CONSULTATION DRAFT

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Core Capabilities Framework for Supporting Autistic People

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Acknowledgements

To be completed...

Will include reference to HEE as the commissioner, project delivery and steering group organisations and input from the co-production workshops / consultation process.

Foreword

To be completed...



Introduction and background

It is estimated that there are more than half a million autistic people in England, equivalent to 1% of the population¹. Many of these people and their families at one time or another, face a battle to get right the information, support and care. When skills, knowledge and understanding are lacking in the public service workforce this can create fundamental barriers for many autistic people in accessing the services we all need.

In 2009, the Autism Act became the first ever disability-specific law in England. The Autism Act 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)². Building on the themes in Fulfilling and Rewarding Lives, a new strategy, 'Think Autism', was later published in April 2014. 'Think Autism' set out a programme of action government departments would take to improve the lives of autistic people.

A key duty in the Autism Act statutory guidance is training for all frontline public service staff, in line with their job role, and developing specialist training for staff in health and social care.

It is therefore the purpose of this framework to support this commitment by setting out the essential capabilities necessary for all staff involved in supporting autistic people across their lifespan. The framework will enable individuals and organisations to:

- Identify key capabilities required for job roles.
- Identify the capabilities needed within a team or service.
- Plan the content for education and training
- Commission education and training
- Conduct training needs analysis
- Support the assessment of capabilities and the sharing of learning and outcomes across the whole workforce.

Use of the framework can also support all aspects of workforce development including recruitment and selection, practice leadership, establishing culture and dealing with poor performance.

¹ HM Government (2014) Think Autism: fulfilling and rewarding lives, the strategy for adults with autism in England: an update. London: HM Government.

² Department of Health (2010) Fulfilling and rewarding lives: the strategy for adults with autism in England. London: Department of Health.

Terminology used in this framework

Throughout this framework, we use identity-first terminology ("autistic people" rather than "people with autism") when referring to autistic people - children, young people and adults. This reflects research published in the Autism journal in 2015 which looked at the preferences of people on the autism spectrum, their families, friends and professionals around the language used to describe autism. The research was conducted by The National Autistic Society, the Royal College of GPs and the UCL Institute of Education.

The research findings confirmed that there is no single term that everyone prefers. However, it suggests a shift towards more positive and assertive language, particularly among autistic communities where autism is seen as integral to the person³. We recognise that some people prefer other terms and all workers should wherever possible find out the term(s) preferred by the person(s) they are working with and respect this.

Unless otherwise stated, reference to 'autistic people' or 'an autistic person' includes children, young people and adults of all ages.

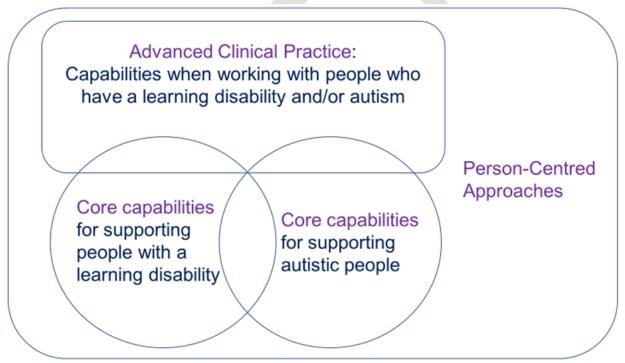
³ Kenny et al (2015), Which terms should be used to describe autism? Perspective from the UK autism community at: https://journals.sagepub.com/doi/10.1177/1362361315588200

Other related frameworks

This framework is one of several related core capabilities frameworks relevant to supporting autistic people and people with a learning disability 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: www.skillsforhealth.org.uk/LDframework
- Advanced Clinical Practice: Capabilities framework when working with people who have a learning disability and/or autism: www.skillsforhealth.org.uk/ACPinLD
- 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/ourwork/learning-disability/workforce-capability
- British Association of Social Workers (BASW) Learning Disability and Autism Frameworks (due 2019)

Structure of the framework

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

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

The framework then comprises 19 capabilities, which are grouped in 5 domains:

Domain A. Understanding autism

Domain B. Personalised support

Domain C. Physical and mental health

Domain D. Risk, legislation and safeguarding

Domain E. Leadership and management, education and research

Each capability comprises the key outcomes of learning or performance.

The capabilities are numbered (1 to 19) for ease of reference. This does not indicate a prescribed pathway, process or hierarchy. Full coverage of all capabilities may be achieved by across a whole team or service, in which case some team members may find that not all capabilities are essential to their individual role.

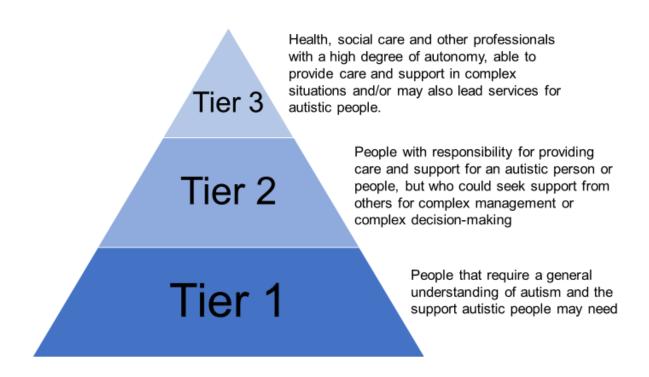
Scope of the framework

The successful delivery of services, both mainstream and autism specific, involves a workforce that is extensive and diverse, including many staff closely engaged in providing care to a known individual or small group, and others offering information, support and assistance in a range of public services - being able to make reasonable adjustments so that their services are welcoming and effective for autistic people.

Social care and health services to support autistic people may be offered in a broad variety of settings including an individual's own home, community settings, public and commercial areas such as leisure and retail facilities, voluntary sector organisations, schools, residential homes and acute hospitals.

Staff in other sectors (e.g. justice, education, housing and employment) will also interact with autistic people, including those who are not diagnosed or do not wish to disclose their diagnosis.

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



The above diagram represents how tier 1 will be relevant to the largest number of people, whereas tiers 2 and 3 are relevant to fewer people but who require increased levels of knowledge and skills.

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

Further explanation of the 3 tiers is provided below.

Tier 1 People that require a general understanding of autism and the support autistic people may need.

This is relevant to those in working in <u>any sector</u> who may occasionally interact with autistic people, but who do not have responsibility for providing direct care or making decisions about autism-specific care or support. For example, this may include those working in public services, commercial or charitable organisations providing health, social care, education, policing, custodial care, housing, employment or benefit services. It would include front-of-house and reception staff in services.

Understanding Autism at Tier 1 would be relevant to introductory autism training. Tiers 2 and 3 provide coverage of capabilities in greater breadth and depth.

Tier 2 People with responsibility for providing care and support for an autistic person or people, but who could seek support from others for complex management or complex decision-making

For example, tier 2 will be relevant to health and social care workers who are not autism specialists and those in other roles such as education and housing services which are providing care and support for autistic people.

Tiers 1 and 2 may also be helpful to autistic people and the family, friends and carers of autistic people, to ensure they are making the most of the support on offer and can plan effectively for their current and future needs.

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

This is relevant to staff working intensively with autistic people, including those who take a lead in decision making, practice management and developing or disseminating good practice. Some indicative roles may include specialist healthcare professionals such as psychologists, psychiatrists, GPs with special interest, learning disability nurses, allied health professionals, social workers etc. It will also include registered managers and other social care leaders including operational managers who have responsibility for services for autistic people. Tier 3 would also be appropriate for autistic people and carers/families of autistic people who are involved in designing and delivering training on autism and/or are working as a self-advocate or expert by experience at a strategic level.

This framework provides a structure to describe the capabilities at varying levels of complexity or responsibility required to support autistic people. It is not possible or intended to be prescriptive about which tier is <u>always</u> relevant to which job role as

this will vary according to local context and different settings. Each employer organisation will evaluate which of their job roles are relevant which tier. Therefore, any reference to job roles for each tier is only intended to be indicative.

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

Full coverage of all capabilities may also be achieved by a team, in which case each team member will know which capabilities are relevant to their individual role, and which team members may have capabilities in other areas.

Who is this framework for?

The framework provides a focus on the skills, knowledge and behaviours expected for the delivery of all services used by autistic people. This should be of particular value to:

Workers and teams

The framework sets out clear expectations for the core capabilities that specific tiers of the workforce should be able to demonstrate. This supports individuals and teams to:

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

Managers in organisations / individual employers

This national framework enables managers and employers, of all types and all sizes, to demonstrate that their staff meet the core capabilities or have developmental plans in place to meet them. This underpins the continuing professional development of workers to ensure their practice remains up-to-date, safe and effective.

Service commissioners

The framework enables commissioners to specify minimum standards of workers' capabilities required in services for autistic people; it sets out clear expectations about what different 'tiers' of the workforce are able to do. It also supports service transformation, for example by using the framework to review current service provision for autistic people and to support collaborative approaches to commissioning.

Subject matter trainers

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

The specific learning outcomes also support the effective evaluation of education and training⁴. Approaches to evaluation can include:

- evaluating whether learners have achieved the required learning outcomes immediately following a learning intervention (e.g. through assessment of knowledge and/or competence)
- evaluating whether the learning is being applied in the workplace (e.g. through longer-term evaluation of impact on practice, possibly as part of supervision or appraisal processes)
- evaluating the impact on quality of care (e.g. measuring service user outcomes and/or levels of satisfaction from autistic people and their families).
 Such evaluation will require data collection to measure what changes.

Education providers

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

Regional and national implementation

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

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

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⁴ E.g. Kirkpatrick's Four-Level Training Evaluation Model

Autistic people and their family, friends and carers (who will also be present in all the above groups)

The framework can be used by autistic people to better understand the capabilities (including knowledge and skills) they can expect from those providing services. This is relevant to autistic people commissioning support (e.g. by employing personal assistants or choosing a service that's right for them) and to plan effectively for their own current and future care. In particular, the framework highlights that autistic people and their family, friends and carers must be able to make informed choices about effective care and support alongside healthcare and other practitioners i.e. to be fully involved in and co-produce care and support planning. People may also use the framework in a campaigning role or at a strategic level (for example on the board of an organisation they use or on a local autism strategy implementation group).

Values and behaviours

The following values and behaviours underpin all the capabilities in this framework and focus on the minimum that autistic people, their family and carers can expect of the people who provide support. These values and behaviours are derived from coproduction workshops with autistic people conducted during the development of this framework. As such, these are supplementary to any existing legal, regulatory and ethical requirements or codes relevant to professional bodies and employers.

The person or practitioner will:

- a) Demonstrate positivity, recognising the strengths and abilities of autistic people.
- b) Gain an understanding of each autistic person's perspective and personal preferences.
- c) Be patient and really listen to what is being communicated by an autistic person
- d) Recognise the presentation, behaviour and identity of autistic people and respond with respect and compassion, without judging them or labelling their behaviour in unhelpful ways.
- e) Value and acknowledge the experience and expertise of autistic people, their families and support networks, enabling choice and autonomy and protecting people's human rights.
- f) Act with integrity, honesty and openness, seeking to develop mutual trust in all interactions with autistic people, their families, carers and communities.
- g) Be committed to integrated current and future care and support through working in partnership with autistic people, teams, communities and organisations.
- h) Value collaborative involvement and co-production with autistic people to improve person-centred design and quality of services.
- i) Recognise, respect and value autistic peoples' differences and challenge negative stereotyping.
- j) Take responsibility for one's own learning and continuing professional development and contributing to the learning of others.

Domain A. Understanding autism

Introduction

Autistic people (children, young people and adults) have the same human rights as anyone else, including the right to 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 lifestyles of their choosing, with the support they need to live healthy, safe and rewarding lives.

