Advanced Clinical Practice: Capabilities framework when working with people who have a learning disability and/or autism

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Finally, we wish to thank the 221 respondents to the online consultation survey.

Further detail of how the framework was developed is presented in Appendix 5.

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Foreword

From Scott Watkins BEM

I welcome this framework. We know people with learning disabilities face lots of health inequalities. I know from my own experience that it can be very challenging to meet our needs. We know that we have a shortage of learning disability nurses and allied health professionals and it is important that we have people with the right skills to support us. Learning Disability Nurses and other Health Professionals are always at the forefront of advocating on our behalf to make sure we get the right health care. We know that other parts of the health service who don't have learning disability experience often find it difficult to know how best to support us. It is important that people working with us have the skills to give us the right care and to support others to meet our health needs. I believe this framework bridges this gap and is essential to giving you the advanced skills which are needed for the whole workforce. When learning skills, I believe one of the valuable experiences you can gain is working alongside people with lived experience as we can tell you what life is like on the ground.

People with a learning disability die much earlier than people without a learning disability. We know that people are sometimes treated differently. Sometimes people will put a DNR in place because they think it's easy to do and use the term learning disability as the reason. This is not acceptable. It is important that professionals care about the lives of people with learning disabilities.   People with learning disabilities can achieve their goals and aspirations in life. The framework sets out how you can help us to achieve our goals and to avoid these inequalities. It sets out the skills and competencies to help you to make these changes at this level of practice.

The framework is very broad and ambitious. This is great for people with learning disabilities and autism as it will help people to live bigger better healthier lives and to achieve their goals which mean everyday will be an extraordinary day.

Scott Watkins BEM

Independent Consultant and Expert by Experience

Foreword

From co-chairs of the steering group

People with a learning disability and/or autism continue to face many challenges when accessing health and social care. These difficulties are exacerbated when there isn't an appropriately skilled workforce to meet needs and to reduce the health inequalities faced. People with a learning disability and/or autism need a health and care system that is flexible and innovative to meet increasing demands.

This capabilities framework sets out the clinical expectations of Allied Health Professionals and Nurses who are working at an advanced level of practice with people with a range of physical, psychological and social health needs. These practitioners will have high levels of autonomy in clinical practice and in the leadership they provide to ensure good outcomes for the people they support.

The framework outlines what good governance of services for people with a learning disability and/or autism should include.   We hope that the framework will have a range of uses by different organisations, including employers and commissioners, as it can be used to underpin commissioning, workforce planning, education and training, as well as the development of career pathways and new ways of working. Ultimately, we hope the framework will support the development of a skilled and effective workforce that is able to reduce the health and social inequalities that people experience.

Dr Della Money

Associate Director for Allied Health Professionals (Nottinghamshire Healthcare NHS Trust) and Co-chair RCSLT National ALD Network

Rebecca Chester MBE

Consultant Nurse for People with a Learning Disability (Berkshire Healthcare NHS Foundation Trust) and Chair UKLDCNN

Introduction and background

Health Education England commissioned the development of this framework to provide a definition of advanced clinical practice for Allied Health Professionals (AHPs) and Nursing staff in learning disabilities and autism services. The framework sets out the capabilities (including knowledge, skills and behaviours) characterised by a high degree of autonomy, complex decision making and management of risks.

In recent years, the learning disabilities and autism workforce has been the focus of much attention, not least as a result of the national Transforming Care Programme which aims to develop health and care services so that people with a learning disability and/or autism can live as independently as possible, 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 greater focus on actions 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. The Interim NHS People Plan (2019) emphasises the aim to transform the workforce - for work to be much more multi-disciplinary and for people to have less linear careers.

Developing the workforce to meet these aims requires a review of roles, teams 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 and/or autism.

Scope of the framework

The framework describes **advanced clinical practice** for Allied Health Professionals (AHPs) and nursing staff working with people who have a learning disability and/or autism. The AHPs who may have specialist roles when working with people who have a learning disability and/or autism include:

- Occupational Therapists
- Physiotherapists
- Dietitians
- Arts Therapists (Art, Drama and Music)
- Speech and Language Therapists
- Orthoptists.

Unless otherwise stated, reference to 'people' or 'a person' with a learning disability and/or autism includes children, young people and adults.

We recognise that some people may prefer alternative terminology, such as 'people with intellectual disability' and/or 'people on the autistic spectrum' or 'autistic people'. However, for brevity and consistency within the framework, we refer to people with a learning disability and/or autism.

This framework describes the enhanced capabilities for **advanced clinical practice** delivered by AHPs and nursing staff in learning disabilities and autism services. This includes 'core capabilities' relevant to all advanced clinical practice, and also 'profession and role specific' capabilities based upon the person's profession and/or clinical area of practice.

For the purposes of this framework we are using the following definition of capability:

> The attributes (skills, knowledge and behaviours) which people bring to the workplace. 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 (for further details, see **Appendix 1**).

Other related frameworks

This framework is one of several, related capabilities frameworks relevant to supporting people with a learning disability and/or autism across a range of different types of service provision. (see Figure 1 below). Other frameworks are:

- Core Capabilities Framework for supporting people with a learning disability
- Core Capabilities Framework for supporting autistic people

  www.skillsforhealth.org.uk/learningdisabilityandautismframeworks

- Person-Centred Approaches: www.skillsforhealth.org.uk/person-centred-framework

Figure 1. The capabilities frameworks for learning disability and autism

Capabilities and competences for specific areas of the workforce such as education, forensic services and social work are also available in other frameworks e.g.

- Autism Education Trust, Schools Programme: Autism Competency Framework: https://www.autismeducationtrust.org.uk/shop/schools-cf-shop/
- Workforce Competency Framework for Providing Community Forensic Services for People with Learning Disabilities and/or Autistic Spectrum Conditions (Health Education England, 2019): https://www.hee.nhs.uk/our-work/learning-disability/workforce-capability
- British Association of Social Workers (BASW): Capabilities statements for social work with autistic adults / adults who have learning disability (2019): https://www.basw.co.uk/

Synergy with the Advanced Clinical Practice (ACP) Framework

This framework builds upon the definitions of advanced clinical practice provided by the Multi-professional framework for advanced clinical practice (ACP) in England (HEE, 2017).

> *Advanced clinical practice is delivered by experienced, registered health and care practitioners. It is a level of practice characterised by a high degree of autonomy and complex decision making. This is underpinned by a master's level award or equivalent that encompasses the four pillars of clinical practice, leadership and management, education and research, with demonstration of core capabilities and area specific clinical competence.*

> *Advanced clinical practice embodies the ability to manage clinical care in partnership with individuals, families and carers. It includes the analysis and synthesis of complex problems across a range of settings, enabling innovative solutions to enhance people's experience and improve outcomes.*

This definition has been developed to provide clarity for employers, service leads, education providers and healthcare professionals, as well as those practising at an advanced level.

All health and care professionals working at the level of advanced clinical practice should have developed their skills and knowledge to the standard outlined in the framework for advanced clinical practice; the capabilities for leadership and management, education and research are common across this level of practice enabling standardisation. As well as demonstrating that health and care professionals have developed to a defined level of practice, there is an expectation that this is sustained through organisational mechanisms such as appraisal, clinical supervision and support for continuing professional development.

ACP capabilities for clinical practice are specific and tailored to populations/specialisms covered by the ACP role. This framework describes the extended ACP capabilities specific to clinical practice for learning disability and autism. This is illustrated by the table below: Domains A to D articulate the specific enhanced learning disability and autism clinical practice capabilities and Domain E is derived from the common ACP capabilities, which apply to all models of advanced clinical practice across sectors, specialties and professions.

Pillars of the ACP Framework	Domains of Learning Disabilities and/or Autism Capabilities Framework
1. Clinical Practice	Domain A. Personalised and collaborative working Domain B. Health and wellbeing Domain C. Personalised care and support Domain D. Risk, legislation and safeguarding
2. Leadership and Management	Domain E. Leadership and management, education and research
3. Education	
4. Research	

Who is this framework for?

Service commissioners

The framework enables commissioners of services to specify minimum standards for clinical employment/placement; it sets out clear expectations about advanced clinical practice delivered by Allied Health Professionals (AHPs) and Nursing staff in learning disabilities and autism services.

The capabilities support the development and planning of the workforce to meet local population need and support a common understanding and expectation of operating at this advanced level of practice, in order to facilitate the development and mobility of this workforce.

Service providers

The framework enables managers to demonstrate that AHPs and nursing staff meet both core and enhanced capabilities or have developmental plans in place to meet this nationally recognised framework. This underpins the continuing professional development of practitioners to ensure their practice remains up-to-date, safe and effective and supports the process of quality assurance to ensure the safety and effectiveness of advanced clinical practice roles.

A further aspiration in providing this framework is to support service transformation i.e. that organisations use the framework to review their current arrangements for advanced clinical practice in learning disabilities and autism services and use the capabilities in developing roles and teams.

Education and training providers

The framework helps those who design and deliver training and development opportunities to focus on the enhanced capabilities that learners need to achieve, which in turn will guide the content to be included and the use of appropriate learning and teaching strategies.

