









## Core Capabilities Framework for Supporting Autistic People













## Acknowledgements

This framework was commissioned by Health Education England as one of the key objectives for workforce development in delivering the Autism Strategy, overseen by the Department of Health & Social Care (DHSC).

Project delivery was led by Skills for Health, working in collaboration with Skills for Care, the National Autistic Society and Opening Minds.

The framework development was guided by a project steering group which included autistic people and people with autistic family members. The steering group was chaired by Dr Ashok Roy, Clinical Lead for Learning Disabilities (Health Education England) and included representatives of the following organisations:

Autism Alliance
British Association of Social Workers
Care Quality Commission (CQC)
Edge Hill University
Health Education England
My Safe Home
National Autistic Society
National Autistic Taskforce
Opening Minds Training & Consultancy
Royal College of Psychiatrists
Royal College of General Practitioners
Royal College of Speech & Language Therapists
Skills for Care
Skills for Health

Development of the framework included a series of co-production workshops which were open to autistic adults, family members, autistic children and young people. We wish to thank those individuals who generously gave their time and shared their experiences.

In addition, we are grateful to the many people who provided comments and feedback on drafts of the framework including 353 respondents to the online consultation survey.

Finally, particular thanks are due to Dr Yo Dunn of the National Autistic Taskforce Executive for providing detailed reviews of the draft framework and for sharing her experience of autism training and consultancy across education, social care, health and criminal justice.

Further details of how the framework was developed is presented in Appendix 1.

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## **Foreword**

By co-chairs of the DHSC Autism Task and Finish Group for Workforce Development.



**Dr Ashok Roy OBE**Clinical Advisor, Health
Education England

Alla



Jim Thomas
Programme Head for
Workforce Innovation,
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Our lives are enriched by our hopes and dreams and we aspire to lives enriched by relationships and fulfilling roles in our workplace. Autistic people however, often encounter obstacles in achieving a good life due to insufficient public understanding of autism. Autistic people can often experience a lack of timely and informed support for themselves and their families, poor access to general health and mental health services, inability to gain and maintain employment commensurate with their strengths and abilities as well as social isolation and loneliness. Many of these factors contribute to autistic people having more physical and/or mental health problems than other people and a higher risk of premature death. They frequently remain undiagnosed, increasing the risks of their needs not being recognised or met.

In order to improve autism services there needs to be improved public understanding of autism, with reasonable adjustments made to educational, recreational, employment, justice and public services which would make for autism friendly environments. Additionally, there needs to be improved understanding of autism by families, professionals, teachers, employers and care staff in primary care, acute, mental health and learning disability services.

There has been governmental recognition of the obstacles faced by autistic people and their families throughout their lives. The autism strategy first published in 2009 has been extensively revised to support autistic children and adults and as part of this initiative the development of a knowledgeable and supportive workforce has been given high priority. In order to deliver timely and effective care and support throughout the lifespan of autistic people, families, carers, service providers and professionals need to acquire and use the optimal level of capability for the role and work in partnership.

This framework has been coproduced with autistic people of all ages and their families in a spirit of collaboration. The steering group, which drew its membership from a wide range of stakeholders, consulted widely and used ideas from engagement events and ensured co-authorship during every stage of drafting the framework. The framework is structured in three tiers directed at a universal level, a practitioner level and an expert level. The level of knowledge at Tier 1 can become the basis of the mandatory training to be provided following the publication of the strategy. The framework covers 19 capabilities arranged in 5 domains in tiers of complexity depending on individual roles. It gives links to key references and documents that will be valuable to those planning training or curriculum content. Importantly it recognises and encourages transferability of knowledge and skills between sectors, encouraging the necessary integration between education, health and social care that this group of people particularly will benefit from. Employers,

Universities, and care providers in both health and social care will find this framework important and helpful in planning their education and training. We expect that the framework will become the standard against which service and workforce quality will be measured. It will need to be supplemented by other training material which can help move from 'classroom-based' education to workplace-based learning and development.

## Statements of support

"The Autism Alliance are delighted to have been part of the working group which created the new Autism Core Capabilities Framework. This framework will be a key driver in creating a better future for people on the autism spectrum. Despite the Autism Act and Strategy, many staff in statutory agencies and wider have not yet received adequate training to support people effectively. This can now be addressed with thousands of autistic people across the country benefiting from smoother pathways and services facilitated by better informed staffing support.

As a group of 17 national charities, we are committed to supporting the implementation of this framework across the country."

## Debra Harrison-Sales, CEO Autism Hampshire / Executive member of the Autism Alliance

"The National Autistic Society has campaigned for many years for better understanding of autism. We are pleased to have played a part in developing this vital framework, which will help make sure that duties on health and care staff in the Autism Act statutory guidance are followed. This framework has been created alongside autistic people and their families and is a leading example of coproduction. We hope it makes a big impact and makes sure that autistic people and their families get the understanding and support from health and care professionals."

## Tim Nicholls, Head of Policy and Public Affairs The National Autistic Society

"As a relatively new organisation, the National Autistic Taskforce is pleased to have been part of the development of the new Core Capabilities Framework for Supporting Autistic People. Wholly run by autistic people, NAT seeks to draw on the collective knowledge and experience of autistic adults to inform and improve care and support, especially for autistic adults whose own voices are rarely heard. This ground-breaking framework has been written in genuine collaboration between autistic people, those with family members who are autistic, professionals from the autism field and professionals with broad experience of health and social care. As a result, this framework stands out by supporting the workforce across the public sector with relevant knowledge of practical strategies and genuine empathy with autistic perspectives. We hope the framework will be widely adopted and integrated into workforce development right across the public sector."

#### Dr Yo Dunn, National Autistic Taskforce Executive

"I'm delighted that our members have contributed to the framework and that it recognises the importance of communication and language for autistic people and how speech and language therapists can support them. Person-centred care, inclusive and accessible communication, and a multi-disciplinary approach are all at the heart of our profession and this is reflected throughout the document. This framework will help set standards for the skills, knowledge and capabilities of speech and language therapists as well as the wider workforce in years to come."

#### Kamini Gadhok MBE, Chief Executive Officer

#### Royal College of Speech & Language Therapists

"This framework sets clear and achievable guidelines for all primary care staff. It will help staff improve equitable access to services for autistic people and their families".

#### **Dr Carole Buckley FRCGP**

#### Royal College of General Practitioners (RCGP), Autism clinical representative

"As a practising clinician as well as RCPsych Autism Champion I am aware that lack of training and understanding about Autism for health and social care staff creates major stresses for Autistic people, their families and supporters and for staff of all types. I am aware that many staff in many services not only seek training but have increasingly attended training in recent years. One of the difficulties for staff and particularly for organisations employing those staff is how does this training fit together, what has been addressed in one training activity or another and where are the gaps. The creation and publication of this framework will greatly assist in that process including how people can include their experiential learning into that framework. I therefore strongly support its uptake by all organisations including those responsible for educating and training staff from post school level (including where relevant undergraduate level) onwards as well as those delivering health or social care services."

## Dr Ian Davidson FRCPsych, Consultant Psychiatrist and Autism Champion, The Royal College of Psychiatrists

"This feels like autism from the inside, too often official documents describe autism from the outside with a total lack of insight. It is obvious autistic people were thoroughly involved in the production of this framework."

#### **Consultation Survey Respondent**

## Introduction and background

It is estimated that there are over 700,000<sup>1</sup> autistic people in the UK, equivalent to around 1.1% of the population<sup>2</sup>. Many of these people and their families at one time or another, face a battle to get the right 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 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)<sup>3</sup>. 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 that 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 of 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.

<sup>&</sup>lt;sup>1</sup> National Autistic Society, Autism facts and history at: <a href="https://www.autism.org.uk/about/what-is/myths-facts-stats.aspx">https://www.autism.org.uk/about/what-is/myths-facts-stats.aspx</a>

<sup>&</sup>lt;sup>2</sup> The NHS Information Centre (2012). Estimating the prevalence of autism spectrum conditions in adults.

<sup>&</sup>lt;sup>3</sup> 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 UK autistic community members – autistic people, 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 person<sup>4</sup>. 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 across the autism spectrum at all levels of intellectual ability.

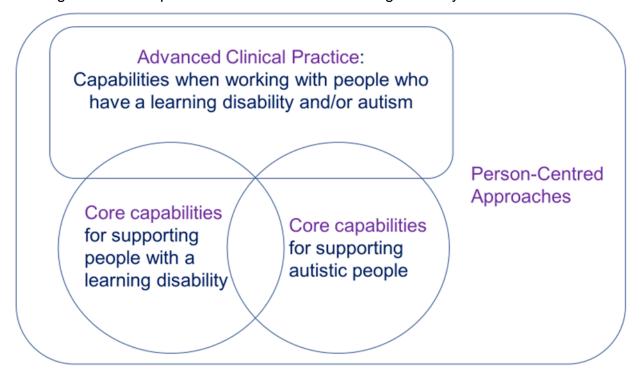
<sup>4</sup> Kenny et al (2015), Which terms should be used to describe autism? Perspective from the UK autism community at: <a href="https://journals.sagepub.com/doi/10.1">https://journals.sagepub.com/doi/10.1</a>177/1362361315588200

### 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: <a href="www.skillsforhealth.org.uk/person-centred-framework">www.skillsforhealth.org.uk/person-centred-framework</a>

Figure 1. The capabilities frameworks for learning disability and autism<sup>5</sup>



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, Early Years, Schools and Post 16 Programmes: Autism Competency Framework. <a href="https://www.autismeducationtrust.org.uk/shop/schools-cf-shop/">https://www.autismeducationtrust.org.uk/shop/schools-cf-shop/</a>
- Workforce Competency Framework for Providing Community Forensic Services for People with Learning Disabilities and/or Autistic Spectrum Conditions (Health Education England, 2019): <a href="https://www.hee.nhs.uk/ourwork/learning-disability/workforce-capability">https://www.hee.nhs.uk/ourwork/learning-disability/workforce-capability</a>
- British Association of Social Workers (BASW) Capabilities Statement for Social Work with Autistic Adults (2019): <a href="https://www.basw.co.uk">www.basw.co.uk</a>

<sup>&</sup>lt;sup>5</sup> This diagram aims to represent the synergies between the frameworks. It is not representative of the proportion of people with both a learning disability and autism.

### 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 across a whole team or service, in which case some team members may find that not all capabilities are essential to their individual role.

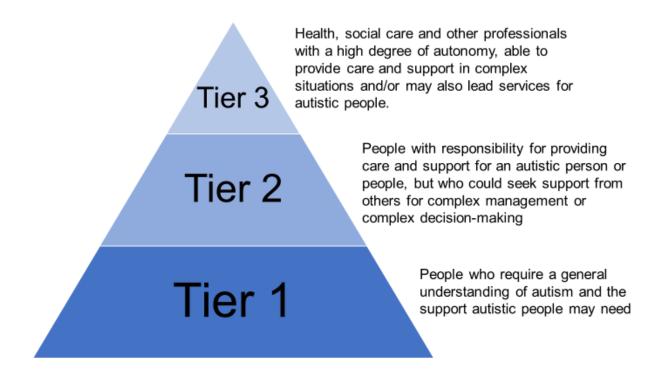
## Scope of the framework

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 who 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, transport, careers, employment or benefit services. It would include front-of-house and reception staff.

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, including frontline care staff who are not autism specialists and those in other roles such as education and housing services that 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, commissioning 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, counsellors, psychotherapists, allied health professionals, social workers, educators 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 to 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 framework applies across England and 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 training<sup>6</sup>. Approaches to evaluation can include:

<sup>&</sup>lt;sup>6</sup> E.g. Kirkpatrick's Four-Level Training Evaluation Model

- 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 service (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.

