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Meeting the needs of autistic adults in mental health services

Guidance for integrated care boards, health organisations and wider system partners

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Foreword

The number of adults diagnosed as autistic in England is rising rapidly; improvements in recent decades in detection and diagnosis in children mean that with each passing year, increasingly large numbers of young people are transitioning into adulthood with an autism diagnosis. Combined with a rising number of people being diagnosed in adulthood and a higher prevalence of mental ill health compared to the general population, adults diagnosed as autistic now represent a significant and fast-growing number of patients supported by adult mental health services in England.

We know that with earlier, well-targeted community support, many admissions and long stays in mental health inpatient units could potentially be avoided.

This guidance will help drive our collective efforts to bring about improvements in the provision of mental health care for autistic adults in all mental health services. It will support staff working in mental health to better understand and feel confident about meeting the needs of autistic people who access their services. We hope too that the information will be useful to commissioners and staff across all health settings including primary care and acute as we collectively seek to improve the health outcomes and experiences of care for autistic people.

We are grateful to those people with lived experience and from clinical, scientific, commissioning and service management backgrounds for their invaluable input in the development of this document.

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Equality and Health Inequalities Statement

This guidance is to help Integrated Care Systems and all partners, in England to deliver high quality mental health services for autistic adults, irrespective of their background, age, ethnicity, sex, gender, disability or other health conditions or sexuality.

Within the guidance are suggestions for ensuring an area has services, care and options for support for people of all ages and all abilities and that these are designed to be fully accessible, minimising disadvantage to any group.

Summary

The proportion of the population diagnosed as autistic in England has grown significantly over recent years and that rate of growth is accelerating, with rising diagnostic rates for both children and adults. Autistic adults are more likely than non-autistic adults to experience mental ill health and are more likely to require mental health services. The numbers of people diagnosed as autistic in mental health inpatient settings is increasing; data collected by NHS England tells us that there was an increase of 7.3% in the numbers of autistic inpatients (both with and without a learning disability) in mental health hospitals between March 2017 and August 2023 and an increase of 51.3% in the numbers of autistic inpatients without a learning disability in the same timeframe. More work is needed to ensure all mental health services are accessible to autistic adults and have capacity to meet their mental health needs, which can range from mild to severe.

The provision of accessible, effective mental health support to autistic adults as early as possible and before symptoms deteriorate may reduce the need for more intensive and more costly inpatient care. For services to be accessible and effective at meeting autistic adults' mental health needs, adjustments for autistic characteristics should be provided.

This guidance provides system partners with advice on how to improve the quality, accessibility and acceptability of care and support for autistic adults through the implementation of 10 principles. The first eight principles should be applied by all partners within an ICB area when planning, designing and delivering mental health services and the final two principles should be applied at Integrated Care Board (ICB) level.

The principles are that services should:

1. ensure all services are accessible and acceptable to autistic adults
2. support access to meaningful activity
3. facilitate timely access to autism assessment, when clinically indicated
4. use evidence to guide intervention choice
5. assess and proportionately manage risk
6. monitor and minimise the use of restrictive practices
7. support cohesive transitions
8. consider the physical health needs of people accessing mental health services

and ICBs should:

9. develop a local commissioning strategy to ensure appropriately adjusted and tailored mental health provision is available for autistic adults, informed by local and national statistical data
10. develop and maintain a well-trained workforce.

We set out four levels of stepped mental health care in this guidance. These levels of care are demarcated by the acuteness and type of mental health need of the patients accessing services within each level. We use this model to demonstrate that good mental health care for autistic adults can be provided by all mental health services; not just those commissioned specifically for autistic people.

The four levels are:

- Level 1: Staying well in the community
- Level 2: Planned mental health care
- Level 3: Crisis care
- Level 4: Inpatient care

We encourage system partners to engage in strategic thinking about the inter-relationship between different services, both within levels and at different levels. For example, if overall support to keep people well in the community is inadequate, there will be consequences for the resource that will be required to support people at higher levels as their needs escalate.

Purpose and scope

This advisory guidance aims to help ICBs across England, to work with all partners, particularly those in provider services, to provide high-quality assessment, intervention and support to autistic adults who have any mental health symptoms or conditions.

Specifically, it is intended to help ICBs to:

1. Improve autistic adults' experiences of accessing NHS mental health services.
2. Increase the capacity and accessibility of mental health care in the community for autistic adults.
3. Prevent abuse, neglect or maltreatment of autistic adults in all services commissioned or provided by an ICB.
4. Reduce restrictive practice with autistic adults, including the:
   - number of inpatient admissions,
   - number and duration of long inpatient stays,
   - frequency of physical and/or pharmacological restraint,
   - use of seclusion,
   - frequency and duration of long-term segregation.
5. Improve the effectiveness of interventions to reduce mental health symptoms and the rate of recovery from mental health conditions for autistic adults.
6. Reduce the number of autistic adults who have recurrent episodes of inpatient mental health care within a given period.

The scope of this guidance includes all services within an ICB area, that have a role in assessing, supporting or treating the mental health of autistic adults, including autistic adults with a learning disability and adults who may be autistic but who do not have a formal clinical diagnosis.

Consideration must be given to services that have been delegated to NHS-led provider collaboratives as part of service planning and delivery. This guidance applies to specialised services that NHS-led provider collaboratives have taken quality and financial responsibility for, as well as services that have been retained by NHS England.

While the post-diagnostic support provided to newly diagnosed autistic adults is recognised as an important element of supporting autistic adults to stay well in the community, it is out of scope in this guidance. More information about the support provided by autism assessment services is provided in the national framework and operational guidance for autism assessment services.

Service provision for autistic people under 18 years of age and for adults with a learning disability who are not autistic falls outside the scope of this guidance. The current guidance does not specifically address the intersection between mental health services and the criminal justice system for autistic people.

Background

Autism is a neurodevelopmental condition impacting how a person perceives and interacts with the world around them. A brief outline of autism diagnostic criteria and characteristics commonly associated with autism are provided in Appendix A.

Autistic traits, alongside many wider determinants of health, place autistic people at a higher likelihood than non-autistic people of needing mental health services during their lifetime, with approximately a third of autistic people reporting a diagnosed mental health condition This increased need is often compounded by autistic people facing more barriers to good mental health care than non-autistic people; barriers include inaccessible services, treatment which is less effective for autistic people than non-autistic people, and services with insufficient capacity to meet demand. A summary of the evidence on autism and mental health is provided in Appendix B.

Many autistic adults are unable to access proactive and effective mental health care. As a result, many autistic adults experience high degrees of unmet health needs, often have poor mental health outcomes, and are admitted to mental health hospitals, sometimes for long stays. For instance, in the Assuring Transformation dataset, there were 1,325 autistic inpatients (both with and without a learning disability) in mental health hospitals at the end of August 2023, an increase of 7.3% since March 2017, when the number of autistic inpatients was 1,235. Notably, autistic inpatients without a learning disability have increased from 585 to 885 in the same timeframe; an increase of 51.3%.

With earlier, well-targeted community support, many admissions to mental health hospital and long stays could potentially be avoided. Improving mental health provision for autistic people has been a longstanding national policy ambition in England but the need for further improvements in both access to and quality of care persist. A summary of the relevant autism and mental health policy is provided in Appendix C.

Provision of mental health support for autistic adults

Principles to apply to mental health services

Good mental health care for autistic adults can be provided by all mental health services; not just those commissioned specifically for autistic people.

To improve the quality, accessibility and acceptability of care and support for autistic adults, to meet their mental health needs, the following 10 principles should be applied at all levels of mental health care described below.

All mental health services should:

1. ensure services are accessible and acceptable to autistic adults
2. support access to meaningful activity
3. facilitate timely access to autism assessment, when clinically indicated
4. use evidence to guide intervention choice
5. assess and proportionately manage risk
6. monitor and minimise the use of restrictive practices
7. support cohesive transitions
8. consider the physical health needs of people accessing mental health services

To achieve this, all ICBs should:

9. develop a local commissioning strategy to ensure appropriately adjusted and tailored mental health provision is available for autistic adults, informed by local and national statistical data
10. develop and maintain a well-trained workforce

Levels of mental health care

In this guidance, we have used four levels of stepped mental health care in describing the mental health care that can be provided for autistic adults. The levels are demarcated by the acuteness and type of mental health need they are designed to treat and support.

This model is intended to support ICBs to consider demand and capacity issues across certain types of services, and the likely optimal models to deliver improved clinical outcomes and value for money.

The levels are not intended to convey that services should be organised according to these levels or that transition between service types is always in sequential increments, for example, a person can go straight from Level 1 care to a Level 4 service without accessing Level 2 or 3 services.

The four levels are:

Level 1: Staying well in the community

This includes all public services that support autistic adults outside of mental health hospital settings. Some of these services are within the NHS; for example, primary care services that support people with their needs such as screening, immunisation, wellbeing and health checks. Some of these services are outside of the NHS; for example, services provided by local authority or education providers to support people with, for example, social care, education, housing and employment. Although this guidance is primarily aimed NHS services, the principles also apply to other services.