Education providers can use the framework to inform the design of their curricula and the delivery of education, training and development programmes, including how they articulate their intended learning outcomes. This will ensure that their learning and development provision contributes to students and practitioners acquiring and demonstrating the full range of knowledge to support the capabilities required for advanced clinical practice in learning disabilities and autism services.

Use of this national framework also supports organisational and system wide effectiveness and efficiencies by encouraging the delivery of education and training that is focused on developing core capabilities and optimises opportunities for inter-professional learning. In so doing, it should help to increase consistency in knowledge and skills development, prevent unnecessary duplication in education and training delivery and strengthen skill mix and teamworking.

Practitioners – people and teams

The framework sets out clear expectations for practitioners about the requirements of effective and safe extended practice roles and transferable skills. It can be used to review and recognise how capabilities are shared across teams and to conduct formal or informal appraisal and training needs analysis, comparing current skills and knowledge with required skills and knowledge. The framework also provides a structure for career progression and development in new and challenging clinical environments and engagement in continuing professional development.

Practitioners may have different starting points, due to their background, clinical training and scope of practice - most practitioners are already likely to meet all or some of the capabilities but may need to develop and orientate themselves to working in learning disabilities and autism services.

Service users and the public

The framework can be used by service users and the public to understand the functions of the learning disabilities and autism workforce and to plan effectively for their own current and future care. In particular, the framework highlights that people must be able to make informed choices about their care and support and be assured that services are delivered safely and effectively alongside healthcare and other practitioners, i.e. to participate in shared decision-making.

About the framework

Structure of the framework

The framework begins with a description of the principles and values that underpin all the capabilities set out under the five domains. Within the domains are a total of 19 capabilities. Each capability comprises the key outcomes of learning or performance.

The domains of the framework are:

>   Domain A. Personalised and collaborative working
>
>   Domain B. Health and wellbeing
>
>   Domain C. Personalised care and support
>
>   Domain D. Risk, legislation and safeguarding
>
>   Domain E. Leadership and management, education and research

The capabilities are numbered for ease of reference. This does not indicate a prescribed pathway, process or hierarchy.

Full coverage of all capabilities is most likely to be achieved by multi-disciplinary teams. Therefore, several capabilities are indicated as 'profession and role specific' and would be applicable according to the individual's professional qualifications, role or scope of practice, which may also change as roles develop and new roles emerge.

The capabilities are all underpinned by the clinical knowledge to promote health and to diagnose health and wellbeing needs and to manage the care of people with a learning disability and/or autism.

The framework does not prescribe how individual practitioners' fulfilment of the capabilities should be demonstrated or assessed and assumes that cyclical appraisal, credentialing and CPD exist within a well governed clinical working environment. This will depend upon the context or setting where the framework is used, individual roles and how people have developed their capability.

Further information on the development of this framework is presented in **Appendix 5.**

Underpinning knowledge

In accordance with the Multi-professional framework for advanced clinical practice in England (HEE, 2017)[1], the language used to describe the capabilities is mapped to level 7 taxonomy to support and make clear the expectation that people working at this level are required to operate at Master's level or equivalent i.e. to have the ability to make sound judgements in the absence of full information and to manage varying levels of risk when there is complex, competing or ambiguous information or uncertainty.

This includes demonstrating skills in problem-solving, critical thinking and evaluating the impact and outcomes of their interventions and demonstrating safe, effective, autonomous and reflective practice, informed by available evidence and established best practice.

It is crucial that this is underpinned by the clinical knowledge to promote health and manage the care of people with a learning disability and/or autism including an advanced understanding of the types, severity, prevalence and main causes of learning disability, the main characteristics of autism, and the impact they have.

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[1] Health Education England (2017), Multi-professional framework for advanced clinical practice in England.
https://www.hee.nhs.uk/our-work/advanced-clinical-practice/multi-professional-framework

Principles and values

This framework has a guiding principle that people with a learning disability and/or autism should be treated with dignity and respect as equal members of our society and that they are entitled to enjoy the same rights and experiences as anyone would expect.

Key principles

All professionals involved with services for people with learning disability and/or autism will need to understand basic ethical principles underlying health care and apply them for the benefit of the people using services. The Learning Disabilities Professional Senate (2014)[2] has set out a number of key principles to provide an ethical framework for decision-making and practice. These are summarised as follows:

- **Autonomy**: People with a learning disability may have impairment of their mental capacity and could face significant obstacles in developing and exercising their individual autonomy. For this reason, it becomes the responsibility of people commissioning and providing services that people are supported in making their own choices about the care they receive and be afforded this with dignity and respect.

- **Acting in best interests:** When working with people who may lack the capacity to make some informed choices, professionals may have to provide care and treatment in the person's best interests. This must be carried out within the framework of the Mental Capacity Act.

- **Doing good (beneficence):** Provision of care and treatment is focussed on enabling people to develop ways of behaving, interacting and communicating that support them to live fulfilling lives and enhance the quality of their lives.

- **Doing no harm:** The moral imperative to do no harm requires professionals to balance the risks and benefits of giving or withholding care and treatment. Consideration of harm would need to be balanced by the benefits of treatment with a reduction of challenging behaviour, an improvement in the quality of life and community participation as well as the increase of opportunities and the reduction of stigma and exclusion.

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[2] Learning Disabilities Professional Senate (2014): Statement of ethics for professionals who work in Learning Disability services post Winterbourne View

Rights and Equality Based Outcomes for People with a Learning Disability (Learning Disability Professional Senate) are presented in **Appendix 2**. These include the principles which underpin all the capabilities in this framework and focus on the expectations of people with a learning disability and/or autism, their family and carers:

- I am respected

- I am safe

- I make choices

- I have a place of my own

- I am active

- I have fulfilling relationships

- I am supported to access services – which are reasonably adjusted to meet my needs

Professional ethics, standards and codes of practice

All professionals are also accountable to the regulatory bodies for their practice. Each of the regulators sets out the expected standards of practice for individuals within their various codes of conduct. This includes (but is not limited to) the following:

Health & Care Professions Council (HCPC):

Standards of conduct, performance and ethics at: https://www.hcpc-uk.org/

Nursing and Midwifery Council

Professional standards of practice and behaviour for nurses, midwives and nursing associates at: https://www.nmc.org.uk/standards/code/

General Dental Council

Standards for the Dental Team; standards of conduct, performance and ethics at: https://www.gdc-uk.org/professionals/standards

NHS Constitution

Commitments to service users and staff, and the responsibilities that the public, service users and staff owe to one another to ensure that the NHS operates fairly and effectively at: https://www.gov.uk/government/publications/the-nhs-constitution-for-england

Domain A. Personalised and collaborative working

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.

Advanced clinical practitioners in learning disability and autism have a key role in provision of care and support. They can lead and contribute to assessments for learning disability and/or autism and develop a formulation or differential diagnoses that will ensure most effective support and referral if needed. This includes demonstrating skills in problem-solving, critical thinking and evaluating the impact and outcomes of their interventions. They analyse and synthesise information, particularly in relation to unfamiliar contexts and presentations where information may be incomplete or contradictory.

Advanced clinical practitioners in learning disability and autism have the interpersonal and communication skills to engage in effective, appropriate interactions with people, families, carers and colleagues in the clinical environments and roles in which they practise. They have the listening, information-processing and empathetic skills to ascertain, understand and respond to peoples' needs and concerns. They use appropriate language and media, are sensitive to individual preferences and needs, and uphold and safeguard peoples' interests.

Capability 1: Collaborative assessment, formulation and diagnosis

The practitioner will:

a) Gather and synthesise information from appropriate sources (including previous histories and assessments) to facilitate person-centred, holistic assessment.

b) Identify different factors that may impact upon presentation of a learning disability and/or autism such as gender or age.

c) Critically appraise complex, incomplete, ambiguous and conflicting information, distilling and synthesising key factors from the appraisal.

d) Identify where further specialist assessment is required and request and/or interpret diagnostic tests.

e) Appraise information obtained, taking account of potential associated conditions, for example, limited vision, epilepsy; physical disabilities; and mental health problems.

f) Develop a differential diagnosis or functional assessment, recognising key biases and common errors (including diagnostic overshadowing) and the issues relating to diagnosis in the face of ambiguity and incomplete data.

g) Effectively communicate highly sensitive information and plan for post-diagnostic follow up, recognising the needs of families and carers providing care and support for a person with a learning disability and/or autism.

Key guidance

Sources of further guidance and references to key legislation are shown in the appendices.

