
- f) know the rights of children and young people with a learning disability and their families
- g) be aware of the key agencies' roles in relation to one's own role
- h) be aware of how support and interventions may inadvertently affect the quality of life of families and carers of children and young people with a learning disability, and know how to minimise this
- i) understand how patterns of communication development may be impaired, and principles for addressing consequent barriers for the child or young person with a learning disability
- j) be able to apply recommended strategies for communicating with a child or young person with a learning disability and to support their participation in interaction and activities, and evaluate their response
- k) be aware of the ways in which a child or young person with a learning disability's communication validates their 'world'
- l) be able to support a child or young person with a learning disability to make informed choices that promote self-esteem and awareness
- m) be able to identify signs of unhappiness and distress in a child or young person with a learning disability
- n) be able to summarise key approaches to promoting positive mental health for children and young people
- o) be aware of the range of professional disciplines and identify their contribution in relation to meeting the needs of children and young people with a learning disability
- p) understand the key aspects of physical/personal care and health support likely to be encountered by a child or young person with a learning disability including where applicable: using the toilet and toilet training; continence care, dressing; eating and drinking and puberty issues
- q) understand how children and young people, their families, carers and other professionals can work together to develop personal care and health management plans
- r) be aware of the right of children and young people with a learning disability to a free annual health check with their GP
- s) understand the thresholds for accessing children's social care, including that all disabled children are eligible for a child in need assessment
- t) be aware of the potential effects of transitions of various kinds on the development of children and young people with a learning disability
- u) know how to respond to evidence or concerns that a child or young person with a learning disability has been bullied
- v) understand how to work with children and young people with a learning disability to support their safety and wellbeing
- w) understand the importance of online safety for children and young people with a learning disability
- x) know the ways in which the social, economic and cultural environment can impact on the outcomes and life chances of children and young people with a learning disability

Tier 3

Tier 2 learning outcomes plus the following

The person or practitioner will:

- a) understand the value of timely intervention on the lives of children and young people with a learning disability and their families
- b) understand the possible impact of a learning disability, special requirements (additional needs) and attitudes on longer term positive outcomes for children and young people
- c) understand the rights of disabled children and young people and those with special educational needs
- d) be able to support age and developmentally appropriate learning, play and leisure opportunities for children or young people with a learning disability
- e) be able to differentiate the emotional and practical needs of various family members
- f) understand the practical and organisational implications of developing partnerships with families
- g) be able to support children and young people with a learning disability and their families and carers to assess their quality of life
- h) understand how quality of life for children and young people with a learning disability and their families and carers can be improved through empowering them
- i) understand how children learn to communicate from engaging in early playful interactions, and the importance of establishing this foundation, in addition to functional strategies, for developing meaningful social communication in children and young people with a learning disability
- j) be able to use and evaluate the effectiveness of a range of social and functional communication strategies in planned and spontaneous interactions with children and young people with a learning disability
- k) be able to plan, implement and evaluate a personalised communication intervention for a child or young person with a learning disability in consultation with other professionals, their family and carers
- l) understand the range of communication that children and young people with a learning disability use to express their needs
- m) be aware of a range of learning activities which encourage good mental health
- n) understand the risk factors impacting on a child or young person with a learning disability's emotional wellbeing
- o) understand the interface between learning disability and mental health, and its impact on learning, progress and attainment
- p) understand the issues relating to promoting collaborative working across the range of professional groups in support of children and young people with a learning disability
- q) be able to assess the development needs of children or young people with a learning disability and prepare a development plan
- r) be able to support the provision of environments and services that promote the development of children or young people with a learning disability
- s) understand how working practices can impact on the development of children and young people with a learning disability
- t) understand and be able to promote the principles of working inclusively with disabled children and young people and those with specific requirements
- u) be able to evaluate, support and develop existing practice with children and young people with a learning disability and their families

Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to supporting children and young people with a learning disability are shown below:

Guidance

- [Generic Service Interventions Pathway: A competency framework to support development of the learning disability workforce, Health Education England \(2015\)](#)
- [Working together to safeguard children: A guide to inter-agency working to safeguard and promote the welfare of children \(HM Government, July 2018\)](#)
- [Special educational needs and disability code of practice: 0 to 25 years \(DFE, 2013\)](#)
- [Department for Education: Training materials for teachers of learners with severe, profound and complex learning difficulties](#)

Legislation

- [Children and Families Act 2014](#)
- [Special educational needs and disability code of practice: 0 to 25 years \(DFE, 2013\)](#)

Indicative mapping to relevant national standards or frameworks

Mapping to be completed...

[Return to contents page](#)

Capability 18: Preparing young people with a learning disability for adulthood

Introduction

The Children and Families Act 2014 introduces a new SEND system. At the heart of these changes is a commitment to ensuring that children, young people and their families are at the centre of decision-making so that they achieve better outcomes.

From at least year 9 the SEND reforms require those supporting young people to focus on preparing for adulthood outcomes such as paid employment; independent living (choice and control over your life and support, and good housing options); community participation (friends, relationships and community inclusion); and health and wellbeing. The new system requires a joined up approach including co-production, holistic planning and multi-agency working.