Level 2: Planned mental health care

This involves provision of mental health support for people with a presenting mental health need. For instance, by primary or secondary care mental health practitioners or planned community and outpatient multi-disciplinary mental health support offered by services including community mental health teams, NHS Talking Therapies and secondary care psychological therapies teams.

Level 3: Crisis, intensive and unscheduled care

This includes crisis care, both in response to a mental health crisis, for example, an unplanned assessment of need and risk, and during the period in which the person continues to require reactive and responsive crisis support in the community, to help avoid increased risk of re-admission. The latter includes support by mainstream mental health services, including crisis resolution and home treatment teams, and autism-specific services, such as intensive support teams. In crisis, autistic adults may present to community mental health services; emergency settings such as accident and emergency departments, urgent treatment centres, crisis text or phone lines; or via emergency service partners such as the police or ambulance service.

It is crucial that during a period of crisis, autistic adults are not disconnected from their usual support services and networks. Care providers who work with autistic adults at Levels 1 and 2 should continue to work with them during a crisis as far as reasonably possible to maintain their usual routines and protective factors. It is important to note that all autistic people have a right to access reasonably adjusted mainstream mental health and emergency services.

Times of crisis vary in duration; for some autistic adults, these may be short-lived, whereas for others these may be longer lasting over weeks or longer and be recurrent. This means autistic adults can also be in contact with community mental health services that provide ongoing support during crisis, as well as crisis resolution and home treatment teams, liaison psychiatry services and in some cases, Intensive Support Teams. Where an Intensive Support Team is available, it should be named and promoted in such a way that makes it clear whether autistic people can access these services or not. It is crucial that all services supporting the autistic person work in partnership, and proactively, sharing information as needed in a timely way.

According to the Building the Right Support National Plan (1), autistic people who are experiencing a mental health crisis, at risk of admission to hospital or who are admitted to hospital because of their mental health should be placed on a dynamic support register (DSR) and offered a care (education) and treatment review (C(E)TR). [1]

Level 4: Inpatient mental health care

This involves care provided through an admission to mental health hospital settings for people whose needs cannot safely be met in a community setting and require assessment or treatment that can only be offered in a mental health hospital environment. These services include mental health acute and rehabilitation wards, secure mental health wards and any Hospital-Based Place of Safety.

All autistic adults should be able to access the support they require for a co-occurring mental health need, regardless of the level at which that support is provided. It may be appropriate for the person to access several types of support concurrently, delivered at more than one level, for example, someone accessing crisis intervention at Level 3 may also be seen by secondary care mental health services that offer ongoing review of mental health and psychological therapies at Level 2. An autistic adult's access to higher levels of support should be driven by need and not necessitated by inadequate capacity at lower levels.

[1] The policy for C(E)TRs was last updated in January 2023 for implementation in May 2023 and now includes the dynamic support register (DSR) to ensure people work together to review the needs of each person on the register.

In the following sections of this document, we introduce and explain each of the 10 principles, and how they may be applied at the different levels of care. Examples are provided to help inform thinking and facilitate discussion, rather than as an exhaustive list.

Autism terminology

The terms used to communicate with, and about, autistic people can have a profound impact on people's attitudes towards autistic people. Healthcare professionals should be mindful that the terms they use to refer to autism conveys powerful messages about their attitudes toward autistic people. Certain terminology is considered unacceptable by some autistic people and, if used, may result in some people lacking faith in a professional or disengaging from a service. Terminology should describe autism in diagnostic, but not in excessively negative or deficit-based ways, for example, autism should not be referred to as a disease or illness. Identity first language, for example, saying autistic person is preferred by more autistic adults than person first language, such as, person with autism (79,80). Services should include autistic adults when producing terminology guidelines. Clinicians should be familiar with common preferences while recognising there is no universally accepted autism terminology. Professionals should ask about, and respect, individual preferences.

1. Ensure all services are accessible and acceptable to autistic adults

Engagement and co-production

Those who are planning and designing mental health services should work in partnership with autistic adults with mental health needs, including those from a range of backgrounds and with a range of co-occurring conditions, to coproduce mental health services frequently accessed by autistic adults. It is especially important to seek the views of autistic adults who experienced barriers when trying to access a service. Stakeholders should work together to design service models that are accessible and acceptable to autistic adults while also being consistent with criteria for the delivery of NHS services, such as being informed by evidence, consistent with clinical consensus and compliant with regulations.

Reasonable adjustments

Reasonable adjustments as described in the Equality Act 2010 require public sector organisations to make changes in their approach or provision to ensure that services are accessible to disabled people. The Adult Autism Strategy: Supporting its use statutory guidance for local authorities and NHS organisations clearly states that autistic people should have support adjusted to their needs if they have a mental health difficulty and the change is considered reasonable. Reasonableness is determined in this guidance by the effectiveness, feasibility and affordability if the change were to be made for disabled people generally or for a specific individual.

A reasonable adjustments digital flag is a visible marker on a person's national care record (previously called the summary care record) so that a person's significant impairments and key conditions can be recorded (for example, autism), along with the reasonable adjustments to care that they need. The Digital Flag has now been mandated by the publication of an Information Standard Notice across all health services, for people of all ages. To record this information, a person will need to consent for it to be recorded and shared with other organisations. For people who do not have the mental capacity to give consent, staff need to follow the requirements of the Mental Capacity Act.

Reasonable adjustments should be reviewed, by staff within the care pathway periodically with the autistic adult and updated as necessary to ensure that their recorded needs remain accurate; collaboration with carers and family members may be essential to understand the specific needs of the individual. It may also be useful for the person to have a health/communication passport that summarises their needs and preferences in relation to autism. Some autistic adults may benefit from support to develop this. This can then be shared with health professionals who provide one-off or ongoing support.

Common barriers to mental health care for autistic people are outlined in Appendix B.

Adjustments that can be adopted to reduce inequalities in mental health outcomes for autistic people caused by these barriers are outlined below:

Communication and interaction difficulties

Autistic people can experience difficulties with communicating in a variety of contexts. These difficulties include interacting in spoken language, whether face-to-face or over the phone, sustaining reciprocal social communication, or understanding ambiguous, sarcastic, metaphorical or euphemistic language.

Autistic people may require more time to process information and to communicate their needs. Concerns about being misunderstood, including due to past experiences of this happening, can contribute to high levels of anxiety for autistic adults accessing services.

Alexithymia often co-occurs with autism. Alexithymia is a difficulty with identifying, distinguishing between, and describing emotions. An autistic adult with alexithymia will likely struggle to self-report their emotional states to healthcare professionals. Difficulties in emotional recognition, emotional regulation and communicating emotional states increase vulnerability to suicidal ideation or impulsive behaviours.

Anxiety about uncertain or unpredictable care

Many autistic adults express a preference for sameness and find change and uncertainty highly distressing. This can translate into a need for predictable and consistent healthcare, healthcare environments and communication with professionals throughout the duration of their care.

Executive functioning difficulties

Some autistic adults may experience difficulties with executive functioning, for example, they may struggle with daily living tasks that require forward planning, organising, multitasking, managing routines, retaining information and switching between tasks. Executive functioning difficulties may impact upon an autistic adult's access to, and experience of, healthcare. For instance, autistic adults may struggle to take medication on time, complete forms independently, schedule, plan travel to or attend appointments.

In some instances, these difficulties may not be immediately apparent; some autistic adults will manage to attend an appointment on time at the expense of other self-care routines such as eating, remembering to take medication, or attending to personal hygiene.

Sensory reactivity

Some autistic adults experience over-reactivity to sensory stimuli, for example, bright lights or a noisy environment may be experienced as aversive or painful. Others may experience under-reactivity where sensory input can produce less response than is typical, like not noticing temperature rising (2). It is also common for autistic adults to seek out sensory experiences that they find enjoyable or soothing, like body rocking, listening to a song on repeat or repeating patterns. An autistic adult may experience a combination of under-reactivity, over-reactivity and sensory seeking in response to sensory stimuli across different sensory modalities and contexts.

Self-stimulatory behaviour, which is also sometimes referred to colloquially as stimming, is a form of sensory seeking behaviour, is the repetitive performance of certain physical movements or vocalisations. This behaviour may be communicative to express feelings or can be calming for some autistic people.

Masking

This refers to an autistic person's management of their social presentation to try and minimise or mask autistic traits from others. Not all autistic people mask, but those who do may not always be aware they are engaging in masking behaviour. Some may struggle not to engage in masking even when consciously trying. It is worth noting that masking may interfere with an autistic adult's ability to communicate their distress or symptoms during an appointment with a healthcare professional. Masking has been associated with an increased risk of suicidality.