Indicative mapping to relevant national standards or frameworks

Core Capabilities Frameworks at:
www.skillsforhealth.org.uk/learningdisabilityandautismframeworks

- Core Capabilities Framework for supporting people with a learning disability: Capability 2. Identification and assessment of learning disabilities

- Core Capabilities Framework for supporting autistic people: Capability 2. Identification, assessment and diagnosis of autism

Capability 2: Leading inclusive communication approaches

Core

The practitioner will:

a) Demonstrate a critical understanding of inclusive communication approaches and act on professional judgement in applying the most appropriate approaches according to the different needs, abilities and preferences of people with a learning disability and/or autism and their carers.

b) Act on professional judgement about when and how to seek help with communication, demonstrating critical reflection on own practice.

c) Appraise the connection between behaviours that challenge, and the communication needs of people with a learning disability and/or autism.

d) Understand the importance of teaching and supporting alternative behaviour matched to the functional needs of behaviours that challenge.

e) Pro-actively advocate for adoption of the Accessible Information Standard for health and social care organisations including requirements for policy, procedures, human behaviour and where applicable, electronic systems.

f) Communicate effectively with families, carers and colleagues using a variety of media (e.g. verbal, written and digital) whilst keeping the service user at the centre of care.

g) Communicate with families, carers and colleagues in ways that build and sustain relationships, seeking, gathering and sharing information appropriately, efficiently and effectively to expedite and integrate people's care.

h) Facilitate and support the effective communication of highly sensitive information and utilise appropriate communication approaches to support shared decision making.

i) Advocate for practices to reduce health inequalities, risks and diagnostic overshadowing and improve both physical and mental health through enabling reasonable adjustments.

j) Role model co-production and use clinical expertise to meaningfully involve a diverse range of people with a learning disability and/or autism to have a voice in service design and delivery in accordance with national agendas and policies.

Profession[3] and role specific

The specialist practitioner will:

a) Conduct a range of comprehensive speech, language and communication assessments using both formal and informal methodologies, including with people who have complex needs.

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[3] For example, Speech and Language Therapist.

b) Use expert clinical reasoning skills to analyse communication assessment findings, appraising complex, incomplete, ambiguous and conflicting information, distilling and synthesising key factors, and identifying those elements that may need to be pursued further.

c) Diagnose and use professional judgement to formulate a personalised communication plan that considers the persons wider social determinants.

d) Create learning and development opportunities across the community in a comprehensive range of inclusive communication approaches (e.g. Makaton, Talking Mats™, Picture Exchange Communication System, Intensive Interaction etc).

e) Work in partnership with people with a learning disability and/or autism and their carers to develop a functional communication system that maximises the individual's communicative capabilities.

f) Support others in the multi-disciplinary team to build inclusive communication capacity and capability through work-based and interprofessional learning, and the application of communication approaches in practice, providing safe professional practice.

g) Develop and promote practice which is embedded in psychologically minded practice i.e. staff are supported to be interested and recognise their own feelings in relation to the people they work with and how they communicate with them.

h) Facilitate a culture of co-production and involve people with complex communication needs, to have a voice in national agendas and policies.

Key guidance

Sources of further guidance and references to key legislation are shown in the appendices. Examples of national guidance with specific relevance to this capability are shown below:

- Accessible Information Standard - NHS England (2017)
- 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)
- Generic Service Interventions Pathway: A competency framework to support development of the learning disability workforce, Health Education England (2015)
- Career & Development Framework for Learning Disability Nursing in Scotland, March 2013

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
- Core Capabilities Framework for supporting people with a learning disability: Capability 13. Communication
- Core Capabilities Framework for supporting autistic people: Capability 4. Communication and interaction

Capability 3: Leading personalised care and support

The practitioner will:

a) Synthesise the theory and principles that underpin personalised care and support for people with a learning disability and/or autism, including principles of shared decision making, behaviour change and activation, and apply those principles in their practice[4].

b) Understand and appraise historical and current understanding of learning disability including bio-social-psychological theories and approaches.

c) Critically evaluate the role of positive risk taking and duty of care in enabling personalised care and support.

d) Lead the development and implementation of systems for goal-based, personalised outcome planning, implementing plans, and monitoring their impact.

e) Proactively initiate person-centred thinking, planning and co-production in the management and development of services, enabling people to maximise empowerment within the limits of their capability in complex systems with changing support.

f) Enable healthy psychological environments for people with a learning disability and/or autism by giving support and advice to carers and families.

g) Explore and appraise the impact that caring for a person with a learning disability and/or autism in the family may have on relationships and family members' own wellbeing (including any psychological impact).

h) Evaluate how family and carer relationships and support needs may change over the life course and during periods of transition and work with the person and others to identify positive and negative aspects of a change.

i) Understand, implement and educate others regarding legislation relevant to families' and carers' rights and act as a source of further information for families and carers around legal issues (e.g. lasting power of attorney, mental capacity and liberty protection safeguards).

j) Utilise and support the implementation of relevant legislation and guidance for consent and shared decision-making (e.g. mental capacity legislation and NICE guidance).

Key guidance

Sources of further guidance and references to key legislation are shown in the appendices. Examples of national guidance with specific relevance to this capability are shown below:

- Generic Service Interventions Pathway: A competency framework to support development of the learning disability workforce, Health Education England (2015)
- Accessible Information Standard - NHS England (2017)

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[4] See Health Education England & Skills for Health (2017), Person-Centred Approaches: http://www.skillsforhealth.org.uk/services/item/575-person-centred-approaches-cstf-download

- 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
- Department of Health and Social Care and Department for Education (2014): SEND Code of Practice: 0-25 years
- NICE guideline - Carers: provision of support for adult carers (expected publication January 2020)

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
- Core Capabilities Framework for supporting people with a learning disability: Capability 14. Empowerment and person-centred care
- Core Capabilities Framework for supporting autistic people: Capability 3. Person-centred care and support

Introduction

People (children, young people and adults) with a learning disability and/or autism 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 and/or autism. There is clear evidence that people with a learning disability experience poorer access to healthcare and worse health outcomes. One of the starkest inequalities is that people with a learning disability experience very high rates of premature mortality. Most 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.

Advanced clinical practitioners support and encourage people to optimise their physical and mental health. They promote and implement reasonable adjustments to enable the health needs of people with a learning disability and/or autism to be met. They focus on how they can have a positive impact on physical and mental health, advise on interventions and therapies, and formulate and enable the development and implementation of management plans. They also have skills and knowledge in devising supports relating to behaviours that services may experience as challenging.

Advanced clinical practitioners demonstrate safe, effective, autonomous and reflective practice, informed by available evidence and established best practice. They work effectively as part of a team, either as a leader or as a team member, contributing to multi-disciplinary team-working to optimise the quality of service and outcomes. They will support and encourage shared decision-making e.g. working together with people, family and carers to agree approaches to health care and support based upon needs and informed preferences.

Capability in physical and mental health is needed by all advanced clinical practitioners as a minimum. In addition, the practitioner may have a greater level of capability related to some interventions depending on their professional scope of practice – these are the 'role specific' capabilities within this domain.

Capability 4: Health equality and reasonable adjustments

The practitioner will:

a) Recognise the biological, psychological and social impact of common health conditions and lead an appropriate response, including for:

    i.   life limiting conditions

    ii.   long term conditions

    iii.   sensory impairment.

b) Demonstrate an advanced knowledge of conditions which affect mortality, and which cause premature death within the context of a changing demography.

c) Recognise health conditions which are more likely to be experienced by people with Profound and Multiple Learning Disabilities (PMLD) and the implications in terms of on-going health checks, person-centred planning and supporting the capabilities of carers to monitor health and wellbeing needs on a day-to-day basis.

d) Recognise the signs, symptoms, prevalence and potential impact on the lives of people with a learning disability and/or autism of mental health conditions including (but not limited to):

    i.   psychoses

    ii.   neuroses and stress related disorders

    iii.   anxiety

    iv.   personality disorders

    v.   other developmental conditions such as ADHD

    vi.   mood disorders (including suicidality)

    vii.   substance misuse

    viii.   dementia and confusional states

    ix.   eating disorders

    x.   sexual and gender identity disorders.

e) Conduct a comprehensive assessment with the ability to recognise when there is a need to make a referral to specialist psychological services such as psychiatry, psychology or arts psychotherapies for complex mental health issues, or a need to make a referral to a therapeutic community group.

f) Understand the importance of activity (e.g. daily living skills, education, paid and unpaid work, leisure) which has meaning and purpose to the individual and may provide social engagement as a 'protective factor' in order to maintain positive mental health.

g) Demonstrate an advanced knowledge of how the environment impacts upon the person's physical, psychological and social wellbeing including home, housing and community.

h) Support and facilitate people with learning disabilities and/or autism to access opportunities for appropriate meaningful activities including social prescribing where appropriate.

i) Ensure that others e.g. family members, care/support staff, other members of the multidisciplinary team and those in mainstream health and social care services, recognise the

value and importance of therapeutic activities and positive risk taking and that this is reflected in people's care plans.

j) Use advanced clinical skills to be responsive to and work in partnership with people with a learning disability and/or autism and others (including family members, other members of the multidisciplinary team and those in mainstream health, education and social care services) to maximise the outcomes of interventions.

k) Analyse why mental health conditions may be overlooked in people with a learning disability and/or autism e.g. due to complex or atypical presentations and/or diagnostic overshadowing.

l) Implement current guidelines and principles aimed at stopping the over-medication of people with a learning disability and/or autism.

m) Advocate for reasonable adjustments and processes to support people with a learning disability (including those with PMLD) and/or autism to access healthcare services.

n) Promote and apply the Accessible Information Standard for health and social care organisations including requirements for policy, procedures, human behaviour and where applicable, electronic systems.

o) Influence commissioning and lead care across organisations and pathways.

p) Critically appraise the outcome of relevant research and use current evidence to underpin own practice and to inform that of others.