This domain is about understanding the numbers of autistic people in the population, the characteristics of autism and the impact which it often has. An understanding of autism, relevant to scope of practice, is essential for all roles and settings and underpins all the capabilities in this framework. The identification, assessment and diagnosis of autism is also key to ensuring the most effective support and referral if needed.

Capability 1. Understanding autism

Understanding autism at Tier 1 is for people that require general awareness of autism and the support autistic people may need. This may provide the minimum learning outcomes for introductory autism training.

Tier 1

The person will:

- a) Know basic facts about autism including:
 - i. how common it is
 - ii. that autism is neurological and life long
 - iii. that every autistic person is affected differently and is unique.
- b) Be able to use respectful terminology.
- c) Understand what common autistic characteristics may look like in real life situations e.g. at home, in the classroom, in care settings, in the community.
- d) Understand the importance of meeting an autistic person's unique communication and information needs:
 - i. understand that communication includes both giving and receiving information and the importance of actively including autistic people in conversations about them
 - ii. be aware how autistic people may become overwhelmed and need time and quiet space to process and understand information. For example when overwhelmed some people may 'shutdown' or simply acquiesce to anything said in order to bring the experience to a close; therefore you will not get accurate information and they will not retain what you have said.
 - iii. be aware of (e.g. through reading their communication passport) and respect the different methods of communication that an autistic person may use such as visual techniques
 - iv. actively listen to what a person is saying and be prepared to use patience and perseverance in communication including being silent to allow thinking time
 - v. be aware that autistic people can favour literal interpretations and therefore use non-confrontational but clear language, responding positively when autistic people use direct language and give direct feedback
 - vi. be aware of difficulties and differences in non-verbal communication / body language / personal distance
 - vii. recognise the impact of stress and anxiety on communication.
- e) Recognise some key differences in social interaction e.g. difficulties with small talk, social rules and processing time.
- f) Understand the role of trauma in the lives of autistic people leading to a wide range of mental health problems in later life and the importance of building trust and making choices for recovery.

- g) Understand how sensory issues can impact on autistic people e.g. oversensitivity or under-sensitivity to lighting, sound, temperature, touch, smell⁵ and how anxiety and stress can contribute to sensory needs.
- h) Be able to make simple changes to ensure an environment is accessible to autistic people, including opportunities to avoid sensory overload (e.g. turning off unnecessary lights, tv / radio, offering quiet space, enabling the use of sensory protection such as noise-cancelling headphones), or consider the use of an alternative location.
- i) Plan changes in advance whenever possible⁶. Provide preparation and information about upcoming events using a variety of communication methods.
- j) Recognise the importance of passionate interests and hobbies⁷.
- k) Be able to consistently put key adaptations into practice, for example:
 - i. Don't spring surprises!
 - ii. Don't touch without consent
 - iii. Slow down and pause
 - iv. Create or find a calm, quiet environment
 - v. Explain FIRST, THEN do.
- I) Know where to access resources and further information about autism.

Tiers 2 and 3 (below) provide for a more in-depth understanding of autism e.g. for those with specific responsibility for delivering and/or leading services which meet the needs of autistic people.

⁷ See Capability 10 Meaningful activity and independence

⁵ See Capability 5. Sensory processing and the environment

⁶ See Capability 7. Supporting change and transitions

Tier 2

Tier 1 outcomes plus the following

The person or practitioner will:

- a) Understand that the spectrum of autism consists of a range of both abilities and disabilities, many of which may not be obvious
- b) Know the importance of equal, timely access to autism assessment and diagnosis and some of the barriers to diagnosis⁸.

Personalised support (Domain B)

- c) Be able to identify practical strategies to offer person-centred support to autistic individuals in a range of day to day situations⁹.
- d) Be able to identify simple adaptations which can be made to meet the communication¹⁰ needs and preferences of autistic people, including using visual information (photos, diagrams, symbols), use of IT, autism alert cards and written information (e.g. text or email) when this works for the individual
- e) Understand how behaviour may indicate stress and avoid assumptions about what a person's behaviour may be trying to communicate¹¹.
- f) Understand that any change in a person's presentation or behaviour may be a sign of a health or emotional problem, distress or sensory overload. Do not assume it is simply an inevitable part of autism even if it presents differently than in other people.
- g) Understand stimming, including why it can be helpful as a form of expression and where to seek support if it seems to be becoming harmful.
- h) Understand activities that people adopt to 'self sooth' or 'self-regulate' or just 'calm down' and make sure people can do these things when they need to.
- i) Be able to execute practical strategies to support autistic people with changes, such as preparation and providing clear information.
- j) Understand the importance of working with others, including the role that family carers and supporters may play in the lives of autistic people¹².
- k) Know how to access further support within one's own organisation to ensure the needs of autistic people are met.

Physical and mental health (Domain C)

 Understand how health inequality affects autistic people and be aware of the main causes of health inequality for autistic people.

⁸ See Capability 2. Identification, assessment and diagnosis of autism.

⁹ See Capability 3. Person-centred care and support

¹⁰ See Capability 4. Communication and interaction

¹¹ See Capability 8. Supporting autistic people where behaviour may challenge

¹² See Capability 6. Families and carers as partners in care and support

- m) Be able to identify and put in place 'reasonable adjustments' in access to health care and other services¹³
- n) Be aware of the role of health action plans/health passports in signposting important adjustments.
- o) Be aware of everyday issues commonly faced by autistic people such as anxiety, fear, depression, stress, low self-esteem etc and how these may be reduced by social lives that are 'autism friendly'.
- p) Understand that autistic people can develop mental health conditions for the same reasons as people without autism, but that the prevalence of mental health conditions in autistic people is higher due to the impact of factors such as social inequality, isolation, stigma and discrimination.

Risk, legislation and safeguarding (Domain D)

- a) Understand that autistic people have a right to be supported to make their own decisions and must be given all practicable help before anyone concludes that they cannot make a decision¹⁴.
- b) Be aware of how views and attitudes of others can impact on the lives of autistic people and their families and carers, such as through social isolation, bullying and social misunderstandings.
- q) Be aware of types of abuse which may be especially relevant for autistic people.
- r) Know how to raise a Safeguarding Concern and whom to contact for information and advice on Mental Capacity Act or Equality issues.

Tier 3

Tiers 1 and 2 outcomes plus the following

The practitioner will:

- a) Understand and appraise historical and current understanding and explanations of autism including cognitive and social-psychological theories.
- b) Appraise medical and social models of disability, and critiques of these models.
- c) Evaluate the impact of historical and current understanding of autism on current service provision.
- d) Understand the key legislation, policy and guidelines relating to autistic people, including one's own responsibilities under the Mental Capacity Act 2005, Mental Capacity (Amendment) Act 2019, the Equality Act 2010, the Care Act 2014, Human Rights Act 1998 and the Accessible Information Standard¹⁵.

¹³ See Capability 13. Health equality and reasonable adjustments

¹⁴ S.1(3) Mental Capacity Act

¹⁵ See Capability 14. Law, ethics and safeguarding and Capability 15. Equality, diversity and inclusion.

Key guidance

General guidance and references to key legislation are shown in the appendices. Guidance or resources with specific relevance to this capability is shown below:

National Autistic Society website: https://www.autism.org.uk/professionals/health-workers.aspx

St. Clement's Practical Autism Video Guides:: Introduction to Autism

Communication Pre-verbal

Communication Verbal

Sensory Issues

Coping with Change

Mental Health

RCNi autism poster: How to support people with autism

Social Care Institute for Excellence (SCiE): Improving access to social care for adults

with autism: Autism: the main issues

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Capability 2. Identification, assessment and diagnosis of autism

Tier 2

The person or practitioner will be able to:

- a) Recognise the indicators of autism that would signal the need for further assessment and conditions which may co-occur with autism.
- b) Be aware of some of the key differences between learning disability, autism, mental health conditions and learning difficulties and understand that individuals may experience more than one of these, or other neurodevelopmental conditions at the same time.
- c) Promote equal access to autism diagnostic assessment, recognising that there may be some girls and women who present with less traditionally obvious characteristics, leading to them historically being excluded from assessment and diagnosis.
- d) Recognise that those who display less traditionally obvious characteristics may be masking their difficulties, which can be a barrier to diagnosis and that this may occur in relation to women and girls, men and boys, as well as those who are gender fluid or non-binary.
- e) Know why timely identification of autism is important and the likely outcomes if assessment for diagnosis is delayed.
- f) Explain the benefits of an assessment for diagnosis of autism with sensitivity and in a way that is appropriate to the autistic person and their families and carers.
- g) Avoid the tendency to underestimate less verbal individuals and overestimate those who are more verbal.
- h) Be aware of relevant specialist services and support networks locally and nationally and appropriately refer autistic people to them.
- i) Effectively engage with both the autistic person themselves and with families and carers providing care and support.

Tier 3

The practitioner will be able to:

- a) Gather and synthesise information from appropriate sources (including previous histories and assessments), in partnership with the autistic person and others to facilitate person centred diagnostic assessment, recognising that gender and age can have an impact upon the presentation of autism.
- b) Conduct a comprehensive diagnostic assessment for autism, utilising appropriate assessment tools and considering differential diagnoses and comorbidities.

- c) Listen, ask questions and obtain further information, with due sensitivity as part of a person-centred assessment.
- d) Appraise information obtained, taking account of potential associated conditions, for example, epilepsy; physical disabilities; and mental health problems.
- e) Appraise complex, incomplete, ambiguous and conflicting information, synthesising key factors from the appraisal, and identifying those elements that may need to be pursued further.
- Work with the multi-disciplinary team to develop a formulation based on all available data.
- g) Develop a differential diagnosis, recognising key diagnostic biases and common errors (including diagnostic overshadowing and masking) and the issues relating to diagnosis in the face of ambiguity and incomplete data.
- h) Develop a profile of an autistic person's strengths, needs, skills and impairments.
- Recognise the experience of autistic people, their families and carers and communicate with sensitivity about the identification of autism and related implications, whilst taking a positive view of the lives of autistic people and not perpetuating negative stereotypes.¹⁶¹⁷¹⁸
- j) Support autistic people to access post-assessment support services including referral for social care assessment. This may include providing necessary support whilst awaiting further assessment evidence
- k) Record the information gathered concisely and accurately in compliance with local protocols, legal and professional requirements.
- Work effectively with colleagues and the multi- professional team, to collate and share data across organisations in compliance with local protocols, legal and professional requirements.

Key guidance

General guidance and references to key legislation are shown in the appendices. Guidance or resources with specific relevance to this capability is shown below:

- NICE Clinical Guidance [CG142], Autism spectrum disorder in adults: diagnosis and management at: https://www.nice.org.uk/guidance/CG142
- NICE Clinical Guidance [CG128], Autism spectrum disorder in under 19s: recognition, referral and diagnosis at: https://www.nice.org.uk/guidance/cg128
- National Autistic Society website: https://www.autism.org.uk/about/diagnosis.aspx
- St. Clement's Practical Autism Video Guides: Diagnosis and Identity

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¹⁶ Diagnosis and Identity (St. Clement's Practical Autism)

¹⁷ Jim Sinclair (1993) 'Don't mourn for us'

¹⁸ Being Autistic

- <u>Social Care Institute for Excellence (SCiE):</u> Improving access to social care for adults with autism: Awareness raising and diagnosis
- Autistica Action Briefing:
 - o Access to adult diagnosis
 - o Adult diagnosis process
 - o Post-diagnostic support for adults
 - o Diagnosing autistic women and girls

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Domain B. Personalised support

Introduction

Personalised support is centred on the needs, preferences and aspirations of autistic children, young people and adults - genuinely promoting the autonomy of the autistic person. This includes effective communication and interaction to meet the different needs, abilities and preferences of autistic people and recognising the sensory processing differences of individuals and the adaptations which may be required. It includes understanding the significance and value of families, carers and social networks, including when and how the autistic person would like them to be involved and the support autistic people may need at times of change and transitions throughout life.

