Essex Partnership University
NHS Foundation Trust

Freedom of Information Request

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Information Requested:

I would also like to request policies and procedures. For adhd and autism under Eput via email

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Response:

The Trust does not have any specific policies on ADHD and Autism but in developing our services, and as a Trust, we are incorporating neurodiversity into our existing policies to ensure that we reflect the needs of neurodivergent individuals. This is being done in conjunction with experts by experience and experts with lived experience.

Any information on criteria for autism and adhd to access services
We have a mix of newer and more established services within the Trust. Our adult ADHD services have only been developed in recent years as has our Autism Service in the North East of Essex. The criteria for access to our ADHD and Autism services are in our service specifications. For the newer services these have obviously been completed relatively recently. In our South Aspergers service, which has been in existence since September 2009, the access criteria in the service specification have developed somewhat since it was written and require updating. This is due to consultation with commissioners due to contract developments. There are issues in relation to access to ADHD and ASD services due to the volume of referrals that come through in these areas and the mismatch in the capacity of the teams which is replicated nationwide.

There are some documents which are guidance for local ICB's in terms of thinking about Autism which are attached. It's also important to note the establishment of an ADHD task force by NHS England which will hopefully produce some guidance around services including access criteria.

Please see the The NHSe ADHD task force link below:

NHS England » NHS to launch cross-sector ADHD taskforce to boost care for patients in England

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Publication Scheme:

As part of the Freedom of Information Act all public organisations are required to proactively publish certain classes of information on a Publication Scheme. A publication scheme is a guide to the information that is held by the organisation. EPUT's Publication Scheme is located on its Website at the following link https://eput.nhs.uk

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A national framework to deliver improved outcomes in all-age autism assessment pathways

Guidance for integrated care boards

Version 1.0

Document name:	A national framework to deliver improved outcomes in all-age autism assessment pathways: Guidance for integrated care boards
Programme name:	National Autism programme
Senior Responsible Owner:	Tom Cahill, National Programme Director Dr Roger Banks, National Clinical Director
Programme Lead:	Claire Dowling, Programme Director, Autism
Version:	1.0
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Equality and health inequalities statement

This national framework sets out the principles that should underpin the planning, design and delivery of an autism assessment pathway that works for everyone irrespective of where they live, their background, age, ethnicity, sex, gender, sexuality, disability, or health conditions. Implementation of this national framework will include taking actions to reduce known sources of health inequality that exist in access to, or experiences of, an autism assessment across England.

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Foreword

Demand for autism assessments has risen rapidly over the past 20 years. Investment in autism assessment capacity has not kept pace with this growth; demand now far exceeds available capacity. Waiting lists for autism assessments across England have reached unsustainable levels. In July 2022, NHS Digital reported there were more than 125,000 people waiting for assessment by mental health services; an increase of 34% from October 2021 (1). These data show that most people wait longer, often much longer, than the three-months recommended in clinical guidelines for an autism assessment to begin (2) and the 18-week maximum waiting time for treatment to begin, as set out in the NHS Constitution (3). As demand continues to grow and capacity has remained stable or has dropped, the demand-capacity gap continues to widen.

In addition to long wait times, improvement in other areas of the autism assessment pathway is also needed. This includes improving the quality of information and support provided during and after assessment, increasing the ease and efficiency with which people transition through stages of the pathway and reducing people's uncertainty about the process. We know services are working extraordinarily hard to keep pace with rising demand, but on account of the demand-capacity gap, the ability to provide timely assessment and support for people is not often currently possible. Strategic action is needed.

The Autism Act 2009 set a statutory duty on NHS organisations and local authorities to provide appropriate services to assess autism in adults and to support autistic adults post-diagnosis. In 2019, the NHS Long Term Plan committed to reducing autism assessment waiting times and delivering packages of post-assessment support for children. In 2021, the National strategy for autistic children, young people and adults (4) expanded upon this ambition, by committing to timely access to diagnosis and demonstrably improved autism assessment pathways for people of all ages by 2026.

We recognise that achieving these policy ambitions requires a multifaceted response, that should include increasing the supply of a specialist workforce, ensuring that resource allocation to autism assessment services is sufficient to close the demand-capacity gap, while adhering to best practice clinical guidelines and deploying existing resources as effectively and efficiently as possible. Increasing workforce supply and resource allocation to autism assessment services are outside of the scope of this work but should remain a focus in efforts to achieve national policy ambitions.