## 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.
- Recognise, respect and value autistic people's 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

An understanding of autism, relevant to scope of practice, is essential for all roles and settings and underpins all the capabilities in this framework. This includes the importance of not making assumptions about each individual's personal experiences, but instead taking time to learn about the individual experiences of the autistic person. The capabilities detailed in this framework should be used in conjunction with a true understanding of each person's experience of autism. With this understanding it will then be possible to move forward to the desired position of acceptance and appreciation of the autistic person's uniqueness.

The human rights of autistic people (children, young people and adults) must always be maintained, 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 includes understanding the numbers of autistic people in the population, the characteristics of autism and the impact which it often has. It also includes identification, assessment and diagnosis of autism, which is key to the wellbeing of autistic people and to ensure that effective support, referrals and adjustments can be made to enable them to live healthy, safe and rewarding lives.

## Capability 1. Understanding autism

I like being different - I'd There will be a logic to what I do, rather be weird than have it just might not be your logic...\* a beard \*\* Some autistic people are really good at doing some things very Tell me what it is you are well or quickly - believe and going to do \*\* value this \* I can hide my autism, but I can't I need things explained to switch it off \* me clearly, be given space and time \*\* You understand autism not just in your head but in your gut and in your On the bus give me time heart \* and don't get annoyed when I do stuff with my body and tics. Believe me when I say I can't help it \*\* If someone at school makes a plan with me for something to happen, they need to stick to it as if they don't, I can get Choices are hard for me really upset \*\* the word 'or' is a horror \*\*

Quotes from coproduction workshops with autistic people and their family members\* and with autistic children and young people\*\*

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

### Capability 1. Tier 1

#### The person will:

- a) Know basic facts about autism including:
  - i. how common it is
  - ii. that autism is neurodevelopmental and life long
  - iii. that every autistic person has a different combination of traits and sensitivities 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) Take responsibility for 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, regardless of their ability to communicate verbally
  - 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
  - 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 processing and understanding spoken language is a challenge for many autistic people, especially when anxious or in difficult sensory environments
  - vi. be aware that autistic people often take language literally so it is important to use clear, unambiguous language, responding positively when autistic people use direct language and give direct feedback
  - vii. be aware of difficulties and differences in non-verbal communication e.g. facial expression; eye contact; and personal distance
- e) Be aware that behaviour seen as challenging may be a form of communication or an indication of distress.
- f) Recognise some key differences in social interaction e.g. processing time, difficulties with small talk, social rules, understanding and interpreting emotions.
- g) Be aware that autistic people may live with other physical or mental health conditions or impairments that will also impact on their lives.

- h) 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.
- i) Understand how sensory issues can impact on autistic people e.g. oversensitivity or under-sensitivity to lighting, sound, temperature, touch, smell<sup>7</sup> and how anxiety and stress can contribute to sensory tolerance.
- j) 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), and consider the use of an alternative location.
- k) Plan changes in advance whenever possible<sup>8</sup>. Provide preparation and information about upcoming events using a variety of communication methods.
- I) Recognise the importance of passionate interests and hobbies<sup>9</sup>.
- m) 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.
- n) Be aware of the Equality Act 2010, Human Rights Act 1998 and Mental Capacity Act 2005.
- o) 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.

<sup>&</sup>lt;sup>7</sup> See Capability 5. Sensory processing and the environment

<sup>&</sup>lt;sup>8</sup> See Capability 7. Supporting change and transitions

<sup>&</sup>lt;sup>9</sup> See Capability 10 Meaningful activity and independence

### Capability 1. 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 diagnosis <sup>10</sup>.

#### 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 situations<sup>11</sup>.
- d) Be able to identify simple adjustments which can be made to meet the communication<sup>12</sup> 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) Avoid the tendency to underestimate the capabilities of less verbal individuals and overestimate the capabilities of those who are more verbal.
- f) Understand how behaviour may indicate stress and avoid assumptions about what a person's behaviour may be trying to communicate<sup>13</sup>.
- g) 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.
- h) 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.
- i) Understand activities that people adopt to 'self soothe' or 'self-regulate' or just 'calm down' and make sure people can do these things when they need to.
- j) Be able to execute practical strategies to support autistic people with changes, such as preparation and providing clear information - and support the autistic person through change to understand the situation through appropriate means
- k) Understand the importance of working with others, including the role that family carers and supporters may play in the lives of autistic people<sup>14</sup>.
- I) 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)

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

<sup>&</sup>lt;sup>10</sup> See Capability 2. Identification, assessment and diagnosis of autism.

<sup>&</sup>lt;sup>11</sup> See Capability 3. Person-centred care and support

<sup>&</sup>lt;sup>12</sup> See Capability 4. Communication and interaction

<sup>&</sup>lt;sup>13</sup> See Capability 8. Supporting autistic people where behaviour may challenge

<sup>&</sup>lt;sup>14</sup> See Capability 6. Families and carers as partners in care and support

- n) Be able to identify and put in place 'reasonable adjustments' in access to health care and other services<sup>15</sup>
- o) Be aware of the role of health action plans/health passports in signposting important adjustments.
- p) 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.
- q) 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)

- r) 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 decision<sup>16</sup>.
- s) 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.
- t) Be aware of types of abuse which may be especially relevant for autistic people.
- u) Know how to raise a Safeguarding Concern and whom to contact for information and advice on Mental Capacity Act or Equality issues.
- v) Be aware of one's own responsibilities under the Equality Act, Human Rights Act and Mental Capacity Act.

## Capability 1. 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, bio-social-psychological and neurodiversity 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 evidence base relating to specific adjustments and approaches that can support autistic people.
- e) Understand the key legislation, policy and guidelines relating to autistic people, including one's own responsibilities such as under the Autism Act 2009, Mental Capacity Act 2005, Mental Capacity (Amendment) Act 2019 (including Liberty Protection Safeguards), Equality Act 2010, Care Act 2014, Human Rights Act

<sup>&</sup>lt;sup>15</sup> See Capability 13. Health equality and reasonable adjustments

<sup>&</sup>lt;sup>16</sup> S.1(3) Mental Capacity Act 2005

- 1998, Accessible Information Standard and relevant legislation or regulations applicable to the setting<sup>17</sup>.
- f) Understand how to enhance the capabilities of the workforce in relation to the needs of autistic people and assume responsibility for implementing these.

### Capability 1. 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: <a href="https://www.autism.org.uk/professionals/health-workers.aspx">https://www.autism.org.uk/professionals/health-workers.aspx</a>

National Autistic Society: What it's Like Being Autistic (Sensory Overload ) Short Film Sensory Overload

National Autistic Taskforce, An independent guide to quality care for autistic people.

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

<u>Social Care Institute for Excellence (SCiE):</u> Improving access to social care for adults with autism: Autism: the main issues

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<sup>&</sup>lt;sup>17</sup> See Capability 14. Law, ethics and safeguarding and Capability 15. Equality, diversity and inclusion.

## Capability 2. Identification, assessment and diagnosis of autism

### Capability 2. Tier 2

(Tier 1 Understanding Autism, plus the following)

#### 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 autistic people can be misdiagnosed and 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 the capabilities of less verbal individuals and overestimate the capabilities of those who are more verbal, recognising that receptive and expressive language may affect a person's ability to engage in conversation/interaction.
- 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.

### Capability 2. 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 (if appropriate to role), 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 neurodiversity and the possibility of associated conditions, for example, epilepsy; physical disabilities; mental health problems and neurodevelopmental diagnoses.
- 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.
- f) Work with the multi-disciplinary team to develop a formulation based on all available data.
- g) Develop a differential diagnosis (if appropriate to role), 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.
- i) 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. 18 19 20
- j) Support autistic people to access referral for social care assessment and other post assessment services. 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.
- I) 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.

<sup>&</sup>lt;sup>18</sup> Diagnosis and Identity (St. Clement's Practical Autism)

<sup>19</sup> Jim Sinclair (1993) 'Don't mourn for us'

<sup>&</sup>lt;sup>20</sup> Being Autistic

### Capability 2. Key guidance

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

- NICE Clinical Guidance [CG142], Autism spectrum disorder in adults: diagnosis and management at: <a href="https://www.nice.org.uk/guidance/CG142">https://www.nice.org.uk/guidance/CG142</a>
- NICE Clinical Guidance [CG128], Autism spectrum disorder in under 19s: recognition, referral and diagnosis at: <a href="https://www.nice.org.uk/guidance/cg128">https://www.nice.org.uk/guidance/cg128</a>
- National Autistic Society website: https://www.autism.org.uk/about/diagnosis.aspx
- National Autistic Taskforce, An independent guide to quality care for autistic people: Key elements of quality care:
  - Accept difference and support positive autistic identity
- St. Clement's Practical Autism Video Guides: Diagnosis and Identity
- <u>Social Care Institute for Excellence (SCiE):</u> Improving access to social care for adults with autism: Awareness raising and diagnosis
- Autistica Action Briefing:
  - Access to adult diagnosis
  - Adult diagnosis process
  - Post-diagnostic support for adults
  - o Diagnosing autistic women and girls

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## Domain B. Personalised support

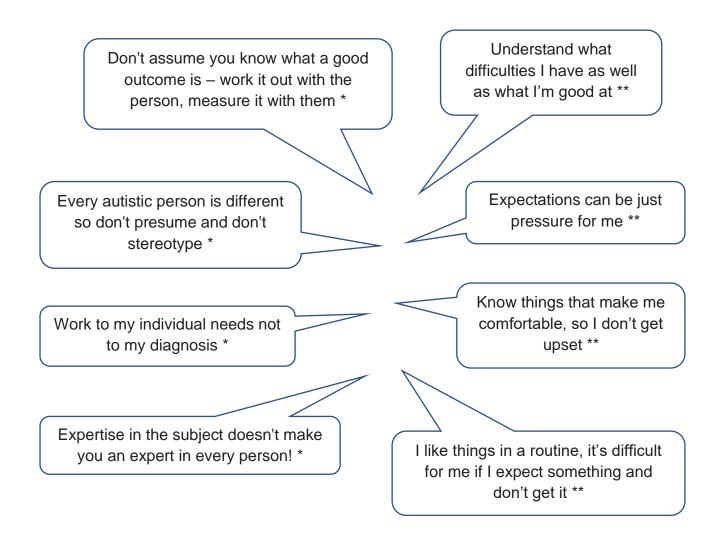
#### Introduction

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



Quotes from coproduction workshops with autistic people and their family members\* and with autistic children and young people\*\*

## Capability 3. Tier 2

(Tier 1 Understanding Autism, plus the following)

#### 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, and recognising difficulties autistic people may have with choice.
- 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 person<sup>21</sup>.
- e) Be aware of statutory rights to independent advocacy<sup>22</sup> 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.
- 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.

<sup>&</sup>lt;sup>21</sup> S.10 & s.20 Care Act 2014 & s.17ZD-F Children Act 1989 as amended by s.97 Children and Families Act 2014

<sup>&</sup>lt;sup>22</sup> 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

- n) Support and facilitate the development of a person's autistic identity, including gender identity<sup>23</sup> 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.

## Capability 3. 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 requirements<sup>24</sup>.
- 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) Advocate for development of person-centred outcomes and be prepared to challenge the intended outcomes and approaches (e.g. are approaches designed to manage behaviour trying to improve wellbeing and reduce distress, or trying to make the autistic person adopt perceived socially acceptable behaviour?).
- h) Utilise and support the implementation of relevant legislation and guidance for consent and decision-making (e.g. Mental Capacity Act 2005, Mental Capacity (Amendment) Act 2019 and NICE guidance<sup>25</sup>), recognising the importance of clearly identifying and separating the decisions of public services from decisions by or on behalf of an autistic person.