Applying the accessibility principle at Level 1

To make all services more accessible and acceptable to autistic adults, the complexity of service design, clarity of information and the terminology used about autism by general services should be considered as accessibility concerns. All health organisations in an ICB area, and their wider system partners should identify adjustments that, if applied to the service as standard practice, would increase accessibility for autistic people and may also benefit others. Examples include changes to lighting or introducing a means to achieve more control over temperature. After these adjustments are made, services should identify ways in which they can make further adjustments to help individual autistic adults, who may have more individualised needs, to access services in their community. Some examples of adjustments are provided.

Accommodating communication difficulties

- Make accessible, detailed and explicit information available to all prospective patients of services to minimise the likelihood that someone will need to contact a service for information or clarification, as this may be distressing or impossible for autistic adults. Provide, for example, details about which services offer what support and where services are located. Metaphorical or otherwise indirect language should be avoided, and multiple formats should be available, such as written leaflets, audio and video recordings.

- Offer methods of contacting all services to book or amend appointments that do not require a phone call or any oral communication, for example, text, email or web bookings and communication options.
- Some autistic adults may benefit from bringing someone with them to appointments to support them to communicate their needs or comprehend information shared. Healthcare professionals should seek and honour autistic adults' preferences about how to communicate with their supporter.
- Consider developing health/communication passports that include information about the patient's communication needs.
- Ensure communication takes place in the autistic adult's stated preferred communication format when this is feasible.
- Where self-reporting tools such as questionnaires are used to assess health symptoms, recognise autistic adults may struggle to accurately rate their symptoms, for example, because of alexithymia, literal interpretation of language used in questions, or difficulty interpreting response options.

Accommodating anxiety about uncertain or unpredictable care

- Provide consistent and familiar staffing, appointment times and appointment locations, wherever possible.
- Support familiarisation with staffing structures, for example, by providing up-to-date, accurate and accessible documentation about staffing.
- Punctuality is important for autistic people; offer appointments at times when slippage or delay is least likely to occur.
- Produce timetables and plans for appointments which the autistic person can understand. When an unexpected change to the plan is necessary, a timely explanation of the change and the reason it is needed may help in reducing the distress anxiety caused to the autistic person by the change of plan.

Accommodating executive functioning difficulties

- Offer appointments at a variety of times of the day and days of the week (and locations where possible). Autistic adults are likely to know the times at which they are least likely to miss or be late for appointments.
- Provide support with planning appointments such as proactively booking follow-up appointments, as the autistic adult struggling with executive functioning may avoid or defer booking follow up appointments themselves.
- Offer text and email reminder services about booked appointments. This should be offered for everyone, but particularly for people who have difficulties with planning or remembering appointments.

Accommodating sensory reactivity

- Help people self-manage their needs by providing information in advance about the layout and sensory environment of clinical spaces. This could be in the form of a video made available on the clinic website of the route from the car park to the treatment room.
- Offer waiting environments that are considerate to sensory reactivity. The NHS England sensory resource pack may be relevant. This includes the Green Light Toolkit which was designed to support service improvement.
- Provide resources to help autistic people cope with the sensory environment, such as sensory care bags in waiting rooms or on hospital wards.

- Assess autistic adults' sensory needs and record identified adjustments in their health/communication passport.
- If a waiting room environment is distressing for an autistic adult, the service should offer a different waiting area where autistic adults have more control over the sound, light, temperature or smells, or it should arrange with the person where they would rather wait; for example in their car outside the clinic until the clinician is ready.

Applying the accessibility principle at Level 2

As well as the adjustments mentioned for Level 1, it is important that autistic adults are supported to understand the planned care, treatment and support options that are available to them when a mental health need is identified. This includes accessible information about the potential risks and benefits of each option to inform choices about care. To avoid escalation of need, Autistic people should be supported in the community while they are waiting for planned care to be provided. Level 2 services, for example, psychological therapies pathways, should make some specific considerations for autistic adults, outlined below.

Accommodating communication difficulties

- Autistic people should be invited to co-design and develop improvements to commonly used patient-facing information or templates. Services should seek feedback to ensure all information is accessible for autistic people.
- Clearly and explicitly communicate evidence for possible gains or negative outcomes associated with certain therapeutic input.
- Offer information about the organisation of services in different formats when this is needed, for example, using pictures, videos, auditory or multi-modal methods to communicate information.
- Be aware of any difficulties with language, emotional recognition, communication and ambiguity and adjust communication as needed.
- Be aware of social interaction difficulties, which may make engaging with a therapist difficult. This may require consideration at the start of therapy, when there may be a greater need for relationship building and the reduction of social pressures.
- Consider offering longer appointments or shorter appointments. Longer appointments may be needed to accommodate discussions about their thoughts and feelings about their autism diagnosis in the context of their mental health. Shorter appointments may be needed in recognition of the high degree of effort that this form of communication may take.

Accommodating executive functioning difficulties

- Offer flexibility around appointment modality when clinically feasible. For example, video or telephone appointments may be easier if planning travel and arriving on time for appointments is a challenge.
- Identify an autistic adult's strengths and incorporate this information in decisions about their treatment, where possible.

Applying the accessibility principle at Level 3

It is important for mental health services that respond to unscheduled or crisis mental health needs to recognise the increased risk of crisis presentation among autistic adults compared to the non-autistic population. Appropriate capacity should be planned for, and Level 3

services should consider accommodations for autistic people, some examples of which are outlined below.

Accommodating communication difficulties

- The significance of language cannot be overstated; it is important to use direct, explicit, unambiguous and sensitive communication when discussing mental health and risk with autistic people.
- Recognise that an autistic adult experiencing crisis may have a reduced ability to communicate and comprehend; adults who are otherwise highly verbal may become minimally- or non-verbal during crisis. Their language comprehension can also decrease at this time.
- If the autistic adult has a friend, family member or carer present, healthcare professionals should not assume that they should not communicate directly with the autistic adult in crisis. Healthcare professionals should check autistic adult’s understanding and communication preferences, before communicating directly with other people present.
- Offer clarity about the remit and role of each crisis service.
- Healthcare professionals should take care to listen carefully to what the autistic adult says and give them enough time to process and answer questions. Healthcare professionals should also check the autistic adult’s understanding of questions or information shared.
- Operationalise terminology about mental health symptoms, for example, depression, hallucinations, risk and physical health symptoms, such as, sleep disturbance and autonomic anxiety symptoms.
- Provide alternate methods of communication, where feasible, such as written and other accessible communication alternatives to assist the autistic adult in monitoring and discussing their symptoms and views. Consider providing this information in advance to allow processing time in a more familiar setting.
- Be sensitive to cultural factors related to the understanding and acceptance of mental health and disability.
- Be aware that alexithymia may impact on an autistic adult’s confidence and ease with discussing emotional wellbeing or physical health, particularly with people unfamiliar to them, and / or at points of crisis.

Accommodating anxiety about uncertain or unpredictable care

- Provide continuity in staffing, when possible, for instance, offer follow up appointments with known healthcare professionals, rather than introducing an unfamiliar healthcare professional at each point of contact.
- Develop flexible and individualised support and care plans that can be responsive to patient preferences, when feasible.
- Develop personalised relapse prevention plans.
- Step down support in a graded way.

Accommodating executive functioning difficulties

- Support autistic adults to navigate services; key working services for autistic young people up to the age of 25, as described in the NHS Long Term Plan, should be provided and can help young autistic adults to navigate services and may help avoid unnecessary admissions to mental health inpatient settings.

- Recognise that autistic people may rely on risky coping mechanisms when in crisis, due to limited or compromised emotional processing abilities. Examples include self-harm.

Accommodating sensory reactivity

- Recognise that emergency departments can be intrinsically overwhelming and distressing for autistic people; the environment is likely to be brightly lit, noisy, unpredictable and may cause distress.
- Consider the impact of crisis which may increase sensory sensitivities, upon the person's ability to engage with the assessment process.

Accommodating masking

- Masking can increase the risk of suicidal thoughts and impact upon an autistic person's ability to seek help, to engage in any assessment or to accurately express their thoughts and feelings.
- Recognise the relevance of masking upon presentation and risk assessment; do not assume an absence of risk in someone who does not report risk.
- Focus on enhancing emotional awareness and regulation skills, employing alternative assessment methods beyond self-report, and considering tailored interventions to address autism-related challenges, to inform an accurate assessment of risk and need.

Applying the accessibility principle at Level 4

In commissioning inpatient services for autistic adults, ICBs should refer to:

- NHS England guidance on acute inpatient mental health care for adults and older adults.
- Department of Health and Social Care discharge guidance.
- NHS staff can access further helpful guidance on the NHS Futures platform, including "National guidance to support ICBs to commission acute mental health inpatient services for adults with a learning disability and autistic adults"

The Mental Health Act Code of Practice acknowledges that compulsory treatment in a mental health hospital setting is rarely likely to be helpful for an autistic person, who may be very distressed by even minor changes in routine and is likely to find detention in hospital anxiety provoking. There are many interactions in a ward environment that can combine to make mental health inpatient units unacceptable, intolerable, or possibly harmful for autistic adults. These environments can cause autistic adults to feel anxious or display signs of distress. These signs can be perceived to pose a risk to the autistic adult or to others, whether this is accurate or not. This may prolong their stay and delay their recovery when in an inpatient unit.