The implications for workforce development are significant, as the SEND reforms represent a change not just in process but also in thinking about outcomes, coproduction, and what it takes to support young people to move into adulthood with ordinary lives.

Target audience

Tier 2 – Health and social care staff and others with responsibility for providing care and support for a person or people with a learning disability, but who would seek support from others for complex management or complex decision-making

Tier 3 – Health, social care and other professionals with a high degree of autonomy, able to provide care in complex situations and/or may also lead services for people with a learning disability..

Key learning outcomes

Tier 2

The person or practitioner will:

- a) be aware of the steps and stages of moving from childhood into adulthood for young people with a learning disability
- b) know how having a learning disability may affect the process of moving from childhood into adulthood
- c) be aware of how the welfare benefits system and other supports systems can help or act as a barrier throughout a young person with a learning disability's transition into adulthood
- d) know the options for supporting a young person with a learning disability to make the transition into adulthood

Tier 3

Tier 2 learning outcomes plus the following

The person or practitioner will:

- a) be able to support a young person with a learning disability through transition into adulthood
- b) be able to support a young person with a learning disability and their family and carers to reflect on the transition into adulthood and understand the importance of this
- c) be aware of changing parental responsibility and decision-making rights from age 16

- d) understand the difference in ethos and practice between statements, LDAs and EHC plans including the right to maintain an EHC plan until the age of 25 if someone is in education or training
- e) know national best practice and the evidence base in relation to helping young people with a learning disability prepare for adulthood
- f) know what is required for an EHC plan to be compliant
- g) understand how specific person-centred practices contribute to the information required in EHC plans
- h) understand the process of the Preparing for Adulthood review
- i) be able to facilitate the Preparing for Adulthood review, and how to ensure that everyone is fully prepared
- j) understand the difference between good and poor outcomes
- k) be able to co-produce summaries that young people with a learning disability and their families and others can understand, under the relevant headings.

Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to preparing young people with a learning disability for adulthood are shown below:

Guidance

- [Special educational needs and disability code of practice: 0 to 25 years \(DFE, 2013\)](#)
- [The Preparing for Adulthood Review: A Good Practice Toolkit \(NDTi, January 2015\)](#)
- [Generic Service Interventions Pathway: A competency framework to support development of the learning disability workforce, Health Education England \(2015\)](#)

Legislation

- [Children and Families Act 2014](#)
- [Care Act 2014](#)
- [Disability Discrimination Act 1995](#)
- [Apprenticeship, Skills, Children and Learning Act 2006](#)
- [Education Act 2011](#)

Indicative mapping to relevant national standards or frameworks

Mapping to be completed...

[Return to contents page](#)

Capability 19: Supporting older people with a learning disability

Introduction

Older people with a learning disability often face specific challenges relating to health and social care needs due to both lifestyle and genetic factors and the history of the care and support they have received.

Some people with a learning disability are genetically predisposed to certain health conditions in later life. For example, prevalence rates of clinically diagnosed dementia are higher for people with Down's syndrome than in the general population. The condition is also likely to develop at a much earlier age, with a small number of people with Down's syndrome diagnosed with dementia when they are in their 30s and the number steadily increases in prevalence into their 60s. According to 'Dementia and people with a learning disability' published by the Royal College of Psychiatrists¹⁸, nearly 70% of older adults with Down's syndrome would be likely to develop dementia symptoms if they all lived to the age of 70. All people with a learning disability are at greater risk of developing dementia than the general population.

Overall, older people with a learning disability are 2.5 times more likely to experience health problems than other people (Department of Health, 2001). Adults with a learning disability are far more likely to have sensory impairment compared to the general population, but are less likely to access sight, hearing and dental checks (Health Inequalities & People with a learning disability in the UK: 2012), especially if they are living independently or with family. Sensory impairment is itself a barrier to social participation and access to health and care services.

Some older people with a learning disability can also be at increased risk of other health problems because of their genetic make-up. For example, musculoskeletal disorders are higher among people with Fragile X syndrome and diabetes is higher among people with Prader–Willi syndrome (Royal College of Nursing, 2011).

As well as health problems, older people with a learning disability may also experience particular difficulty in finding housing and social care services which meet their particular needs. Two-thirds of adults with a learning disability live with their families, usually their parents. Of these, 40% live with a parent aged over 60 and 33% with a parent aged over 70 (British Institute of Learning Disabilities, 2012). If their parents become frail, the person with a learning disability may assume a caring role and the family members may become interdependent. If their parents die or themselves need residential care, the person with a learning disability may remain in the family home or if their home is unsuitable, they may be placed in an older people's residential services at a much younger age than the general population. Older people with a learning disability living in the community may not be known to health, social care or housing services; data from the Department of Health in 2001 showed that up to 25% of people with a learning disability living with older family carers are not known to services until there is a crisis (BILD Supporting Older People with a Learning Disability, 2014).). It is common in these situations that poor decisions are made on a person's behalf and in a rush in the absence of services that could support them.

It is important to note that all of the capabilities in this framework include learning outcomes that are relevant to older people with a learning disability. This capability area includes specific learning outcomes that relate to care and support for older people with a learning disability and dealing with transitions that are not covered elsewhere in the framework.