Key guidance

Sources of further guidance and references to key legislation are shown in the appendices. Examples of national guidance with specific relevance to this capability are shown below:

- 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)
- Social prescribing: applying All Our Health, Public Health England (2019)
- All Our Health: personalised care and population health, Public Health England (2019)
- Making Every Contact Count (Health Education England)
- Learning Disabilities Mortality Review (LeDeR) Programme, University of Bristol (2017)
- 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)
- The Health Equality Framework and Commissioning Guide
- NICE Guidance: Mental health problems in people with learning disabilities: prevention, assessment and management [NG54] (2016)
- 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)

- Standards of Proficiency: Arts Therapists, Health & Care Professions Council (2013)

- Professional Standards for Occupational Therapy Practice, Royal College of Occupational Therapists (2018)

- Occupational therapy and people with learning disabilities: Findings from a research study, Royal College of Occupational Therapists (2010)

- Standards of Proficiency: Occupational Therapists, Health & Care Professions Council (2013)

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

- Core Capabilities Framework for supporting people with a learning disability: Capability 8. Health equality and reasonable adjustments

- Core Capabilities Framework for supporting autistic people: Capability 14. Health equality and reasonable adjustments

- Dementia Training Standards Framework

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Capability 5: Nutrition and hydration

Core

The practitioner will:

a) Support and advocate for a balance between a nutritionally balanced diet and providing the opportunity for people with a learning disability and/or autism to enjoy safely the food and drink of their choice.

b) Evaluate how to improve the provision of nutrition and hydration through monitoring food and drink intake using appropriate tools and the evaluating factors that influence a positive mealtime experience.

c) Monitor for other health conditions which may result from poor nutrition and hydration (e.g. skin integrity, diabetes).

d) Involve a person's family and/or care staff where there may be conflict or differences of opinion if the person lacks capacity to work with professionals to develop their own management approaches.

e) Recognise that adults with a learning disability are a high-risk group for deaths from respiratory problems and ensure robust care planning to avoid these risks.

f) Recognise that people with a learning disability and/or autism are at higher risk of malnutrition, being obese, including developing morbid obesity at an earlier age, being constipated and of dysphagia and gastrointestinal disorders – and co-morbidities associated with these conditions. Proactively manage these risks and provide interventions to prevent avoidable deterioration.

g) Be aware of the risk of re-feeding syndrome in people who are severely underweight and who have had a period of acute starvation and identify appropriate referrals to promote safe re-feeding.

h) Refer people with dysphagia to specialised multi-disciplinary assessment to ensure their needs are fully addressed in a timely manner.

i) Screen for the risk of choking and dysphagia and promote approaches to reduce the risks of choking, ensuring appropriate referral to a dysphagia trained practitioner.

j) Understand the importance of good oral hygiene, including the impact of gum disease, mouth ulcers, broken teeth, tooth decay, a dental abscess and missing teeth on eating, drinking and respiratory health and wellbeing.

Profession[5] and role specific

As part of the multi-professional team, the specialist practitioner may:

a) Recognise the main clinical causes of dysphagia and actively identify groups of people with a learning disability and/or autism who are at a particularly high risk for dysphagia including those with neuromuscular degenerative disorders.

b) Develop a person-centred nutritional care plan together with people with a learning disability and/or autism, that considers environmental factors and is based on an assessment of the person's capacity and any support needed; 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.   the best environment in which to eat and drink
    vii.   nutrient drug interactions
    viii.   fluid intake
    ix.   food fortification
    x.   menu planning and shopping.

c) Work collaboratively with psychologists and sensory specialists to manage disordered or restricted eating behaviours in adults with autism.

d) Evaluate the risk of re-feeding syndrome in people who are severely underweight and who have had a period of acute starvation.

e) Conduct detailed and accurate assessment of dysphagia, which may be observational or instrumental, such as Video Fluroscopic Swallow Study (VFSS) or Fibreoptic Endoscopic Evaluation of Swallowing (FEES).

f) Understand swallow mechanisms and prescribe exercises or techniques that may help people eat and drink more successfully.

g) Critically evaluate how other health conditions have been associated with dysphagia e.g. under-nutrition, weight loss, urinary tract infections, headaches, constipation, oesophagitis and reduced ability to fight infections.

h) Recognise when dysphagia is severe and evaluate other methods of getting adequate nutrition and hydration, such as enteral feeding.

i) Evaluate decisions regarding methods of getting adequate nutrition and hydration with the person themselves and if possible, their family, care team, core professionals, the GP, and specialist professionals.

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[5] For example, dietitian, dysphagia trained nurse, occupational therapist, physiotherapist, speech and language therapist.

j) Develop a personalised care plan for people with a learning disability and/or autism and dysphagia to ensure their needs are fully addressed in a timely manner.

k) Support others in the learning disability and/or autism workforce to recognise causes of dysphagia and those at risk of dysphagia through work-based and interprofessional learning, and the application of agreed standards (within scope of practice) to ensure safety and competency in the workforce.

Key guidance

Sources of further guidance and references to key legislation are shown in the appendices. Examples of national guidance with specific relevance to this capability are shown below:

- British Dietetic Association (2017), The Nutritional Care of Adults with a Learning Disability in Care Settings
- British Dietetic Association Food Fact Sheets
- International Dysphagia Diet Standardisation Initiative (IDDSI)
- The Eatwell Guide - NHS
- Dysphagia and people with learning disabilities, Public Health England (2016)
- Hampshire multi-agency choking review

Indicative mapping to relevant national standards or frameworks

Core Capabilities Frameworks at:
www.skillsforhealth.org.uk/learningdisabilityandautismframeworks

- Core Capabilities Framework for supporting people with a learning disability: Capability 9. Nutrition, hydration and dysphagia

National Occupational Standards

CHS92 Review and monitors a patient's nutritional wellbeing

CHS146 Monitor individual's progress in relation to managing their body weight and nutrition

CHS148 Provide information and advice to individuals on eating to maintain optimum nutritional status

CHS149 Monitor and review individuals progress in relation to maintaining optimum nutritional status

CHS159 Provide support to individuals to develop their skills in managing dysphagia

CHS160 Assist others to monitor individuals' attempts at managing dysphagia

DYS1 Undertake protocol-guided swallow screening / Assessments

DYS2 Undertake a comprehensive dysphagia assessment

DYS3 Undertake a specialist dysphagia assessment

DYS4 Develop a dysphagia care plan.

Capability 6: Positive behaviour support

The practitioner will:

a) Develop inclusive, co-produced, multi-element positive behaviour support plans with people, their families and carers, and the appropriate members of the multi-disciplinary team.

b) Actively support and co-produce strategies to enable appropriate and person-centred functional risk assessment.

c) Synthesise appropriate evidence to formulate a comprehensive functional assessment of needs related to behaviours described as challenging.

d) Construct evidenced based functionally equivalent support strategies to meet individual needs.

e) Develop multi-element constructionally based individualised interventions to support pro social skills development.

f) Devise comprehensive positive behaviour support based interventions and strategies that enable safe evidence-based least restrictive reactive strategies where required.

g) Advocate and teach support skills that will facilitate person centred positive behaviour support plans.

h) Provide clinical support and supervision to colleagues and families to identify and ameliorate mediator issues.

i) Provide comprehensive monitoring and evaluation of positive behaviour support (PBS) plans to support quality of life measures.

j) Be cognisant of appropriate individualised positive risk-taking strategies and implications.

NB. Recognise the inter-relation of other capabilities within this framework associated with the communicative function of behaviour e.g. inclusive communication and sensory integration.

Key guidance

Sources of further guidance and references to key legislation are shown in the appendices. Examples of national guidance with specific relevance to this capability are shown below:

- [Reducing Restrictive Intervention of Children and Young People (The Challenging Behaviour Foundation, 2019)](#)
- [Restrictive interventions in in-patient intellectual disability services: How to record, monitor and regulate (RC Psych, 2018)](#)
- [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)](#)
- [BILD, Restraint Reduction Network](#)

Indicative mapping to relevant national standards or frameworks

Core Capabilities Frameworks at:
www.skillsforhealth.org.uk/learningdisabilityandautismframeworks

- Core Capabilities Framework for supporting people with a learning disability: Capability 7. Supporting people at risk of behaviours that challenge

- Core Capabilities Framework for supporting autistic people: Capability 8. Supporting autistic people where behaviour may challenge

Capability 7: Palliative and end of life care

The practitioner will:

a) Proactively work with people with a learning disability and/or autism and their families and carers, and others, to develop a person-centred end of life care plan that balances treatment with care and support needs and preferences.

b) Demonstrate a comprehensive understanding of the processes involved in deciding when a person with a learning disability and/or autism is deemed to be at end of life and the actions needed.

c) 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.

d) Use specialist knowledge and skills and educate others to identify acute onset illness and deterioration in people with learning disabilities and develop care plans to support access to health services.

e) Synthesise guidance, risks and benefits, and ethical considerations associated with individual's food and drink related needs, including that related to clinically assisted nutrition and hydration.

f) Understand referral criteria and initiate processes for referral to specialist services to meet the needs of people with a learning disability and/or autism and those important to them.

g) Critically evaluate ways to overcome potential barriers people with a learning disability and/or autism may face in accessing end of life care.

h) Advocate for reviews of death of people with a learning disability and know which organisations should be contacted following the death of a person with a learning disability.

i) Contribute to the development of practices and services that meet the end of life needs of people with a learning disability and/or autism ensuring that all agencies are committed to providing urgent and timely interventions which can save lives.