However, where an autistic adult is acutely mentally unwell, an inpatient admission for the purposes of mental health assessment and treatment may be the most clinically appropriate option. As well as the adjustments suggested for Levels 1, 2 and 3, some other adaptations can make inpatient services more accessible and acceptable for autistic adults. This should include considerations around communication, treatment, the ward environment and staffing.

Accommodating communication difficulties

- Ask the autistic adult in their initial admission assessment for their preferences around pace of conversations, for example, autistic adults may need information to be presented slowly, allowing more time for processing; they may want opportunities to ask questions or they may wish to receive information more than once.
- Provide autistic adults with information about their rights under the Mental Health Act. Ensure they understand any relevant terminology and have opportunities to ask questions.
- Make sure information is accessible and is made available in a format that the autistic adult can engage with, recognising that they are likely to be acutely unwell when accessing it.
- Give autistic adults enough time to discuss different treatment options and to ask questions to help them decide. They should not be required to make immediate decisions if this is not clinically necessary.
- Allow flexibility in communication formats. For example, where meetings or reviews on the ward may be undertaken either virtually or in person, it should be determined what would work best for the autistic adult. These decisions should be reviewed periodically with the person.
- Factor in the impact of the patient's autistic characteristics into any formulation of presenting problems, with a view to understanding the person better and developing an informed treatment approach.
- Recognise that standardised rating scales may not be appropriate for measuring change and improvement in an autistic adult's symptoms.

Accommodating anxiety about uncertain or unpredictable care

- Conduct night-time visual checks for breathing in a way to minimise the disturbance to an autistic adult's sleep and to avoid surprises. Safety will clearly be a priority but needs to be balanced with the implications of disturbed sleep on an autistic adult's mental wellbeing.
- Ensure that any changes to set plans or schedules are clearly communicated to the autistic adult. For instance, if the order that patients are going to be seen during a review on a ward needs to change, or an appointment is delayed, the autistic adult should be informed.
- Offer familiarisation with the ward environment. Information should be kept up to date, provided in accessible language and offered in the preferred format of each autistic adult who receives it. It could, for example, provide details about the different members of staff patients are likely to meet, how they can tell who a patient is and who is a member of staff, the security measures that are in place, the routine of the ward, rules or guidelines about the use of communal areas and how to ask for help if they need it.
- Provide clear and appropriate signage to reduce anxiety associated with being in unfamiliar settings.
- Accommodate an autistic adult's preferred routines where this is possible. For example, an autistic adult may wish to be seen first during a review on the ward to reduce the anxiety of waiting to be seen.
- Consider how an autistic adult can engage in ward activities such as community meetings with the patients and staff on shift, that focus on what is happening on the ward and things that patients would like to change.
- Provide continuity of care and staffing to autistic adults whenever possible.

- Familiarise locum staff with the patient. Ensure a thorough handover is given and have a summary available that highlights any key engagement needs.
- Where continuous one-to-one observations are required, ensure that this is discussed, explained and agreed with the person, focusing on how, where, and what will it look like. Ensure that observations are undertaken by appropriately skilled and experienced staff who, where possible, are familiar to the autistic adult and have access to relevant information about them.

Accommodating executive functioning difficulties

- Ensure the autistic adult can engage in occupational or psychological therapies that are meaningful to them, with the right level of support for them.

Accommodating sensory sensitivities

- All staff working with an autistic adult should use wellbeing documentation and/or health passports, if these have been produced. Documentation should include information, which has been agreed with the patient, about sensory triggers and contributory factors for stress or distress, ways to recognise that this is occurring and actions to be taken when they do.
- Undertake routine physical examinations like blood tests or taking blood pressure, in a way that recognises and minimises the distress caused by sensory sensitivities, including a dislike of being touched.
- Identify areas within the setting that are acceptable to the autistic adult from a sensory perspective. Autistic adults may have different sensory sensitivities and needs from each other. For example, each autistic patient could identify different environments that meet their individual needs.
- Consider the autistic adult's needs at mealtimes, which can be particularly distressing to autistic adults, given social pressures and concurrent sensory information. Find out from each autistic person about their preferences or concerns around eating in a communal area with peers and think together about how to mitigate potential distress.

2. Support access to meaningful activity

Regular engagement in activities that are meaningful to the autistic adult, including education, employment or social and leisure activities that fit their interests, is important for enabling social connections, developing skills and enhancing a sense of self-worth and confidence.

Autistic adults can be supported by healthcare professionals across the four levels described in this guideline to identify how they would like to spend their time, including supporting interests, how they may access opportunities and what reasonable adjustments, if any, they may benefit from.

Conversations should not be rushed; it can take time for some autistic adults to feel comfortable and confident to talk about these themes and instances of past failure or rejection by others may impact upon their confidence. Additionally, mental health symptoms associated with co-occurring diagnoses, including depression, anxiety, psychosis and bipolar affective disorder, can affect motivation, capacity for feeling enjoyment and confidence to be around other people. It is important for healthcare professionals to develop an understanding of the potential role of autistic characteristics, such as sensory sensitivities and

communication difficulties, and associated characteristics, such as executive functioning difficulties and mental health symptoms, in influencing engagement in meaningful activity.

Applying the meaningful activity principle at Level 1

- An example of input at Level 1 includes, for example, social prescribing to non-clinical services, such as those offered by the voluntary, community and social enterprise sector.
- Specialist autism teams or any other services who routinely diagnose autism should consider their offering for recently diagnosed autistic adults. Specifically, post-diagnostic support and/or psychoeducation to help people accept their diagnosis, develop a positive autistic identity, meet other autistic adults in their community have been shown to improve mental health (7).

Applying the meaningful activity principle at Levels 2, 3 and 4

- Consider providing support to engage in group activities offered in secondary care mental health and inpatient services.
- Offer an autistic adult to meet group facilitators first and have a couple of sessions individually, before joining peers at group sessions, where possible.
- Share session agendas in advance and provide clarity about what will and will not happen in advance of a session.
- Where autistic adults need to take leave from their education or employment because of mental ill health, healthcare professionals should offer support to consider the duration of leave and how to phase their return in a way that seems manageable.
- Support discussions around any adjustments to studying or working, for example, due to sedating effects of some medications.

3. Facilitate timely access to autism assessment, when clinically indicated

The national framework and operational guidance for autism assessment services set out the principles that should underpin the planning, design and delivery of an autism assessment pathway.

At all levels of care, early consideration should be given to the possibility that a person presenting with mental ill health may meet the clinical criteria for a diagnosis but is not yet diagnosed as autistic. When the possibility that someone may be autistic is clinically identified, timely access to a diagnostic assessment should be facilitated by mental health services at all levels. Timely assessment and diagnosis may allow opportunities to identify and better meet autistic adults’ mental health needs and to reduce known risk factors for mental ill health (4) and it can inform clinical formulation decisions about providing general or autism-specific evidence based interventions (5). Timely access to a diagnosis and the information/support provided by an autism assessment team, therefore, could potentially reduce the need for an inpatient admission, or could support therapeutic recovery and discharge into the community (3).

Consideration needs to be given about the appropriateness of an autism assessment at a given point in time, for example, if someone is well enough for observations of their behaviour to be used for diagnostic purposes or if they are receptive to a possible diagnosis.

Diagnostic overshadowing

Diagnostic overshadowing may occur in a mental health setting when a patient's autistic traits are misattributed to a diagnosed mental health or other neurodevelopmental condition. This means that they may not be offered an autism assessment when this would be appropriate, or that their autism is not considered in the formulation of their treatment and care. A patient's mental health symptoms or traits of other neurodevelopmental conditions may also be misattributed solely to an autism diagnosis, meaning that autistic people may not be offered appropriate care for their mental health or given access to assessment for other neurodevelopmental conditions.

Diagnostic overshadowing can also result in an existing autism diagnosis being questioned or removed in the context of an escalation in mental health needs. There are two scenarios possible here: that the person received an inaccurate diagnosis, where its removal is remedying this previous error, or that a previous diagnosis was correct, but is removed in error. If a diagnosis of autism is removed from a person's medical records during an inpatient stay, a C(E)TR should take place. All these scenarios highlight the need for accurate diagnosis and knowledge of co-occurring conditions in autistic people accessing mental health settings.

Applying the assessment principle at Levels 1 and 2

- Access to mental health care must not be limited because someone has an autism diagnosis or is awaiting autism assessment. This is especially important given autistic people's increased likelihood of experiencing poor mental health outcomes, relative to non-autistic people.
- Primary care and mental health services should use data to understand the size of the autistic population in their area alongside information about rates of referrals to plan for the mental health needs of autistic people in their area.
- Some planned mental health care services, such as NHS Talking Therapies or other psychological therapy services may record an autism diagnosis or introduce standardised protocols for identifying possible autism and agreed referral pathways with their local autism assessment services.