Personalised support includes supporting autistic people where behaviour may challenge, avoiding assumptions that this is an inevitable part of autism and seeking to identify underlying causes and meet needs.

Autistic people (children, young people and adults) have the right to the same opportunities as anyone to develop and maintain safe and age appropriate relationships and get the support they need to develop and continue their interests, social life and community involvement. This includes the recognition and encouragement of passionate interests and hobbies.

Capability 3. Person-centred care and support

Tier 2

The person or practitioner will be able to:

- a) Understand how to use and adapt care and support approaches in a personcentred way to meet the needs of autistic people.
- b) Facilitate and seek to increase an autistic person's choice and control over major life decisions in addition to everyday choices, whenever possible.
- c) Understand the important role of family and carers in person-centred thinking and planning.
- d) Assess and plan for the needs of families and carers providing care and support for an autistic person¹⁹.
- e) Be aware of statutory rights to independent advocacy²⁰ and make or support referrals as appropriate
- f) Communicate clearly and straightforwardly about the care and support needs of autistic people
- g) Contribute to gathering information about a person's strengths, needs and preferences for their person-centred plan.
- h) Schedule and measure progress towards goals important to the autistic person.
- i) Evaluate the extent to which each autistic adult wants and benefits from activities such as social interaction; constant activity; community participation; and other outcomes which may prioritise 'a normal life' over wellbeing and reflect this in person-centred care plans.
- j) Recognise that whilst encouraging new experiences that an autistic person might like based on their preferences is advocated, they may prefer repetition and routine rather than unpredictability. This may include providing autistic children and young people with a range of experiences to develop their interests and skills.
- k) Provide care and support to an autistic person in the ways identified in their person-centred plan.
- I) Understand the principles and follow the practice of co-production.

¹⁹ S.10 & s.20 Care Act 2014 & s.17ZD-F Children Act 1989 as amended by s.97 Children and Families Act 2014

²⁰ s.67 & 68 Care Act 2014; s.37-39 and Sch.AA1 Mental Capacity Act 2005 (as amended); SEND Code of Practice 8.18, 9.29; Children Act 1989 s.26A (as amended); and The Advocacy Services and Representations Procedure (Children) (Amendment) Regulations 2004

- m) Understand the importance of an autistic person getting the support they need to make choices and decisions and to increase their skills and experience of doing so accounting for their age and ability.
- n) Support and facilitate the development of a person's autistic identity, including gender identity²¹ and access to autistic culture and autistic space.
- o) Understand the role of positive risk taking in enabling a person-centred approach and enabling new experiences based on the person's preferences.

Tier 3

The practitioner will be able to:

- a) Support and promote the development of community-based services to meet the needs of all autistic people and actively contribute to the development and implementation of strategic planning to bring to an end reliance on inappropriate placements for autistic people.
- b) Promote person-centred care and support in therapeutic relationships and communication and ensure that person-centred care genuinely promotes the autonomy of autistic people.
- c) Use self-management and enablement to help autistic adults manage their own levels of stress when dealing with choices and decision making and support autistic children to develop these skills.
- d) Work in partnership with autistic people, and if appropriate, their families and carers, and others to facilitate and support person-centred assessment, including evaluating the provision of advocacy services in line with statutory requirements²².
- e) Promote and advocate for person-centred thinking and planning in the management and development of services, enabling people to maximise empowerment within the limits of their capability, recognising that autism is a lifelong condition which may give rise to lifelong needs for care and support
- f) Advocate for and facilitate the use of co-production in the management and development of services.
- g) Challenge the intended outcome of programmes and approaches including those designed to manage behaviour, not just their effectiveness (e.g. are they trying to help the autistic person's wellbeing and reduce distress, or trying to make the autistic person more 'normal' and/or stop displaying distress?)

²¹ 'Gender Identity', St Clement's Practical Autism

²² s.67 & 68 Care Act 2014; s.37-39 and Sch.AA1 Mental Capacity Act 2005 (as amended); SEND Code of Practice 8.18, 9.29; Children Act 1989s.26A (as amended); and The Advocacy Services and Representations Procedure (Children) (Amendment) Regulations 2004

h) Utilise and support the implementation of relevant legislation and guidance for consent and decision-making (e.g. Mental Capacity Act 2005 and NICE guidance²³), recognising the importance of clearly identifying and separating the decisions of public services from decisions by or on behalf of an autistic person.

Key guidance

General guidance and references to key legislation are shown in the appendices. Guidance or resources with specific relevance to this capability is shown below:

- National Autistic Society website: https://www.autism.org.uk/professionals/health-workers/person-centred-planning.aspx
- <u>National Autistic Taskforce</u>, An independent guide to quality care for autistic people: Key elements of quality care:
 - Provide care which is autistic person-centred
 - Respect and promote autonomy
 - Accept difference and support positive autistic identity
- Autism Education Trust, Autism Competency Framework.
 https://www.autismeducationtrust.org.uk/shop/schools-cf-shop/
- <u>Social Care Institute for Excellence (SCiE)</u>: Improving access to social care for adults with autism: Personalising services
- Advocacy Focus: <u>Justice for LB Toolkit</u>
- Core Skills/Capabilities Frameworks (www.skillsforhealth.org.uk/cstf): Person-Centred Approaches: A Core Skills Education and Training Framework

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²³ Nice guidance on decision making and mental capacity

Capability 4. Communication and interaction

Tier 2

The person or practitioner will be able to:

- a) Understand that effective communication, in all areas of life, is critical for supporting the autonomy, wellbeing and quality of life of autistic people and continue to support the development of functional communication throughout the lifespan.
- b) Advocate for communication adjustments for autistic people when accessing nonspecialist and community services.
- c) Understand and promote the role of non-verbal communication e.g. written information, signing, symbol-based communication, assistive technology and the appropriate (and inappropriate) use of touch - and provide access to non-verbal means of communicating whenever appropriate.
- d) Understand the importance of providing time and space for autistic people to process and understand information and to make and communicate decisions.
- e) Recognise behaviour can be a form of communication and avoid assumptions about the meanings that can be attached to behaviour.
- f) Understand the importance of being able to communicate basic needs to reduce frustration.
- g) Use a range of communication techniques to convey information, according to the different abilities and preferences of autistic people, recognising that each autistic person may have a unique way of communicating.
- h) Understand why individualised communication plans should be developed, implemented and reviewed with the autistic person, avoiding assumptions which may over or under-estimate an autistic person's ability to communicate.
- Recognise the impact of the environment and sensory needs on communication

 knowing how to find the right time, place and situation for important communications.
- j) Understand the importance of and promote effective communication with families and carers. Recognise the expertise that families and carers may be able to offer to support effective communication with the autistic person.
- k) Communicate effectively with colleagues using a variety of media formats (e.g. verbal, written and digital) and in accordance with legal requirements.
- Signpost to appropriate specialist speech and language therapy advice and make timely referrals where appropriate.

m) Be aware of and support the legal frameworks (Equality Act, Mental Capacity Act and Accessible Information Standard) to make adjustments to all forms of care, treatment, communication and information.

Tier 3

The practitioner will be able to:

- a) Effectively utilise and advocate for a range of communication techniques according to the different needs, abilities and preferences of autistic people.
- b) Facilitate the development, implementation and review of individualised communication plans with autistic people, actively discouraging assumptions which may over or under-estimate an autistic person's ability to communicate.
- c) Critically evaluate communication systems and practices to support positive outcomes for autistic people, utilising feedback from autistic people, families and carers.
- d) Appraise and support the use of a range of augmentative and alternative communication methods and services, including assistive technology, that meet the communication needs of autistic people.
- e) Appraise the connection between behaviours that challenge, and the communication needs of autistic people recognising the importance of enabling communication of basic needs to alleviating frustration.
- f) Advocate for full implementation of the Accessible Information Standard for health and social care organisations²⁴ including requirements for policy, procedures, human behaviour and where applicable, electronic systems.
- g) Communicate with colleagues in ways that build and sustain relationships, seeking, gathering and sharing information appropriately, efficiently and effectively to enable and integrate people's care.

Key guidance

General guidance and references to key legislation are shown in the appendices. Guidance or resources with specific relevance to this capability is shown below:

- <u>National Autistic Taskforce</u>, An independent guide to quality care for autistic people: Key element of quality care: Support communication effectively throughout the lifespan
- National Autistic Society website: https://www.autism.org.uk/about/communication.aspx
- Accessible Information Standard NHS England (2017)

²⁴ s.250 Health and Social Care Act 2012 requires all public bodies carrying out health or social care functions and all organisations providing health or social care services to publicly funded services users to 'have regard' to the Accessible Information Standard.

- 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)
- Autism Education Trust, Autism Competency Framework. https://www.autismeducationtrust.org.uk/shop/schools-cf-shop/
- Core Skills/Capabilities Frameworks (www.skillsforhealth.org.uk/cstf): Person-Centred Approaches: A Core Skills Education and Training Framework

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Capability 5. Sensory processing and the environment

Tier 2

The person or practitioner will be able to:

- a) Understand that not every autistic person will have the same level of over-or under-sensory sensitivity, or indeed any sensory sensitivity in some areas and that each person's tolerance of sensory stimuli will vary according to other factors and over time.
- b) Create environments to support autistic people and understand how to adjust environments to enable areas to be inclusive and welcoming to everyone.
- c) Recognise the importance of and provide break out spaces, low arousal environments, escape plans, with 'permission to leave' and acceptance/provision of adaptations (such as noise cancelling headphones, sunglasses etc.).
- d) Be proactive in approaches to the environment e.g. making sure that assessments, meetings, interviews, appointments are planned for, asking the question about any adjustments that might be required to the environment utilising the expertise of autistic people to identify sensory issues.
- e) Be able to recognise sensory overload and know how to respond.
- f) Acknowledge, understand and encourage sensory stimulation behaviours (e.g. 'stimming'), intervening only on the basis of an agreed plan led by the autistic person if they are suffering distress or harm.
- g) Seek to provide access to sensory stimulation opportunities appropriate to individual needs and include these in care plans where appropriate.

Tier 3

The practitioner will be able to:

- a) Recognise and promote the understanding of the sensory processing differences of autistic people.
- b) Lead development of organisational policies which prioritise autistic sensory needs e.g. advocate for regular sensory reviews of environments where autistic people spend time, utilising the expertise of autistic people to identify sensory issues.
- c) Ensure provision of appropriate sensory adaptation equipment such as noisecancelling headphones, coloured lenses/filters, accessibility settings on technology etc and access to sensory stimulation opportunities
- d) Promote 'reasonable adjustments' and the legal requirement for organisations to ensure equality of access for people with a disability, including the need to critically appraise policies and procedures.

Key guidance

General guidance and references to key legislation are shown in the appendices. Guidance or resources with specific relevance to this capability is shown below:

- Autistica Action Briefing: Enabling Environment
- <u>National Autistic Taskforce</u>, An independent guide to quality care for autistic people: Key element of quality care: Tackle environmental and other stressors
- National Autistic Society website: https://www.autism.org.uk/about/behaviour/sensory-world.aspx
- Autism Education Trust, Autism Competency Framework. https://www.autismeducationtrust.org.uk/shop/schools-cf-shop/

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Capability 6. Families and carers as partners in care and support

Tier 2

The person or practitioner will be able to:

- a) Understand and promote the significance and value of families, carers and social networks (where an autistic person has and wishes to involve these) in planning and providing care and support for autistic people, including in Best Interests decision making.
- b) Establish and maintain positive relationships with families and carers and understand the importance of discussing when and how they would like to be involved in the person's care or support and when and how the autistic person would like them to be involved in their care or support.
- c) Recognise the positive and negative impact that caring for an autistic person in the family may have on relationships and family members' own wellbeing, including the possibility of parents, carers, and/or family members being autistic themselves and be able to signpost to carer assessments²⁵ as appropriate.
- d) Understand the importance of providing information and advice and where appropriate, training, to families and carers. Utilise their expertise (in addition to that of autistic people) in developing training.
- e) Work with families to enable them to access support in their role as carers. This may include providing sensitive and balanced support for parents in denial or under great stress, parents who struggle to accept a disabled person's adulthood and those whose focus is on curing or eliminating autistic traits.
- f) Recognise that the needs and wishes of family members and/or carers may not be the same as the needs and wishes of the autistic person
- g) Be aware of and responsive to each families' own culture, traditions and style of interaction.
- h) Contribute to the development of practices and services that actively reflect the wishes and needs of families and carers.