With respect to effective and efficient use of existing resource, we have developed two documents to support integrated care boards (ICB) in England. We anticipate

ICBs will use these documents to work with other organisations that may provide some of the autism assessment offer in their integrated care system (ICS) footprint. We have produced this national framework that sets out general principles to be applied during the commissioning cycle for an autism assessment offer in each area of the country. We have also produced operational guidance that places these general principles in operational context in terms of how they can be applied in each area.

Both documents have been created with input from clinical, lived experience, scientific, commissioning and service management experts. Both documents incorporate relevant, evidence-based recommendations from NICE guidance.

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Context

Brief introduction to autism diagnosis

Autism spectrum disorder (referred to as autism in this national framework and the operational guidance) is the official name of a diagnosis within a broader category called neurodevelopmental disorders in the International Statistical Classification of Diseases, eleventh edition (ICD-11; 5)[1]. The ICD is the only assessment manual that officially applies in the NHS in England. This global assessment standard states that for a person to be diagnosed as autistic, all the following criteria must apply:

- “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.[2]

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[1] NHS England recognises that some autistic people dislike the presence of the word disorder in the official diagnostic category and that the terminology used is considered by some to be excessively negative. Nevertheless the ICD is the mandated diagnostic information standard in the NHS in England and the official diagnosis given by any clinical professional on behalf of the NHS must be as described, and named, in the ICD manual.

[2] This includes sensory sensitivity, including hypo- and hyper-sensitivity and sensory seeking behaviour.

- 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" (5)

ICD-11 was endorsed by the World Health Organisation in February 2022 but does not have a mandatory implementation date. This means that each health service around the world that uses the ICD manual sets its own timeline for adoption. In the NHS in England, there is, as yet, no definitive date for the ICD-11 to be mandated; the tenth edition of the ICD (6) remains the mandated information standard for use about diagnosis while clinical records systems are updated to reflect the eleventh edition. 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.

Autism is also a diagnosis described in the Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5; 7). 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 diagnostic criteria are referred to in clinical guidelines. Also, some standardised assessment tools used in England were designed using DSM-5 criteria or criteria from the previous edition. Additionally, some services used DSM-5 criteria while awaiting publication of the latest edition of the ICD. For consistency across the NHS, ICD-11 criteria should be used for the primary description of autism, but assessment tools based on DSM criteria and health record codes based on ICD-10 can still be used.

There are no diagnostic biomarkers for autism. This means there are no objective biological tests or scans used in confirming or refuting an autism diagnosis[3]. Autism is therefore a clinical diagnosis; diagnosis is based on expert clinical judgement about whether a person's observable behaviour and their own or another person's report about their developmental history and behaviours meet the clinical threshold for each of the above criteria.

None of the individual autism diagnostic criteria are exclusive to autism; that is, there is considerable overlap in diagnostic features of several communication, neurodevelopmental and mental health conditions (8). Autism also co-occurs with other conditions more often than it occurs as a sole diagnosis (9,10). For these reasons, consideration of differential, that is, alternative or co-occurring diagnoses, is necessary as part of an autism assessment to establish whether a person's

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[3] Genetic or other medical tests may be required to identify if a genetic syndrome or other medical condition explains some of the traits that led to a referral, but there are no diagnostic biomarkers for autism itself.

behaviour is explained by none, one, or more than one of a range of possible diagnosable conditions. Autism should not be assessed without also considering the possibility of differential or co-occurring diagnoses.

The purpose of an autism diagnosis

Autism is not an illness or disease, and autistic traits are not a universally agreed intervention target for every autistic person. However, an autism diagnosis can serve several important purposes as set out below. This is why universal, equitable and timely access to autism assessment in every ICB is important.

Firstly, an autism diagnosis is important in the context of healthcare. While not the case for all, many autistic people do seek interventions that are safe and effective for improving particular skills and abilities that overlap with diagnostic traits, for example, language and communication (11). A diagnosis enables clinicians to recommend interventions that have been tested for safety, acceptability, efficacy and effectiveness with people meeting the same diagnostic criteria as the person they are supporting; a critical tenet of evidence-based care. This may be, for example, interventions with an autistic person (12), or parents (13), to improve communication, behavioural or well-being outcomes.