<sup>&</sup>lt;sup>23</sup> 'Gender Identity', St Clement's Practical Autism

<sup>&</sup>lt;sup>24</sup> 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

<sup>&</sup>lt;sup>25</sup> Nice guidance on decision making and mental capacity

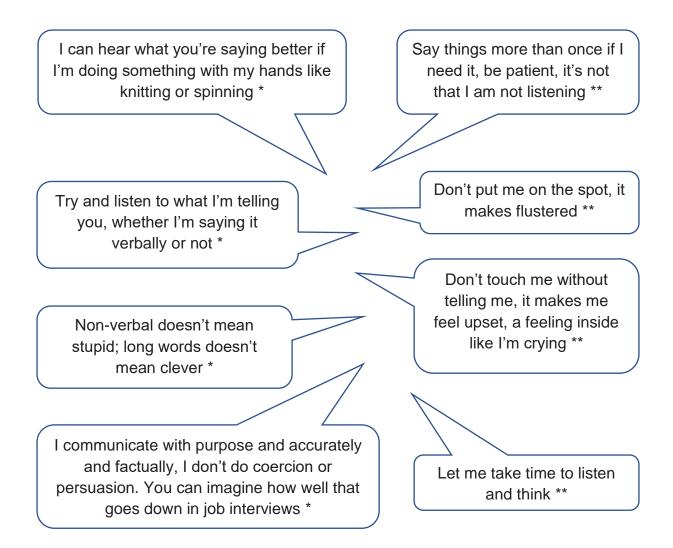
## Capability 3. Key guidance

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: <a href="https://www.autism.org.uk/professionals/health-workers/person-centred-planning.aspx">https://www.autism.org.uk/professionals/health-workers/person-centred-planning.aspx</a>
- National Autistic Society, Autism Accreditation Framework of Best Practice in Supporting Autistic People: <a href="https://www.autism.org.uk/professionals/accreditation.aspx">https://www.autism.org.uk/professionals/accreditation.aspx</a>
- National Autistic Taskforce, <u>An independent guide to quality care for autistic people</u>: 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. <a href="https://www.autismeducationtrust.org.uk/shop/schools-cf-shop/">https://www.autismeducationtrust.org.uk/shop/schools-cf-shop/</a>
- <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 (<u>www.skillsforhealth.org.uk/cstf</u>): Person-Centred Approaches: A Core Skills Education and Training Framework

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## Capability 4. Communication and interaction



Quotes from coproduction workshops with autistic people and their family members\* and with autistic children and young people\*\*

### Capability 4. Tier 2

(Tier 1 Understanding Autism, plus the following)

#### 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 (including text and email), 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) Ensure provision of information is specific and clear avoiding ambiguities.
- e) Understand the importance of providing time and space for autistic people to process and understand information and to make and communicate decisions.
- f) Recognise behaviour can be a form of communication and avoid assumptions about the meanings that can be attached to behaviour.
- g) Understand the importance of being able to communicate basic needs to reduce frustration.
- h) Use a range of communication techniques<sup>26</sup> 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.
- i) 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.
- j) Recognise the impact of the environment and sensory needs on communication

   knowing how to find the right time, place and situation for important communications.
- k) 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.
- I) Communicate effectively with colleagues using a variety of media formats (e.g. verbal, written and digital) and in accordance with legal requirements.

<sup>&</sup>lt;sup>26</sup> 'communication techniques' do not only refer to using visual support, objects or social stories to convey information – but also to adapting own communication style, e.g. avoiding abstract language, allowing time for the individual to process and understand, using shorter sentences where appropriate.

- m) Signpost to appropriate specialist speech and language therapy advice and intervention and make timely referrals where appropriate.
- n) 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.

## Capability 4. 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 understanding language and enabling communication of basic needs to alleviating frustration and be able to link communication to the cognitive and social-psychological theories of autism.
- f) Advocate for full implementation of the Accessible Information Standard for health and social care organisations<sup>27</sup> 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.

<sup>&</sup>lt;sup>27</sup> 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.

### Capability 4. 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 Taskforce, <u>An independent guide to quality care for autistic people</u>: Key element of quality care:
  - Support communication effectively throughout the lifespan
- National Autistic Society website: https://www.autism.org.uk/about/communication.aspx
- National Autistic Society, Autism Accreditation Framework of Best Practice in Supporting Autistic People: https://www.autism.org.uk/professionals/accreditation.aspx
- Accessible Information Standard NHS England (2017)
- Five good communication standards: Reasonable adjustments to communication that individuals with learning disability and/or autism should expect in specialist hospital and residential settings - Royal College of Speech and Language Therapists (2013)
- Autism Education Trust, Autism Competency Framework. <a href="https://www.autismeducationtrust.org.uk/shop/schools-cf-shop/">https://www.autismeducationtrust.org.uk/shop/schools-cf-shop/</a>
- St. Clement's Practical Autism Video Guides:
  - o Communication Pre-verbal
  - Communication Verbal
- Core Skills/Capabilities Frameworks (<u>www.skillsforhealth.org.uk/cstf</u>): Person-Centred Approaches: A Core Skills Education and Training Framework

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## Capability 5. Sensory processing and the environment

I don't like bright lights and loud noises, they hurt me and then I can't concentrate I am terrified of the school bell. I didn't want to come to school. The school bell is now turned off.

Let me cover my eyes, my ears and pick my fingers... it helps make me calm, don't tell me to stop

When I get nervous, I think I may be in trouble so I run away and hide

Music in the taxi calms me, but I'm not allowed it

Some colours, pink and red make me feel upset, when I've told people this they have said 'get what you're given'

I'm better with familiar environments. When supply teachers don't stick to the agreed seating plan, it can really mess things up

Let me use my equipment like my ear defenders, don't make me share these in assembly

Quotes from coproduction workshop with autistic children and young people (May 2019)

## Capability 5. Tier 2

(Tier 1 Understanding Autism, plus the following)

- 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 accessible quiet spaces and the autistic person's right to take a break if that is their choice - and acceptance/provision of adaptations (such as noise cancelling headphones, sunglasses, dimmable lights etc).
- d) Utilise the expertise of autistic people to identify sensory issues and in developing proactive 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.
- 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, or where intervention may be legally required (e.g. as a duty of care).
- g) Seek to provide access to sensory stimulation opportunities appropriate to individual needs and include these in care plans where appropriate.
- h) Understand that some autistic people have a high pain threshold and may not report injuries or illness, even when severe.

## Capability 5. Tier 3

#### The practitioner will be able to:

- a) Promote understanding of the sensory processing differences of autistic people and the impact on their ability to participate in daily activities.
- 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.

## Capability 5. 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>Autistica Action Briefing:</u> Enabling Environment
- National Autistic Taskforce, <u>An independent guide to quality care for autistic people</u>: Key element of quality care:
  - Tackle environmental and other stressors
- National Autistic Society website: https://www.autism.org.uk/about/behaviour/sensory-world.aspx
- National Autistic Society, Autism Accreditation Framework of Best Practice in Supporting Autistic People: <a href="https://www.autism.org.uk/professionals/accreditation.aspx">https://www.autism.org.uk/professionals/accreditation.aspx</a>
- Autism Education Trust, Autism Competency Framework. https://www.autismeducationtrust.org.uk/shop/schools-cf-shop/
- St. Clement's Practical Autism:
  - Sensory Issues

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

## Capability 6. Tier 2

(Tier 1 Understanding Autism, plus the following)

- 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 assessments<sup>28</sup> 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 coming to terms with their child's differences or who are under great stress, parents who struggle to accept an autistic 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 culture, wishes and needs of families and carers.

<sup>&</sup>lt;sup>28</sup> S.10 & 20 Care Act 2014 & s.17ZD-F Children Act 1989 as amended by s.97 Children and Families Act 2014

## Capability 6. 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 carers' needs are met in line with statutory requirements<sup>29</sup>.
- 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 needs<sup>30</sup>, including access to carers' personal budgets.
- e) Support access to statutory, voluntary and community support for carers (such as parent/carer 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' rights<sup>31</sup> 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 and liberty protection safeguards).
- g) Co-ordinate and contribute to reviewing partnership work with families and carers.

<sup>&</sup>lt;sup>29</sup> 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

<sup>&</sup>lt;sup>30</sup> 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.

<sup>&</sup>lt;sup>31</sup> Particularly Care Act 2014, Children Act 1989, Children and Families Act 2014

## Capability 6. 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
- 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: 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.
- Aukids Magazine

# Capability 7. Supporting changes throughout life

## Capability 7. Tier 2

(Tier 1 Understanding Autism, plus the following)

- a) Support people to express their personal preferences and anxieties when going through change and adapt support methods to take account of their views, using a person-centred 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 assessments<sup>32</sup>.
- 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, accommodation, retirement, bereavement, palliative or end of life care.
- g) Be aware that timely counselling and coaching can prevent escalation of the difficulties people may face.
- h) Identify recent or imminent changes affecting autistic people and support them to assess the implications and likely impacts of the change identified, recognising that even "minor" transitions can be significant.
- i) 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.
- k) Provide accessible information, advice and support which is tailored to an individual's communication needs.
- Identify how and when to seek additional expertise and advice when supporting a person through change.

<sup>&</sup>lt;sup>32</sup> s.58 & s.60 Care Act 2014 require 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.

## Capability 7. 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, moving out of a parent's home, further/higher education, graduation, employment, accommodation, 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 (at any age) 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 requirements<sup>33</sup>.
- 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.

<sup>&</sup>lt;sup>33</sup> s.58 & s.60 Care Act 2014 require 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

## Capability 7. 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/transition.aspx
  - https://www.autism.org.uk/about/family-life.aspx
- National Autistic Taskforce, <u>An independent guide to quality care for autistic people</u>: Key element of quality care:
  - Ensure better transitions
- Council for Disabled Children (2017) These are our children.
   <a href="https://www.ncb.org.uk/sites/default/files/field/attachment/These%20are%20Our%20CHildren\_Lenehan\_Review\_Report.pdf">https://www.ncb.org.uk/sites/default/files/field/attachment/These%20are%20Our%20CHildren\_Lenehan\_Review\_Report.pdf</a>
- 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: Transition
- St. Clement's Practical Autism:
  - o Coping with change

# Capability 8. Supporting autistic people where behaviour may challenge

Don't ask me why I'm angry or anxious, help me get through it and figure it out later \*

I like to go to somewhere quiet when I am starting to get angry or upset \*\*

When I have a meltdown and upset other people, I get so upset \*

Be calm with me when I am cross or angry \*\*

Don't define someone by their behaviour \*

They need to know if I am starting to get angry that I might want to tell them that I'm getting angry inside \*\*

Sometimes a stress toy can calm me down when I am upset \*

When I get stressed, I need to walk away, let me do it and stop asking me questions \*\*

Quotes from coproduction workshops with autistic people and their family members\* and with autistic children and young people\*\*

## Capability 8. Tier 2

(Tier 1 Understanding Autism, plus the following)

- 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 that behaviour perceived as challenging is not an inevitable part of autism but may be a possible indication of distress and focus on the removal of communication barriers, environmental and other stressors as a priority over modification of the behaviour.
- c) Recognise that the actions of staff and carers can increase or reduce the likelihood of behaviour which challenges.
- 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, including contingency planning which seeks the person's advance wishes.
- 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) Be able to apply strategies to manage the risk of serious aggression and selfinjurious behaviour.
- j) 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'.
- k) 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.
- Be able to follow a behaviour support plan in the wider context of an overall care plan; according to specified responsibilities and timeframes.
- m) 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'.