²⁵ S.10 & 20 Care Act 2014 & s.17ZD-F Children Act 1989 as amended by s.97 Children and Families Act 2014

Tier 3

The practitioner will be able to:

- a) Ensure that the impact that caring for an autistic person may have on relationships and family members' own wellbeing are assessed including the sustainability of the caring relationship and that carer's needs are met in line with statutory requirements²⁶.
- b) Evaluate how family and carer relationships and needs may change over the life course and during periods of transition, organising services to provide effective transition pathways which promote early planning.
- c) Resolve dilemmas arising where there are differing needs or aspirations between autistic people and their families and carers and be able to advise practitioners on how these can be resolved.
- d) Be able to co-produce a plan to support families and carers providing care for an autistic person and ensure support is provided in line with statutory duties to meet those needs²⁷, including access to carers' personal budgets.
- e) Support access to statutory, voluntary and community support for carers (such as parental support groups, family support groups, and community groups), considering the needs of parent/carers and carers of autistic people, including those who may be autistic themselves.
- f) Understand and implement legislation relevant to families' and carers' rights²⁸ and act as a source of further information for families and carers around legal issues (e.g., mental capacity law including best interests' decision making, deputyship, deprivation of liberty).
- g) Co-ordinate and contribute to reviewing partnership work with families and carers.

Key guidance

General guidance and references to key legislation are shown in the appendices. Guidance or resources with specific relevance to this capability is shown below:

- NICE Clinical Guidance [CG142], Autism spectrum disorder in adults: diagnosis and management/1.7 Assessment and interventions for families, partners and carers at: https://www.nice.org.uk/guidance/CG142
- National Autistic Society: https://www.autism.org.uk/about/family-life.aspx

²⁶ Local authorities have a statutory duty to carry out Parent/carer assessments under s17ZD- s17ZF Children Act 1989 (as amended by Children & Families Act 2014) and Carer assessments (for Carers of adults) under s.10 Care Act 2014

²⁷ s.17 Children Act 1989 requires local authorities to decide whether the provision of care and support could meet the needs of parent/carers. For carers of adults, s.13 and s.20 Care Act require local authorities to consider the eligibility of a Carers needs (under national statutory eligibility criteria) and to meet eligible needs.

²⁸ Particularly Care Act 2014, Children Act 1989, Children and Families Act 2014

- Autism Education Trust, Autism Competency Framework. https://www.autismeducationtrust.org.uk/shop/schools-cf-shop/
- Social Care Institute for Excellence (SCiE): Improving access to social care for adults with autism: Carers
- Department of Health (2014), Care and Support Statutory Guidance: Issued under the Care Act 2014
- Department of Health (2014), Care Act Factsheets, Factsheet 8: The law for carers
- NICE guideline Carers: provision of support for adult carers (expected publication January 2020)
- Skills for Care, guide to working with families.

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Capability 7. Supporting changes throughout life

Tier 2

The person or practitioner will be able to:

- Support people to express preferences and anxieties when going through change and adapt support methods to take account of their views, using a personcentred approach.
- b) Support autistic people to develop and maintain routines, structure and systems to create order in ways that are helpful to them.
- c) Recognise that uncertainty and unpredictability cause stress and provide clear information that reduces stress.
- d) Be honest with people about transitions, recognising that withholding potentially upsetting information may worsen rather than alleviate distress.
- e) Recognise and provide support for the challenges an autistic person may face with moving from childhood into adulthood, including carrying out timely transition assessments²⁹.
- f) Provide information, advice and support for autistic people, their families and carers to enable involvement, choice and control at times of change. For example, practical and emotional support may relate to finances, education, employment, retirement, bereavement, palliative or end of life care.
- g) Identify recent or imminent changes affecting autistic people and support them to assess the implications and likely impacts of the change identified.
- h) Evaluate the impact of age-related changes on older autistic people, including dementia and frailty, and how services can best meet their needs.
- Recognise the importance of identifying and assessing the changing health and social care needs of autistic people.
- j) Provide accessible information, advice and support which is tailored to an individual's communication needs.
- k) Identify how and when to seek additional expertise and advice when supporting a person through change.

²⁹ s.58 & s.60 Care Act 2014 requires local authorities to carry out assessments of a young person's adult needs for care and support and those of their carer at a time appropriate to the young person in advance of them turning 18.

Tier 3

The practitioner will be able to:

- a) Develop policies and procedures which prioritise autistic needs for:
 - i. accurate, honest and specific information
 - ii. routine, structure and predictability
 - iii. preparation for transitions/changes.
- b) Take a 'whole life' approach: recognising and planning well in advance for transitions throughout the lifespan (e.g. moving to adult services, further/higher education, graduation, employment, marriage, bereavement and ageing).
- c) Analyse factors that may make change a positive or a negative experience and support the development of policies, routines and systems where these may benefit autistic people.
- d) Implement approaches likely to enhance a person's ability to manage change and experience change positively, including changes to the organisation of services.
- e) Recognise and promote the value of early and timely intervention on the lives of children and young autistic people and their families.
- f) Be able to support an autistic young person and their family and carers to reflect on the transition into adulthood, promoting and facilitating access to transition assessments in line with statutory requirements³⁰.
- g) Evaluate the support provided during each period of change, working with the person and others to identify positive and negative aspects of a change.
- h) Support an autistic individual to maximise their control of changes and transitions and make choices.
- i) Advocate for advance planning and for the importance of continuity from commissioners and manage services in a way which minimises unnecessary change and maximises early planning for transitions at all ages.

³⁰ s.58 & s.60 Care Act 2014 requires local authorities to carry out assessments of a young person's adult needs for care and support and those of their carer at a time appropriate to the young person in advance of them turning 18

General guidance and references to key legislation are shown in the appendices. Guidance or resources with specific relevance to this capability is shown below:

- National Autistic Society:
 - o https://www.autism.org.uk/about/transition.aspx
 - https://www.autism.org.uk/about/family-life.aspx
- <u>National Autistic Taskforce</u>, An independent guide to quality care for autistic people: Key element of quality care: Ensure better transitions
- Council for Disabled Children (2017) These are our children.
 https://www.ncb.org.uk/sites/default/files/field/attachment/These%20are%20Our%20CHildren_Lenehan_Review_Report.pdf
- Autism Education Trust, Autism Competency Framework. https://www.autismeducationtrust.org.uk/shop/schools-cf-shop/
- <u>Social Care Institute for Excellence (SCiE):</u> Improving access to social care for adults with autism: Transition

Capability 8. Supporting autistic people where behaviour may challenge

Tier 2

The person or practitioner will be able to:

- a) Understand and support the important role families and carers have in supporting autistic people where behaviour may challenge, in addition to the full involvement of the person themselves.
- b) Recognise behaviour perceived as challenging as a possible indication of distress and focus on the removal of environmental and other stressors as a priority over modification of the behaviour.
- c) Avoid assumptions that behaviour which may challenge is an inevitable part of autism and seek to identify underlying causes and meet needs, such as reducing sensory overload, providing information or avoiding unpredictability.
- d) Consult the autistic person and their family/support regarding what causes distress or anxiety in order to understand and respect an autistic person's perspective.
- e) Support autistic people to have a 'plan B' or a range of responses should things become difficult.
- f) Be proactive in de-escalating situations, for example, preventing 'meltdown' or 'shutdown' by facilitating ways to alleviate stress (such as access to a quiet space or ending an interaction).
- g) Be able to accept, understand and accommodate behaviours that are unique to the autistic person and which do not infringe the rights or safety of others.
- h) Understand stimming, including promoting it when it can be helpful and know where to seek support if it becomes harmful.
- i) Understand the interactions between the quality of a person's life (including physical health problems / pain and exposure to sources of stress including uncertainty, change, interaction/communication/sensory overload and demands) and behaviours that may be interpreted as 'behaviours that challenge'.
- j) Understand that autistic people may be at increased risk of misuse of restrictive practices, including physical and chemical restraint and seek to provide care and support in ways which avoid and prevent any need for restrictive practices.
- k) Be able to follow a behaviour support plan in the wider context of an overall care plan; according to specified responsibilities and timeframes.

I) Understand when the support of a 'specialist' might be needed and how to access them, avoiding assumptions and labels such as 'unpredictable', 'complex' or 'challenging'.

Tier 3

The practitioner will be able to:

- a) Co-produce with people, their families and carers, and the appropriate members of the multi-disciplinary team least restrictive behaviour support plans, which seek to identify unmet needs and environmental factors, rather than focusing narrowly on eliminating problematic behaviours
- b) Formulate and advocate for appropriate reactive strategies that are person centred and evidence based³¹, whilst seeking to develop and promote preventative strategies that work with the autistic person to minimise the need for reactive strategies.
- c) Promote, teach and support skills that will facilitate person-centred behaviour support plans, including challenging assumptions that 'behaviour' is an inevitable part of autism.
- d) Provide supervision to colleagues and teams following an intervention, recognising the impact of behaviours that challenge on people supporting an autistic person.
- e) Monitor the delivery of a behaviour support plan and contribute to the evaluation/review of its effectiveness and its consistency with the wellbeing and quality of life of the autistic person.

Key guidance

General guidance and references to key legislation are shown in the appendices. Guidance or resources with specific relevance to this capability is shown below:

- National Autistic Society:
 - https://www.autism.org.uk/about/behaviour.aspx
 - o https://www.autism.org.uk/about/behaviour/challenging-behaviour.aspx
- <u>National Autistic Taskforce</u>, An independent guide to quality care for autistic people: Key element of quality care: Recognise behaviour as distress
- Autism Education Trust, Autism Competency Framework. https://www.autismeducationtrust.org.uk/shop/schools-cf-shop/
- Health Education England (2019), Providing community forensic services for people with Learning Disabilities and/or Autistic Spectrum Conditions: Workforce

³¹ See '<u>The Autism Dividend'</u>, National Autism Project for a comprehensive review of the (very limited) evidence base

- Competency Framework: https://www.hee.nhs.uk/our-work/learning-disability/workforce-capability
- Reducing Restrictive Intervention of Children and Young People (The Challenging Behaviour Foundation, 2019)
- Stopping over medication of people with a learning disability, autism or both (STOMP)
- <u>Supporting Treatment and Appropriate Medication in Paediatrics (STAMP)</u> https://www.england.nhs.uk/learning-disabilities/improving-health/stamp/
- NICE Clinical Guidance [CG142], Autism spectrum disorder in adults: diagnosis and management/1.5 Interventions for challenging behaviour at: https://www.nice.org.uk/quidance/CG142
- NICE Autism Quality Standard https://www.nice.org.uk/guidance/qs51
- NICE Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges https://www.nice.org.uk/guidance/ng11
- Skills for Care: Behaviours which challenge https://www.skillsforcare.org.uk/Learning-development/ongoing-learning-and-development/behaviours-which-challenge/Behaviours-which-challenge.aspx
- BILD, Restraint Reduction Network
- Bradley, Elspeth & Caldwell, Phoebe (2013) Mental Health and Autism: Promoting Autism FaVourable Environments (PAVE), Journal on Developmental Disabilities . 2013, Vol. 19 Issue 1, p8-23. 16p.
- National Autistic Society SPELL https://www.autism.org.uk/about/strategies/spell.aspx
- Mills, R & McCreadie, M (2018) SYNERGY: Knowing me knowing me.
 Changing the story around 'behaviours of concern'. Promoting self-awareness,
 self-control and a positive narrative Milton, D et al (2016) TEN RULES for
 ensuring people with learning disabilities and those who are on the autism
 spectrum develop 'challenging behaviour' ... and maybe what to do about it.
 Hove: Pavillion