Key guidance

Sources of further guidance and references to key legislation are shown in the appendices. Examples of national guidance with specific relevance to this capability are shown below:

- [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)](#)
- [Learning Disabilities Mortality Review (LeDeR) Programme, University of Bristol (2017)](#)
- [Delivering high quality end of life care for people with learning disabilities, NHSE (2017)](#)

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
- Core Capabilities Framework for supporting people with a learning disability: Capability 12: End of life care

Capability 8: Sensory processing

Profession[6] and role specific

The specialist practitioner will:

a) Understand the implications of sensory impairments on the lives of people with a learning disability and/or autism including those with PMLD.

b) Synthesise and appraise the neuroscience and evidence base underpinning theories relating to the processing and integration of sensory stimuli which impact on the lives of people with a learning disability and/or autism.

c) Assess, and evidence the need for interventions for development of sensory integration.

d) Select and plan interventions for development of sensory integration, including selection of appropriate outcome measures.

Key guidance

Sources of further guidance and references to key legislation are shown in the appendices.

Indicative mapping to relevant national standards or frameworks

Core Capabilities Frameworks at:
www.skillsforhealth.org.uk/learningdisabilityandautismframeworks

- Core Capabilities Framework for supporting autistic people: Capability 5. Sensory processing and the environment

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[6] For example, occupational therapist, speech and language therapist.

Capability 9: Movement and posture

Profession[7] and role specific

The specialist practitioner will:

a) Understand the impact of poor posture on a person's health and the impact of interventions to reduce poor posture and be able to conduct a comprehensive assessment of positioning and posture.

b) Demonstrate and implement creative solutions to meet the postural needs of people with complex presentations e.g. for people with profound learning disabilities who are unable to change their own body position.

c) Appraise how people with a learning disability and/or autism and their family and carers are involved with assessment, selection and issue of equipment and review to ensure equipment and guidelines are acceptable and 'fit' with family life.

d) Critically evaluate how any prescribed postural-care equipment improves quality of life.

Key guidance

Sources of further guidance and references to key legislation are shown in the appendices. Examples of national guidance with specific relevance to this capability are shown below:

[Postural Care and people with learning disabilities guidance, Public Health England (2018)](#)

Indicative mapping to relevant national standards or frameworks

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

- Core Capabilities Framework for supporting people with a learning disability: Capability 11. Supporting people with Profound and Multiple Learning Disabilities (PMLD)

- Frailty: A Framework of Core Capabilities

National Occupational Standards

CHS135 Implement programmes and treatments with individuals who have restricted movement / mobility

CHS136 Assist in the implementation of programmes and treatments with individuals who have severely restricted movement / mobility

CHS137 Implement mobility and movement programmes for individuals to restore optimum movement

CHS138 Assist in the implementation of mobility and movement programmes for individuals to restore optimum movement and functional independence.

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[7] For example, physiotherapist.

Capability 10: Epilepsy

Profession[8] and role specific

The specialist practitioner will:

a) Synthesise current national guidelines in relation to assessment and treatment of epilepsy.

b) Demonstrate a comprehensive understanding of the classification of seizures and be able to differentiate, through appropriate use of history taking and assessment tools, the type of seizure, syndrome and non-seizure activity.

c) Synthesise data to create a formulation for a person with a learning disability and/or autism and epilepsy and devise appropriate person-centred care and support plans.

d) Evaluate the complexity and comorbidity of epilepsy in people with a learning disability and/or autism in order to more effectively manage the person's condition to improve their quality of life and support them to reduce health inequalities.

e) Proactively assess and manage risk related to epilepsy in people with a learning disability and/or autism.

f) Initiate, monitor and evaluate epilepsy treatment, including knowing the specific idiosyncratic effects in people with a learning disability and/or autism and the need to take into account potential comorbidities such as dysphagia.

g) Proactively develop and disseminate health promotion advice to people with a learning disability and/or autism, their families and carers in relation to epilepsy in accordance with contemporary legislation and guidelines.

Key guidance

Sources of further guidance and references to key legislation are shown in the appendices. Examples of national guidance with specific relevance to this capability are shown below:

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

Indicative mapping to relevant national standards or frameworks

Core Capabilities Frameworks at:
www.skillsforhealth.org.uk/learningdisabilityandautismframeworks

- Core Capabilities Framework for supporting people with a learning disability: Capability 10. Epilepsy

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[8] For example, specialist learning disability nurse.

Domain C. Personalised care and support

Introduction

People (children, young people and adults) with a learning disability and/or autism 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 includes the right to develop friendships and relationships, including sexual relationships.

Advanced clinical practitioners support people with a learning disability and/or autism to have the same choice and control in their lives as other people – recognising that their needs and abilities may change over time.

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 activity. It is important for people with a learning disability and/or autism to be active in daily life as it affects health, wellbeing and quality of life.

Capability 11: Wellbeing and independence

The practitioner will:

a) Advocate for personalisation in care and support for people with a learning disability and/or autism.

b) Actively assist people with a learning disability and/or autism to develop support plans to meet their identified needs, interests and right to make choices - and to enable them to realise and implement these plans. This may include support to:

   i. maintain and develop skills for everyday life

   ii. access services and facilities including housing, transport, community and leisure services

   iii. access education, training and employment.

c) Evaluate the value of a broad range of assistive living technologies (new and emerging) in developing a support plan for people with a learning disability and/or autism.

d) Synthesise the theories and principles that underpin outcome-based practice for people with a learning disability and/or autism.

e) Promote and contribute to the development of practices and services that meet the individual needs of people with a learning disability and/or autism.

Key guidance

Sources of further guidance and references to key legislation are shown in the appendices. Examples of national guidance with specific relevance to this capability are shown below:

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

Indicative mapping to relevant national standards or frameworks

Core Capabilities Frameworks at:
www.skillsforhealth.org.uk/learningdisabilityandautismframeworks

- Core Capabilities Framework for supporting people with a learning disability: Capability 16. Wellbeing and independence

- Core Capabilities Framework for supporting autistic people: Capability 11. Meaningful activity and independence

Capability 12: Relationships, sexuality and sexual health

The practitioner will:

a) Evaluate factors that can influence the process of a relationship and work with people with a learning disability and/or autism to review and evaluate the support they need to maintain and develop relationships.

b) Appraise the relevance of relationship theories to learning disability care and support.

c) Appraise the impact of relationships and social networks on wellbeing and self-esteem and actively promote and support people with a learning disability or autism participating in their local community or social network.

d) Identify and evaluate issues of sexual expression and sexual health for people with a learning disability and/or autism and how these can be supported.

e) Evaluate the impact of social and family contextual factors on the sexual and sexual health needs of people with a learning disability and/or autism.

f) Synthesise relevant legislation influencing the support of sexuality and sexual health for people with a learning disability and/or autism.

g) Appraise the potential for people with a learning disability and/or autism to be at risk of entering the criminal justice system due to perceived inappropriate sexual behaviour.

Key guidance

Sources of further guidance and references to key legislation are shown in the appendices. Examples of national guidance with specific relevance to this capability are shown below:

- 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

Indicative mapping to relevant national standards or frameworks

Core Capabilities Frameworks at:
www.skillsforhealth.org.uk/learningdisabilityandautismframeworks

- Core Capabilities Framework for supporting people with a learning disability: Capability 17. Relationships, sexuality and sexual health
- Core Capabilities Framework for supporting autistic people: Capability 10. Relationships, sexuality and sexual health

Capability 13: Navigation through life stages

The practitioner will:

a) Appraise types of change that may occur in the life stages of a person with a learning disability and/or autism and how their needs and abilities may change over time.

b) Analyse factors that may make change a positive or a negative experience and approaches likely to enhance a person's capacity to manage change and experience change positively.

c) Support people to express preferences and anxieties when going through change and adapt support methods to take account of preferences or anxieties.

d) Recognise and promote the value of early intervention on the lives of children and young people with a learning disability and/or autism and their families and lead a coordinated approach across a range of services e.g. health, education and social services.

e) Be able to support a young person with a learning disability and/or autism and their family and carers to reflect on the transition into adulthood.

f) Evaluate the impact of age-related changes on older people with a learning disability, including dementia, frailty and falls and how they affect people with a learning disability and/or autism.

g) Evaluate the support provided during a period of change, working with the person and others to identify positive and negative aspects of a change and to seek additional expertise and advice if required.

h) Provide accessible information, advice and support which is tailored to an individual's communication needs.