¹⁸ 'Dementia and people with learning disabilities' (Royal College of Psychiatrists, 2015),

Target audience

Tier 3 – Health, social care and other professionals with a high degree of autonomy, able to provide care in complex situations and/or may also lead services for people with a learning disability..

Key learning outcomes

Tier 3

The person or practitioner will:

- a) understand the impact of age-related changes and activity on older people with a learning disability
- b) understand factors relating to a person with a learning disability's experience of dementia
- c) understand the impact of recognition and diagnosis of dementia for a person with a learning disability
- d) understand the importance of identifying and assessing the health and social care needs of older people with a learning disability specifically related to ageing
- e) be able to undertake care and support planning and crisis and positive risk taking with older people with a learning disability, including joint working with housing, employment, education and related services
- f) be able to undertake ongoing review of changing needs, crisis management, contingency and future planning
- g) be able to provide practical and emotional support with ageing (for example, relating to finances, retirement, bereavement and life changes)
- h) understand that people's needs for meaningful activity, sexual expression and good relationships do not diminish with age and know how to help people overcome any barriers they face as they get older.

Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to supporting older people with a learning disability and autism are shown below:

Guidance

- [Care and support of people growing older with learning disabilities, NICE Guideline \[NG96\] \(2018\)](#)
- [Supporting older people with learning disabilities: a toolkit for health and social care commissioners, BILD and NDTi: 2014](#)
- [Royal Colleges \(Dementia and people with learning disabilities\)](#)
- [Social Care Institute for Excellence \(Learning disabilities and dementia\)](#)

Legislation

- [Care Act 2014](#)
- [Equality Act 2010](#)
- [Mental Capacity Act 2005](#)
- [Disability Discrimination Act 1995](#)

Indicative mapping to relevant national standards or frameworks

Core Skills/Capabilities Frameworks (at: www.skillsforhealth.org.uk/cstf)

- Dementia Training Standards Framework
- Frailty: A framework of core capabilities

Mapping to be completed...

[Return to contents page](#)

DRAFT

Capability 20: Forensic support

Introduction

This capability is about provision of community forensic support to meet the daily living needs of people with a learning disability in the community.

It is important to note that many of the other capabilities in this framework are also relevant to community forensic support. However, this capability is about the additional knowledge and skills in supporting people with a learning disability and their forensic needs in the community, in particular, the assessment and management of forensic risk. Such risks involve those to the person from themselves in the form of self-harm, recklessness or misuse of substances; risks to the public from the individual from the issue that has resulted in them coming into contact with the criminal justice service; (including violence, fire setting and sexually offending behaviour) and to the person from the public across a number of issues including retribution, exploitation or victimisation.

Many of the capabilities for provision of forensic support would be undertaken by appropriately qualified and professionally regulated groups, which is beyond the scope of this framework. Further details are available in the Workforce Competency Framework for Providing Community Forensic Services for People with Learning Disabilities and/or Autistic Spectrum Conditions (Health Education England, 2019).

Target audience

Tier 2 – Health and social care staff and others with responsibility for providing care and support for a person or people with a learning disability, but who would seek support from others for complex management or complex decision-making

Tier 3 – Health, social care and other professionals with a high degree of autonomy, able to provide care in complex situations and/or may also lead services for people with a learning disability..

Key learning outcomes

Tier 2

The person or practitioner will:

- a) carry out a risk assessment, relevant to the context of the person with a learning disability and integrate risk assessment into the planning and provision of care
- b) work to assess and manage risk in conjunction with the multi-disciplinary team, in a multi-agency environment
- c) contribute to the formulation of crisis and emergency plans
- d) manage actual or potential aggression in line with current legal requirements
- e) recognise the impact of the person's activities on family and friends
- f) recognise the impact of any victim considerations and ministry of justice restrictions
- g) recognise early signs of relapse and crisis and how to articulate this in relation to the person with a learning disability and their family
- h) recognise own emotional response to the person's risk factors and actions and use techniques to minimise the impact on the service and the person themselves.

Tier 3

Tier 2 learning outcomes plus the following

The person or practitioner will:

- a) be able to develop and implement risk and safety management plans, using collaborative approaches
- b) understand the person's forensic background and how to effectively manage the risk to themselves and to others
- c) undertake dynamic assessment of risk to the public/other people and the person with a learning disability
- d) be able to assess and prioritise people's eligibility for services and ensure that relevant and objective information is obtained from referrers
- e) be able to support access to own agency in accordance with the terms of the service including eligibility criteria/ requirements (e.g. age, disability, level of risk)
- f) work with families, referrers, and social care support to ensure there is a shared understanding of the expectations and boundaries of the service
- g) understand the role of liaison professionals, particularly in relation to the Criminal Justice System
- h) build relationships, engage and motivate people with a learning disability who are reluctant to use the service
- a) be able to plan a pathway with a person, recognising the role of other service and organisations and the importance of effective care coordination
- b) recognise a person's strengths and resilience and how to support the most appropriate care or referral taking into account the views and needs of the person with a learning disability
- c) know how to ensure care planning is compliant with requirements of the specific legislation relating to mental health in the community particularly where a person with a learning disability has specific conditions relating to their discharge or treatment
- d) evaluate factors that cause or maintain offending behaviours and will limit the person's opportunities
- e) be aware of multiple/simultaneous perspectives of the person with a learning disability, who maybe both victim and perpetrator
- f) understand how autistic spectrum conditions, mental health, personality disorder and post-traumatic stress disorder affect the presentation and offending behaviour in the person and the impact this has on the planning of care and/or treatment
- g) know how to plan transfers and transitions between, and discharge from services
- h) understand relevant legislation and law, codes of practice, protocols and procedures relating to transfers, transitions and discharge and the associated roles and responsibilities
- i) understand the importance of record keeping in managing forensic risk.

Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to end of life care are shown below:

Guidance

Health Education England (2019), Providing community forensic services for people with Learning Disabilities and/or Autistic Spectrum Conditions: Workforce Competency Framework (due in 2019).

Legislation

- [Care Act 2014](#)
- [Children and Families Act 2014](#)

- [Equality Act 2010](#)
- [Human Rights Act 1998](#)
- [Mental Capacity Act 2005](#)
- [Safeguarding Vulnerable Groups Act 2006](#)
- [Disability Discrimination Act 1995](#)

Indicative mapping to relevant national standards or frameworks

Mapping to be completed...

[Return to contents page](#)

DRAFT

Domain E. Risk, legislation and safeguarding

Insert image

Capability 21: Law, ethics and safeguarding

Introduction

Anyone involved in supporting people (children, young people and adults) with a learning disability must be fully aware of their duty of care, particularly where they may be required to make a decision when the person is unable to make that decision for themselves. Duty of care is about always acting in the best interests of others and not acting or failing to act in ways that result in harm.

This is likely to include ethical issues such as the need to balance a person's safety with their right to independence, knowing how to apply the mental capacity act, enabling people to make their own decisions and defending those decisions and sometimes (where relevant) deciding the best interests for the person deciding the best interests for the person with a learning disability (e.g. when making a decision about consent to treatment). It involves recognising that a person's needs and choices may sometimes conflict with the needs or views of others, especially their families and carers.

People with a learning disability may also be vulnerable to situations where they could suffer neglect, harm or exploitation. In recent years a number of high profile cases have highlighted distressing examples where there have been failings in the duty of care as documented in the Francis Report (2013)¹⁹ and Transforming care: A national response to Winterbourne View Hospital (2012)²⁰. These cases serve to highlight the vital importance of raising concerns as soon as possible and continuing to highlight concerns until there is an adequate response. Therefore, health and social care staff must be able to recognise and address any areas of concern and have the confidence to speak out when required.

Target audience

Tier 2 – Health and social care staff and others with responsibility for providing care and support for a person or people with a learning disability, but who would seek support from others for complex management or complex decision-making

Tier 3 – Health, social care and other professionals with a high degree of autonomy, able to provide care in complex situations and/or may also lead services for people with a learning disability..

¹⁹ Francis R (2013), Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry

²⁰ DH (2012), Transforming care: A national response to Winterbourne View Hospital

Key learning outcomes

Tier 2

The person or practitioner will:

- a) understand how legislation and policies protect the rights of people with a learning disability
- b) be aware of key legislation relevant to mental capacity, deprivation of liberty, equality and human rights
- c) understand that people with a learning disability have the right to make their own decisions and must be assumed to have capacity to do so unless it is proved otherwise
- d) understand that people with a learning disability have a right to be supported to make their own decisions and must be given all appropriate help before anyone concludes that they cannot make a decision
- e) understand that adults with a learning disability must retain the right to make what might be seen as eccentric or unwise decisions
- f) be able to support a person to get advocacy to help them make a decision
- g) understand that if a person is not capable of making a decision then anything done on their behalf must be in their best interest and must be the least restrictive of their rights
- h) understand that lacking capacity to make a decision at the time it needs to be made doesn't mean that the person is not capable of making that decision another time or of making other decisions.
- i) understand how duty of care contributes to safe practice in learning disability care and support
- j) be aware of dilemmas that may arise between the duty of care and a person with a learning disability's rights and/or family and carers wishes
- k) be able to communicate effectively about proposed care and support to enable a person with a learning disability to make informed choices
- l) know how to recognise signs of abuse or neglect in a person with a learning disability
- m) be able to recognise a range of factors which may indicate neglect, abuse or exploitation is happening
- n) know what to do if neglect, abuse, unsafe practices or exploitation is suspected, including how to raise concerns within local safeguarding or whistle blowing procedures
- o) understand the national and local context of safeguarding and protection from abuse for people with a learning disability, including 'making safeguarding personal'
- p) understand ways to reduce the likelihood of abuse for people with a learning disability
- q) understand the risks associated with the internet and online social networking.