Capability 9. Forensic support

Tier 2

The person or practitioner will be able to:

- a) Confidently identify, advocate for and implement reasonable adjustments for autistic people within the Criminal Justice System.
- b) Be aware of the likelihood of past, present and future trauma and risk of victimisation of autistic people and recognise vulnerability and needs, alongside any risks of offending behaviour.
- c) Carry out a risk assessment, relevant to the autistic person and integrate risk assessment into the planning and provision of care, clearly distinguishing between offending behaviour and autistic behaviour which does not infringe the rights of others.
- d) Work to assess and manage risk in conjunction with the multi-disciplinary team, in a multi-agency environment, including helping to identify and monitor factors (both internal and external to the autistic person) which indicate increased or reduced risk.
- e) Contribute to the formulation of crisis and emergency plans, including supporting the development of an autistic person's own coping strategies
- f) Contribute to the identification of and provision to meet educational and support needs relevant to offending behaviour: such as sex and relationships education; social understanding and skills including support to recognise exploitation; emotional regulation skills; and positive ways to meet sensory needs.
- g) Become aware of good practice and know how to adapt approaches to working with autistic offenders.
- h) Manage actual or potential aggression in line with current legal requirements and best practice (see Capability 8).
- Respond to an autistic person's communication needs and recognise the roles of unmet communication needs and miscommunication in risky and challenging behaviour.
- j) Recognise the impact of the autistic person's activities on family and friends.
- k) Recognise the impact of any victim considerations and ministry of justice restrictions.
- I) Identify early signs of relapse and crisis and how to articulate this in relation to the autistic person and their family.
- m) Recognise own emotional response to the autistic person's risk factors and actions and use techniques to minimise the impact on the service and the person themselves.

Tier 3

The practitioner will be able to:

- a) Appraise factors which contribute to risk of autistic people entering the criminal justice system and promote and facilitate preventative strategies within and beyond own agency.
- b) Promote 'reasonable adjustments' within the Criminal Justice System and the legal requirement for organisations to ensure equality for people with a disability, including the need to critically appraise policies and procedures.
- c) Promote and facilitate diversion from the Criminal Justice System when appropriate.
- d) Develop and implement risk and safety management plans, using collaborative approaches which respect the autistic person's own perspective.
- e) Understand the autistic person's forensic background and how to effectively manage the risk to themselves and to others, clearly distinguishing between offending behaviour and autistic behaviour which does not infringe the rights of others.
- f) Undertake dynamic assessment of risk to the public/other people and the autistic person, informed by awareness of the likelihood of past, present and future trauma and risk of victimisation of autistic people and importance of recognising vulnerability and needs, alongside any risks of offending behaviour.
- g) Assess and prioritise autistic people's eligibility for services and ensure that relevant and objective information is obtained from referrers and shared with those providing care and support, in accordance with the law³²
- h) Support access to own agency in accordance with the terms of the service including eligibility criteria/requirements (e.g. age, level of risk), offering reasonable adjustments and, whenever possible, flexibility.
- i) Apply knowledge of Mental Capacity and Mental Health law appropriately in Criminal Justice practice situations involving Autistic Individuals.
- j) Work with the autistic person, families, referrers, and social care support to ensure there is a shared understanding of the expectations and boundaries of the service.
- k) Understand the role of liaison professionals, particularly in relation to the Criminal Justice System.
- I) Build relationships, engage and motivate autistic people who are reluctant to use the service, adapting communication as appropriate (see Capability 4).
- m) Plan a pathway with an autistic person (in line with Capability 3), recognising the role of other services and organisations and the importance of effective care coordination.

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³² GDPR and Data Protection Act 2018

- n) Recognise an autistic person's strengths and resilience and how to support the most appropriate care or referral taking into account the views and needs of the autistic person (in line with Capability 3).
- o) Know how to ensure care planning, transfers, transitions and discharge are compliant with requirements of Mental Health, Mental Capacity and Criminal law codes of practice, protocols and procedures particularly where an autistic person has specific conditions relating to their discharge or treatment.
- p) Evaluate factors that cause or maintain offending behaviours and will limit the autistic person's opportunities, including those internal and external to the autistic person.
- q) Be aware of multiple/simultaneous perspectives of the autistic person, who maybe both victim and perpetrator.
- r) Understand how autism, mental health, personality disorder and post-traumatic stress disorder affect the presentation and offending behaviour in the person and the impact this has on the planning of care and/or treatment.
- s) Know how to plan transfers and transitions between, and discharge from services, seeking to provide care and support in the least restrictive and most community-based way possible.
- t) Understand the importance of record keeping and appropriate, lawful information sharing in managing forensic risk.

General guidance and references to key legislation are shown in the appendices. Guidance or resources with specific relevance to this capability is shown below:

- Providing community forensic services for people with Learning Disabilities and/or Autistic Spectrum Conditions: Workforce Competency Framework, Health Education England (2019), (https://www.hee.nhs.uk/)
- National Autistic Society website/Criminal Justice: https://www.autism.org.uk/professionals/others/criminal-justice.aspx
- Autism West Midlands (2016) Autism and the Criminal Justice System: Advice and Guidance for professionals, http://www.gain-grantham.co.uk/wp-content/uploads/2016/12/ASD-and-Criminal-Justice.pdf
- ARC UK (2016) People with learning disabilities in the Criminal Justice System: a guide for carers and learning disability services, https://arcuk.org.uk/wp-content/uploads/2016/04/PWLD-in-the-CJS-Guide.pdf
- Gwillim, Peter (2009) Police awareness of autism and how to deal with the criminal justice system, Presentation at Autscape: http://www.autscape.org/2009/presentations#police-autism
- The Advocate's Gateway, Planning to Question someone with an autistic spectrum disorder including Asperger Syndrome, https://www.theadvocatesgateway.org/images/toolkits/3-planning-to-question-someone-with-an-autism-spectrum-disorder-including-asperger-syndrome-

<u>2016.pdf</u>Judicial College (2018) Equal Treatment Bench Book, https://www.judiciary.uk/wp-content/uploads/2018/02/equal-treatment-bench-book-february-v6-2018.pdf

- Dickie, Iain, Reveley, Shirley and Dorrity, Austin (2018) The criminal justice system and people on the autism spectrum: perspectives on awareness and identification. Journal of Applied Psychology and Social Science, 4 (1). pp. 1-21. http://insight.cumbria.ac.uk/id/eprint/3933
- Clare S. Allely, (2018) "A systematic PRISMA review of individuals with autism spectrum disorder in secure psychiatric care: prevalence, treatment, risk assessment and other clinical considerations", Journal of Criminal Psychology, Vol. 8 Issue: 1, pp.58-79, https://doi.org/10.1108/JCP-06-2017-0028



Capability 10. Relationships, sexuality and sexual health

Tier 2

The person or practitioner will be able to:

- Support autistic people to maintain their relationships with family members and other people in their social network and to develop new friendships and relationships, if desired
- Support autistic people to maintain existing relationships and develop new friendships and relationships if desired
- c) Support and facilitate the delivery of age appropriate and autism specific sex and relationships education across the lifespan, including support in recognising healthy and unhealthy relationships and online risks and issues³³
- d) Understand how to support people to say no to unwanted relationships including when they may be at risk of 'mate crime' or 'cuckooing', including recognising the role of public services in taking appropriate actions directed towards perpetrators of abuse to prevent and intervene in criminal activity.
- e) Be able to support the sexual expression of an autistic adult, including with LGBTQ+ issues using appropriate (including age-appropriate) approaches
- f) Know how to support autistic young people and adults to identify, access and use services to meet their sexual health needs as appropriate, including the importance of preventive education and healthcare.

Tier 3

The practitioner will be able to:

a) Support autistic people to identify healthy relationships, develop new friendships and relationships if desired and to maintain existing relationships.

Autism and appropriate touch

Family Planning Association Talking together about Growing Up

Family Planning Association Talking together about sex and relationships

Hartman, Davida Sexuality and Relationship Education for

Children and Adolescents with ASD

Kate Reynolds Sexuality and Severe Autism

2008 Review of Resources

Kate E. Reynolds books

An Exceptional Children's Guide to Touch: Teaching Social and

Physical Boundaries to Kids

The Growing up book for boys

The growing up guide for girls

Sex and the law - for young people

³³ Family Planning Association (2007) Jiwsi: A pick 'n' mix of sex and relationships education activities (free download)

- b) Evaluate factors that can influence the process of a relationship and work with autistic people to review the support they need to maintain and develop relationships.
- c) Evaluate factors affecting the ability of autistic people to develop and/or maintain friendships and relationships and recognise the impact of relationships and social networks on wellbeing and self-esteem.
- d) Actively promote and support autistic people to participate in their local community or social network if they wish to do so.
- e) Identify and evaluate needs for autism-specific sex and relationship education across the lifespan and across the spectrum and how these needs can be met, including taking account of the impact of changing and developing technology.
- f) Appraise the potential for autistic adults to be at risk of entering the criminal justice system due to perceived inappropriate sexual behaviour.
- g) Evaluate the impact of social and family contextual factors on the sexual and sexual health needs of autistic adults.
- h) Recognise the risk of 'setting the bar too high' in assessing capacity to consent to sex, marriage and civil partnerships and support autistic adults to develop capacity to make their own decisions in these areas whenever possible.
- i) Enable autistic adults who are parents to access appropriate support if needed, including consideration of the relevance of parenting responsibilities in meeting adult social care needs³⁴
- j) Support autistic people to develop the ability to recognise abuse, sexual offences and hate crime whenever possible.

General guidance and references to key legislation are shown in the appendices. Guidance or resources with specific relevance to this capability is shown below:

- National Autistic Society: https://www.autism.org.uk/sexeducation
- St. Clement's Practical Autism Video Guides: Sexuality
- Care Quality Commission (CQC): <u>Relationships and sexuality in adult social care</u> services
- <u>National Autistic Taskforce</u>, An independent guide to quality care for autistic people: Key element of quality care: Accept difference and support positive autistic identity

³⁴ Reg. 2(2)(j) The Care and Support (Eligibility Criteria) Regulations 2015

Capability 11. Meaningful activity and independence

Tier 2

The person or practitioner will be able to:

- a) Be aware of how views and attitudes of others can impact on the lives of autistic people and their families and carers.
- b) Know how to support autistic people to develop and continue their interests, social life and community involvement and know why this is important³⁵.
- c) Recognise and encourage the importance of passionate interests and hobbies.
- d) Support autistic people to develop, retain or regain skills for everyday life, including practical tasks, decision making and positive risk taking, accounting for age.
- e) Provide support for autistic people to manage their finances and maximise their capacity to make their own financial decisions
- f) Be able to support autistic people to maximise their control over their own support, including through the use of direct payments.
- g) Support autistic people to choose and use professional services and facilities and decide how long to use them for (for example, housing, transport and leisure services).
- h) Understand the rights of an autistic person in relation to reasonable adjustments when accessing and using services and support them to advocate for adjustments and adaptations as necessary.
- Understand the value of engagement in education, training, employment or meaningful occupation for autistic people and their potential to contribute to society.
- j) Be aware of the support available to autistic people to access education, training and employment.
- k) Understand factors that impact on autistic people being able to navigate their physical and social environment, including discrimination, bullying and hate crime.
- I) Be aware of how everyday technology such as google maps, skype and apps for task planning, calendars online shopping etc. can be used to enable autistic people to choose and use the full range of social interaction available in a way which works for them.
- m) Recognise and respond to the cultural, religious and spiritual needs of autistic people.