Key guidance

Sources of further guidance and references to key legislation are shown in the appendices. Examples of national guidance with specific relevance to this capability are shown below:

- Generic Service Interventions Pathway: A competency framework to support development of the learning disability workforce, Health Education England (2015)
- Health Education England, Learning Disabilities Transition Pathway Competency Framework.
- Working together to safeguard children: A guide to inter-agency working to safeguard and promote the welfare of children (HM Government, July 2018)
- NICE Guideline (2018), Care and support of people growing older with learning disabilities
- Public Health England (2017), 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

Indicative mapping to relevant national standards or frameworks

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

- Core Capabilities Framework for supporting people with a learning disability:
  - o Capability 18. Supporting children and young people with a learning disability
  - o Capability 19. Preparing young people with a learning disability for adulthood
  - o Capability 20. Supporting older people with a learning disability
- Core Capabilities Framework for supporting autistic people: Capability 7. Supporting changes throughout life
- Frailty: A Framework of Core Capabilities

Domain D. Risk, legislation and safeguarding

Introduction

Advanced clinical practitioners in learning disability and autism are fully aware of their duty of care, particularly where they may be required to make decisions in situations where people are unable to make decisions for themselves. This is likely to include ethical issues such as the need to balance a person's safety with their right to independence, a positive, person-centred approach to risk and deciding the best interests for the person (e.g. when making decisions about consent to treatment). It is also recognising that a person's needs and preferences may sometimes conflict with the needs of others, especially their families and carers.

People with a learning disability and/or autism 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) and Transforming care: A national response to Winterbourne View Hospital (2012). These cases serve to highlight the vital importance of raising concerns and acting on them before it is too late.

Learning disabilities and autism affect people from all cultural and ethnic backgrounds. Issues of cultural and ethnic diversity may have an impact on how people experience a learning disability and/or autism, 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 and/or autism, including but not limited to a person's sexuality, gender or geographical location.

Capability 14: Law, ethics and safeguarding

The practitioner will:

a) Appraise the legislation, regulations and policies that underpin the protection of people with a learning disability and/or autism including key legislation relevant to mental capacity, deprivation of liberty, equality and human rights.

b) Analyse implications for practice of key legal and ethical issues, including how different areas of legislation may interact and impact.

c) Evaluate the options available when informed consent may be compromised.

d) Lead service provision that protects people with a learning disability and/or autism at risk of harm or abuse including the monitoring and evaluation systems, processes and practice.

e) Demonstrate a comprehensive understanding of the roles and responsibilities of the different agencies involved in investigating allegations of harm or abuse.

f) Manage inter-agency, joint or integrated working in order to protect people with a learning disability and/or autism at risk of harm or abuse including the appropriate sharing of safeguarding information with the relevant agencies.

g) Critically evaluate the role of self and others when supporting people with a learning disability and/or autism who have experienced harm or abuse.

h) Actively challenge others who are not behaving in an ethical way.

Key guidance

Sources of further guidance and references to key legislation are shown in the appendices. Examples of national guidance with specific relevance to this capability are shown below:

- [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)](#)

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:
  - Subject 8: Safeguarding Adults
  - Subject 9: Safeguarding Children
- Core Capabilities Framework for supporting people with a learning disability: Capability 21. Law, ethics and safeguarding
- Core Capabilities Framework for supporting autistic people: Capability 15. Law, ethics and safeguarding

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Capability 15: Equality, diversity and inclusion

The practitioner will:

a) Understand the prevalence of learning disabilities and autism and the importance of equal access to learning disabilities and/or autism assessment for people from diverse communities.

b) Appraise the legislation, regulations and policies that underpin equality, diversity and human rights.

c) Analyse the impact that discrimination, stigma and unconscious bias may have on the life of a person with a learning disability and/or autism, their family and carers, including those for whom a number of protected characteristics may be applicable.

d) Lead practice and an organisational culture that values and respects equality, inclusion and the diversity of people with a learning disability and/or autism.

e) Develop, promote and co-produce systems and processes that promote diversity, equality and inclusion.

f) Recognise when own or others' behaviour undermines equality, diversity and human rights and take rectifying action.

Key guidance

Sources of further guidance and references to key legislation are shown in the appendices. Examples of national guidance with specific relevance to this capability are shown below:

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

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: Subject 1. Equality, Diversity and Human Rights

- Core Capabilities Framework for supporting people with a learning disability: Capability 22. Equality, diversity and inclusion

- Core Capabilities Framework for supporting autistic people: Capability 16. Equality, diversity and inclusion

Capability 16: Positive risk taking

The practitioner will:

a) Appraise ways in which risk is an integral part of everyday life.

b) Evaluate the links between risk-taking and responsibility, empowerment and social inclusion considering the needs and abilities of people with a learning disability and/or autism.

c) Promote the importance of a positive, person-centred approach to risk assessment and how to apply the principles and methods of a person-centred approach to the process of risk assessment.

d) Evaluate how a service focused approach to risk assessment would differ from a person-centred approach.

e) Synthesise and explain the legal and policy framework underpinning an individual's right to make decisions and take risks.

f) Ensure that people with a learning disability and/or autism are facilitated to balance their choices with their own and others' health, safety and wellbeing in light of mental capacity.

g) Demonstrate a critical self-awareness of how one's values, belief systems and experiences may affect working practice when supporting people to take risks.

Key guidance

Sources of further guidance and references to key legislation are shown in the appendices.

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

Domain E. Leadership and management, education and research

Introduction

All health and care professionals working at the level of advanced clinical practice should have developed their skills and knowledge to the standard outlined in the Multi-Professional Framework for Advanced Clinical Practice Framework (HEE, 2017); the capabilities are common across this level of practice enabling standardisation.

The four pillars that underpin this practice are:

1. Clinical Practice

2. Leadership and Management

3. Education

4. Research

The knowledge, skills and behaviours specific to **advanced clinical practice for learning disabilities and autism** are articulated in Domains A to D of this framework.

The capabilities for Leadership and Management, Education and Research, which apply to all models of advanced clinical practice across sectors, specialties and professions are presented in this domain.

The Multi-Professional Framework for Advanced Clinical Practice Framework in England (2017)[9] builds upon the Framework for Advanced Nursing, Midwifery and Allied Health Professional Practice in Wales (2010)[10] and Supporting the Development of Advanced Nursing Practice (Scottish Government 2008, reviewed 2013)[11].

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[9] https://www.hee.nhs.uk/sites/default/files/documents/Multi-professional%20framework%20for%20advanced%20clinical%20practice%20in%20England.pdf

[10] https://www.wales.nhs.uk/sitesplus/documents/829/NLIAH%20Advanced%20Practice%20Framework.pdf

[11] http://www.advancedpractice.scot.nhs.uk/media/1371/supporting%20the%20development%20of%20advanced%20nursing%20practice.pdf

Capability 17: Leadership and management

Advanced Clinical Practice Pillar 2 (common capabilities)

The practitioner will:

a) Pro-actively initiate and develop effective relationships, fostering clarity of roles within teams, to encourage productive working.

b) Role model the values of their organisation/place of work, demonstrating a person-centred approach to service delivery and development.

c) Evaluate own practice, and participate in multi-disciplinary service and team evaluation, demonstrating the impact of advanced clinical practice on service function and effectiveness, and quality (i.e. outcomes of care, experience and safety).

d) Actively engage in peer review to inform own and other's practice, formulating and implementing strategies to act on learning and make improvements.

e) Lead new practice and service redesign solutions in response to feedback, evaluation and need, working across boundaries and broadening sphere of influence.

f) Actively seek feedback and involvement from individuals, families, carers, communities and colleagues in the co-production of service improvements.

g) Critically apply advanced clinical expertise in appropriate faciliatory ways to provide consultancy across professional and service boundaries, influencing clinical practice to enhance quality, reduce unwarranted variation and promote the sharing and adoption of best practice.

h) Demonstrate team leadership, resilience and determination, managing situations that are unfamiliar, complex or unpredictable and seeking to build confidence in others.

i) Continually develop practice in response to changing population health need, engaging in horizon scanning for future developments (e.g. impacts of genomics, new treatments and changing social challenges).

j) Demonstrate receptiveness to challenge and preparedness to constructively challenge others, escalating concerns that affect individuals, families, carers, communities and colleagues' safety and well-being when necessary.

k) Negotiate an individual scope of practice within legal, ethical, professional and organisational policies, governance and procedures, with a focus on managing risk and upholding safety.

Enhanced capabilities in learning disabilities and autism

The practitioner will:

l) Evaluate key drivers and policies which influence national learning disability and/or autism strategy and service development and analyse how these can be used to improve service delivery.

m) Advocate for the rights of people with a learning disability and/or autism and for reasonable adjustments to meet their needs in the planning and development of services.

n) Promote a culture where needs and risks are balanced with health and safety practice in learning disability and/or autism care and support.

o) Collate and share data across organisations in compliance with local protocols, legal and professional requirements.

p) Develop relationships with service commissioners to develop the capacity and capability for an integrated care system.

Key guidance

Sources of further guidance and references to key legislation are shown in the appendices. Examples of national guidance with specific relevance to this capability are shown below:

- [The Leadership Qualities Framework For Adult Social Care (NSA)](#)
- [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

Core Capabilities Frameworks at:
www.skillsforhealth.org.uk/learningdisabilityandautismframeworks

- Core Capabilities Framework for supporting people with a learning disability: Capability 23. Leadership and management

- Core Capabilities Framework for supporting autistic people: Capability 17. Leadership and management

Capability 18: Education and personal development

Advanced Clinical Practice Pillar 3 (common capabilities)

The practitioner will:

a) Critically assess and address own learning needs, negotiating a personal development plan that reflects the breadth of ongoing professional development across the four pillars of advanced clinical practice.