Secondly, an autism diagnosis is a mechanism to ensure reasonable adjustments are made in general physical health or mental health services (14,15). A diagnosis is often vital in clinical formulation and treatment planning for co-occurring conditions. For example, some common mental health interventions are known to be less effective or can require adaptations for autistic people (16). For example, cognitive behavioural therapy for anxiety or depression (17) or intervention for feeding and eating disorders (18).

Thirdly, clarity about autism diagnosis can be validating for many people in their day-to-day lives. For example, this can help with the development of a positive autistic self-identity and foster connections with the autistic community (19).

Fourthly, an autism diagnosis can help facilitate access to some forms of statutory protection beyond the healthcare context. For example, an autism diagnosis may be considered when a person seeks an Education, Health and Care Plan, a legal document setting the support children and young people receive. The Equality Act 2010 can be a source of protection for people with a disability, the definition of disability according to the Act is available here. Further, autistic people have been shown to be better able to advocate for reasonable adjustments in the workplace if they have clarity about an autism diagnosis (20). Additionally, according to the statutory guidance (21) of the Autism Act 2009, autistic adults are entitled to a care assessment under the Care Act 2014 and, in some cases, an assessment report may be considered in assessing a person’s support needs.

For an undiagnosed autistic person access to personal understanding, healthcare, education, social care, reasonable adjustments in the workplace, statutory protection from discrimination, or benefits may be withheld. For these reasons, it is important that ICBs do not restrict or withhold access to an autism diagnosis, for example, because locally a decision has been taken by health to conduct only a needs-based assessment. Barriers to a diagnosis increase a person’s risk for poor outcomes in life, for example, late diagnosed autistic adults commonly experience multiple forms of abuse (22) and can experience poorer mental health, suicidality or hospital admission (23,24). As a result, autistic people, and especially people without an intellectual disability, represent a significant proportion of the mental health inpatient population in England (25).

An autism diagnosis should always be made by clinical professionals in a health service. Delayed or unequal access to autism assessment can result in missed opportunities for support from education, social care, voluntary, community and social enterprise. In turn, this can increase the likelihood that people require restrictive and costly hospital care (23,24). That is, while broad and timely access to an autism diagnosis is costly to the health service, narrow and delayed access may be more costly still.

Definitions of terms used

- Suspected or possible autism: an administrative term used to denote when a person is identified as having traits and difficulties suggestive of autism, that warrant formal assessment.

- Autism assessment: an assessment that takes place to determine if a person with suspected or possible autism meets the diagnostic criteria for autism (that is, is autistic). It is essential that the assessment of autism is not undertaken in isolation from screening or assessment of other conditions that may be the cause of, contribute to, or be associated with traits and difficulties identified; often referred to as differential or co-occurring diagnoses.

- Autism assessment service: any service commissioned to conduct autism assessments, as described above, when these represent a significant proportion of the service’s activity. Some autism assessments take place in services that do not routinely conduct autism assessments, such as, by secondary care mental health services, in an inpatient ward or during contact with the criminal justice system. This national framework and the operational guidance were not developed with these services in mind. However, any service that conducts autism assessments should consider the principles of service design and delivery in both documents. This term is used to refer to a range of services with a variety of local naming conventions, including child development centres, social-communication teams, community paediatrics, neurodevelopmental assessment teams, children and young people’s mental health services (CYPMHS), services providing autism assessments or independent services.

- Autism assessment offer: the overall NHS autism assessment capacity in each area when capacity for all autism assessment services is considered collectively. Services contributing capacity towards the autism assessment offer may be a combination of NHS services and independent providers.

- Autism assessment pathway: the journey a person takes from the moment they are identified as potentially warranting an autism assessment until the point at which they are discharged from an autism assessment service. Discharge can take place, for example, after there has been a screening and triage process that suggests a full assessment is not clinically indicated, after the autism assessment has been conducted and the person is given an assessment outcome, or after post-assessment support has been delivered. See **Figure 2** for a graphical schematic depiction of the pathway.

- Standard autism assessment: an autism assessment conducted by a single clinician, or two or more clinicians, appropriately qualified to diagnose or rule out possible autism (see **Table** 4). The assessment includes at a minimum, a clinical interview, behavioural observation, integration of developmental and corroborative information and consideration of possible differential and co-occurring diagnoses not identified at triage (especially when there has been a delay between initial referral, triage and main assessment).