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^{35 &#}x27;Social Skills', St. Clement's Practical Autism

- n) Support autistic people to draw on their strengths to manage setbacks and personal difficulties.
- o) Understand the importance of a positive, person-centred approach to risk and how this is supported by the legal framework³⁶.

Tier 3

The practitioner will be able to:

- a) Recognise the development of 'asset-based' approaches which considers the strengths and potential of people and communities, whilst discouraging inappropriate use as a substitute for the role of statutory services in meeting needs.
- b) Actively assist autistic people to develop support plans to meet their identified needs, interests and right to make choices. This may include support to:
 - I. develop and maintain skills for everyday life, including decision-making and self-advocacy
 - II. access services and facilities including housing, transport, community and leisure services and rights of citizenship (including voting)
 - III. access education, training and employment and make a meaningful contribution to society.
- c) Understand why appropriate housing is especially important to autistic people and recognise the advantages and disadvantages of; remaining in the family home; residential care; group living, renting and home ownership (either family funded or possibly through the Government backed HOLD³⁷ model).
- d) Understand how to support access to housing where an individual may lack capacity to make a homelessness application or sign a tenancy³⁸
- e) Signpost and facilitate access to Disabled Facilities Grants and equipment when appropriate.
- f) Evaluate the value of a broad range of assistive living technologies (new and emerging) in developing a support plans for autistic people, depending on their suitability to the needs of the individual³⁹.
- g) Facilitate the implementation of care and support plans led by the autistic person and working with others including family members and those in mainstream health and social care services.

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³⁶ Care Act 2014, Mental Capacity Act 2005, Human Rights Act 1998

³⁷ Home Ownership for people with Long-term Disabilities

³⁸ By making applications to the Court of Protection when needed.

³⁹ See <u>LGO report</u>

- h) Facilitate a person-centred review of support plans in partnership with the autistic person and others⁴⁰.
- i) Support autistic people to manage their finances and maximise their capacity to make their own financial decisions, including how to use their personal budget to help them live well and take part in meaningful activities.
- j) Demonstrate a comprehensive understanding of how to signpost and refer to professional advice services, including services to support an autistic person and/or their family to challenge the decisions of professionals.
- k) Critically evaluate the role of positive risk taking and duty of care in enabling a person-centred approach, supporting legally literate and defensible decisionmaking which recognises the need for a rights-based approach balancing protection and autonomy⁴¹.
- I) Promote and contribute to the development of practices and services that meet the individual needs of autistic people.

General guidance and references to key legislation are shown in the appendices. Guidance or resources with specific relevance to this capability is shown below:

- National Autistic Society:
 - Autism Employment Gap: https://www.autism.org.uk/get-involved/campaign/employment.aspx
 - https://www.autism.org.uk/about/adult-life/work.aspx
- Autistica Action Briefing: Employment
- National Autistic Taskforce, An independent guide to quality care for autistic people: Key element of quality care: Respect and promote autonomy
- Autism Education Trust, Autism Competency Framework. https://www.autismeducationtrust.org.uk/shop/schools-cf-shop/
- NHS England, LGA and ADASS (2016), Building the Right Home. https://www.england.nhs.uk/learningdisabilities/wp-content/uploads/sites/34/2015/11/building-right-home-quidance-housing.pdf

⁴⁰ As required by s.27 Care Act 2014, s.44 Children and Families Act 2014, s.17 Children Act 1989.

⁴¹ See for example CQC State of Care 2017-8, p.123

Domain C. Physical and mental health

Introduction

Autistic people (children, young people and adults) have a right to access good quality healthcare. Autistic people generally have more health problems than other people and a higher risk of premature death. There are many reasons including above average rates of co-occurring conditions; lack of understanding and awareness among health and other professionals; difficulties faced by some autistic people and those who support them in recognising symptoms and expressing their needs; poor information systems; and the fact that many autistic people are economically and socially disadvantaged⁴²⁴³.

Health and social care staff need the capabilities to support and encourage autistic people to optimise their physical and mental health. They need to promote and implement reasonable adjustments, remove barriers to access and enable the health needs of autistic people to be met.

⁴² Westminster Commission on Autism (2016) A spectrum of Obstacles https://westminsterautismcommission.files.wordpress.com/2016/03/ar1011_ncg-autism-report-july-2016.pdf

⁴³ National Autism Project (2017), The Autism Dividend

Capability 12. Physical health

Tier 2

The person or practitioner will be able to:

- a) Be aware that autistic people may live with other conditions or impairments that will also impact on their lives, for example physical impairments, visual impairment, mental health conditions (including eating disorders) or epilepsy or other neurodevelopmental conditions such as ADHD.
- b) Recognise the signs, symptoms, prevalence and potential impact on the lives of autistic people of common health conditions
- c) Know the function of different healthcare services that autistic people may need to access, such as psychologists, speech and language therapists, occupational therapists, dietitians and physiotherapists - and the barriers autistic people may face in accessing them.
- d) Suggest, encourage, support and promote healthy lifestyle options and make referral to services providing healthy lifestyle advice and options including support to take up offers of general health screening, whilst also respecting the rights of autistic adults to make unwise choices on an equal basis with others in society.
- e) Understand the benefits and risks of prescribed medication (including psychotropic medication) on the physical and mental health and the choices and rights of patients – including the potential for autistic people to have atypical reactions to medication.
- f) Fulfil professional duties related to the safe administration of medication where appropriate, identifying and supporting with additional needs around taking medication (such as needing prompting).
- g) Understand the role of families and carers in supporting the health and wellbeing of autistic people.
- h) Contribute to development of health action plans with autistic people, including identifying reasonable adjustments and unmet support needs.
- Recognise the potential impact of sensory differences on the autistic person being able to recognise themselves when they are feeling unwell, and the potential for differences in interpreting pain sensations
- j) Refer autistic people to specialist healthcare services for assessment, diagnosis and support and encourage them to persist in liaison with specialist services, providing support to do so when needed.
- Support autistic people to make healthcare decisions including advocating for reasonable adjustments such as provision of accessible information and processing time

Tier 3

The practitioner will be able to:

- a) Promote and advocate for reasonable adjustments and processes to support autistic people to access healthcare services, including support for healthcare decision making.
- b) Support others to develop, implement, and monitor health action plans and participate effectively in care and treatment reviews, actively supporting movement towards community-based care.
- c) Monitor, evaluate and improve the effectiveness of health promotion activities.
- d) Identify the function of different healthcare services and the role of professionals within different healthcare services that autistic people may need to access.
- e) Recognise when an autistic person may need support to access healthcare services and/or to execute healthcare plans
- f) Refer autistic people to specialist healthcare services for assessment and diagnosis where appropriate.

Key guidance

General guidance and references to key legislation are shown in the appendices. Guidance or resources with specific relevance to this capability is shown below:

- National Autistic Society:
 - https://www.autism.org.uk/about/health.aspx
 - https://www.autism.org.uk/professionals/health-workers.aspx
 - https://www.autism.org.uk/about/health/doctor.aspx
- Autistica Action Briefing:
 - Eating disorders
 - Epilepsies
 - Other co-occurring conditions
 - Health checks

Capability 13. Mental health

Tier 2

The person or practitioner will be able to:

- a) Understand that mental health conditions are frequent and commonly overlooked in autistic people.
- b) Understand the role of trauma in the lives of autistic people which may lead to a wide range of mental health problems in later life and the importance of building trusting relationships and providing support to making choices to enable empowerment
- c) Recognise that mental health conditions may develop and present in different ways from non-autistic people and recognise signs or symptoms e.g. repeated self-harm or self-injurious behaviour.
- d) Recognise when an autistic person may be experiencing mental distress, including suicidal thoughts and intentions.
- e) Support autistic people to develop and maintain good mental health including lifestyle choices such as exercise, pets and social interaction of the person's choice and through developing positive attitudes to autism.
- Recognise the issue of over-medication of autistic people and know how to address this.
- g) Understand that autistic people with mental health needs may present with complex or challenging behaviour which masks other difficulties such as with communication.
- h) Create opportunities for autistic people to express their feelings, including feelings of loss, grief and bereavement, and anger and frustration, in ways which are meaningful to them.
- i) Know the function of different mental health services that autistic people may need to access (such as occupational therapists, counsellors, psychologists, psychiatrists, and mental health nurses) and where to refer an autistic person with a suspected mental health condition.
- j) Coordinate and communicate with key people and services in the life of the autistic person and a mental health condition.

Tier 3

The practitioner will be able to:

- a) Recognise the signs, symptoms, prevalence and potential impact on the lives of autistic people of mental health conditions including (but not limited to)
 - i. psychoses
 - ii. neuroses and stress related disorders
 - iii. personality disorders
 - iv. other neuro-developmental conditions such as ADHD
 - v. mood disorders (including suicidality)
 - vi. substance misuse
 - vii. dementia and confusional states
 - viii. eating disorders
 - ix. sexual and gender identity
- b) Evaluate the importance of autonomy through occupations, meaningful activity and social engagement as 'protective factors' in maintaining positive mental health.
- c) Analyse why autistic people are at increased risk of mental health conditions.
- d) Be able to provide trauma informed care so that autistic people are not traumatised by services
- e) Analyse why mental health conditions may be overlooked in autistic people e.g. due to complex or atypical presentations and/or diagnostic overshadowing.
- f) Understand that autistic people commonly need adapted mental health therapies and that typical therapies (such as group CBT) are likely to be both ineffective if not adapted and very challenging to access due to sensory and social challenges.
- g) Explore and appraise the needs of autistic people and a mental health condition, supporting and actively planning for community-based services and to minimise the use of compulsion under the Mental Health Act.
- h) Support an autistic person with a mental health condition to access and use specialist and personalised assessment, and care, treatment and support, recognising that reasonable adjustments may be required to standard mental health assessments, approaches and treatments.

Key guidance

General guidance and references to key legislation are shown in the appendices. Guidance or resources with specific relevance to this capability is shown below:

 NICE Clinical Guidance [CG142], Autism spectrum disorder in adults: diagnosis and management/1.6 Coexisting mental disorders at: https://www.nice.org.uk/guidance/CG142

- National Autistic Society:
 - Transforming Care: Our Stories: https://www.autism.org.uk/get-involved/media-centre/news/2017-09-26-transforming-care.aspx
 - Beyond Transforming Care: https://www.autism.org.uk/get-involved/media-centre/news/2018-12-06-beyond-transforming-care.aspx
 - https://www.autism.org.uk/about/health/mental-health.aspx
 - o https://www.autism.org.uk/about/health/mental-health-care.aspx
- Autistica Action Briefing:
 - o Adult mental health
 - o Children and young people's mental health
 - Suicide prevention
- Core Skills/Capabilities Frameworks (<u>www.skillsforhealth.org.uk/cstf</u>)
 - o Mental Health Core Skills Education and Training Framework
 - Dementia Training Standards Framework

Capability 14. Health equality and reasonable adjustments

Tier 2

The person or practitioner will be able to:

- a) Understand the health inequalities commonly experienced by autistic people, including early mortality.
- b) Understand the importance of access to appropriate healthcare for autistic people.
- c) Understand the key barriers that may prevent autistic people accessing appropriate healthcare, including diagnostic overshadowing, failure to follow legal duties in the Mental Capacity Act, inappropriate decisions not to treat or withhold lifesaving care, inaccessible information, lack of co-ordination of care, failure to make reasonable adjustments and failure to provide necessary support to carry out healthcare activities or follow advice.
- d) Be aware of current legislation, policies and guidance relevant to autistic people accessing healthcare⁴⁴.
- e) Understand how annual health checks and health action plans can underpin long term health and wellbeing for autistic people.
- f) Know the importance of health passports, communication passports, health action plans, hospital traffic lights or hospital passports / books and how these can provide important information about a person's communication and care needs and any potential hazards such as a risk of choking, known allergies and epilepsy and how to interpret and use the information within them.
- g) Identify a number of methods by which a person's support needs may be flagged to healthcare providers, including the GP Learning Disability Register and additional information on summary care records (SCRs).
- h) Understand the unique roles that both health and social care professionals may play in the care and support of an autistic person and be aware of the importance of care co-ordination and working together.
- Understand how limited communication and health literacy may reduce the ability
 of autistic people to convey health needs effectively to others and the
 adjustments to practice, and support available, to overcome this.