Tier 3

Tier 2 learning outcomes plus the following

The person or practitioner will:

- a) understand key legislation relevant to mental capacity, deprivation of liberty, equality and human rights
- b) understand implications for practice of key legal and ethical issues
- c) understand the options available when informed consent may be compromised
- d) understand the legislation, regulations and policies that underpin the protection of people with a learning disability

- e) be able to lead service provision that protects people with a learning disability from harm or abuse
- f) understand safeguarding should be a personalised approach, done with, not to, people to achieve meaningful improvement to their circumstances rather than just a process of 'investigation' and 'conclusion'
- g) be able to manage inter-agency, joint or integrated working in order to protect people with a learning disability at risk of harm or abuse
- h) be able to monitor and evaluate the systems, processes and practice that safeguards people with a learning disability at risk of harm or abuse
- i) understand the roles and responsibilities of the different agencies involved in investigating allegations of harm or abuse
- j) understand the importance of sharing safeguarding information with the relevant agencies
- k) know the actions to take if there are barriers to alerting the relevant agencies
- l) understand the role of self and others when supporting people with a learning disability who have experienced harm or abuse
- m) be able to support people with a learning disability to disclose harm or abuse
- n) be able to support people with a learning disability who have experienced harm or abuse
- o) be able to challenge others who are not behaving in an ethical way

Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to law, ethics and safeguarding in learning disability care and support are shown below:

Guidance

- [Department of Health \(2009\), Reference guide to consent for examination or treatment](#)
- [Department of Health \(2014\), Care and Support Statutory Guidance: Issued under the Care Act 2014](#)
- [Making Safeguarding Personal \(Local Government Association\)](#)
- [Working Together to Safeguarding Children: A guide to inter-agency working to safeguard and promote the welfare of children \(HM Government, July 2018\)](#)

Legislation

- [Children and Families Act 2014](#)
- [Care Act 2014](#)
- [Data Protection Act 1998](#)
- [Human Rights Act 1998](#)
- [Mental Capacity Act 2005](#)
- [Safeguarding Vulnerable Groups Act 2006](#)
- [Sexual Offences Act 2003](#)
- [Disability Discrimination Act 1995](#)

Indicative mapping to relevant national standards or frameworks

Core Skills/Capabilities Frameworks (at: www.skillsforhealth.org.uk/cstf)

- Statutory/Mandatory Core Skills Education and Training Framework

Mapping to be completed...

[Return to contents page](#)

DRAFT

Capability 22: Equality, diversity and inclusion

Introduction

Learning disabilities affect people (children, young people and adults) from all cultural and ethnic backgrounds.

Issues of cultural and ethnic diversity may have an impact on how people experience a learning disability, including the acceptance of the condition within their family or community.

In addition, many of the characteristics covered by the Equality Act and related to the wider determinants of health can have a significant bearing on experiences of learning disabilities, including but not limited to a person with a disability's sexuality, gender, faith or geographical location.

Target audience

Tier 2 – Health and social care staff and others with responsibility for providing care and support for a person or people with a learning disability, but who would seek support from others for complex management or complex decision-making

Tier 3 – Health, social care and other professionals with a high degree of autonomy, able to provide care in complex situations and/or may also lead services for people with a learning disability..

Key learning outcomes

Tier 2

The person or practitioner will:

- a) be aware of their own values and beliefs
- b) know what is meant by:
 - diversity
 - equality
 - inclusion
 - discrimination
 - ethnicity and religion
- c) know ways in which discrimination may deliberately or inadvertently occur in a learning disability setting and/or a person with a learning disability's local community
- d) understand how practices that support equality and inclusion reduce the likelihood of discrimination
- e) know how to work in an inclusive way
- f) know which legislation and codes of practice relating to equality, diversity and discrimination apply to your own role and to other services that people you support may use
- g) be able to interact with people in ways that respects their beliefs, culture, values and preferences
- h) know how to challenge discrimination in a way that encourages positive change
- i) know a range of sources of information, advice and support about diversity, equality and inclusion and who to ask for advice and support about equality and inclusion
- j) know ways of working with a range of people with a learning disability to ensure diverse needs are met

- k) be able to adapt assessment, support and care planning taking account of equality issues (e.g. cultural diversity, disabilities, gender and sexual orientation)
- l) understand diversity in family arrangements and the local community
- m) be aware of the stigma, myths and stereotypes associated with learning disability
- n) be aware of socio-cultural differences in how the care giving role is viewed e.g. based on gender
- o) be able to actively challenge any discriminatory practice that may compromise the right of a person with a learning disability to dignity, respect and safety.

Tier 3

Tier 2 learning outcomes plus the following

The person or practitioner will:

- a) understand legislation relevant to equality, diversity and human rights
- b) understand the impact that discrimination and stigma may have on the life of the person (child, young person and adult) with a learning disability, their family and carers
- c) be able to lead practice and an organisational culture that values and respects equality, inclusion and the diversity of people with a learning disability and those who work in the service and encourages challenges to any form of discrimination
- d) understand how to develop systems and processes that promote diversity, equality and inclusion.

Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to equality, diversity and inclusion in learning disability care and support are shown below:

Guidance

- [Department of Health \(2014\), Care and Support Statutory Guidance: Issued under the Care Act 2014](#)

Legislation

- [Care Act \(2014\)](#)
- [Children and Families Act 2014](#)
- [Equality Act 2010](#)
- [Disability Discrimination Act 1995](#)
- [Human Rights Act 1998](#)

Indicative mapping to relevant national standards or frameworks

Core Skills/Capabilities Frameworks (at: www.skillsforhealth.org.uk/cstf)

- Statutory/Mandatory Core Skills Education and Training Framework

Mapping to be completed...