## Capability 8. 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 focussing narrowly
  on eliminating problematic behaviours
- b) Formulate and advocate for appropriate reactive strategies that are person centred and evidence based<sup>34</sup>, whilst seeking to develop and promote preventative strategies that work with the autistic person to minimise the need for reactive strategies.
- c) Actively support and co-produce strategies to enable appropriate and personcentred risk assessment with regard to the current context (e.g. mental state and environment).
- d) Promote, teach and support skills that will facilitate person-centred behaviour support plans, including challenging assumptions that 'behaviour' is an inevitable part of autism.
- e) Provide supervision to colleagues and teams following an intervention, recognising the impact of behaviours that challenge on people supporting an autistic person.
- f) 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.

# Capability 8. 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/1.5 Interventions for challenging behaviour at: https://www.nice.org.uk/guidance/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
- National Autistic Society:
  - o https://www.autism.org.uk/about/behaviour.aspx
  - https://www.autism.org.uk/about/behaviour/challenging-behaviour.aspx

<sup>&</sup>lt;sup>34</sup> See '<u>The Autism Dividend'</u>, National Autism Project for a comprehensive review of the (very limited) evidence base

- National Autistic Society, Autism Accreditation Framework of Best Practice in Supporting Autistic People: <a href="https://www.autism.org.uk/professionals/accreditation.aspx">https://www.autism.org.uk/professionals/accreditation.aspx</a>
- National Autistic Taskforce, <u>An independent guide to quality care for autistic people</u>: Key element of quality care:
  - Recognise behaviour as distress
- Autism Education Trust, Autism Competency Framework. <a href="https://www.autismeducationtrust.org.uk/shop/schools-cf-shop/">https://www.autismeducationtrust.org.uk/shop/schools-cf-shop/</a>
- Health Education England (2019), Providing community forensic services for people with Learning Disabilities and/or Autistic Spectrum Conditions: Workforce Competency Framework: <a href="https://www.hee.nhs.uk/our-work/learning-disability/workforce-capability">https://www.hee.nhs.uk/our-work/learning-disability/workforce-capability</a>
- 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)
- Supporting Treatment and Appropriate Medication in Paediatrics (STAMP) https://www.england.nhs.uk/learning-disabilities/improving-health/stamp/
- 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:
   <u>Promoting Autism FaVourable Environments (PAVE)</u>, Journal on Developmental Disabilities . 2013, Vol. 19 Issue 1, p8-23. 16p.
- National Autistic Society SPELL <a href="https://www.autism.org.uk/about/strategies/spell.aspx">https://www.autism.org.uk/about/strategies/spell.aspx</a>
- Mills, R & McCreadie, M (2018) <u>SYNERGY: Knowing me knowing me.</u>
   Changing the story around 'behaviours of concern'. Promoting self-awareness, <u>self-control and a positive narrative</u>
- Milton, D et al (2016) <u>TEN RULES for ensuring people with learning disabilities</u> and those who are on the autism spectrum develop 'challenging behaviour' ... and maybe what to do about it. Hove: Pavillion
- St. Clement's Practical Autism:
  - School Refusal
  - o Food and Dietary Issues

## Capability 9. Forensic support

## Capability 9. Tier 2

(Tier 1 Understanding Autism, plus the following)

- 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) Be 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) Contribute to the assessment and modifying of offender rehabilitation and treatment programmes to make sure that they meet the communication needs of autistic people (See Capability 4).
- k) Recognise the impact of the autistic person's activities on family and friends.
- Recognise the impact of any victim considerations and Ministry of Justice restrictions.
- m) Identify early signs of relapse and crisis and how to articulate this in relation to the autistic person and their family.

 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.

#### Capability 9. 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 law<sup>35</sup>.
- 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 (including Liberty Protection Safeguards), 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).

<sup>35</sup> GDPR and Data Protection Act 2018

- 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.
- 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, and also (where relevant) any co-occurring mental health conditions, personality disorder or post-traumatic stress disorder, may 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.

## Capability 9. 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:

- Providing community forensic services for people with Learning Disabilities and/or Autistic Spectrum Conditions: Workforce Competency Framework, Health Education England (2019), (<a href="https://www.hee.nhs.uk/">https://www.hee.nhs.uk/</a>)
- National Autistic Society website/Criminal Justice: <a href="https://www.autism.org.uk/professionals/others/criminal-justice.aspx">https://www.autism.org.uk/professionals/others/criminal-justice.aspx</a>
- National Autistic Society, Autism Accreditation Framework of Best Practice in Supporting Autistic People: <a href="https://www.autism.org.uk/professionals/accreditation.aspx">https://www.autism.org.uk/professionals/accreditation.aspx</a>
- RCLST, Communication help for the justice system: https://www.rcslt.org/learning/the-box-training
- Autism West Midlands (2016) Autism and the Criminal Justice System: Advice and Guidance for professionals, <a href="http://www.gain-grantham.co.uk/wp-content/uploads/2016/12/ASD-and-Criminal-Justice.pdf">http://www.gain-grantham.co.uk/wp-content/uploads/2016/12/ASD-and-Criminal-Justice.pdf</a>

- ARC UK (2016) People with learning disabilities in the Criminal Justice System: a guide for carers and learning disability services, <a href="https://arcuk.org.uk/wp-content/uploads/2016/04/PWLD-in-the-CJS-Guide.pdf">https://arcuk.org.uk/wp-content/uploads/2016/04/PWLD-in-the-CJS-Guide.pdf</a>
- 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, <a href="https://www.theadvocatesgateway.org/images/toolkits/3-planning-to-question-someone-with-an-autism-spectrum-disorder-including-asperger-syndrome-2016.pdf">https://www.theadvocatesgateway.org/images/toolkits/3-planning-to-question-someone-with-an-autism-spectrum-disorder-including-asperger-syndrome-2016.pdf</a>
- Judicial College (2018) Equal Treatment Bench Book, <a href="https://www.judiciary.uk/wp-content/uploads/2018/02/equal-treatment-bench-book-february-v6-2018.pdf">https://www.judiciary.uk/wp-content/uploads/2018/02/equal-treatment-bench-book-february-v6-2018.pdf</a>
- Iain Dickie, Shirley Reveley and Austin Dorrity (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

I don't have to always be included to make me ok, sometimes it is better when I have time on my own. Adults think inclusion is always best, but it isn't. I want to join in things with other people. Talk to me, have fun with me, help me be more confident.

I have friends but I am not bothered about minor friends

Let me be in my own world to calm down \*\*

Quotes from coproduction workshop with autistic children and young people (May 2019)\*\*

## Capability 10. Tier 2

(Tier 1 Understanding Autism, plus the following)

#### 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 they wish to do so.
- b) Support and facilitate the delivery of person-centred/age appropriate and autism specific sex and relationships education across the lifespan, including support in recognising healthy and unhealthy relationships and online risks and issues<sup>36</sup>.
- c) 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.
- d) Be able to support the sexual expression of an autistic adult, including LGBTQ+ issues, using appropriate person-centred (including age-appropriate) approaches.
- e) Know how to support autistic young people and adults to access and use help, advice or services to meet their sexual health needs as appropriate, including the importance of preventive education and healthcare.

## Capability 10. Tier 3

#### The practitioner will be able to:

a) Support autistic people to identify healthy relationships, and to maintain existing relationships and develop new friendships and relationships, if they wish to do so.

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.

Family Planning Association (2010) Talking together about Growing Up

Family Planning Association (2010) Talking together about sex and relationships

Hartman, Davida (2014) Sexuality and Relationship Education for Children and Adolescents with ASD Kate Reynolds (2014) Sexuality and Severe Autism

Health Scotland (2008) <u>Sexual Health and Relationships: A Review of Resources for people with learning disabilities</u>

Kate E. Reynolds (2014) What's happening to Tom/Ellie (puberty), Tom/Ellie needs to go (public toilets), Things Tom/Ellie likes (sexuality and masturbation). London: Jessica Kingsley Manasco, Hunter (2012) An Exceptional Children's Guide to Touch: Teaching Social and Physical

Hartman, Davida (2015) The Growing up book for boys/The growing up guide for girls. London: Jessica Kingsley

Health for Teens (2019) The law and consenting to sex: just the facts

Boundaries to Kids. London: Jessica Kingsley

https://www.healthforteens.co.uk/sexual-health/the-law-and-consenting-to-sex-just-the-facts-2/

<sup>&</sup>lt;sup>36</sup> Family Planning Association (2007) Jiwsi: A pick 'n' mix of sex and relationships education activities http://www.fpa.org.uk/sites/default/files/jiwsi-sre-activities-english.pdf

James, Abigail Werner (2015) Autism and appropriate touch. London: Jessica Kingsley

- 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 needs<sup>37</sup>.
- j) Support autistic people to develop the ability to recognise abuse, sexual offences and hate crime whenever possible.

## Capability 10. 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/sexeducation
- St. Clement's Practical Autism Video Guides:
  - Sexuality
  - Social Skills
- Care Quality Commission (CQC): <u>Relationships and sexuality in adult social care services</u>
- National Autistic Taskforce, <u>An independent guide to quality care for autistic people</u>: Key element of quality care:
  - Accept difference and support positive autistic identity

<sup>&</sup>lt;sup>37</sup> Reg. 2(2)(j) The Care and Support (Eligibility Criteria) Regulations 2015

# Capability 11. Meaningful activity and independence

The things that matter to me really matter and if you dismiss them, I will be hurt \*

I'm positive about achieving things. I might not be able to do things in the same way as other children, yet I find different ways and I don't give up \*\*

You can have great strengths and great needs at the same time \* Gaming helps me when I get stressed. It calms me down. \*\*

You will learn more about me if you talk to me about things that I'm interested in, even if they seem boring or silly to you \*

If I get something wrong, please will you let me try again \*\*

I'm good at my job, but that's a controlled environment; I struggle at home as it's not controlled and I can't cope with it \*

Sometimes I act silly, when I do it helps if you talk to me about something that interests me \*\*

Quotes from coproduction workshops with autistic people and their family members\* and with autistic children and young people\*\*

## Capability 11. Tier 2

(Tier 1 Understanding Autism, plus the following)

#### 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 important<sup>38</sup>.
- c) Recognise and encourage the importance of passionate interests and hobbies.
- d) Support autistic people to develop and retain 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.
- n) Support autistic people to draw on their strengths to manage setbacks and personal difficulties.

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<sup>38 &#</sup>x27;Social Skills', St. Clement's Practical Autism

o) Understand the importance of a positive, person-centred approach to risk and how this is supported by the legal framework<sup>39</sup>.

## Capability 11. Tier 3

#### The practitioner will be able to:

- a) Recognise the development of 'asset-based' approaches which consider 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:
  - 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, voluntary opportunities 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; social housing; private renting and home ownership (either family funded or possibly through the Government backed HOLD<sup>40</sup> model).
- d) Understand how to support access to housing where an individual may lack capacity to make a homelessness application or sign a tenancy<sup>41</sup>.
- 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 individual<sup>42</sup>.
- 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.
- h) Facilitate a person-centred review of support plans in partnership with the autistic person and others<sup>43</sup>.

<sup>&</sup>lt;sup>39</sup> Care Act 2014, Mental Capacity Act 2005, Mental Capacity (Amendment) Act 2019, Human Rights Act 1998

<sup>&</sup>lt;sup>40</sup> Home Ownership for people with Long-term Disabilities

<sup>&</sup>lt;sup>41</sup> By making applications to the Court of Protection when needed.