⁴⁴ Equality Act 2010; Mental Capacity Act 2005; Human Rights Act 1998; Transforming Care; Learning Disability Mortality Review

- j) Identify the need for, and implement, reasonable adjustments to enable the health needs of autistic people to be met. Adjustments may include consideration around appointment times, duration and support required as well as adaptations to decision making (e.g. providing information about medication and other treatments in accessible formats and giving processing time).
- k) Understand how to identify the need for, and provide accessible information, as required by the Accessible Information Standard, tailored to the communication needs of autistic people including:
 - i. know how to find out if people have any information or communication needs and how to meet their needs
 - ii. understand how to seek out information around communication needs and respond to flags or additional information provided within a person's records or correspondence
 - iii. understand how to share information about people's communication needs with other providers of NHS and adult social care, and the legal basis for doing so⁴⁵.

Tier 3

The practitioner will be able to:

- a) Devise, implement and promote reasonable adjustments to meet people's support needs to improve outcomes for people, including greater independence and participation.
- b) Appraise how limited communication and health literacy may reduce the ability of autistic people to convey health needs effectively to others.
- c) Promote methods of sharing knowledge of an autistic person's health and communication needs e.g. health/hospital/communication passports/books. Advise how they provide important information about a person's communication and care needs (including for autistic people who do not have a Learning Disability) and any potential hazards such as a risk of choking, known allergies and epilepsy
- d) Implement current guidelines and principles aimed at stopping the overmedication of people with a learning disability and/or autism.

⁴⁵ While consent is good practice where possible, consent is not required. Under GDPR, personal information (including sensitive information) needed to carry out public tasks (such as the provision of health or social care) can be lawfully shared with professionals subject to professional confidentiality in order to provide health or social care. GDPR Article 6(1)(e) & s. 2 Sch.1 Data Protection Act 2018

- e) Work collaboratively across agencies and boundaries to improve inter-agency collaboration and communication, including best practice around named healthcare co-ordinators⁴⁶.
- f) Support and enable capacity building and partnership working to promote health equality and reasonable adjustments, challenging poor practice if appropriate.
- g) Implement appropriately and effectively, and communicate current legislation, policies and guidance relevant to autistic people accessing healthcare⁴⁷.
- h) 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. This includes the five-step process for:
 - i. Identification of needs
 - ii. Recording of needs
 - iii. Flagging of needs
 - iv. Sharing of needs
 - v. Meeting of needs.
- i) Actively promote sources of relevant local or national guidance, information and support⁴⁸.

General guidance and references to key legislation are shown in the appendices. Guidance or resources with specific relevance to this capability is shown below:

- National Autistic Society: https://www.autism.org.uk/about/health.aspx
- Autistica Action Briefing: Reasonable adjustments
- <u>National Autistic Taskforce</u>, An independent guide to quality care for autistic people: Key element of quality care: Remove barriers to access
- <u>Social Care Institute for Excellence (SCiE):</u> Improving access to social care for adults with autism: Assessment, accessibility and acceptability

⁴⁶ Learning Disability Mortality Review; also see for example Safeguarding Adults Review: Judy Benn https://www.cumbria.gov.uk/AdultSafeguarding/theboard/adultreviews.asp

⁴⁷ Equality Act 2010; Mental Capacity Act 2005; Human Rights Act 1998; Transforming Care; Learning Disability Mortality Review

⁴⁸ National Autistic Taskforce (2019) An independent guide to quality care for autistic people

Domain D. Risk, legislation and safeguarding

Introduction

Autistic people (children, young people and adults) have a right to live independent and fulfilling lives, including choice and control over any care and support they may need – recognising that their needs and abilities may change over time.

People providing care and support must therefore be fully aware of ethical issues such as the need to balance a person's safety with their right to make their own decisions, adopting a positive, person-centred approach to risk and, when necessary, best interests decision making. This includes recognising that autistic people must be given all practicable help before anyone concludes that they cannot make a decision – and that a person's needs and preferences sometimes conflict with those of others, including their families and carers.

Systems, processes and practice must be in place to effectively safeguard autistic people at risk of neglect, harm or exploitation. Issues of cultural and ethnic diversity, discrimination and stigma may also impact on the lives of autistic people, including the acceptance of the condition within their family or community. In addition, many of the characteristics covered by the Equality Act are related to the wider determinants of health of autistic people, including but not limited to a person's sexuality, gender or geographical location.

Capability 15. Law, ethics and safeguarding

Tier 2

The person or practitioner will be able to:

- a) Understand how legislation and policies protect the rights of autistic people.
- b) Be aware of key legislation relevant to mental capacity, deprivation of liberty, equality and human rights and differences between the rights of children and of adults.
- c) Understand that autistic adults have the right to make their own decisions and that, while capacity may be questioned and assessed, an adult does not have to prove they are able to make a decision themselves. If a person thinks an adult may lack capacity to make a decision, then they must demonstrate why that is the case.
- d) Understand that autistic adults may make what might be seen as eccentric or unwise decisions and that these, by themselves, do not necessary mean that they lack capacity to make their own decisions.
- e) Understand what practical steps can be taken to support an autistic person with making a decision⁴⁹
- f) Be able to support a person to get advocacy to help them make and communicate a decision⁵⁰.
- g) Understand that if a person is not capable of making a decision then anything done on their behalf must be in their best interests, in which their wishes and feelings and those of family/friends must be considered, and must be the least restrictive of their rights, in accordance with the Mental Capacity Act⁵¹.
- h) Understand that lacking capacity to make a decision at the time it needs to be made doesn't mean that the person is not capable of making that decision another time or of making other decisions.
- Know where to get advice to resolve tensions between duty of care and an autistic person's and/or family and carers wishes. Be aware of the importance of Human Rights in resolving such dilemmas.
- j) Communicate effectively about proposed care and support to enable an autistic person to make informed choices.
- k) Recognise a range of signs and factors which may indicate that an autistic person is experiencing neglect, abuse or exploitation.

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⁴⁹ s.1(3) Mental Capacity Act 2005

⁵⁰ s.67 & 68 Care Act 2014; s.37-39 and Sch.AA1 Mental Capacity Act 2005 (as amended); SEND Code of Practice 8.18, 9.29; Adoption and Children Act 20027(amended Children Act 1989)8; and The Advocacy Services and Representations Procedure (Children) (Amendment) Regulations 2004

⁵¹ s.1(5) & (6) & s.4 Mental Capacity Act 2005 and Chapter 5 MCA Code of Practice

- Know what to do if neglect, abuse, unsafe practices or exploitation is suspected, including how to raise concerns within local safeguarding or whistle blowing procedures.
- m) Understand the national and local context of safeguarding and protection from abuse for autistic people, including 'making safeguarding personal'.
- n) Effectively support autistic people to disclose harm or abuse.
- o) Understand ways to reduce the likelihood of abuse for autistic people.
- p) Understand the risks associated with the internet and online social networking and balance these with rights to equality and freedom of expression in accordance with the law⁵²
- q) Actively challenge others who are not behaving in an ethical way.

Tier 3

The practitioner will be able to:

- a) Understand and be able to follow in practice key legislation and case law relevant to mental capacity, deprivation of liberty, equality and human rights.
- b) Analyse implications for practice of key legal and ethical issues, including the importance of rights-based thinking in balancing protection and autonomy and clearly distinguishing between the decision making of public bodies and the decision making of autistic people
- Understand the legislation, regulations, case law and policies that underpin the Safeguarding of autistic people and recognise the potential for them to be used oppressively⁵³
- d) Evaluate the options available when informed consent may be compromised, including as a result of undue influence⁵⁴.
- e) Lead service provision that safeguards autistic people at risk of harm or abuse, including protecting their rights and freedoms.
- f) Manage inter-agency, joint or integrated working in order to safeguard autistic people at risk of harm or abuse.
- g) Monitor and evaluate the systems, processes and practices that safeguard autistic people at risk of harm or abuse.

⁵² See Re A (Capacity: Social Media and Internet Use: Best Interests) [2019] EWCOP 2 and Re B (Capacity: Social Media: Care and Contact) [2019] EWCOP 3

⁵³ Competence 8 National Competence Framework for Safeguarding Adults

⁵⁴ Consideration of the necessity and proportionality of options including prosecution or civil legal action against a perpetrator of undue influence, applications to the Inherent Jurisdiction of the High Court, Best Interests decision making in accordance with the Mental Capacity Act and, when necessary, applications to the Court of Protection

- h) Demonstrate a comprehensive understanding of the roles and responsibilities of the different agencies involved in safeguarding adults and children.
- i) Initiate and promote the appropriate sharing of safeguarding information with the relevant agencies, understanding and ensuring that staff understand how to do so lawfully⁵⁵.
- j) Recognise the actions to take if there are barriers to alerting the relevant agencies.
- k) Critically evaluate the role of self and others when supporting autistic people who have experienced harm or abuse.
- I) Initiate support for autistic people who have experienced harm or abuse.
- m) Recognise disability hate crime and how to report such incidents.

General guidance and references to key legislation are shown in the appendices. Guidance or resources with specific relevance to this capability is shown below:

- National Autistic Society:
 - https://www.autism.org.uk/about/strategy.aspx
 - https://www.autism.org.uk/about/health/mental-health-care.aspx
- National Autistic Taskforce, An independent guide to quality care for autistic people: Key element of quality care: Fight stigma and discrimination
- British Institute for Human Rights Practitioner's Guides
- Autism Alliance: Know your rights
- 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)
- Adult Safeguarding: Roles and Competencies for Health Care Staff (2018)
- <u>Safeguarding Children and Young People: Roles and Competencies for</u> Healthcare Staff (2019)

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⁵⁵ GDPR and Data Protection Act 2018

Capability 16. Equality, diversity and inclusion

Tier 2

The person or practitioner will be able to:

- a) be aware of one's own values and beliefs, including unconscious bias.
- b) know what is meant by:
 - i. diversity
 - ii. equality
 - iii. inclusion
 - iv. discrimination
 - v. ethnicity and religion
- c) Know ways in which discrimination may deliberately or inadvertently occur in an autistic person's local community.
- d) Understand how practices that support equality and inclusion reduce the likelihood of discrimination.
- e) Interact with people in ways that respect their beliefs, culture, values, preferences and right to equality with others, including where this does not involve treating people the same.
- f) Know how to challenge discrimination in a way that encourages positive change.
- g) Know who to ask for advice and support about equality and inclusion.
- h) Adapt assessment, support and care planning taking account of equality issues (e.g. cultural diversity, disabilities, gender and sexual orientation), including autism-specific needs.
- i) Recognise diversity in family arrangements and the local community.
- j) Actively challenge any discriminatory practice that may compromise the right of an autistic person to dignity, respect, safety and equality
- k) Be aware of the key legislation, policy and guidelines relating to autistic people, including one's own responsibilities under the Mental Capacity Act 2005, Mental Capacity (Amendment) Act 2019, the Equality Act 2010, the Care Act 2014, Human Rights Act 1998 and the Accessible Information Standard.