[Return to contents page](#)

Domain F. Leadership and management, education and research

Insert image

Capability 23: Leadership and management

Introduction

The delivery of high-quality learning disability care and support requires skilled and confident leaders and managers.

People working in a leadership or management role in care and support for people with a learning disability are not only responsible for supporting those who need care and support, but for taking care of their staff and influencing the quality of care across the sector.

Leaders at all levels have a responsibility to provide direction, disseminate best practice and to motivate and support colleagues in meeting their objectives. This requires an understanding of the environment in which the organisation or team operates and an understanding of current research and developments in learning disability care and support. Leaders can also influence the culture of their workplace regarding desired attitudes and ways of working (such as promoting value based, person-centred approaches to care). As well as supporting staff in their own organisation, leaders will be required to work collaboratively to deliver integrated services as part of a multi-agency team.

Target audience

Tier 2 – Health and social care staff and others with responsibility for providing care and support for a person or people with a learning disability, but who would seek support from others for complex management or complex decision-making

Tier 3 – Health, social care and other professionals with a high degree of autonomy, able to provide care in complex situations and/or may also lead services for people with a learning disability..

Key learning outcomes

Tier 2

The person or practitioner will:

- a) understand the importance of co-production with people with a learning disability and their families and carers
- b) understand the changing nature of learning disability care and support and the impact of current developments on own role
- c) know why management and leadership styles need to be adapted to manage different situations in learning disability care and support
- d) understand the features of effective team performance within learning disability care and support

- e) be able to support a positive culture within the team for learning disability care and support
- f) be able to promote a shared vision within the team for a learning disability setting
- g) be able to develop a plan with team members to meet agreed objectives for a learning disability setting
- h) be able to support individual team members to work towards agreed objectives in learning disability care and support
- i) be able to describe strategies and tools that could be adopted to reduce stress levels, to build resilience and to maintain the wellbeing of staff within the team
- j) be able to manage conflict situations during professional supervision in learning disability care and support
- k) be able to evaluate own practice when conducting professional supervision in learning disability care and support
- l) be able to lead inclusive provision that gives individuals' choice and control over the outcomes they want to achieve
- m) know the appropriate type and level of resources required to deliver safe and effective services in learning disability care and support
- n) know the induction requirements for staff in learning disability care and support

Tier 3

Tier 2 learning outcomes plus the following

The person or practitioner will:

- a) be able to work with people with a learning disability and families and carers to co-produce services, resources, and support models
- b) understand the importance of collaborative working and coproduction in the provision of care and support for people with a learning disability and their families and carers
- c) be aware of the key drivers and policies which influence national learning disability strategy and service development
- d) be able to anticipate and prepare for the future by scanning for ideas, best practice and emerging trends that will have an impact on outcomes for people with a learning disability
- e) be aware of evidence-based research, innovations and developments in learning disability care and support
- f) understand the current legislative framework and organisational health, safety and risk management policies, procedures and practices that are relevant to learning disability care and support
- g) be able to lead the implementation of policies, procedures and practices to manage risk to individuals and others in learning disability care and support
- h) be able to promote a culture where needs and risks are balanced with health and safety practice in learning disability care and support
- i) be able to improve health, safety and risk management policies, procedures and practices in learning disability care and support
- j) know the importance of challenging poor and unethical practice in learning disability care and support
- k) understand the importance of demonstrating leadership in delivering compassionate person-centred care
- l) understand the importance of learning and development and support in meeting the needs of people with a learning disability

- m) understand the importance of collecting quality assurance information including feedback from people with a learning disability and their families and carers
- n) be able to obtain and act on the feedback and experiences of people with a learning disability and their families and carers
- o) be able to develop creative solutions to transform care and support for people with a learning disability
- p) be aware of the roles and responsibilities of different agencies involved in learning disability care and support
- q) understand the importance of systems leadership in supporting people with a learning disability
- r) be able to work across services and organisations to meet the needs of the growing number of people with a learning disability and complex medical conditions and those who rely on care and support from different agencies.

Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to leadership and management in learning disability care and support settings are shown below:

Guidance

- [The Leadership Qualities Framework For Adult Social Care \(NSA\)](#)
- [Positive Behavioural Support A Competence Framework - Positive Behavioural Support \(PBS\) Coalition UK \(May 2015\)](#)
- [NHS Leadership Academy](#)

Indicative mapping to relevant national standards or frameworks

Multi-professional framework for advanced clinical practice in England (NHS 2017)

- Pillar 2. Leadership and Management

[Return to contents page](#)

Capability 24: Education and personal development

Introduction

People working in learning disability services need to maintain their own continuing professional development in order to ensure their professional practice remains current, safe and effective. This includes recognising and planning for a range of formal and informal learning opportunities, including learning with colleagues and from the lived experience of people who have a learning disability and their families and carers.

Target audience

Tier 2 – Health and social care staff and others with responsibility for providing care and support for a person or people with a learning disability, but who would seek support from others for complex management or complex decision-making

Tier 3 – Health, social care and other professionals with a high degree of autonomy, able to provide care in complex situations and/or may also lead services for people with a learning disability..