<sup>42</sup> See LGO report

<sup>&</sup>lt;sup>43</sup> As required by s.27 Care Act 2014, s.44 Children and Families Act 2014, s.17 Children Act 1989.

- 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 autonomy<sup>44</sup>.
- I) Promote and contribute to the development of practices and services that meet the individual needs of autistic people.

## Capability 11. 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:
  - Autism Employment Gap: <a href="https://www.autism.org.uk/get-involved/campaign/employment.aspx">https://www.autism.org.uk/get-involved/campaign/employment.aspx</a>
  - https://www.autism.org.uk/about/adult-life/work.aspx
- National Autistic Society, Autism Accreditation Framework of Best Practice in Supporting Autistic People: <a href="https://www.autism.org.uk/professionals/accreditation.aspx">https://www.autism.org.uk/professionals/accreditation.aspx</a>
- <u>Autistica Action Briefing:</u> Employment
- National Autistic Taskforce, <u>An independent guide to quality care for autistic people</u>: 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.
   <a href="https://www.england.nhs.uk/learningdisabilities/wp-content/uploads/sites/34/2015/11/building-right-home-guidance-housing.pdf">https://www.england.nhs.uk/learningdisabilities/wp-content/uploads/sites/34/2015/11/building-right-home-guidance-housing.pdf</a>

<sup>&</sup>lt;sup>44</sup> See for example <u>CQC State of Care 2017-8, p.123</u>

# 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 disadvantaged<sup>45</sup> 46.

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.

You might not be able to tell when I'm in pain or distress \*

Don't get stuck aiming for 100% right, we don't get everything right for everyone! \*

Don't tell me something won't hurt if it will \*

I make reasonable adjustments all the time for neurotypical people and it exhausts me \*

Quotes from coproduction workshops with autistic people and their family members\* and with autistic children and young people\*\*

<sup>&</sup>lt;sup>45</sup> Westminster Commission on Autism (2016) A spectrum of Obstacles <a href="https://westminsterautismcommission.files.wordpress.com/2016/03/ar1011\_ncg-autism-report-july-2016.pdf">https://westminsterautismcommission.files.wordpress.com/2016/03/ar1011\_ncg-autism-report-july-2016.pdf</a>

<sup>46</sup> National Autism Project (2017), The Autism Dividend

## Capability 12. Physical health

## Capability 12. Tier 2

(Tier 1 Understanding Autism, plus the following)

- 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, chromosome disorders, mental health conditions (including eating disorders), 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, optometrists, 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.
- i) 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 ensure they are aware of any expected timeframes. 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
- I) Understand that some autistic people may not report pain or seek help early due to a variety of factors such as communication difficulties, anxiety, difficulties with initiative and/or their high pain threshold.

## Capability 12. 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 autistic people to make healthcare decisions.
- 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) Work with other health professionals / colleagues to make sure that the advice and intervention they are providing is clear and makes sense to autistic people.
- g) Refer autistic people to specialist healthcare services for assessment and diagnosis where appropriate.

## Capability 12. 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:
  - o 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

## Capability 13. Tier 2

(Tier 1 Understanding Autism, plus the following)

- a) Understand that mental health conditions are common and can be 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 make 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 that some forms of self-injurious behaviour (e.g. hitting oneself) may be an indication of distress in contrast to self-harm which may relate to a mental health condition.
- e) Recognise when an autistic person may be experiencing mental distress, including suicidal thoughts and intentions.
- f) 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.
- g) Recognise that autistic people have a right to equitable access to treatment, including appropriate medication, whilst also recognising the issue of overmedication of autistic people and know how to address this.
- h) Understand that autistic people with mental health needs may present with behaviour which may challenge, masking other difficulties such as with communication.
- i) 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.
- j) Know the function of different mental health services that autistic people may need to access (such as occupational therapists, counsellors, speech and language therapists, psychologists, psychiatrists, and mental health nurses) and where to refer an autistic person with a suspected mental health condition.
- k) Coordinate and communicate with key people and services in the life of the autistic person and a mental health condition.

## Capability 13. 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
- Evaluate the importance of autonomy through occupations, meaningful activity and social engagement as potential 'protective factors' in maintaining positive mental health.
- c) Analyse why autistic people are at increased risk of mental health conditions.
- d) Understand the potential role of traumatic events in the lives of autistic people, including by families and peers such as childhood neglect and bullying.
- e) Be able to provide trauma informed care so that autistic people are not traumatised by services.
- f) Analyse why mental health conditions may be overlooked in autistic people e.g. due to complex or atypical presentations and/or diagnostic overshadowing.
- g) Understand that autistic people commonly need adapted mental health therapies and that certain therapies (such as group CBT) are likely to be both ineffective if not adapted and very challenging to access due to sensory, language and/or social challenges.
- h) Explore and appraise the needs of autistic people who also have a mental health condition, supporting and actively planning for community-based services and to minimise the use of compulsion under the Mental Health Act.
- i) 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.

# Capability 13. 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: <a href="https://www.nice.org.uk/guidance/CG142">https://www.nice.org.uk/guidance/CG142</a>
- NICE Clinical Guidance [CG128], Autism spectrum disorder in under 19s: recognition, referral and diagnosis at: <a href="https://www.nice.org.uk/guidance/cg128">https://www.nice.org.uk/guidance/cg128</a>
- National Autistic Society:
  - Transforming Care: Our Stories: <a href="https://www.autism.org.uk/get-involved/media-centre/news/2017-09-26-transforming-care.aspx">https://www.autism.org.uk/get-involved/media-centre/news/2017-09-26-transforming-care.aspx</a>
  - Beyond Transforming Care: <a href="https://www.autism.org.uk/get-involved/media-centre/news/2018-12-06-beyond-transforming-care.aspx">https://www.autism.org.uk/get-involved/media-centre/news/2018-12-06-beyond-transforming-care.aspx</a>
  - https://www.autism.org.uk/about/health/mental-health.aspx
  - https://www.autism.org.uk/about/health/mental-health-care.aspx
- Autistica Action Briefing:
  - o Adult mental health
  - Children and young people's mental health
  - o Suicide prevention
- Core Skills/Capabilities Frameworks (<u>www.skillsforhealth.org.uk/cstf</u>)
  - Mental Health Core Skills Education and Training Framework
  - Dementia Training Standards Framework
- St. Clement's Practical Autism:
  - Mental Health
- Sense: Jo Cox Commission on Ioneliness, Someone cares if I'm not there: https://www.sense.org.uk/support-us/campaign/loneliness/
- Cassidy, S & Rodgers, J (2017) Understanding and prevention of suicide in autism, *The Lancet* Volume 4, ISSUE 6, Pe11, June 01 <a href="https://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(17)30162-1/fulltext">https://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(17)30162-1/fulltext</a>
- Mills, R (2016) Reflections on stress and autism https://network.autism.org.uk/sites/default/files/ckfinder/files/Stress%20article%20 Final(2).pdf

# Capability 14. Health equality and reasonable adjustments

## Capability 14. Tier 2

(Tier 1 Understanding Autism, plus the following)

- 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 healthcare<sup>47</sup>.
- 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 additional information on summary care records (SCRs) and, for those with a learning disability, the GP Learning Disability Register.
- 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.
- i) Understand how limited, or unconventional, communication and poor health literacy may reduce the ability of autistic people to convey health needs

<sup>&</sup>lt;sup>47</sup> Equality Act 2010; Mental Capacity Act 2005; Mental Capacity (Amendment) Act 2019; Human Rights Act 1998; Transforming Care; Learning Disability Mortality Review

- effectively to others and the adjustments to practice, and support available, to overcome this.
- 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 that decision-making in healthcare is a demand which can be very difficult for autistic people to cope with if not supported appropriately.
- I) 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 so<sup>48</sup>.

## Capability 14. 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.
- Appraise how limited, or unconventional, communication and poor 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 and any potential hazards such as a risk of choking, known allergies and epilepsy.

<sup>&</sup>lt;sup>48</sup> 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

- d) Implement current guidelines and principles aimed at stopping the overmedication of people with a learning disability and/or autism.
- e) Work collaboratively across agencies and boundaries to improve inter-agency collaboration and communication, including best practice around named healthcare co-ordinators<sup>49</sup>.
- 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 healthcare<sup>50</sup>.
- 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:
  - 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 support<sup>51</sup>.

<sup>&</sup>lt;sup>49</sup> Learning Disability Mortality Review; also see for example Safeguarding Adults Review: Judy Benn <a href="https://www.cumbria.gov.uk/AdultSafeguarding/theboard/adultreviews.asp">https://www.cumbria.gov.uk/AdultSafeguarding/theboard/adultreviews.asp</a>

<sup>&</sup>lt;sup>50</sup> Equality Act 2010; Mental Capacity Act 2005; Mental Capacity (Amendment) Act 2019; Human Rights Act 1998; Transforming Care; Learning Disability Mortality Review

<sup>&</sup>lt;sup>51</sup> National Autistic Taskforce (2019) An independent guide to quality care for autistic people

## Capability 14. 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: <a href="https://www.autism.org.uk/about/health.aspx">https://www.autism.org.uk/about/health.aspx</a>
- National Autistic Society, Autism Accreditation Framework of Best Practice in Supporting Autistic People: <a href="https://www.autism.org.uk/professionals/accreditation.aspx">https://www.autism.org.uk/professionals/accreditation.aspx</a>
- 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
- Westminster Commission on Autism (2016) <u>A Spectrum of Obstacles: An inquiry</u> into access to healthcare for autistic people
- Doherty, Mary E., O'Sullivan, Jane D., Neilson, Stuart D. (forthcoming) Barriers to healthcare for autistic adults; consequences & policy implications. A crosssectional study.

# Domain D. Risk, legislation and safeguarding

#### Introduction

Autistic people (children, young people and adults) have a right to live 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. It may also involve recognising when dealing with choice is difficult for autistic people.

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, age or disability.

# Capability 15. Law, ethics and safeguarding

I can get bullied by people that don't understand why I do things; this makes me feel sad \*\*

Don't think I don't get upset when I'm bullied it makes me feel horrible \*\*

When I tell someone I'm being bullied I need adults to listen, take it seriously, I don't lie \*\* Trying to make the autistic 'normal' is one I face daily, my manager says I'm over sensitive and treats me different to everyone else. He is not interested in understanding only berating/shaming me. \*

Quotes from coproduction workshops with autistic people and their family members\* and with autistic children and young people\*\*

## Capability 15. Tier 2

(Tier 1 Understanding Autism, plus the following)

- a) Understand how legislation and policies promote and protect the rights of autistic people.
- b) Be aware of key legislation relevant to mental capacity, liberty protection safeguards, 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<sup>52</sup>.
- 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<sup>53</sup>.

 <sup>52</sup> s.1(2) Mental Capacity Act 2005. Further Guidance: https://www.39essex.com/wp-content/uploads/2017/11/Mental-Capacity-Guidance-Note-Capacity-Assessment-March-2019.pdf
 53 s.1(4) Mental Capacity Act 2005

- e) Understand what practical steps can be taken to support an autistic person with making a decision<sup>54</sup>.
- f) Be able to support a person to get advocacy to help them make and communicate a decision<sup>55</sup>.
- 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 Act<sup>56</sup>.
- h) Understand that lacking capacity to make a decision at the time it needs to be made doesn't mean that the person is not capable of making that decision another time or of making other decisions.
- i) 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.
- I) 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 law<sup>57</sup>.
- q) Actively challenge others who are not behaving in an ethical way.