Applying the assessment principle at Level 3

- Consider if it is clinically appropriate to undertake an autism assessment at the point of crisis, for example, if a reliable assessment of someone's communication or social interaction skills can be safely used for diagnostic purposes. Decisions about when an assessment is appropriate should be made on an individual basis, as the duration of crisis varies between people.

Applying the assessment principle at Level 4

Given the historical under-identification of autism we know that there are many undiagnosed autistic adults and especially older adults in England, some who require inpatient mental health care.

- Consider the possibility that a patient may be autistic. This means inpatient mental health settings should facilitate timely access to diagnostic assessment when this is clinically indicated.
- Discuss if the assessment should be conducted by members of the mental health hospital team, by an adult autism assessment service in the area or jointly by the autism assessment service and the hospital-based team.

- Ensure assessments are undertaken by professionals with the skills and capabilities to comply with NICE and NHS England guidance (6,7).

4. Use evidence to guide intervention choice

The NHS Constitution for England sets out principles that guide the NHS, including that the NHS provides high quality care that is safe, effective, focused on patient experience and provides best value for taxpayers' money (8). Additionally, the five-year NHS autism research strategy for England sets out that NHS care for autistic people should always be based on the judicious use of the best and current evidence (9). This helps to ensure that patients are offered treatment with proven outcomes, clinicians can reliably advise patients about known benefits and risks of treatment, and public resource is not wasted on ineffective or harmful interventions.

Prescribe medication with care and consideration

Treating mental health conditions with pharmaceutical interventions can reduce mental health symptoms and improve overall functioning and quality of life for people with mental health conditions (10–12). Diagnosed autistic adults are more likely to be prescribed psychotropic medication than the general population; while this may partly be explained by higher rates of many mental health conditions in autistic adults, many diagnosed autistic people are prescribed these medications with no recorded clinical indication (13). Providers and clinicians should recognise that over-prescribing of psychotropic medication for autistic people can cause harmful side effects to physical and mental health. A continued focus is needed to ensure psychotropic medications are not over-prescribed to treat an autistic adult's co-occurring conditions, for more see stopping over-medication of people with a learning disability, autism or both (STOMP).

An accurate diagnosis is essential in the prescription of medication. To date, there have been very few high-quality randomised controlled trials with autistic adults to test the efficacy and side effect profiles of medications. Also, autism is sometimes used as an exclusion criterion for clinical trials, which further impacts empirical evidence about medication effects and tolerability.

The patient and all relevant health professionals, including the GP, pharmacist, psychiatrist and care coordinator, should have a shared understanding of the purpose of any prescribed medications, and should monitor their effects. For more information about prescribing medication for autistic people, see the consensus guidelines on assessment, treatment and research from the British Association for Psychopharmacology.

Using evidence to guide non-pharmaceutical intervention choices

The evidence principle should be similarly applied to the use of non-pharmaceutical interventions. A non-pharmaceutical intervention is any type of health intervention that is not a medication or pharmaceutical device. A range of non-pharmaceutical interventions have demonstrated evidence-based benefits for promoting good mental health and reducing mental health symptoms. For instance, in the case of depression and generalised anxiety disorder, psychological therapies, psychoeducation, behavioural activation, exercise or problem solving skill development have demonstrable benefits (10,11).

As with pharmaceutical interventions, there is limited evidence from non-pharmacological interventions where they have been tested specifically with autistic adults. There have been some studies testing, for example, cognitive behavioural therapy and mindfulness-based

approaches with autistic people. Some psychological or talking therapies may require adaptation to make these more accessible and acceptable for autistic adults (6,14–17).

Applying the evidence principle at Level 1

- Have a named person to monitor medication use and ensure a coherent and considered plan is in place for prescribing or deprescribing, with a multi-disciplinary team approach in place for the monitoring and reviewing of the prescribed medications, and their possible interactions.
- Encourage open communication between the person and the service providers or specific therapists involved in their care in the therapeutic process and the provision of personalised and effective interventions.
- Ensure a shared awareness that autistic people may have sensitivities that increase or change side effects of certain medications, for example, medication may increase sensory reactivity and reduce tolerability.
- Autistic adults should be supported to communicate how they are feeling because of the medication they are using, and to understand its effects and possible side effects, as well as any symptoms of withdrawal that can occur.
- Healthcare professionals should be considerate of relevant preferences or sensory sensitivities that may impact medication compliance, for example, the preparation, texture, colour, and shape of medication prescribed. For instance, if an autistic adult finds swallowing tablets anxiety-provoking, it may be feasible to prescribe a suspension form alternative.

Applying the evidence principle at Levels 2, 3 and 4

- Recognise that previous experience with therapy that was not adapted with consideration of autistic people's needs may impact on a person's future willingness to re-engage in therapy. Flexibility in delivery may be needed.
- When deprescribing medication, healthcare professionals should ensure that this is person-centred and individualised. The autistic adult should be informed about the reasons for deprescribing and involved in the process wherever possible. The decision to deprescribe should be led by a multi-disciplinary team with relevant expertise. The autistic adult's preferences and needs, such as sensory sensitivities and preferred routines, should be accommodated in this decision, where possible.
- When deprescribing, consider allowing more time for the autistic adult to adjust dosage as there may be a sensitivity to the physiological effects of change, or distress caused by changes to the autistic adult's usual medication schedule.

5. Assess and proportionately manage risk

The process of risk formulation plays a key role in the delivery of all aspects of mental health care. In any formulation of risk for an autistic adult including decisions relating to risk to others, such as risk to staff, healthcare professionals need to be mindful of the way such risks are described and assessed. In accordance with the NICE clinical guideline about self-harm (18) professionals should never use risk assessment tools that create generic global stratification scores grouped into low, medium or high risk or seek to predict individual rates of repetition of self-harm or future suicide risk. This is because these tools do not provide accurate, reliable or valid estimates of risk but may lead people to believe they know more than they do about a person's risk. Instead, individual risk formulation should be undertaken by skilled clinicians.

Autistic people are at a higher risk of suicide and are more likely to experience non-suicidal self-injury than the general population. This needs to be balanced against the need for proactive risk taking in certain circumstances that is formulated upon a clear understanding of the needs of the autistic person. Positive and proactive risk taking can create positive outcomes for the autistic adult, for example, by promoting independence. There should be explicit communication between healthcare professionals and patients about risks of harms and joint decision making should take place.

Applying the risk principle at Levels 1 and 2

- When considering risk to self or to others, health care professionals should focus on the person's needs and how to support their immediate and longer-term psychological and physical safety.
- Engage in activity to enhance emotional awareness and regulation skills, employ alternative assessment methods beyond self-report, and consider tailored interventions to support autistic people.

Applying the risk principle at Level 3

- Review the role of organisational or systemic culture of risk aversion and its role in contributing to high degrees of restriction being maintained.
- Consider if typical service responses to individual incidents often prompt an immediate response of imposing additional restrictions and, if so, if this is always appropriate.

Applying the risk principle at Level 4

- Acute mental health inpatient services should have access to relevant specialist support to assist in the process of individualised risk formulation and treatment planning.
- Be aware of the risks associated with reductions in levels of support that may lead to decompensation; that is, a worsening of symptoms in a patient whose mental health was previously well-managed. This could include the point of discharge from an inpatient setting or the step down from one-to-one observations or intensive support.
- Be aware of risks to others, including risks to members of staff, that may occur alongside reductions in support. Healthcare professionals should acknowledge risk to others in assessments of risk and plan to reduce this risk when reducing levels of support to decrease any potential uncertainty around care planning.

6. Monitor and minimise the use of restrictive practices.

A restrictive practice is any practice that impacts on a person's autonomy, agency, and access to resources. ICBs should undertake a thorough examination of the use of all practices operating within both community and inpatient mental health services with a view to identifying and reducing the level of overt and more subtle restrictions they impose. Examples of restrictions faced by autistic adults are provided for information below.

Lack of choice or control

Some mental health services may limit autistic adults' options for treatment or decision-making, leaving them with limited control over their care. This may be influenced by a lack of understanding about autistic people's needs by staff within a service. Lack of choice or

control for autistic adults can manifest through a narrower range of services, therapies, medications, or opportunities for involvement in treatment planning than is the case for non-autistic adults.

Overreliance on crisis intervention

When community mental health services primarily focus on crisis intervention rather than proactive and preventive measures, autistic adults may experience restricted access to early intervention and ongoing support. This can limit their ability to address mental health concerns before escalation into crisis.

Seclusion, restraint and long-term segregation

The wellbeing of patients in a mental health ward environment is closely tied to the effective implementation of individualised care planning and comprehensive risk management plans and strategy. Factors such as cultural influences, understaffing, inadequate staff training, lack of well-defined therapeutic goals, and the purpose of admission may all play a role in perpetuating the issue of the inconsistent and/or high levels of restraint, seclusion and long-term segregation experienced by autistic adults, which is of particular concern.