Key learning outcomes

Tier 2

The person or practitioner will:

- a) understand the importance of continuing professional development
- b) understand the process for agreeing a personal development plan and who should be involved
- c) know why feedback from others is important in helping to develop and improve working practice
- d) understand the principles of reflective practice and why it is important
- e) understand the purpose and benefits of supervision and appraisal or similar arrangements
- f) be aware of a range of learning opportunities and how they can be used
- g) be able to implement a personal development plan through accessing development opportunities
- h) use opportunities with others to reflect on learning in order to continuously improve practice
- i) disseminate information about knowledge and evidence-based practice that will be useful to others
- j) challenge poor practice in ways that promote the use of knowledge and evidence-based practice to safeguard individuals and enhance their wellbeing
- k) appreciate and utilise the lived expertise of people who have a learning disability and their families and carers in one's own personal development
- l) undertake personal development based on the changing needs of the individuals using the service to ensure that the service provided meets those needs.

Tier 3

Tier 2 learning outcomes plus the following

The person or practitioner will:

- a) critically assess and address own learning needs, negotiating a personal development plan that reflects the breadth of ongoing professional development
- b) engage in self-directed learning, critically reflecting to maximise clinical skills and knowledge, as well as own potential to lead and develop both care and services
- c) advocate for and contribute to a culture of organisational learning to inspire future and existing staff
- d) facilitate collaboration of the wider team and support peer review processes to identify individual and team learning
- e) identify further developmental needs for the individual and the wider team and supporting them to address these
- f) supporting the wider team to build capacity and capability through work-based and interprofessional learning, and the application of learning to practice
- g) act as a role model, educator, supervisor, coach and mentor, seeking to instil and develop the confidence of others.

Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to education in learning disability care and support settings are shown below:

Guidance

Indicative mapping to relevant national standards or frameworks

Multi-professional framework for advanced clinical practice in England (NHS 2017)

- Pillar 3. Education

[Return to contents page](#)

Capability 25: Research and evidence-based practice

Introduction

The continuing development of learning disability care and support requires on-going research and development of evidence-based practice. This includes evaluating the outcomes and impact of services and interventions. When people (children, young people and adults) with a learning disability agree to participate in research activities this must be handled with due regard for the ethical issues involved.

Target audience

Tier 2 – Health and social care staff and others with responsibility for providing care and support for a person or people with a learning disability, but who would seek support from others for complex management or complex decision-making

Tier 3 – Health, social care and other professionals with a high degree of autonomy, able to provide care in complex situations and/or may also lead services for people with a learning disability..

Key learning outcomes

Tier 2

The person or practitioner will:

- a) know the importance of research and evidence-based practice and support for people with a learning disability and their families and carers
- b) know where to find research and development evidence (including the rich qualitative data available from people with lived experience) and how to use it to underpin ways of working to benefit a person with a learning disability
- c) be able to report data and outcomes as required in a learning disability setting
- d) know how to interpret and use data as evidence effectively in a learning disability setting
- e) be able to translate research into practice when supporting people with a learning disability
- f) know how to adapt and develop monitoring and measuring tools to collect appropriate information, in line with current research and evidence
- g) be able to present data relating to intervention and outcomes in a user-friendly format
- h) understand the difference between service evaluation and research
- i) be able to participate in service evaluation and research in a learning disability setting
- j) know how people with a learning disability, their families and carers may be involved in service evaluation and research
- k) be able to support people with a learning disability and/or family members to direct research, or to be co-researchers
- l) be able to share knowledge and good practice
- m) be able to incorporate new knowledge into own practice
- n) be able to evaluate the sharing of knowledge and good practice

Tier 3

Tier 2 learning outcomes plus the following

The person or practitioner will:

- a) understand systematic research methods to facilitate evidence-based practice in a learning disability setting
- b) understand the range of evidence that informs decision-making, care practice and service delivery
- c) understand approaches to evaluating services and measuring impact, including the use of outcomes reported by people with a learning disability
- d) understand the ethical issues related to conducting research with people with a learning disability
- e) be able to justify a topic for research within services for people with disabilities
- f) be able to contribute to a research project within services for people with a learning disability as a part of a research team
- g) be able to analyse research findings
- h) be able to disseminate research findings clearly and accurately in written reports or verbal presentations
- i) understand the importance of continuing professional development to ensure that research and evaluation methods used are robust, valid and reliable

Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to research and evidence-based practice in learning disability care and support are shown below:

Guidance

[The National Institute for Health and Care Excellence \(NICE\)](#) provides national guidance and advice to improve health and social care. They do this by:

- Producing evidence-based guidance and advice for health, public health and social care practitioners
- Developing quality standards and performance metrics for those providing and commissioning health, public health and social care services
- Providing a range of informational services for commissioners, practitioners and managers across the spectrum of health and social care
- Research and evaluation
- Sharing knowledge and good practice.

Indicative mapping to relevant national standards or frameworks

Multi-professional framework for advanced clinical practice in England (NHS 2017)

- Pillar 4. Research

[Return to contents page](#)

Appendix 1: How this framework was developed

To be completed...