<sup>54</sup> s.1(3) Mental Capacity Act 2005

<sup>&</sup>lt;sup>55</sup> 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

<sup>&</sup>lt;sup>56</sup> s.1(5) & (6) & s.4 Mental Capacity Act 2005 and Chapter 5 MCA Code of Practice <sup>57</sup> See Re A (Capacity: Social Media and Internet Use: Best Interests) [2019] EWCOP 2 and B v A Local Authority [2019] EWCA Civ 913

## Capability 15. 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, liberty protection safeguards, 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 (or a best interests decision on their behalf).
- c) Understand the legislation, regulations, case law and policies that underpin the safeguarding of autistic people and recognise the potential for them to be used oppressively<sup>58</sup>.
- d) Evaluate the options available when informed consent may be compromised, including as a result of undue influence<sup>59</sup>.
- 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.
- 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 lawfully<sup>60</sup>.
- 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.

<sup>&</sup>lt;sup>58</sup> Competence 8 National Competence Framework for Safeguarding Adults

<sup>&</sup>lt;sup>59</sup> 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

<sup>60</sup> GDPR and Data Protection Act 2018

## Capability 15. 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/strategy.aspx
  - <a href="https://www.autism.org.uk/about/health/mental-health-care.aspx">https://www.autism.org.uk/about/health/mental-health-care.aspx</a>
- National Autistic Taskforce, <u>An independent guide to quality care for autistic</u> people: Key element of quality care:
  - o Fight stigma and discrimination
- British Institute for Human Rights Practitioner's Guides
- Autism Alliance: Know your rights
- <u>Department of Health (2009)</u>, <u>Reference guide to consent for examination or treatment</u>
- 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)
- Safeguarding Children and Young People: Roles and Competencies for Healthcare Staff (2019)

## Capability 16. Equality, diversity and inclusion

## Capability 16. Tier 2

(Tier 1 Understanding Autism, plus the following)

#### 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 (including social networking).
- 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, age, 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.

## Capability 16. Tier 3

#### The practitioner will be able to:

- a) Understand and 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 several 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.

## Capability 16. 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: <a href="https://www.autism.org.uk/about/bame-autism.aspx">https://www.autism.org.uk/about/bame-autism.aspx</a>
- National Autistic Taskforce, <u>An independent guide to quality care for autistic people</u>: 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
- St. Clement's Practical Autism:
  - Gender Identity

# Domain E. Leadership and management, education and research

#### Introduction

The delivery of high-quality care and support for autistic people 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 care and support for autistic people requires ongoing 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. Autism-related research should meaningfully involve autistic people and families in its design, oversight and dissemination.

## Capability 17. Leadership and management

## Capability 17. Tier 2

(Tier 1 Understanding Autism, plus the following)

#### The person or practitioner will be able to:

- a) Understand the features of effective team performance within care and support for autistic people, 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 care and support for autistic people, 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 staff 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 care and support for autistic people.

## Capability 17. 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 care and support for autistic people 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) Understand the regulatory framework in applicable settings.
- e) Advocate for the rights of autistic people for reasonable adjustments to meet their needs in the planning and development of services.
- f) Promote a culture where needs and rights are balanced with health and safety practice in care and support for autistic people.

- g) Collate and share data across organisations in compliance with local protocols, legal<sup>61</sup> and professional requirements.
- b) Build relationships with service commissioners to develop the capacity and capability for an integrated care system. Identify gaps in provision, particularly for community-based care and support, and encourage the development of services to meet needs.
- i) Challenge poor and unethical practice in care and support for autistic people, including risk averse practice.
- j) Demonstrate leadership in delivering compassionate, trauma informed, personcentred care.
- k) Understand the roles and responsibilities of different agencies involved in care and support for autistic people.
- 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.

## Capability 17. 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:

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

<sup>61</sup> GDPR and Data Protection Act 2018

## Capability 18. Education and personal development

## Capability 18. Tier 2

(Tier 1 Understanding Autism, plus the following)

#### 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 evidence-based, legally and ethically 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.
- Undertake personal development based on the changing needs of the individuals using the service to ensure that the service provided meets those needs.

## Capability 18. 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 development needs for the individual and the wider team and support 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.

## Capability 18. 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 Taskforce, <u>An independent guide to quality care for autistic people</u>: Key element of quality care:
  - o Ensure ongoing, practical, autism-specific staff training

## Capability 19. Research and evidence-based practice

## Capability 19. Tier 2

(Tier 1 Understanding Autism, plus the following)

#### 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 including outcome measures such as quality of life.
- f) Understand the importance of a research-active workforce.

## Capability 19. 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) Critique poor quality research and be aware how it can lead to harmful interventions when applied.
- f) Identify poor legal literacy and take steps to address learning needs to enhance confidence in practice.
- g) 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.

- h) 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).
- i) Facilitate collaborative links between practice and research through proactive engagement, networking with autistic people, academic, clinical, legal and other active researchers.
- j) Coproduce approaches to evaluating services and measuring impact, including the use of outcomes reported by autistic people, their families and carers.
- k) Promote a systematic approach to using and developing outcome measures to underpin current and future practice.
- I) Advocate for reasonable adjustments to enable autistic people to co-produce audits, evaluation and research in line with best practice<sup>62</sup>.
- m) Ensure research materials and processes are accessible for autistic people where appropriate.
- n) Critically appraise the ethical issues and influence processes related to conducting research with autistic people, including gaining consent for their participation.

## Capability 19. 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:

- 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.

<sup>&</sup>lt;sup>62</sup> For example: Best Practice Guidance for conducting research with the autistic community <a href="http://www.autism.manchester.ac.uk/media/mhs/bmh-faculty/autismmanchester/GuidelinesSept2017.pdf">http://www.autism.manchester.ac.uk/media/mhs/bmh-faculty/autismmanchester/GuidelinesSept2017.pdf</a>

## Appendix 1. How this framework was developed

Development of the framework was commissioned by Health Education England. Project delivery was led by Skills for Health, working in collaboration with Skills for Care, National Autistic Society and Opening Minds Training & Consultancy.

The framework development was guided by a project steering group which included autistic people and people with autistic family members. The steering group comprised representatives of a range of stakeholder organisations including voluntary sector organisations, autistic people's organisations, service commissioners, higher education institutions, regulators, professional bodies and royal colleges.

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

Initial desk research was undertaken to identify key references and resources (see Appendix 5. Sources of further guidance and information, and Appendix 7. Bibliography). Each of the capabilities was also cross-referenced to other relevant frameworks.

During January 2019 a series of ten co-production workshops were organised at locations across England (Bristol, Sheffield, London, Manchester and Birmingham). These initial workshops were open to autistic adults, family members and workers. Later in May 2019, further co-production workshops were held specifically for autistic children and young people.

Initial drafts of the framework were based on the findings of the desk research, findings of the co-production workshops and consultation with the project steering group. Subsequently, during June and July 2019 the draft framework was made available with an online consultation survey. The draft framework was downloaded by over 700 individuals, with a total of 353 respondents to the survey. Based on analysis of these survey outcomes, and following further consultation with the steering group, a final draft of the framework was completed in August 2019.

## 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 Autism and others for: Learning Disability; Dementia; Mental Health; End of Life Care; Person-centred Approaches; Musculoskeletal and Frailty.

All core skills/capabilities frameworks can be accessed from: <a href="https://www.skillsforhealth.org.uk/cstf">www.skillsforhealth.org.uk/cstf</a>.

#### **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 <a href="report">report</a>, 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. Delivery of education, training and learning opportunities

The capabilities described in this framework provide learning outcomes which can be used to guide the content of education, training and follow-up.

However, this is about more than just the delivery of education and training. Achieving successful implementation across organisations requires clear and strong leadership, together with systems and processes that support behaviour change for workforces<sup>63</sup>.

#### Behaviour change<sup>64</sup>

To achieve and sustain positive impact for workforces who are adapting and/or adopting new ways of working, recent research<sup>65</sup> suggests that taking a behavioural approach (including capability, opportunity and motivation) to supporting staff is more successful than isolated training.

Development of capability must simultaneously be supported with the right processes, system and opportunity together with locally relevant incentives, which build those intrinsic and extrinsic motivations.

The principles of behaviour change for the workforce are essential to understand, whatever methodology is used to deliver the training or education. There are factors that can impact the ability of staff to learn and their motivation and confidence to implement new skills and behaviours. These include psychological, social, economic and cultural factors within their lives and working environment.

In practice, this means people need to:

- Know what to do
- Know how to do it
- Think it is a good thing
- Believe that they are capable
- Believe that it is their role
- Believe that people who are important to them think it is the right thing to do.

#### **Reflective practice**

To develop person-centred behaviours and approaches, it is important for staff members to take time to think about what they are doing and how they are doing things and the impact this has on autistic people. This draws on the worker's experiences, knowledge, values and feedback (and evidence where appropriate) to analyse and identify opportunities to change their thoughts and behaviours<sup>66</sup>.

<sup>&</sup>lt;sup>63</sup> The Health Foundation (2016), Realising the Value.

<sup>&</sup>lt;sup>64</sup> Person-Centred Approaches framework: www.skillsforhealth.org.uk/person-centred-framework

<sup>&</sup>lt;sup>65</sup> Realising the Value (2016), Supporting self-management at:

http://www.nesta.org.uk/sites/default/files/rtv-supporting-self-management.pdf

 $<sup>\</sup>frac{66}{\text{http://www.open.edu/openlearn/health-sports-psychology/social-care/social-work/introduction-social-work/content-section-2.4}$ 

Examples of how this might be achieved include:

- keeping a diary
- talking to peers,
- focusing on specific events,
- informal or formal mentoring<sup>67</sup>
- local role specific activities such as Schwatrz rounds<sup>68</sup>
- listening and acting on feedback from autistic people who have used services and their families and carers.

#### **Delivering Tier 1**

The baseline nature of Tier 1 means that it is important to make the training available, appropriate and accessible to the majority of the workforce.

At Tier 1, training must contain an element of face to face delivery, though this may form part of scalable blended approaches incorporating e-learning and interactive exercises to experience using this capability.

Delivery of tier 1 training may be aligned with wider statutory/mandatory training, such as that for Equality, Diversity and Human Rights. However, it is vital that autism training is sufficiently distinct and is delivered by trainers with relevant, practical, autism-specific knowledge.

Local Authority, NHS bodies and NHS Foundation Trusts should:

 Ensure autism awareness training is included within general equality and diversity training programmes for all staff working in health and care...<sup>69</sup>

#### **Delivering Tiers 2 and 3**

At tiers 2 and 3, training, education and learning opportunities should be using blended approaches, for example; face to face experiential learning, multi-disciplinary and scenario-based discussion. Where possible, there should be follow-up and ongoing learning through, for example, team action learning sets, coaching and mentoring.

Therefore, E-learning may be appropriate to impart underpinning knowledge, but it is important to recognise when face to face training, practical methods or a blended approach may be more effective.

<sup>67</sup> http://www.csp.org.uk/faqs/cpd/what-reflective-practice-how-do-i-do-it

<sup>&</sup>lt;sup>68</sup> A Schwartz Round is a structured forum for staff from all backgrounds to come together to talk about the emotional and social challenges of working in healthcare. The aim is to offer staff a safe environment in which to share their stories and offer support to one another.

<sup>&</sup>lt;sup>69</sup> Department of Health (2015), Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy.

#### **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 recognise 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<sup>70</sup>

As well as articulating the experiences and perspectives of autistic people, coproduction demonstrates the wider positive strengths, contributions and impact that they can make.