Ineffective transition planning

Poorly coordinated transitions between different levels of care, such as from inpatient to community services, or from children and young people's services to adult services, can result in fragmented support and restricted continuity of care. Inadequate planning and communication during these transitions can negatively impact autistic adults' wellbeing and impede their recovery (see principle 7).

The Mental Health Units (Use of Force) Act 2018, means that mental health hospitals must actively take steps to reduce the use of force against patients, including by providing better training on managing difficult situations. The law also requires data to be collected and reported on the use of force.

Secure services should note the requirements to report the use of restraint as outlined in the adult secure service specification.

Applying the reduction of restrictive practice principle at Levels 1 and 2

- Work with wider system partners, including the local authority and third sector partners, to encourage the development and increased provision of community supports for autistic adults that can foster positive emotional wellbeing and reduce the need for higher level services for escalating mental health needs.
- Ensure community mental care is accessible by autistic adults in the area. This could include reviewing the exclusion criteria used by community mental health services.
- Engage in proactive transition planning between services.

Applying the reduction of restrictive practice principle at Levels 3 and 4

- Ensure that rules imposed in mental health hospitals, such as around locked front doors, lack of access to the kitchen to make a hot drink, strict lights out policies, no smoking policies and use of escorted or unescorted leave, are explained to patients at the outset of an admission and as and when there are any changes to this.
- Consider if any rules in place are likely to disproportionately impact autistic patients and if any are identified, include autistic adults in efforts to minimise this impact.

- Monitor the use of physical, mechanical and chemical restraints with autistic people and put plans in place to reduce these practices.
- Review the frequency and duration of instances of seclusion and segregation in care for autistic adults and make plans to actively reduce these practices.

7. Support cohesive transitions

The transition from child and adolescent to adult or from adult to older adult mental health services can often be characterised by reactivity and disjointedness, resulting in failures in the provision of care (19). There are also other life transitions that can be relevant for general wellbeing and mental health, such as moving home, being bereaved, relationship breakdowns or physical health changes, such as the onset of menopause or onset of long-term health conditions. Factors contributing to the challenges of transition include a lack of equivalence between services, differences in eligibility thresholds and limited mechanisms for sharing information. These factors, combined with various barriers to accommodation, employment, further education, meaningful occupation and access to financial assistance can make transitions particularly challenging for autistic adults.

It is crucial that the risks associated with the period of transition, for both diagnosed and undiagnosed autistic people are recognised by all services. There are several ways in which autistic people can be supported during the transition process, some examples are outlined below.

Joined-up and inter-agency working

Service providers and commissioners should have agreements in place regarding how professionals can work collaboratively with autistic adults and problem-solve complexities associated with interagency working.

Comprehensive transition plans

A transition plan should be in place that is documented, with contributions from all stakeholders. Documents need to be written in a manner that is accessible to autistic adults and their families. Copies should be available to all services involved.

Person-centred planning

Each autistic person should be at the centre of their own transition and be supported to participate from the outset. Adaptations should be introduced as needed, so that they can assert their thoughts and concerns.

A named professional supporting transition

Autistic children and young people up to the age of 25 may benefit from having an allocated transition keyworker or coordinator; a professional who is knowledgeable about autism, the various children and young people and adult services that patients may be in contact with, and who can support them and their families throughout the process.

Starting transitions earlier with an extended handover period

Ideally, planning for transition should start quite some time in advance of the point of transition, to initiate discussions about how best to support the autistic person and their family before, during and after the transition. Optimal handover periods will be best decided on an individual basis but would ideally span much of the transition period.

Enhancing knowledge and understanding

Transitions are likely to be more successful when autistic people are given clear information about the process, as well as the factors that mean transition planning is needed. Information dissemination should be conducted proactively, but sensitively, and with clear opportunities to ask questions.

8. Consider the physical health needs of people accessing mental health services

Autistic adults are at an increased risk of having physical health conditions compared to non-autistic adults (20). Moreover, physical health conditions and poor physical health are associated with premature mortality (21,22) and mental ill health (23) for autistic people. Optimising physical health management for autistic adults is crucial for addressing morbidity and mortality and reducing the further detrimental effects of acute and chronic physical health conditions upon the autistic adult's mental health. Healthcare professionals should be aware of the co-occurrence of both physical health issues and mental ill health in autistic adults.

Reduced access to timely, effective and reasonably adjusted healthcare for autistic adults potentially means that they are more likely to have unmet physical and mental health needs compared to non-autistic adults. In part, this may be because reasonably adjusted and accessible care is not available to autistic adults.

The link between physical and mental health in autistic people cannot be neatly separated. While physical health conditions can impact upon the mental health of autistic adults, mental conditions can also impact upon their physical health. Autistic adults with mental health conditions often have poor physical health outcomes. For example, an autistic adult experiencing a period of mental ill health may have a reduced ability to meet their everyday needs and stick to sleep and food routines, which can impact upon their physical health.

Applying the physical health principle at Levels 1 and 2

- Healthcare professionals should be mindful of communication difficulties, sensory sensitivities, interoception difficulties and alexithymia on an autistic adult's ability to characterise and describe their physical health symptoms.
- Healthcare professionals should also ensure that they have understood an autistic adult's description of symptoms or that the autistic adult has understood any rating scales used to assess physical symptoms. This could include an understanding that autistic adults may have a particularly high or low pain threshold.

Applying the physical health principle at Levels 3 and 4

- Healthcare professionals should be aware of bi-directional links between physical and mental health.
- Consideration should be given that diagnostic overshadowing of physical health conditions can occur when physical health symptoms are misattributed to autism or a mental health condition, or when symptoms of a mental health condition are misattributed to a physical health condition.
- Autistic adults should be offered appropriate assessment and care for their physical and for their mental health symptoms and assumptions that physical health symptoms are explained by an autism diagnosis should be avoided. For example, distressed or

withdrawn behaviour in autistic people is often assumed to be related to mental ill health, although this can also be an expression of physical pain and discomfort.

- Mental health professionals should be aware that autistic people may experience significant anxiety about physical health procedures such as monitoring, phlebotomy and radiological imaging. Mental health professionals should consider working with these physical health services to provide reasonable adjustments and increase accessibility of these procedures for autistic adults, if required.
- Ensuring effective liaison between physical and mental health services is important to help services work to achieve parity of esteem and ensure that all aspects of an autistic adult's health are given appropriate consideration.

9. Create a local commissioning strategy, informed by statistical data

For ICBs to ensure that the mental health needs of autistic adults can be met in the community, they will need to ensure that sufficient capacity is available to meet not only the current, but also the projected need.

This includes anticipating the likely growth in the number of people diagnosed as autistic, and considering the proportion of autistic people that are likely to need to access mental health services in the community.

The commissioning strategy should ensure the availability of high quality, reasonably adjusted mental health care for autistic adults in both community and inpatient mental health settings.

In 2022, NHS England published the Autistic people's healthcare information strategy for England which set out plans to improve the collection and reporting of data about autistic people's health and healthcare use. Specifically, it described the development of three dashboards describing autism assessment services, healthcare use of autistic people and mental health service use by autistic people. NHS England has developed data dashboards to support commissioners by providing national and ICB level data about the provision of services for autistic people. This data should inform local demand-capacity estimates to ensure adequate local provision of mental health services for autistic adults.[2]

ICBs should ensure their governance arrangements make provision for the need to provide relevant services for autistic adults. This includes ensuring there is adequate service provision at each of the four levels to reflect the needs of autistic adults in the area.

Several pieces of guidance have been produced to help people commissioning services for autistic adults (and people with a learning disability) to work together to ensure that autistic people have equitable access to the services needed as the rest of the population. These include:

- Commissioning services for autistic people: A cross-system framework for commissioning social care, health and children's services for autistic people, which outlines a suggested framework to support ICBs to think about what actions they should undertake and who they should engage with when taking local commissioning decisions about health, education and social care services for autistic people.

[2] Data dashboards are available to NHS and social care staff via the Futures Platform

- Supporting people with a learning disability and autistic people to live happier, healthier, longer lives: Bitesize guide for local systems, which is a bite-size guide that can help those in a commissioning role to commission a whole-life-approach which is flexible, personalised and based on enabling each person to become and be recognised as valued.
- Embedding personalised care is a key priority in the NHS Long Term Plan. Skills for Health have produced guidance on implementing person-centred approaches.
- Capabilities statement for social work with autistic adults, which is a guide developed by the British Association of Social Workers that provides guidance for professionals and other stakeholders involved in delivering social work to autistic adults.

To reflect the complexities of commissioning for people with a learning disability and autistic people, there is a principles of commissioning for wellbeing level 5 qualification learning disability and autism version available to support people who commission services for autistic people and people with a learning disability. The principles are centred around personalised and outcome focused approaches to commissioning designed to enable meaningful and fulfilled lives. The qualification is suited for people with commissioning-related roles working in social care and health.