DRAFT

Appendix 2: Related standards and frameworks

National Occupational Standards (NOS)

National Occupational Standards (NOS) are statements of the standards of performance for individuals when carrying out functions in the workplace, together with specifications of the underpinning knowledge and understanding. NOS are developed for employers by employers through the relevant Sector Skills Council or Standards Setting Organisation.

All national occupational standards are available from the [NOS Directory](#)

Competence search tools are also available from the [Skills for Health Tools web site](#).

Core Skills Training Frameworks

Skills for Health originally developed the UK Core Skills Training Framework which sets out the expected learning outcomes and standards for delivery of training related to the most common statutory and mandatory training subjects within the health sector. The aim is to help ensure the quality and consistency of such training, and to help prevent unnecessary duplication of training.

In addition, a range of other core skills/capabilities frameworks are now offered as guidance and good practice for development of the current and future workforce, including this framework for Learning Disability and others for, Dementia; Mental Health; End of Life Care; Person-centred Approaches; Musculoskeletal and Frailty.

All core skills/capabilities frameworks can be accessed from: www.skillsforhealth.org.uk/cstf.

Care Certificate Standards

Following the Francis Inquiry, Camilla Cavendish was asked by the Secretary of State to review and make recommendations on the recruitment, learning and development, management and support of healthcare assistants and social care support workers. The resulting [report](#), published in July 2013, found that the preparation of healthcare assistants and social care support workers for their roles within care settings was inconsistent, and one of the recommendations was the development of the Care Certificate.

Skills for Health, Health Education England, and Skills for Care worked together to develop and pilot the draft Care Certificate documents. The Care Certificate was formally launched in April 2015, replacing both the National Minimum Training Standards and the Common Induction Standards. Further information about the Care Certificate is available from [Skills for Health](#) and [Skills for Care](#).

Appendix 3: Suggested standards for training delivery

The employing organisation should be assured that learning facilitators have the appropriate experience and background to deliver training to a satisfactory standard. For guidance, this may include the following:

- a current and thorough knowledge of the relevant subject
- experience of teaching and learning, including the ability to meet the competences expected for [LSILADD04 Plan and prepare specific learning and development opportunities](#).

The organisation should also ensure that they have put in place a quality assurance mechanism, whereby the accuracy of the content and the effectiveness of its delivery has been quality assured and is subject to periodic observation.

Where e-learning is used, the organisation must ensure the accuracy of the content and its coverage of the required learning outcomes. Consideration must also be given to whether e-learning is appropriate, recognising when face to face training, practical methods or a blended approach may be more effective.

Co-producing training

The LeDeR programme recommended that learning disability awareness training should be delivered in conjunction with people with a learning disability and their families. As well as articulating the experiences and perspectives of people with a learning disability, co-production demonstrates the wider positive strengths, contributions and impact that they can make.

Therefore, the active involvement of people with a learning disability, family and carers is central to effective training delivery and where possible, sessions should be co-designed to model person-centred approaches and to meet learning outcomes.

People with a learning disability may also contribute by sharing their story (either in person, or through a medium such as video or podcast) while others may wish to actively co-deliver as much as possible.

It is important to recognize that how people train is as important as what is taught. Education should include training that is co-designed and co-delivered by people with lived experience, in community settings” (Realising the Value 2016²¹)

The [Education Outcomes Framework \(Department of Health 2013\)](#) provides further guidance on the quality of training with a focus on improvements in patient care, health outcomes and addressing variation in standards.

The [Health Education England \(HEE\) Strategic Framework 15](#) provides the context and strategic direction for the education and training of the current and future healthcare workforce.

²¹ Realising the Value, The Health Foundation (2016) at: <https://www.health.org.uk/collection/realising-value>

Appendix 4: Sources of further guidance and information

The following are some suggested sources of further guidance and information (this list is not exhaustive). Click on the links below to access the relevant web sites:

- [Ambitious about Autism](#)
- [Autism Alliance UK](#)
- [Autism Plus](#)
- [British Institute of Learning Disabilities \(BILD\)](#)
- [British Psychological Society](#)
- [Challenging Behaviour Foundation](#)
- [Disability Matters / Autism Spectrum Matters](#)
- [Down's Syndrome Association](#)
- [Foundation for people with learning disabilities](#)
- [General Medical Council \(GMC\) / Learning Disabilities](#)
- [Health Education England \(HEE\) / Learning disability](#)
- [Mencap](#)
- [National Autistic Society](#)
- [NICE](#)
- [NHS Leadership Academy](#)
- [NHS England / Learning Disabilities](#)
- [NHS England / Accessible Information Standard / Resources](#)
- [PBS Academy](#)
- [PHE Learning Disabilities Observatory \(IHaL\)](#)
- [Royal College of General Practitioners / Health checks for people with learning disabilities toolkit](#)
- [Royal College of Nursing](#)
- [Royal College of Psychiatrists](#)
- [Royal College of Speech and Language Therapists](#)
- [Scope](#)
- [Social Care Institute for Excellence \(SCIE\)](#)
- [Skills for Care](#)
- [Skills for Health](#)
- [University of Bristol, Learning Disabilities Mortality Review \(LeDeR\) Programme](#)

Appendix 5: Bibliography

To be completed...

DRAFT