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) Engage with, appraise and respond to people's motivation, development stage and capacity, working collaboratively to support health literacy and empower people to participate in decisions about their care and to maximise their health and well-being.

d) Advocate for and contribute to a culture of organisational learning to inspire future and existing staff.

e) Facilitate collaboration of the wider team and support peer review processes to identify individual and team learning.

f) Identify further developmental needs for the individual and the wider team and supporting them to address these.

g) Support the wider team to build capacity and capability through work-based and interprofessional learning, and the application of learning to practice.

h) Act as a role model, educator, supervisor, coach and mentor, seeking to instil and develop the confidence of others.

Enhanced capabilities in learning disabilities and autism

The practitioner will:

i) Promote the roles and professions who work with people with a learning disability to build the future workforce.

j) Support and enable the development of others, including students, parents and carers.

k) Facilitate the coproduction (design and delivery) of education and training, working in partnership with people with a learning disability and/or autism.

l) Evaluate the effectiveness of teaching and learning interventions[12].

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[12] See Appendix 4: Suggested standards for training delivery

Key guidance

Sources of further guidance and references to key legislation are shown in the appendices.

Indicative mapping to relevant national standards or frameworks

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

- Pillar 3. Education

Core Capabilities Frameworks at:
www.skillsforhealth.org.uk/learningdisabilityandautismframeworks

- Core Capabilities Framework for supporting people with a learning disability: Capability 24. Education and personal development
- Core Capabilities Framework for supporting autistic people: Capability 18. Education and personal development

Capability 19: Research, audit and evaluation

Advanced Clinical Practice Pillar 4 (common capabilities)

The practitioner will:

a) Critically engage in research activity, adhering to good, ethical research practice guidance, so that evidence-based strategies are developed and applied to enhance quality, safety, productivity and value for money.

b) Evaluate and audit own and others' clinical practice, selecting and applying valid, reliable methods, then acting on the findings.

c) Critically appraise and synthesise the outcome of relevant research, evaluation and audit, using the results to underpin own practice and to inform that of others.

d) Take a critical approach to identify gaps in the evidence base and its application to practice, alerting appropriate individuals and organisations to these and how they might be addressed in a safe and pragmatic way.

e) Actively identify potential need for further research to strengthen evidence for best practice. This may involve acting as an educator, leader, innovator and contributor to research activity and/or seeking out and applying for research funding.

f) Develop and implement robust governance systems and systematic documentation processes, keeping the need for modifications under critical review.

g) Disseminate best practice research findings and quality improvement projects through appropriate media and fora (e.g. presentations and peer review research publications).

h) Facilitate collaborative links between clinical practice and research through proactive engagement, networking with academic, clinical and other active researchers.

Enhanced capabilities in learning disabilities and autism

The practitioner will:

i) Coproduce approaches to evaluating services and measuring impact, including the use of outcomes reported by people with a learning disability and/or autism, their families and carers.

j) Promote a systematic approach to using and developing outcome measures to underpin current and future practice.

k) Advocate for reasonable adaptations to enable people with a learning disability and/or autism to participate in audit, evaluation and research.

l) Ensure research materials and processes are accessible for people with a learning disability and/or autism where appropriate.

m) Critically appraise the ethical issues and influence processes related to conducting research with people with a learning disability and/or autism, including gaining consent to their participation.

Key guidance

Sources of further guidance and references to key legislation are shown in the appendices. Examples of national guidance with specific relevance to this capability are shown below:

- Learning Disability Professional Senate: Rights and Equality Based Outcomes for Learning Disability Services

- [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

Core Capabilities Frameworks at:
www.skillsforhealth.org.uk/learningdisabilityandautismframeworks

- Core Capabilities Framework for supporting people with a learning disability: Capability 25. Research and evidence-based practice
- Core Capabilities Framework for supporting autistic people: Capability 19. Research and evidence-based practice

Appendix 1. About 'capabilities'

Capabilities are the attributes (skills, knowledge and behaviours) which individuals bring to the workplace. This includes the ability to be competent and beyond this, to:

- manage change
- be flexible
- deal with situations which may be complex or unpredictable and,
- continue to improve performance.

Therefore, 'capability' can be more than 'competence'. To be competent is to consistently perform to defined standards required in the workplace – usually focused on the outputs of work and observable performance. Competence tends to describe practice in stable environments with familiar problems. Whereas 'capabilities' describe the ability to be competent, and beyond this, to work effectively in situations which may be complex and require flexibility and creativity.

In practice, the terms 'capability' and 'competence' and are both widely used in educational and workforce development literature and they have often been used interchangeably, with little clear distinction between the two. Both capability and competence:

- are about 'what people can do'

- describe knowledge, skills and behaviours

- can be the outcome of education, training or experience.

However, for the purposes of this framework we are using the term 'Capabilities' as this describes the ability to be competent, and *beyond this,* to work effectively in situations which may require flexibility and creativity.

Appendix 2: Rights and equality-based outcomes for people with a learning disability

The following principles have been derived from the Human Rights Act, the Equalities Act, the European Convention on the Rights of the Disabled, the UN Convention on the Rights of the Disabled, the NHS England service Model (Building the Right Support), current Department of Health policy development along with existing outcome measures. The majority of these principles apply to both children and adults although some are more applicable to adults *(Ref: Learning Disability Professional Senate: Rights and Equality Based Outcomes for Learning Disability Services).*

I am respected:

> I am recognised and respected as the person I am.

> I am free from discrimination and my difference is recognised, accepted and respected.

I am safe:

> I am free from abuse and harm.

> I am free from degrading, inhuman or cruel treatment.

> I am treated fairly by the criminal justice system.

I make choices:

> I am supported to be understood and to understand the world around me and the choices I have. I have information that I understand to help with this.

> My choices and opinions are respected (even if others do not agree).

> I am supported to participate in democratic processes.

I have a place of my own:

> I live in the community of my choice, with privacy and contact with those I choose.

> My living standard is adequate for my needs.

> I am supported to be part of my community and culture.

> I have possessions and property that are my own and are respected.

> I am able to go where I want.

I am active:

> I am supported to develop and learn.

> I have opportunities to engage in meaningful activities, including work.

> I have time and support to rest and relax and to do things that help with this.

I have fulfilling relationships

I have a range of relationships of my choosing including personal and intimate relationships.

My rights to family life are recognised and supported including marriage.

I am supported to access services – which are reasonably adjusted to meet my needs

My health needs are met / managed in a way that reduces likely inequality and reflects my choice.

My social care needs are met / managed in a way that reduces inequality and reflects my choice.

My psychological and emotional needs are met / managed in a way that reduces inequality and reflects my choice.

Appendix 3: 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.

Regulated Qualification Framework (RQF)

The Regulated Qualification Framework (RQF) sets out the general and vocational qualifications in England (and Northern Ireland) and how they relate to each other. Its intention is to improve consistency around how awarding organisations describe the size and challenge, or demand, of the qualifications they offer.

Regulated qualifications of particular relevance to learning disabilities and autism are:

Learning disability pathways in level 2 and level 3 diplomas

Level 2 Award in Supporting Individuals with Learning Disabilities

Level 2 Certificate in Supporting Individuals with Learning Disabilities

Level 3 Award in Supporting Individuals with Learning Disabilities

Level 3 Certificate Supporting Individuals with Learning Disabilities

Level 4 Diploma in Adult Care (England)

Level 5 Diplomas in Leadership In Health And Social Care And Children And Young People's Services

The Register of Regulated Qualifications can be searched at: https://www.gov.uk/find-a-regulated-qualification

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.

Appendix 4: 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 i.e. people working at Master's level or equivalent.

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.

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 2016[13])*

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.

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[13] Realising the Value, The Health Foundation (2016) at; https://www.health.org.uk/collection/realising-value

Appendix 5: How this framework was developed

Development of the framework was commissioned by Health Education England and guided by a steering group including Health Education England, NHS England, Skills for Health and a range of key stakeholder organisation including Royal Colleges, NHS Trusts, voluntary sector organisations and professional bodies.

A wider stakeholder list was also established to include a more diverse range of organisations and individuals that wished to be up-dated on the development of the framework and to provide comments or feedback as part of the consultation process. Individuals were able to register their interest from a project web page.

Initial desk research was undertaken to identify key references and resources (see Appendix 6. Sources of further guidance and information, and Appendix 9. Bibliography). Each of the capabilities was also cross-referenced to other relevant frameworks for learning disabilities and autism.

Initial revisions to the framework were based on the findings of the desk research and consultation with the project steering group. Subsequently, during March 2019 a wider online consultation survey was conducted, with a total of 221 respondents. Based on analysis of these survey outcomes, and following consultation with the steering group, a final draft of the framework was competed in April 2019.