- Enhanced autism assessment: an autism assessment conducted by two or more clinicians, appropriately qualified to diagnose or rule out possible autism. The assessment includes at a minimum, a clinical interview, behavioural observation, integration of developmental and corroborative information, use of validated assessment tools, a broader assessment of clinical presentation (such as estimated intellectual functioning or sensory processing) and additional liaison with referrers and other involved service(s). Siblings, partners or friends may provide corroborative information.

- Clinician or clinical professional: a health professional who has graduate or postgraduate qualifications in a health or related discipline, as well as current registration or accreditation with one of the following professional bodies: the General Medical Council, Health and Care Professions Council[4] or Nursing and Midwifery Council. Registration with a professional body does not, by definition, equip an individual to be competent in autism assessment, without appropriate skills and training in autism assessment and diagnosis.

- Staff under clinical supervision: people who may work directly with people being assessed by an autism assessment team and their family/carer under the supervision of a clinical professional, but who do not themselves have a clinical qualification or accreditation with professional bodies listed above. This includes, for example, assistant psychologists and staff in training.

- Autism assessment team: the multidisciplinary team that works in an autism assessment service. Professionals in an autism assessment team must collectively have skills to assess autistic traits and differential and co-occurring diagnoses. The National Institute for Health and Care Excellence

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[4] The Health and Care Professions Council maintains a register of professionals who have designated titles that are protected by law. Professionals who would not be appropriate members of an autism assessment team are also included in the register, for example, sports and exercise psychologists or art therapists.

(NICE) recommends professionals who should be represented in teams for children and young people under 19 years of age, and teams for adults. For a more detailed breakdown of autism assessment team membership see Appendix B.

- Autism assessment tool: a standardised assessment tool that has been designed and carefully tested to provide clinical professionals with information that can inform their decision about whether somebody is autistic. While these tools provide useful information, they are not diagnostic on their own and must be interpreted by clinical professionals. These include questionnaires, structured observational assessments, and developmentally focused interviews.

- Pre- and post-assessment support: any support that a person or their family/carer is offered while they are on the autism assessment pathway. This includes providing people with high-quality, accurate and timely information throughout the process such as communication about the assessment process, updates about what will happen and when, and where and how to get practical support. This may include signposting or facilitating introductions to other services within or beyond health. Post-assessment support can include signposting to sources of help for other conditions or provision of support around accepting and understanding an autism diagnosis. This phrase can be used to include evidence-based interventions, but also includes other broader forms of educational or informational support.

The impact of COVID-19 on autism assessment services

The impact of the COVID-19 pandemic on autism assessment services was acute and prolonged; some autism services were suspended entirely, or capacity was profoundly reduced for periods throughout 2020 (26). Some services were disrupted due to staff redeployment to the COVID-19 response effort, or to facilitate services to rapidly change their protocols and procedures, such as using telehealth methods, social distancing and personal protective equipment, or to adhere to COVID-19 lockdowns (27). Additionally, autistic people and those supporting them reported exacerbations of pre-pandemic health and educational inequalities (28,29). This suggests that people referred for autism assessment may be more likely to also have unmet social care, mental health or educational needs than was typical pre-pandemic.

The purpose of the national framework and operational guidance

Despite successive policy commitments to improve the quality and increase capacity of autism assessment services in England, gaps remain in setting out actions that need to be taken to achieve these improvements. Here, we set out two interrelated pieces of guidance to address this gap.

We have developed a national framework to deliver improved outcomes in all-age autism assessment pathways. It has three sections:

- a brief overview of the most relevant policy context
- general principles underpinning autism assessment services
- how to apply these principles during a commissioning cycle.

Additionally, we have developed operational guidance to deliver improved outcomes in all-age autism assessment pathways. The operational guidance outlines detailed information about how to deliver individual autism assessment services and how these should be configured to form an overall autism assessment offer in each area of England. This guidance is designed to help areas ensure that every person referred for an autism assessment experiences an efficient, high-quality pathway, with clarity about what will happen and confidence in the diagnostic outcomes. The guidance is comprised of three sections:

- specifications for the five stages of the autism assessment pathway
- common variations in how the autism assessment is conducted
- non-clinical tasks commonly undertaken by autism assessment services.