10. Develop and maintain a well-trained workforce

To deliver consistently high-quality care for autistic people, all statutory bodies within each ICB area should develop and maintain the workforce needed. Summarised below is the work underway to support the areas highlighted and aligns to the NHS Long Term Workforce Plan.

- Autism knowledge for the whole workforce: promotion and roll out of the Oliver McGowan Mandatory Training on Learning Disability and Autism
- Upskilling and expanding the workforce who care for autistic people
- Retaining the workforce who care for autistic people
- Workforce planning, transformation, and data collection

Autism knowledge for the whole workforce: Oliver McGowan Mandatory Training on Learning Disability and Autism

It is essential that the mainstream health and care workforce recognises the importance of and has the skills to provide reasonable adjustments and person-centred care for autistic people.

The Health and Care Act 2022 (24) placed a duty on all Care Quality Commission- regulated health and social care providers to ensure their staff receive training on learning disability and autism that is appropriate to their role. The Secretary of State is required to publish a code of practice on this duty which, when published, will set standards for the training.

Training should be based on the core capabilities framework for supporting autistic people and/or people with a learning disability. This framework outlines three tiers of capabilities (i.e., skills, knowledge and behaviours) that anyone working within any health or social care setting need to support autistic people. Tier 1 capabilities are for people who require a general understanding of autism as they may interact with autistic people, but are not involved in care decisions, or provision of care and support for autistic people. Tier 2 capabilities are for people who provide support or care for an autistic person or autistic people, but who could seek support from others for complex decision-making. Tier 3

capabilities are for people who provide care in complex situations, with a high degree of autonomy or who may lead services for autistic people. The framework is incremental; that is, to possess capabilities of any given tier someone must possess the capabilities described in preceding tiers (25).

The Oliver McGowan Mandatory Training on Learning Disability and Autism is the preferred and recommended training package developed by the Department of Health and Social Care. There are Tier 1 and Tier 2 packages of this training available, and these packages align with the tiers in the core capabilities framework. Additional training is likely to be required for staff who require additional Tier 2 or Tier 3 capabilities that are not covered in the Oliver McGowan Mandatory Training on Learning Disability and Autism.

Upskilling and expanding the workforce caring for and supporting autistic people

All NHS organisations and wider system partners should make use of both national and local resources to improve organisational culture and leadership and find ways to attract people to work across different health and care settings. ICBs should take measures to ensure their workforce is diverse and is representative of the local population. The NHS culture and leadership programme is an established programme and provides resources for health and care organisations to improve their culture.

Multi-disciplinary autism-focused training and education programmes are available to support the development of a workforce with the necessary values, skills and capabilities. Based on the Building the Right support action plan commitments, funding is available for Advancing practice in learning disability and autism. This includes development of learning disability and autism credentials, a multi-professional Advanced Practice MSc development offer for staff working in learning disability and autism and development of a multi-professional consultant pathway. These offers are aligned to the Advanced clinical practice: Capabilities framework when working with people who have a learning disability and/or autism and the centre-endorsed credential specifications.

Where it can be agreed locally, training and support may be offered by the autism assessment service. The national framework to deliver improved outcomes in all-age autism assessment pathways: guidance for integrated care boards states that "The autism assessment service should provide training about autism to organisations that refer people for autism assessments in order to increase efficiency and use of resources. This could include, for example, information about writing a focused referral letter, information about valid and reliable screening tools a person or their family/carer can complete to better understand if an autism assessment would likely benefit them, the remit of the service, and need for other services or joint working."

A national autism trainer programme is also available to mental health professionals working in all-age community mental health settings. This programme has been developed by the Anna Freud Centre and AT-Autism and it is co-designed and co-delivered by autistic people, trainers, and clinicians. This training is additional to the Oliver McGowan Mandatory Training on Learning Disability and Autism.

Support for autistic adults can also be offered by autism peer support workers. These roles are for autistic people to provide support to other autistic people who are experiencing health difficulties, based on their own lived experience of autism. Autism peer support may also extend to include roles for carers/family members to provide support to other carers/family

members of autistic people accessing services. The capability framework for autism peer support workers outlines the skills and capabilities required for Autism Peer Support Workers. Autism central for parents and carers has also been established to offer resources for autism education, training and support.

Retaining the workforce who care for and support autistic adults

Retaining the workforce caring for and supporting autistic people across mental health settings is a strategic priority for the NHS. The NHS Long Term Workforce Plan outlines the commitment to reduce the overall leaver rate for NHS employed staff from 9.1% in 2022 to between 7.4% and 8.2% over the course of a 15-year modelling period (running until 2036/37). ICBs should be guided by this commitment in planning their mental health workforce retention targets. This Plan also outlines a need to grow the overall mental health, learning disability and autism workforce at the fastest rate of all care settings, at 4.4% per year until 2036/37, this growth is required to meet increasing demand and to ensure that mental health is given equal priority to physical health (26). NHS Employers offers guidance for line managers and employers on improving staff retention.

Workforce planning, transformation, and data collection

In March 2023, ICBs, along with other ICS statutory partners, produced joint forward plans which include priorities for attracting, training and retaining their workforce. These plans include integrated workforce plans and build upon both talent and succession plans and workforce transformation plans for the learning disability and autism workforce. This approach is supported in the key actions set out in 2023/24 priorities and operational planning guidance.

Appendix A. Autism identification and diagnosis

Diagnostic criteria

Autism Spectrum Disorder (referred to as autism in this guidance) is the official name of a clinical diagnosis in the International Classification of Diseases, Eleventh Edition (ICD-11; 27), within the broader category of Neurodevelopment Disorders.

The ICD is the mandated clinical classification standard that is used nationally across the NHS in England; this agreed standard states that for a person to be diagnosed as autistic, all the following criteria must apply[3]:

- "Persistent deficits in initiating and sustaining social communication and reciprocal social interactions that are outside the expected range of typical functioning given the person's age and level of intellectual development.
- Persistent restricted, repetitive, and inflexible patterns of behaviour, interests, or activities that are clearly atypical or excessive for the person's age and sociocultural context.

[3] ICD-11 was endorsed by the World Health Organisation in 2022 but does not have a mandatory implementation date, each health service around the world sets its own timeline for adoption. In the NHS in England, there is not yet a definitive date for the ICD-11 to be mandated; the tenth edition of the ICD (78) remains the mandated information standard while clinical records systems are updated. ICD-11 codes can be used locally before being mandated nationally. However, ICD-11 codes cannot yet be submitted to national datasets and will need to be mapped onto ICD-10 codes for this purpose, see this page for more information.

- The onset of the disorder occurs during the developmental period, typically in early childhood, but characteristic symptoms may not fully manifest until later, when social demands exceed limited capacities.
- The symptoms result in significant impairment in personal, family, social, educational, occupational, or other important areas of functioning. Some people with Autism Spectrum Disorder are able to function adequately in many contexts through exceptional effort, such that their deficits may not be apparent to others" (27).

Sensory reactivity differences are included under the restricted, repetitive, and inflexible patterns of behaviour, interests, or activities diagnostic criteria and have been found to be present in around 94% of autistic adults (2,28). This includes sensory sensitivities where people are over- or under-sensitive to stimuli or engage in sensory seeking behaviours. Difficulties coping with uncertainty is also included within this criterion.

Autism is also a diagnosis described in the Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5; 29). The DSM-5 is the official assessment manual in the United States of America. It has no official status in the NHS in England. Despite this, given its prominence in the scientific literature, DSM-5 diagnostic criteria are referred to in the NICE clinical guidelines.

In addition to the core diagnostic criteria, autistic people often exhibit other characteristics that, while not universally present, are commonly observed. These characteristics include masking autistic traits in order to conform to social expectations and fit in with a social context (30) autistic people may also experience being overwhelmed by certain situations or stimuli, leading to a state of shutdown or outbursts of emotion, commonly known as meltdowns (31) another area of difficulty for autistic people is interoception, which is the ability to perceive and understand internal bodily signals, such as heart rate, hunger, thirst, temperature, breathing and pain. Difficulties with interoception can further contribute to challenges in understanding, managing and communicating emotional and internal states (32); furthermore, alexithymia, which refers to challenges in recognising and describing emotions and can affect emotion regulation, frequently co-occurs with autism, affecting around 50% of autistic people compared to only 5% of the non-autistic population (33).

A growing proportion of the population is recognised as being autistic

Between 1998 and 2018 there was a 787% increase in the number of people who had a new autism diagnosis added to their primary care record in a given year (34). A recent analysis of English primary care data estimated that, as of 2018, between 59 and 72% of autistic people in England were undiagnosed (35). Assuring Transformation data shows that 16% of autistic adults in mental health inpatient settings are diagnosed as autistic after they are admitted to a mental health hospital (36). This means previously undiagnosed autistic people represent a considerable proportion of the autistic people who need inpatient mental health care. This may be because undiagnosed autistic people have no support in understanding their autistic traits or do not have access to reasonably adjusted care in community mental health services.