#### **Proposed frequency of refresher training**

At tier 1, it is recommended that training for understanding autism is refreshed at least **every 3 years**. This is consistent with recommendations for other 'statutory/mandatory' subjects such as those for Equality, Diversity and Human Rights, Safeguarding Adults and Safeguarding Children (Ref: UK Core Skills Training Framework at: <a href="https://www.skillsforhealth.org.uk/cstf">www.skillsforhealth.org.uk/cstf</a>)

At tiers 2 and 3, each employer organisation will need to determine the required refresher education and training as part of the continuing professional development for staff groups providing care and support for autistic people. Employing organisations are responsible for assuring that their employees have the required capabilities to undertake their roles, ensuring that sufficient time is afforded to employees to enable acquisition and maintenance of skills and knowledge relevant to their area of practice.

Local Authority, NHS bodies and NHS Foundation Trusts should:

• Ensure that both general awareness and specialist autism training is provided on an ongoing basis and that new staff or staff whose roles change are given the opportunity to update their autism training and knowledge<sup>71</sup>.

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<sup>&</sup>lt;sup>70</sup> The Health Foundation (2016), Realising the Value.

<sup>&</sup>lt;sup>71</sup> Department of Health (2015), Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy

#### **Evaluation and measuring impact**

The capabilities in this framework support the effective evaluation of education and training. Kirkpatrick's evaluation model<sup>72</sup> identifies four stages:

- Reaction what participants thought and felt about the training (satisfaction; "smile sheets")
- Learning the resulting increase in knowledge and/or skills and change in attitudes. This evaluation occurs during the training in the form of either a knowledge demonstration or test.
- Behaviour transfer of capability to the workplace. This is longer-term evaluation of impact on practice, possibly as part of supervision or appraisal processes.
- Results the impact that occurred because of attendance and participation in a training program (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.

<sup>&</sup>lt;sup>72</sup> Kirkpatrick's Four-Level Training Evaluation Model: <a href="https://en.wikipedia.org/wiki/Donald-Kirkpatrick">https://en.wikipedia.org/wiki/Donald-Kirkpatrick</a>

## 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</u> (2010).

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 would 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)

#### Chronically Sick and Disabled Persons Act 1970 s.2

S.2 Chronically Sick and Disabled Persons Act sets out the statutory duties owed by Local Authorities to make arrangements to meet specific types of social care needs of individual disabled children in their area.

#### Children Act 1989

The Children Act sets out a general duty on local authorities to promote the welfare of children in need by providing a range and level of services appropriate to those children's needs. The Children Act says that disabled children are 'children in need'. Schedule 2 sets out some specific duties on local authorities to protect and promote the welfare of children in particular circumstances.

#### 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 to make a decision by providing a flexible framework that places individuals at the heart of the decision-making process
- by allowing people to plan ahead for a time in the future when they might lack the capacity to make their own decisions

#### 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. The NHS Act (2006) sets out the key statutory duties owed to patients.

#### Health and Social Care Act 2008 (Regulated Activities) Regulations 2014

The Health and Social Care Act regulations provides the basis (including fundamental standards) against which the <u>Care Quality Commission (CQC)</u> inspects and monitors health and social care services. The fundamental standards include:

Regulation 9. Person-centred care

Regulation 10. Dignity and respect

Regulation 11. Need for consent

Regulation 12. Safe care and treatment

Regulation 13. Safeguarding service users from abuse and improper treatment

Regulation 14. Meeting nutritional and hydration needs

#### Equality Act (2010)

The Equality Act 2010 legally protects people from discrimination in the workplace, when using service (including health and social care services) 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 is unlawful to treat someone in a discriminatory way and the requirement to make reasonable adjustments to enable equality of access.

#### 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 the rights of people who are NHS patients. 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 brought together care and support legislation in England with the principle of well-being at its heart. The Care Act changed 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 public bodies and service providers (see also the <u>Care and support statutory guidance</u>).

#### Children and Families Act (2014),

An Act to make provision for children, families, and young 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 was 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 was 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 was intended to mean that fewer people will need to go into hospital for their care.

There was 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. The programme came to an end in March 2019, but the government has stated the intention to have a successor programme.

#### 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 has developed and rolled 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 have regard to 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) and are due to be implemented from October 2020.

#### 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 and Irish Orthoptics Society (BIOS)
- British Psychological Society
- Care Quality Commission (CQC)
- 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
	<ul> <li>Listening for key words as signposts to emotions</li> </ul>
	Understanding the meaning of silence
	<ul> <li>Using body language and facial expression to indicate interest and empathy.</li> </ul>
ADHD / ADD	Attention deficit hyperactivity disorder (ADHD) is a behavioural disorder that includes symptoms such as inattentiveness, hyperactivity and impulsiveness. Some people may have problems with inattentiveness, but not with hyperactivity or impulsiveness. This is known as attention deficit disorder (ADD) and can sometimes go unnoticed because the symptoms may be less obvious.
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 (staff) bring to the workplace. This includes the ability to be competent and beyond this, to manage change, be flexible, deal with situations which may be unpredictable and continue to improve performance.
Carer	Someone who spends a significant amount of their time providing unpaid support to a family member or friend.
Communication passport	Personal Communication Passports are a practical and person-centred way of supporting children, young people and adults who cannot easily speak for themselves. Passports are a way of pulling complex information together and presenting it in an easy-to-follow format, to enable people providing care or support to the person to adapt their communication.
Coproduction	This can mean everyone who is involved in or using a service or project working together to plan, design and deliver support together. This could include autistic people, parents or carers, practitioners, researchers or managers.
Cuckooing	A form of crime in which drug dealers take over the home of a vulnerable person in order to use it as a base for drug dealing or other criminal activity.

Term	Definition
Diagnostic overshadowing	The tendency to underdiagnose mental or physical health problems in autistic people and/or erroneously attribute symptoms of mental or physical illness as a characteristic of autism.
End of Life Care	Care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.
Frailty	A long-term condition particularly related to the ageing process in which multiple body systems gradually lose their in-built reserves. It is now widely recognised as a state of reduced resilience and increased vulnerability, which results in some people becoming more vulnerable to relatively minor changes in their circumstances which can lead to a deterioration in their health and/or ability to live independently.
Mate crime	A form of crime in which a perpetrator befriends a vulnerable person with the intention of then exploiting the person financially, physically or sexually or coercing them to engage in criminal activity.
Mental capacity	'Mental capacity' means being legally able to make your own decision. 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.
Orthoptics	The study or treatment of irregularities of the eyes, especially those of the eye muscles that prevent normal binocular vision.
Personalisation and Person-centred care	Care that takes account of and actively promotes individuality, rights, choices, privacy, independence, dignity, respect and partnership.
Person-centred planning	A way of helping someone to plan their life and support, focusing on what's important to the person.
Person-centred thinking	A set of values and approaches used to get to know someone and discover what they find important and what they want out of life.
Practitioner	Multi-disciplinary staff working in health, social care and other services.

Term	Definition
Reasonable adjustments	Taking positive steps to ensure that disabled people are able to access and participate in environments, services and support as required by the Equality Act 2010.
Schwartz Round	A structured forum for staff from all backgrounds to come together to talk about the emotional and social challenges of working in healthcare. The aim is to offer staff a safe environment in which to share their stories and offer support to one another.
Stimming	Self-stimulatory behavior which usually refers to specific behaviors such as hand-flapping, rocking, spinning, or repetition of words and phrases.
Trauma informed care	Taking into account past trauma and the resulting coping mechanisms when attempting to understand behaviors and provide person-centred care.

## 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:

Autism Education Trust (2012/2015) *Autism Competency Framework*. https://www.autismeducationtrust.org.uk/shop/schools-cf-shop/

Autism Education Trust (2012), *So what exactly is autism?* <a href="http://www.aettraininghubs.org.uk/wp-content/uploads/2012/08/1\_So-what-exactly-is-autism.pdf">http://www.aettraininghubs.org.uk/wp-content/uploads/2012/08/1\_So-what-exactly-is-autism.pdf</a>

ADASS, CQC, DH, HEE, LGA and NHS England (2015), *Transforming Care for People with Learning Disabilities-Next Steps.* <a href="http://www.england.nhs.uk/wp-content/uploads/2015/01/transform-care-nxt-stps.pdf">http://www.england.nhs.uk/wp-content/uploads/2015/01/transform-care-nxt-stps.pdf</a>

BILD (2014), BILD Code of Practice for minimizing the use of restrictive physical interventions: planning, developing and delivering training. (4th edition) <a href="http://www.bild.org.uk/our-services/books/positive-behaviour-support/bild-code-of-practice/">http://www.bild.org.uk/our-services/books/positive-behaviour-support/bild-code-of-practice/</a>

Bradley, E & Caldwell, P (2013), 'Mental health and autism: Promoting Autism FaVourable Environments (PAVE)', *Journal on Developmental Disabilities*, 19(1), 1-23 <a href="https://oadd.org/wp-content/uploads/2013/01/41015\_JoDD\_19-1\_8-23\_Bradley\_and\_Caldwell.pdf">https://oadd.org/wp-content/uploads/2013/01/41015\_JoDD\_19-1\_8-23\_Bradley\_and\_Caldwell.pdf</a>

Care Quality Commission (CQC) (2019), *Guidance for Providers*. <a href="https://www.cqc.org.uk/guidance-providers/nhs-trusts/guidance-providers">https://www.cqc.org.uk/guidance-providers/nhs-trusts/guidance-providers</a>

Department of Health (2009), *Valuing People Now: a new three-year strategy for people with learning disabilities.* London: Department of Health. <a href="http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\_093377">http://www.dh.gov.uk/en/PublicationsAndGuidance/DH\_093377</a>

Department of Health (2010), *Fulfilling and rewarding lives: the strategy for adults with autism in England.* London: Department of Health. <a href="https://webarchive.nationalarchives.gov.uk/20130104203954/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH">https://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH</a> 113369

Department of Health/Department for Children, Schools and Families (2009), Healthy Lives, Brighter Futures. The strategy for children and young people's health. London: Department of Health.

http://www.ncb.org.uk/media/42243/healthy\_lives\_brighter\_futures\_vcs\_brief.pdf

Department of Health (2012), Winterbourne View Review: Concordat: Programme of Action. London: Department of Health.

https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/21321 7/Concordat.pdf Department of Health (2014), Positive and Proactive Care: reducing the need for restrictive interventions.

https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/30029 3/JRA\_DoH\_Guidance\_on\_RP\_web\_accessible.pdf

Department of Health (2015), *No voice unheard, no right ignored – a consultation for people with learning disabilities, autism and mental health conditions.* London: Department of Health.

https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/40981 6/Document.pdf

Department of Health (2015), Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy. <a href="https://www.gov.uk/government/publications/adult-autism-strategy-statutory-guidance">https://www.gov.uk/government/publications/adult-autism-strategy-statutory-guidance</a>

Department of Health (2015), *Care and support statutory guidance*. <a href="https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance">https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance</a>

Department of Health & Social Care / NHS England (2018), *The Government response to the Learning Disabilities Mortality Review (LeDeR) Programme Second Annual Report.* <a href="https://www.gov.uk/government/publications/government-response-to-the-learning-disabilities-mortality-review-leder-programme-2nd-annual-report">https://www.gov.uk/government/publications/government-response-to-the-learning-disabilities-mortality-review-leder-programme-2nd-annual-report</a>

Health Education England (2017), *Multi-professional framework for advanced clinical practice in England*. <a href="https://www.hee.nhs.uk/our-work/advanced-clinical-practice/multi-professional-framework">https://www.hee.nhs.uk/our-work/advanced-clinical-practice/multi-professional-framework</a>