Together, these documents are intended to help people in commissioning, clinical, management, lived experience and administrative roles, to make decisions to deliver high quality all-age autism assessment pathways. Specifically, these documents are designed to be used to:

- Reduce the number of referrals to autism assessment services that are declined on account of insufficient information being provided.
- Reduce the number of people referred to autism assessment services when a referral is not warranted, for example, when there is no reason to suspect possible autism or when a referral to a different service would be more appropriate.
- Increase satisfaction of people referred for an autism assessment, including those who are not assessed and those who are not diagnosed as autistic, and by their family/carers, irrespective of their age, ability, or background.
- Increase confidence in decisions among all stakeholders, including the person assessed, their family/carers and all organisations that the decision is relevant to.
- Reduce the number of people who are referred to and assessed by multiple services for different conditions, especially when duplicated assessment occurs and when a single service has the capability required to conduct all the assessments that are clinically indicated.

- Increase the proportion of people who receive packages of support while awaiting assessment and soon after receiving a diagnosis.
- Maximise resource spent on well evidenced support and minimise the amount of resource allocated on un-evidenced or under-evidenced interventions.
- Ensure that autism assessment services offer attractive career options by having varied and stimulating roles for all relevant clinical professionals, to aid workforce recruitment and retention.

This national framework does not intend to:

- facilitate the complete elimination of autism assessment waiting times
- establish a single service to assess for all neurodevelopmental conditions (commonly referred to as neurodevelopmental services)
- replace existing clinical guidelines
- address models of ongoing intervention and care, beyond the immediate post-assessment period.

For more information about how both the national framework and operational guidance were developed, including the evidence considered and stakeholders consulted, see Appendix A.

Current national policy

A brief overview of policies and laws relevant to autism assessment service delivery is provided below.

Building the Right Support (2015)

The Building the Right Support national plan (30) and national service model (31) were developed to support the NHS and local authorities to reduce the number of autistic people and people with an intellectual disability in mental health hospitals, by increasing the provision of support in their local community.

The NHS Long Term Plan (2019)

The NHS Long Term Plan set out a 10-year vision for improving the NHS in England, including, for the first-time, recognising autism as a national priority. The commitments in the Long Term Plan outline a vision for changes needed in the whole NHS by 2029 to best support autistic people to lead happier, healthier, and longer lives, including:

- “Reduce waiting times for specialist services”
- “Achieving timely diagnostic assessments in line with best practice guidelines”

- “Together with local authority children’s social care and education services as well as expert charities, we will jointly develop packages to support children with autism or other neurodevelopmental disorders”.

The national strategy for autistic children, young people, and adults (2021)

The national strategy for autistic children, young people and adults: 2021 to 2026 (4) committed to ‘demonstrable improvements’ in reducing waiting times and improving assessment pathways across all age groups and across the country. Additionally, an autism strategy implementation plan was published for 2021 to 2022 (32).

Requirements of the Autism Act 2009 are that the national autism strategy is kept under review and that there is always associated statutory guidance in place setting out what local authorities, NHS organisations, and NHS Trusts must do to implement the current autism strategy and to deliver on the requirements of the Act.

The Health and Care Act 2022

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.

ICSs are partnerships of organisations that come together to plan and deliver joined up health and care services across the ICS footprint. They are designed to improve health outcomes for their population and create efficiencies by making it easier for local authorities and NHS organisations to collaborate. Within an ICS, an ICB is the statutory NHS organisation, superseding Clinical Commissioning Groups, that develop a plan for meeting the health needs of the population, managing the NHS component of the budget required to achieve that plan and arranging for the provision of health services.

Personalised care

The Long Term Plan stated that personalised care, whereby people get more control over their own health and more personalised care when they need it, will become business as usual in the health and care system (33). Guidance about how to achieve this by 2023/2024 has also been published (34). Further information is available on the NHS England website and in the Finance, Commissioning and Contracting Handbook for the NHS England Comprehensive Model for Personalised Care.

Universal personalised care is defined by six components.

- Shared decision making – people are supported to understand the care, treatment and support options available, as well as the risks, benefits and consequences of each option and to use this information to decide on their preferred course of action.

- Personalised care and support planning - this is about focusing on what matters to the person and their skills and strengths, as well as their clinical and support needs. It leads to a single plan, owned by the person and accessible to the people supporting them.
- Enabling choice – the NHS Constitution for England (3) recognises patients' right to make informed choices about the services commissioned by the NHS and information to support making decisions about these choices.
- Social prescribing and community-based support – this enables all local agencies to refer people to a social prescribing link worker to connect them into community-based support, building on what matters to the person and their family/carers, as identified through shared decision making, personalised care and support planning, and making the most of community and informal support.
- Supported self-management – this refers to increasing the knowledge, skills and confidence a person has in managing their own health and care, referred to as patient activation. This is done through putting in place interventions such as health coaching, self-management education and peer support.
- Personal health budgets – this is an amount of money to support a person's identified health and wellbeing needs, planned and agreed between them and their local ICB. This may lead to integrated personal budgets for people with both health and social care needs.