Tier 3

The practitioner will be able to:

- a) Understand and be able to support practitioners to understand legislation and case law relevant to equality, diversity and human rights.
- b) Analyse and seek to address the impact that discrimination, stigma and unconscious bias may have on the life of an autistic person, their family and carers, including those for whom a number of protected characteristics may be applicable.
- c) Lead practice and an organisational culture that values and respects equality, inclusion and the diversity of autistic people.
- d) Develop, promote and co-produce systems and processes that promote diversity, equality and inclusion.
- e) Recognise when own or others' behaviour undermines equality, diversity and human rights and take rectifying action.

Key guidance

General guidance and references to key legislation are shown in the appendices. Guidance or resources with specific relevance to this capability is shown below:

- National Autistic Society: https://www.autism.org.uk/about/bame-autism.aspx
- National Autistic Taskforce, An independent guide to quality care for autistic people: Key element of quality care: Fight stigma and discrimination
- British Institute for Human Rights Practitioner's Guides
- Department of Health (2014), Care and Support Statutory Guidance: Issued under the Care Act 2014
- Statutory/Mandatory Core Skills Education and Training Framework (CSTF) at: www.skillsforhealth.org.uk/cstf
 - Subject 1. Equality, diversity and human rights

Domain E. Leadership and management, education and research

Introduction

The delivery of high-quality autism care and support requires skilled and confident leaders and managers. People working in a leadership or management role are not only responsible for supporting autistic people (children, young people and adults), but also for taking care of their staff and influencing the quality of care across their organisation or sector.

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

The continuing development of autism care and support requires on-going research and development of evidence-based practice. This includes evaluating the outcomes and impact of services and interventions. When autistic people (children, young people and adults) agree to participate in research activities this must be handled with due regard for the ethical issues involved. Research should always meaningfully involve autistic people and families in its design, oversight and dissemination.

Capability 17. Leadership and management

Tier 2

The person or practitioner will be able to:

- a) Understand the features of effective team performance within autism care and support, including consistency and clear communication of information.
- b) Advocate for and practice co-production with autistic people and their families and carers.
- c) Support a positive culture and shared vision within the team and with autistic people for autism care and support.
- d) Support individual team members to work towards agreed objectives in autism care and support, ensuring that these objectives are consistent with promoting the wellbeing and quality of life of autistic people.
- e) Describe strategies and tools that could be adopted to reduce stress levels, to build resilience and to maintain the wellbeing of staff within the team.
- f) Know the appropriate type and level of resources required to deliver safe and effective services in autism care and support.

Tier 3

The practitioner will be able to:

- a) Evaluate key drivers and policies which influence national policy and service development, both specifically focussed on autism and in the context of health and social care policy more broadly, and analyse how these can be used to improve service delivery.
- b) Anticipate and prepare for the future by scanning for ideas, best practice and emerging trends that will have an impact on outcomes for autistic people.
- c) Understand the current legislative framework and organisational health, safety and risk management policies, procedures and practices that are relevant to autism care and support and support staff in positive risk taking, including implementing and learning lessons from analyses of past events (such as Safeguarding Adults Reviews) both locally and nationally.
- d) 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.
- e) Promote a culture where needs and rights are balanced with health and safety practice in autism care and support.

- f) Collate and share data across organisations in compliance with local protocols, legal⁵⁶ and professional requirements.
- g) Develop relationships with service commissioners to develop the capacity and capability for an integrated care system and Identify gaps in provision, particularly for community-based care and support, and encourage the development of services to meet needs
- h) Challenge poor and unethical practice in autism care and support, including risk averse practice.
- i) Demonstrate leadership in delivering compassionate, trauma informed, personcentred care.
- j) Understand the roles and responsibilities of different agencies involved in care and support for autistic people.
- k) Work across services and organisations to meet the needs of autistic people and complex medical conditions and those who rely on care and support from different agencies.

General guidance and references to key legislation are shown in the appendices. Guidance or resources with specific relevance to this capability is shown below:

- The Leadership Qualities Framework For Adult Social Care (NSA)
- NHS Leadership Academy

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⁵⁶ GDPR and Data Protection Act 2018

Capability 18. Education and personal development

Tier 2

The person or practitioner will be able to:

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

Tier 3

The practitioner will be able to:

- a) Critically assess and address own learning needs, negotiating a personal development plan that reflects the breadth of ongoing professional development.
- b) Engage in self-directed learning, critically reflecting to maximise own skills and knowledge, as well as own potential to lead and develop both care and services.
- c) Appraise and respond to people's motivation, development stage and current skills and experience working collaboratively to support health and care 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, including a culture of reflective practice and robust professional challenge.
- 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, including the role of autistic people, families and carers in identifying learning needs for those who support them.
- g) Support the wider team to build capacity and capability through work-based and interprofessional learning, and the application of learning to practice.
- h) Facilitate the coproduction (design and delivery) of education and training, working in partnership with autistic people.
- i) Provide training in trauma informed care so that autistic people are not traumatised by services/
- j) Act as a role model, educator, supervisor, coach and mentor, seeking to instil and develop the confidence of others.

General guidance and references to key legislation are shown in the appendices. Guidance or resources with specific relevance to this capability is shown below:

 <u>National Autistic Taskforce</u>, An independent guide to quality care for autistic people: Key element of quality care: Ensure ongoing, practical, autism-specific staff training

Capability 19. Research and evidence-based practice

Tier 2

The person or practitioner will be able to:

- a) Recognise the importance of research, evidence-based and legally literate practice and support for autistic people and their families and carers.
- b) Know where to find research and development evidence (including the rich qualitative data available from people with lived experience) and up-to-date legal knowledge and how to use it to underpin ways of working to benefit autistic people.
- c) Understand the strengths and weaknesses of different types of evidence.
- d) Understand the importance of collecting quality assurance information including feedback from autistic people and their families and carers.
- e) Be able to obtain and act on the feedback and experiences of autistic people and their families and carers.
- f) Understand the importance of a research-active workforce.

Tier 3

The practitioner will be able to:

- a) Critically engage in research activity, adhering to good, ethical research practice guidance, so that evidence-based and legally literate strategies are developed and applied to enhance quality, safety, productivity and value for money.
- b) Evaluate and audit own and others' 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, and developments in the legal frameworks affecting services and use 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) Identify poor legal literacy and take steps to address learning needs to enhance confidence in practice
- f) 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.

- g) Disseminate best practice research findings, understanding of changes to legal frameworks and quality improvement projects through appropriate media and fora (e.g. presentations and peer review research publications).
- h) Facilitate collaborative links between practice and research through proactive engagement, networking with autistic people, academic, clinical, legal and other active researchers.
- i) Coproduce approaches to evaluating services and measuring impact, including the use of outcomes reported by autistic people, 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 adjustments to enable autistic people to co-produce audits, evaluation and research in line with best practice⁵⁷.
- I) Ensure research materials and processes are accessible for autistic people where appropriate.
- m) Critically appraise the ethical issues and influence processes related to conducting research with autistic people, including gaining consent to their participation.

General guidance and references to key legislation are shown in the appendices. Guidance or resources with specific relevance to this capability is shown below:

- 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.

⁵⁷ For example: Best Practice Guidance for conducting research with the autistic community http://www.autism.manchester.ac.uk/media/mhs/bmh-faculty/autismmanchester/GuidelinesSept2017.pdf

Appendix 1. How this framework was developed

To be completed...

To include a description of the development process, including the desk research, co-production workshops and wider consultation...



Appendix 2. Related standards and frameworks

Core Skills Training Frameworks

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

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

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

Care Certificate Standards

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

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

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.

Appendix 3. Suggested standards for training delivery

Employing organisations should be assured that learning facilitators have the appropriate experience and background to deliver training to a satisfactory standard, recognising that those with less conventional experience or backgrounds may also be able to demonstrate the skills to deliver training to a satisfactory standard. Organisations should also ensure that they have put in place a quality assurance mechanism, whereby the accuracy of the content and the effectiveness of its delivery has been quality assured and is subject to periodic observation.

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

Co-producing training

The active involvement of autistic people, family and carers is central to effective training delivery and, sessions should be designed by or with autistic people to model person-centred approaches and to meet learning outcomes.

Autistic people 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 deliver or co-deliver as much as possible. Whilst flexibility is important, it is also important not to patronise autistic people involved in training, nor to assume that because someone is autistic all they have to contribute is their "personal story".

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 2016⁵⁸)

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

The <u>Health Education England (HEE) Strategic Framework 15</u> provides the context and strategic direction for the education and training of the current and future healthcare workforce.

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⁵⁸ The Health Foundation (2016), Realising the Value.

Appendix 4. Relevant policy and legislation

Autism strategy

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: <u>Fulfilling and Rewarding Lives (2010)</u>.

Building on the themes in Fulfilling and Rewarding Lives (2010), a new strategy, <u>Think Autism</u>, 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 (Department of Health 2015: Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy).

Other relevant legislation and policy (in chronological order) 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) 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 decisionmaking process
- by allowing people to plan ahead for a time in the future when they might lack the capacity, for any number

National Health Service Act (2006)

An Act to consolidate certain enactments relating to the health service and set out the structure of the NHS in England.

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.

NHS (2011), The NHS Constitution

In March 2011, the Department of Health published the NHS Constitution (updated in 2015). 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.

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 (see also the Care and support statutory guidance).

Children and Families Act (2014), Children Act 1989 and s.2 Chronically Sick and Disabled Persons Act 1970

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).

Transforming Care Programme (2015)

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 (2016)

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.

Integrated Care Systems (2016)

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 mandate 2018 to 2019

The mandate to NHS England sets out the government's objectives and budget for the public body.

Mental Capacity (Amendment) Act 2019

The Mental Capacity (Amendment) Act 2019 and accompanying regulations and Code of Practice sets out the procedures to be followed by Local Authorities and NHS bodies to ensure the protection of Human Rights and provide legal Safeguards where an individual who lacks capacity to consent may be deprived of their liberty. These arrangements (known as the Liberty Protection Safeguards (LPS)) replace the previous Deprivation of Liberty Safeguards (DOLS).

NHS Long Term Plan (2019)

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.

Appendix 5. Other 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
- AT-Autism
- Autism Alliance UK
- Autism Centre for Education and Research (ACER)
- Autism Education Trust
- Autism Plus
- Autism Rights Group Highland (ARGH)
- Autistic UK
- Autistica
- British Institute of Learning Disabilities (BILD)
- British Psychological Society
- Challenging Behaviour Foundation
- Disability Matters / Autism Spectrum Matters
- Health Education England / Autism
- Mencap
- MySafeHome
- National Autistic Society
- National Autistic Taskforce
- NICE
- NHS Leadership Academy
- NHS England / Autism
- NHS England / Accessible Information Standard / Resources
- Participatory Autism Research Collective (PARC)
- Royal College of General Practitioners / Autistic Spectrum Disorders Toolkit
- Royal College of Nursing
- Royal College of Psychiatrists
- Royal College of Speech and Language Therapists
- Scope
- Social Care Institute for Excellence (SCIE)
- Skills for Care

- Skills for Health
- Studio 3
- The Autism Academy UK (TAAUK)
- The Tizard Centre
- University of Bristol, Learning Disabilities Mortality Review (LeDeR) Programme



Appendix 6. 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.
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 (for further details
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.
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

Term	Definition
	can lead to a deterioration in their health and/or ability to live independently.
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 in health, social care and other services.
Reasonable adjustments	Making it as easy for disabled people to use health and other services as it is for people who are not disabled.

Appendix 7. Bibliography

References relevant to specific capabilities are shown as footnotes. The following bibliography lists source documents identified and reviewed as part of the framework development process:

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