Appendix B. Additional information on Autism and mental health

Autistic adults are more likely than non-autistic adults to report poorer adult life outcomes (37), lower quality of life (38), symptoms of mental ill health and to be diagnosed with a mental health condition (39–41).

Many autistic people have at least one co-occurring condition, including mental and physical health conditions, other neurodevelopmental conditions, learning difficulties or a learning disability (20,39,42). For instance, an estimated 12-30% of autistic people have a co-occurring learning disability (42,43) and approximately a third report a diagnosed mental health condition (44,45). Additionally, other neurodevelopmental conditions often co-occur with autism, for example, attention deficit/hyperactivity disorder (ADHD) has been found to have a lifetime prevalence of 40.2% in autistic people (46).

Mental ill health is a significant aspect of increased mortality for autistic adults. Autistic adults are up to nine times more likely than non-autistic adults to experience suicidal ideation (47,48). Overall, autistic adults are up to seven times more likely to die by suicide than non-autistic adults (21,49). The relative risk may be greater for autistic people with co-occurring ADHD (50) and for autistic women, who have been found to be 13 times more likely than non-autistic women to die by suicide (21). Prevalence of non-suicidal self-injury in autistic people is also high, with a recent meta-analysis suggesting this may be around 42% (51).

The high co-occurrence of mental health conditions in autistic adults presents several challenges for mental health service providers; for instance, decision making about how best to support someone and make differential and co-occurring diagnoses. When criteria are met for more than one diagnosis, diagnostic overshadowing may occur; this is where symptoms of one condition are mistakenly attributed to another condition (52–55).

There are multiple known risk factors for mental ill health in autistic adults. Some of the core characteristics of autism, as well as some commonly associated characteristics, are linked to mental ill health. For example, intolerance of uncertainty, sensory processing and reactivity differences, repetitive behaviours, masking and alexithymia increase the risk of poor mental health (2,56,57).

Wider determinants of autistic people's mental ill health

Autistic adults are also more likely than non-autistic people to experience many known wider determinants of poor health, compounding their vulnerability to mental ill health. These include, for example, social isolation (58), insecure housing (59), financial difficulty, difficulty finding employment (60) and contact with the criminal justice system (61). Autistic adults are less likely to enrol in postsecondary education and those who do are more likely to drop out compared to their non-autistic peers (62). Autistic adults who do graduate from university earn less, on average, than their non-autistic peers (63). Overall, only 29% of diagnosed autistic adults living in the UK reported being in any type of employment during 2021 (60). Autistic people are more frequently exposed to possibly traumatising events and more likely to find these events traumatic (64).

Societal stigma and discrimination can limit autistic adults' opportunities for employment, education, housing, and social inclusion, thereby reducing their quality of life and increasing their need for mental health services (65,66).

Some autistic adults engage in a range of activities they find interesting and enjoyable, as frequently as suits them and in the manner that they wish. This includes employment However, many do not. For example, many autistic adults drop out of higher education and have trouble finding and sustaining employment, irrespective of often high and broad capabilities. This can be, for example, due to a lack of reasonable adjustments to tailor the sensory environment to their needs, excessive pressure to interact socially, a lack of psychoeducation to understand and accept their autistic identity or a lack of other therapeutic support to help develop skills.

Additionally, many autistic adults report being socially isolated and experiencing feelings of loneliness, with friendship networks that are typically smaller than the person would like and with few opportunities to extend these, particularly for autistic adults that are not in employment or education (58,67). Reasons for increased loneliness in autistic adults are multi-faceted, including autistic characteristics, such as communication differences and sensory overwhelm that affects comfort and attention in social situations. Anxiety and low mood or a history of aversive or unpleasant social experiences can also affect confidence to meet new people (67).

Together, limited opportunities to engage in meaningful and valued activities can negatively impact attainment of independence and quality of life (58). This also increases the vulnerability for poor mental health, further social isolation and engagement in risk behaviours, such as self-harm (67,68).

Common barriers to mental health care for autistic people

Autistic adults report more unmet mental health needs compared to non-autistic adults (68,69). Failure to provide mental health support to autistic adults when they seek it can result in people's symptoms becoming more acute and more chronic, which in turn increases the likelihood they will require more restrictive and more costly care (3). Delayed access to assessment, diagnosis and support is also associated with a greater risk for developing physical and mental health conditions (4). There are many factors known to make mental health service provision inaccessible to autistic adults that remain common in many services.

Some of the barriers to accessing mental health support for autistic adults are service-related factors. For example, some autistic adults report their referral being rejected by mental health services on account of their autism diagnosis (55). Available services are sometimes tailored towards autistic children and their families/carers, with little support available for adults (70). This can be particularly difficult for autistic adults who have recently transitioned from children and young people to adult services (71).

When mental health support is available for autistic adults, accessing these services can be complex, confusing and disjointed, with an overwhelming number of steps, inflexible service models and lack of transparency around the process (55). Booking and triage systems may also not be suited to autistic adults' communication preferences, as services often rely heavily on phone communication and this can create barriers to access for autistic adults (72). Reasonable adjustments are often not proactively offered or embedded into routine care or interventions, which can result in autistic adults withdrawing from services (71). When autistic adults are offered un-adapted treatment that they are unable to engage with, services may also discharge them early because of a mistaken perception that they fail to respond to treatment (55).

Healthcare professional-related factors may also act as barriers to autistic adults accessing mental health care, including a lack of understanding of autism and limited training about

assessing mental health and risk in autistic adults (55,70). This, in turn, can mean healthcare professionals also lack the confidence to work with autistic adults in mental health care settings (55,73). In some cases, autistic adults have described healthcare professionals not acknowledging, or acting upon, their preferred communication methods or requested reasonable adjustments (55).

Individual-related factors for an autistic adult may also impact upon their access to mental health care. For example, previous negative experiences with healthcare professionals and apprehension about approaching them again may prevent autistic adults from accessing support when needed (55,70). Autistic adults may also experience difficulties with communication or may communicate differently to non-autistic people. This can result in them finding it difficult to communicate with healthcare professionals and other staff, such as administrators (55). Co-occurring alexithymia may also cause communication difficulties for autistic adults, as they may find it difficult to recognise and describe internal states, or to distinguish between symptoms of mental ill health and their own autistic traits (33). If reasonable adjustments are not made in healthcare settings an autistic adult may experience sensory overwhelm, meltdowns or shutdowns such that they struggle to access any services in these settings (74).

Appendix C. Policy context

In 2019, the NHS Long Term Plan committed to reducing health inequalities for autistic people and people with a learning disability, including improving access to mainstream mental health settings. The Long Term Plan was preceded by the Building the Right Support national plan and national service model, published in 2015. Building the Right Support set to increase the provision of support in the community, reduce overuse of hospital admission, ensure hospital care is always high-quality and to reduce longer than necessary hospital stays.

The Autism Act 2009 set a duty to provide relevant services for the identification, diagnosis, needs assessment and support of autistic adults (75). Additionally, the Act stipulated that a national strategy for meeting the needs of autistic adults must be published and kept under review. In 2021, the National strategy for autistic children, young people and adults: 2021 to 2026 reaffirmed and expanded upon Building the Right Support and Long Term Plan commitments to increase community support and improve the quality of inpatient care. The Autism Act also specified that statutory guidance for local authorities and NHS organisations must be published and kept under review. Statutory guidance for the Autism Act was published in 2015 (76)

One responsibility for NHS organisations and Local Authorities set out in the statutory guidance of the Autism Act is to ensure the duty to plan for the provision of relevant services for autistic people as they move from being children to adults (76). This guidance recognises the introduction of education, health and care plans (EHCPs), as set out by the Children and Families Act 2014 and the Special Educational Needs and Disability Code of Practice. Given that EHCPs can be issued for anyone up to the age of 25 years, there is a key role within the application and funding of interventions to allow younger adults to access relevant educational, health and social support to stay well in the community.

The Health and Care Act 2022 represented a landmark re-organisation of health and care services in England with the establishment of integrated care systems (ICSs) across England. The purpose of ICSs is to bring partner organisations together to: i) improve outcomes in population health and healthcare, ii) tackle inequalities in outcomes, experience

and access; iii) enhance productivity and value for money, iv) help the NHS support broader social and economic development. They are designed to make it easier for all partners (including stakeholders in health, social care, local government, the voluntary, community and social enterprise sector and other strategic partners and organisations) to work collaboratively to improve health outcomes and wellbeing of local populations.

The DSR and C(E)TR policy, published by NHS England in 2023, sets the expectations for ICBs in England to maintain a register of autistic people and people with a learning disability in the area who are at risk of being admitted to mental health inpatient settings (77). This policy also outlines a process, known as a Care (Education) and Treatment Review, that should take place when an autistic adult or an adult with a learning disability is at risk of hospital admission to check community support is in place or if someone is in hospital to support timely discharge Additionally, if an autism diagnosis is removed during a person's stay in a mental health hospital, a C(E)TR should occur.

Appendix D. How we developed this guidance

With thanks to the following people for their help in developing this guidance:

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