Health Education England (2019), Providing community forensic services for people with Learning Disabilities and/or Autistic Spectrum Conditions: Workforce Competency Framework. <a href="https://www.hee.nhs.uk/our-work/learning-disability/workforce-capability">https://www.hee.nhs.uk/our-work/learning-disability/workforce-capability</a>

Health Education England (2015), Generic Service Interventions Pathway: A competency framework to support development of the learning disability workforce. <a href="https://www.hee.nhs.uk/sites/default/files/documents/Generic%20service%20interventions%20pathway.pdf">https://www.hee.nhs.uk/sites/default/files/documents/Generic%20service%20interventions%20pathway.pdf</a>

Health Education England (2016), *Learning Disabilities Transition Pathway Competency Framework*. <a href="https://g-care.glos.nhs.uk/uploads/files/Transition%20pathway%20Final(1).pdf">https://g-care.glos.nhs.uk/uploads/files/Transition%20pathway%20Final(1).pdf</a>

Health Education England and Skills for Health (2019), Advanced Clinical Practice: Capabilities framework when working with people who have a learning disability and/or autism. <a href="https://www.skillsforhealth.org.uk/ACPinLD&A">www.skillsforhealth.org.uk/ACPinLD&A</a>

Health Education England & Skills for Health (2017), *Person-Centred Approaches*. <a href="http://www.skillsforhealth.org.uk/services/item/575-person-centred-approaches-cstf-download">http://www.skillsforhealth.org.uk/services/item/575-person-centred-approaches-cstf-download</a>

Health Education England, Skills for Health, and Skill for Care (2017), *End of Life Care Core Skills Education and Training Framework*. https://www.skillsforhealth.org.uk/services/item/536-end-of-life-care-cstf-download

HM Government (2014), *Think Autism: fulfilling and rewarding lives, the strategy for adults with autism in England: an update.* London: HM Government. <a href="https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/299866/Autism\_Strategy.pdf">https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/299866/Autism\_Strategy.pdf</a>

Lorcan Kenny, Caroline Hattersley, Bonnie Molins, Carole Buckley, Carol Povey, Elizabeth Pellicano (2015), *Which terms should be used to describe autism? Perspectives from the UK autism community.* 

https://journals.sagepub.com/doi/pdf/10.1177/1362361315588200

Local Government Association and NHS England (2014), Ensuring quality services. Core principles for the commissioning of services for children, young people, adults and older people with learning disabilities and/or autism who display or are at risk of displaying behavior that challenges. London: LGA. <a href="https://www.networks.nhs.uk/nhs-networks/south-transforming-care/documents/ensuring-quality-services/file\_popview">https://www.networks.nhs.uk/nhs-networks/south-transforming-care/documents/ensuring-quality-services/file\_popview</a>

Local Government Association & ADASS (2016), *Promoting less restrictive practice:* Reducing restrictions tool

https://www.local.gov.uk/sites/default/files/documents/promoting-less-restrictiv-b0f.pdf

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 (update of paper previously published in Learning Disability Today), <a href="https://www.atautism.org/wp-content/uploads/2018/06/Knowing-me-knowing-me-June-18-Final-version.pdf">https://www.atautism.org/wp-content/uploads/2018/06/Knowing-me-knowing-me-June-18-Final-version.pdf</a>

National Autism Project (2017), *The Autism Dividend*. <a href="http://nationalautismproject.org.uk/wp-content/uploads/2017/01/autism-dividend-report.pdf">http://nationalautismproject.org.uk/wp-content/uploads/2017/01/autism-dividend-report.pdf</a>

National Autistic Society (2012), Good practice in autism training: A code of practice.

National Autistic Society (2016) *Improving Care for People Living with Autism*, <a href="http://www.skillsforhealth.org.uk/news/blog/item/406-improving-care-for-people-living-with-autism">http://www.skillsforhealth.org.uk/news/blog/item/406-improving-care-for-people-living-with-autism</a>

National Autistic Society (date unknown) *SPELL* <a href="https://www.autism.org.uk/about/strategies/spell.aspx">https://www.autism.org.uk/about/strategies/spell.aspx</a>

National Autistic Taskforce (2019), *An independent guide to quality care of autistic people*. <a href="https://nationalautistictaskforce.org.uk/wp-content/uploads/RC791\_NAT\_Guide\_to\_Quality\_Online.pdf">https://nationalautistictaskforce.org.uk/wp-content/uploads/RC791\_NAT\_Guide\_to\_Quality\_Online.pdf</a>

NHS England, LGA and ADASS (2016), *Building the Right Home*. <a href="https://www.england.nhs.uk/learningdisabilities/wp-content/uploads/sites/34/2015/11/building-right-home-guidance-housing.pdf">https://www.england.nhs.uk/learningdisabilities/wp-content/uploads/sites/34/2015/11/building-right-home-guidance-housing.pdf</a>

NHS England (2017), *Accessible Information Standard*. https://www.england.nhs.uk/ourwork/accessibleinfo/

NHS England, LGA, ADASS (2015), *Building the right support*, <a href="https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf">https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf</a>

NHS England (2015), Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition. https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-serv-model-er.pdf

NHS Improvement (2018), The learning disability improvement standards for NHS trusts.

https://improvement.nhs.uk/documents/2926/v1.17 | Improvement | Standards | added | note.pdf

NICE Clinical Guidance [CG142], *Autism spectrum disorder in adults: diagnosis and management.* <a href="https://www.nice.org.uk/guidance/CG142">https://www.nice.org.uk/guidance/CG142</a>

NICE Clinical Guidance [CG128], *Autism spectrum disorder in under 19s: recognition, referral and diagnosis.*: <a href="https://www.nice.org.uk/guidance/cg128">https://www.nice.org.uk/guidance/cg128</a>

PBS Academy (2017), *Improving the quality of Positive Behavioural Support (PBS):* The standards for training. <a href="http://pbsacademy.org.uk/wp-content/uploads/2017/10/PBS-Standards-for-Training-Oct-2017.pdf">http://pbsacademy.org.uk/wp-content/uploads/2017/10/PBS-Standards-for-Training-Oct-2017.pdf</a>

Positive Behavioural Support (PBS) Coalition UK (2015), *Positive Behavioural Support: A competence framework*. <a href="http://www.skillsforcare.org.uk/Document-library/Skills/People-whose-behaviour-challenges/Positive-Behavioural-Support-Competence-Framework.pdf">http://www.skillsforcare.org.uk/Document-library/Skills/People-whose-behaviour-challenges/Positive-Behavioural-Support-Competence-Framework.pdf</a>

Public Health England (2017), Improving healthcare access for people with learning disabilities: Guidance for social care staff on how to help people with learning disabilities get better access to medical services to improve their health. <a href="https://www.gov.uk/government/publications/improving-healthcare-access-for-people-with-learning-disabilities">https://www.gov.uk/government/publications/improving-healthcare-access-for-people-with-learning-disabilities</a>

Public Health England (2018), Reasonable adjustments for people with a learning disability Guides on how reasonable adjustments to health services and adjustments to help people with learning disabilities to access services. <a href="https://www.gov.uk/government/collections/reasonable-adjustments-for-people-with-a-learning-disability">https://www.gov.uk/government/collections/reasonable-adjustments-for-people-with-a-learning-disability</a>

Royal College of Speech & Language Therapists (2013, updated 2016), Five good communication standards: Reasonable adjustments to communication that individuals with learning disabilities and/or autism should expect in specialist hospital and residential settings. <a href="https://www.rcslt.org/news/good\_comm\_standards">www.rcslt.org/news/good\_comm\_standards</a>

Royal College of Psychiatrists (2017), *Good Practice Guide CR203: Management of epilepsy in adults with intellectual disability.* https://www.rcpsych.ac.uk/usefulresources/publications/collegereports/cr/cr203.aspx

Royal College of Psychiatrists (2018), *Restrictive interventions in in-patient intellectual disability services: How to record, monitor and regulate* <a href="https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr220.pdf?sfvrsn=c74ad0e4">https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr220.pdf?sfvrsn=c74ad0e4</a> 2

Scottish Government (2018), *The microsegmentation of the autism spectrum research project.* <a href="https://www.gov.scot/publications/microsegmentation-autism-spectrum/pages/4/">https://www.gov.scot/publications/microsegmentation-autism-spectrum/pages/4/</a>

RCNI (2015), Essential Guide: Developing specialist skills in autism practice. https://rcni.com/sites/rcn\_nspace/files/RCNi-Autism-Booklet-2015.pdf

Royal College of Psychiatrists (2014), *Good practice in the management of autism (including Asperger syndrome) in adults.* <a href="https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr191.pdf?sfvrsn=4cd65cde">https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr191.pdf?sfvrsn=4cd65cde</a> 2&sfvrsn=4cd65cde 2

SCIE (2017), Autism: Improving access to social care for adults. <a href="https://www.scie.org.uk/autism/">https://www.scie.org.uk/autism/</a>

Skills for Care and Skills for Health (2015), *How to be a great autistic individual employer*. <a href="http://www.skillsforhealth.org.uk/images/resource-section/service-area/autism/How%20to%20be%20a%20great%20autistic%20individual%20employer.pdf">http://www.skillsforhealth.org.uk/images/resource-section/service-area/autism/How%20to%20be%20a%20great%20autistic%20individual%20employer.pdf</a>

Skills for Care and Skills for Health (2015), *How to be a great personal assistant for someone with autism.* <a href="http://www.skillsforhealth.org.uk/images/resource-section/service-">http://www.skillsforhealth.org.uk/images/resource-section/service-</a>

<u>area/autism/How%20to%20be%20a%20great%20personal%20assistant%20for%20</u> someone%20with%20autism.pdf

Skills for Health (2016), *Learning Disabilities Core Skills Education and Training Framework*. <a href="http://www.skillsforhealth.org.uk/services/item/146-core-skills-training-framework">http://www.skillsforhealth.org.uk/services/item/146-core-skills-training-framework</a>

Skills for Care & Skills for Health (2011), Autism Skills and Knowledge list, for workers in generic social care and health services.

http://www.skillsforhealth.org.uk/images/resource-section/service-area/autism/autism-skills-and-knowledge-list-05-2011.pdf

Skills for Care & Skills for Health (2011), Implementing the Autism Skills and Knowledge list through staff training and development.

https://www.skillsforcare.org.uk/Documents/Topics/Autism/Implementing-the-autism-skills-and-knowledge-list-through-staff-training-and-development.pdf

The Challenging Behaviour Foundation (2019), Reducing Restrictive Intervention of Children and Young People

Stopping over medication of people with a learning disability, autism or both (STOMP)

Transforming Care and Commissioning Steering Group (2014), Winterbourne View – Time for Change. Transforming the commissioning of services for people with learning disabilities and/or autism. <a href="http://www.england.nhs.uk/wp-content/uploads/2014/11/transforming-commissioning-services.pdf">http://www.england.nhs.uk/wp-content/uploads/2014/11/transforming-commissioning-services.pdf</a>

University of Bristol (2017), *The Learning Disabilities Mortality Review (LeDeR) Programme*, *Annual Report December 2017*. <a href="https://www.hqip.org.uk/wp-content/uploads/2018/05/LeDeR-annual-report-2016-2017-Final-6.pdf">https://www.hqip.org.uk/wp-content/uploads/2018/05/LeDeR-annual-report-2016-2017-Final-6.pdf</a>

Westminster Commission on Autism (2016), A spectrum of Obstacles: an inquiry into access to healthcare for autistic people.

https://westminsterautismcommission.files.wordpress.com/2016/03/ar1011\_ncg-autism-report-july-2016.pdf

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