Appendix 6: 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
- Chartered Society of Physiotherapists
- 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
- National Development Team for Inclusion
- National Learning Disability Professional Senate
- 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 Occupational Therapists
- Royal College of Psychiatrists
- Royal College of Speech and Language Therapists
- Sensory Integration Education
- Scope
- Social Care Institute for Excellence (SCIE)

- [Skills for Care](#)
- [Skills for Health](#)
- [The Association for Dance Movement Psychotherapy](#)
- [The Association of UK Dietitians](#)
- [The British Association for Art Therapy](#)
- [The British Association for Music Therapy](#)
- [University of Bristol, Learning Disabilities Mortality Review (LeDeR) Programme](#)

Appendix 7. Relevant policy and legislation

Learning disability and autism - strategy and policy

Valuing People: A New Strategy for Learning Disability for the 21st Century (2001)

This White Paper in 2001 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.

Putting people first: a shared vision and commitment to the transformation of adult social care (2007)

The cross-government concordat, Putting People First (2007) 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.

Valuing People Now: a new three year strategy for people with learning disabilities (2009)

Valuing People Now (2009) reaffirmed the principles of the original Valuing People strategy (2001) 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.

In addition to those providing health and social care to people with a learning disability, others who come into contact with them and their families and carers need to have an awareness and understanding of their specific needs and those of their families and carers.

Autism Act (2009)

The Autism Act (2009) put a duty on the Government to produce a strategy for autistic adults in England, which was published in March 2010: Fulfilling and Rewarding Lives (2010).

Building on the themes in Fulfilling and Rewarding Lives (2010), a new strategy, Think Autism, was then published in April 2014. Think Autism set out a programme of action the Department of Health and other government departments will take to improve the lives of autistic people.

One of the key goals of the autism strategy is a commitment to increasing understanding of autism by improving autism awareness training for all frontline public service staff, in

line with the needs of their job, and developing specialist training for staff in health and social care.

Transforming Care Programme

Transforming care is a programme with the aim to develop health and care services so that more people with a learning disability and/ or autistic people can live in the community, with the right support, and close to home. This means that fewer people will need to go into hospital for their care.

There is a national plan about how to do this called 'Building the right support' (October 2015), and there are 48 transforming care partnerships (TCPs) across England to support this.

Learning Disabilities Mortality Review (LeDeR) Programme (2015-2019)

The Learning Disabilities Mortality Review (LeDeR) Programme is the first national programme of its kind aimed at making improvements to the lives of people with a learning disability. The Programme is developing and rolling out a review process for the deaths of people with a learning disability, helping to promote and implement the new review process, and providing support to local areas to take forward the lessons learned in the reviews in order to make improvements to service provision.

Accessible Information Standard

All organisations that provide NHS care and/or publicly-funded adult social care are legally required to follow the Accessible Information Standard. The Standard sets out a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss.

Other relevant strategy and policy

Disability Discrimination Act (1995)

An Act to make it unlawful to discriminate against disabled persons in connection with employment, the provision of goods, facilities and services or the disposal or management of premises; to make provision about the employment of disabled persons; and to establish a National Disability Council.

Human Rights Act (1998)

The Human Rights Act gives effect to the human rights set out in the European Convention on Human Rights. These rights are called Convention rights. Examples of Convention or human rights include:

- the right to life
- the right to respect for private and family life
- the right to freedom of religion and belief.

The Human Rights Act means you can take action in the UK courts if your human rights have been breached.

Mental Capacity Act (2005)

The Mental Capacity Act (MCA) has been in force since 2007 and applies to England and Wales. The primary purpose of the MCA is to promote and safeguard decision-making within a legal framework. It does this in two ways:

- by empowering people to make decisions for themselves wherever possible, and by protecting people who lack capacity by providing a flexible framework that places individuals at the heart of the decision-making process
- by allowing people to plan ahead for a time in the future when they might lack the capacity, for any number.

Equality Act (2010)

The Equality Act 2010 legally protects people from discrimination in the workplace and in wider society. It replaced previous anti-discrimination laws with a single Act, making the law easier to understand and strengthening protection in some situations. It sets out the different ways in which it's unlawful to treat someone.

Care Act (2014)

The Care Act brings together care and support legislation in England with the principle of well-being at its heart. The Care Act changes the way councils, care providers and user organisations work. It changes peoples' roles in the delivery of care, and the expectations and duties placed on people.

Children and Families Act (2014)

An Act to make provision about children, families, and people with special educational needs or disabilities; to make provision about the right to request flexible working; and for connected purposes.

NHS England (2014), Five Year Forward View

The NHS Five Year Forward View was published on 23 October 2014 and sets out a new shared vision for the future of the NHS based around the new models of care. It has been developed by the partner organisations that deliver and oversee health and care services including Care Quality Commission, Public Health England and NHS Improvement (previously Monitor and National Trust Development Authority).

NHS (2015), The NHS Constitution

In March 2011, the Department of Health published the NHS Constitution. It sets out the guiding principles of the NHS and your rights as an NHS patient. The seven key principles guide the NHS in all it does. They are underpinned by core values which have been derived from extensive discussions with staff, patients and the public.

Integrated Care Systems

In 2016, NHS organisations and local councils came together to form 44 sustainability and transformation partnerships (STPs) covering the whole of England and set out their proposals to improve health and care for patients.

In some areas, a partnership will evolve to form an integrated care system, a new type of even closer collaboration. In an integrated care system, NHS organisations, in partnership with local councils and others, take collective responsibility for managing resources, delivering NHS standards, and improving the health of the population they serve.

NHS Long Term Plan

The NHS Long Term Plan sets out a strategy for development of the NHS over the next 10 years, recognising that as medicine advances, health needs change and society develops, so the NHS has to continually move forward. It aims to give everyone the best start in life; deliver world-class care for major health problems, such as cancer and heart disease, and help people age well.

Appendix 8: Glossary of terms

Term	Definition
Activation	A person's knowledge, skill and confidence for managing their own health and health care.
Active listening	Fully concentrating on what is being said, including: • Ability to pick up on non-verbal cues • Listening for key words as signposts to emotions • Understanding the meaning of silence • Using body language and facial expression to indicate interest and empathy.
ADHD	Attention deficit hyperactivity disorder (ADHD) is a behavioural disorder that includes symptoms such as inattentiveness, hyperactivity and impulsiveness.
AHPs (Allied Health Professions)	The Allied Health Professions are 14 degree level, regulated, professionally autonomous practitioners. AHPs provide system-wide care to assess, diagnose and treat people through adopting an holistic approach to healthcare. Their focus is on prevention and improvement of health and wellbeing to maximize the potential for individuals to live full and active lives within their family circles, social networks, education/training and the workplace.
Asset-based approach	A way of working that considers the strengths and potential of individuals and communities.
Capabilities	The attributes (skills, knowledge and behaviours) which people bring to the workplace. 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.
Carer	Someone who spends a significant amount of their time providing unpaid support to a family member or friend.
Coproduction	At the level of individuals, services and systems, co-production means professionals and citizens sharing power to plan, design and deliver support together, recognising that everyone has an important contribution to make to improve quality of life for people and communities.
Dysphagia	Dysphagia describes eating, drinking and swallowing difficulties in infants, children and adults. People with dysphagia often have other health conditions that they are being treated for which affects their eating, drinking and swallowing abilities. It may also affect the person's quality of life, as eating and drinking is important for social life.

Term	Definition
End of Life Care	Care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.
Frailty	A long-term condition particularly related to the ageing process in which multiple body systems gradually lose their in-built reserves. It is now widely recognised as a state of reduced resilience and increased vulnerability, which results in some people becoming more vulnerable to relatively minor changes in their circumstances which can lead to a deterioration in their health and/or ability to live independently.
Health Coaching	Enabling a person to maximise their own health through raising individuals' awareness and responsibility for their own health. Key characteristics include a focus on a person's goals rather than what professionals think they should do; empowering people to take ownership and responsibility for their health; and helping people plan and break down their goals into manageable steps[14].
Inclusive communication	Inclusive communication encompasses all means of understanding and expression and all tools which enable and support communication. This includes strategies to overcome high level language difficulties, through to creative and multi-modal techniques to engage people with profound and multiple learning disabilities. Inclusive communication is personalised - what counts as inclusive communication for one person will not necessarily be so for someone else.
Mental capacity	'Mental capacity' means being able to make your own decisions. Someone lacking capacity cannot do one or more of the following four things: • Understand information given to them about a particular decision • Retain that information long enough to be able to make the decision • Weigh up the information available to make the decision • Communicate their decision.
Personalisation and Person-centred care	Care that takes account of and actively promotes individuality, rights, choices, privacy, independence, dignity, respect and partnership.
Practitioner	Multi-disciplinary staff working clinically in health, social care and other services.

[14] Realising the Value (2016), Realising the Value: Ten key actions to put people and communities at the heart of health and wellbeing

Term	Definition
Profound and Multiple Learning Disabilities (PMLD)	A profound and multiple learning disability (PMLD) is when a person has a severe learning disability and other disabilities that significantly affect their ability to communicate and be independent. Someone with PMLD may have severe difficulties seeing, hearing, speaking and moving. They may have complex health and social care needs due to these or other conditions.
Reasonable adjustments	Making it as easy for disabled people to use health and other services as it is for people who are not disabled.
Specialist practitioner	A practitioner with specialist skills and knowledge within a defined scope of practice.
Shared decision-making	Putting people at the centre of decisions about their own treatment and care by: • exploring care or treatment options and their risks and benefits • discussing choices available • reaching a decision about care or treatment, together with their health or social care professional or support worker.

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