Criminal justice

NHS England's health and justice and specialised commissioning teams are responsible for commissioning healthcare for people across a wide range of secure and detained settings including prisons, secure facilities and immigration removal centres. This national framework and operational guidance should be considered in the context of existing guidance from these teams about healthcare in these contexts. This includes, for example, meeting the healthcare needs of adults with a learning disability and autistic adults in prison (35) and provision for people with a known or suspected learning disability, autism or both in liaison and diversion services (36).

In response to an inspectorate report on neurodiversity in the criminal justice system (37) the Ministry of Justice has published a neurodiversity in the criminal justice system action plan, this includes a focus on identification and diagnosis.

Principles that guide commissioning of an autism assessment service

Here we set out 10 principles that should guide all decision making by anyone planning, designing, procuring, delivering, and evaluating an autism assessment offer. These principles are that an autism assessment offer should always be:

1. ethical
2. evidence based
3. respectful
4. delivered by an appropriately skilled multidisciplinary workforce
5. a comprehensive, coherent offer
6. accessible
7. co-designed by clinicians and people who access the services
8. based on shared and current conceptualisation of autism
9. transparent
10. described in, and informed by, national statistical data.

These principles are set out in the sections below.

Ethical

Autism assessment pathways, from the outset (that is, from the time potential autistic traits are identified, up until discharge from an autism assessment service), should not cause harm to people. This fundamental principle should guide decision making at every level to ensure services design and delivery is ethical. Ethical considerations should be made on several grounds.

Firstly, consider if actions taken by an autism assessment service have the potential to harm someone who is referred for assessment by that service. This may be, for example, considering how service level exclusion criteria or the sharing of inaccurate or potentially harmful information with someone before, during or after an assessment, could potentially cause harm.

Secondly, consider if actions taken by people performing commissioning functions are appropriately protecting people from risk. This could include, for example, taking appropriate precautions to ensure an ICB is satisfied each service that contributes to the autism assessment offer in each area is appropriately regulated, or when a service is not registered with the Care Quality Commission, that the ICB is satisfied with the steps taken to appraise that service and communicate what this means to prospective patients. Additionally, if a service routinely produces assessment decisions that are not trusted by other providers, consider the potential for this to cause harm both to the person assessed and to the wider autism assessment offer in the area. This may result in another service re-validating a decision incurring additional resource and questioning the decision may be distressing for the person who was assessed.

Thirdly, consider if activities commissioned or delivered represent value for public funds. This may be, for example, considering if an intervention or process within the autism assessment offer has evidence to demonstrate it is the most effective means of achieving its intended outcome. When evidence is found of superior cost effectiveness to an existing practice, it should be replaced.

Finally, consider if claims made by autism assessment services are well founded. Any intervention delivered by an autism assessment service that claims to lead to a potential therapeutic benefit, such as, an improvement in a skill or a reduction in a symptom should have evidence of efficacy and effectiveness and have been tested for potential adverse outcomes. It is not ethical for services to claim an intervention produces therapeutic benefits when scientific and clinical consensus have not yet been established.

Evidence based

For the NHS to achieve its founding principles to provide the highest standard of excellence and best value for taxpayers' money, care must be designed and delivered based on the best, currently available evidence.

NICE has published three clinical guidelines[5] that, together, describe how health and social care services should be delivered to identify, assess for and care for people diagnosed as autistic. The autism NICE clinical guidelines were also instrumental in the development of a NICE quality standard for autism[6]. The NICE autism publications are:

- Clinical guideline 128: Autism spectrum disorder in under 19s: recognition, referral and diagnosis (2)
- Clinical guideline 170: Autism spectrum disorder in under 19s: support and management (38)
- Clinical guideline 142: Autism spectrum disorder in adults: diagnosis and management (39)
- Quality standard 51: Autism (40)

NICE guidelines remain the primary source of information to inform decisions about how to apply evidence to service design and delivery. Compliance with NICE guidelines should always inform decision making about design and delivery of a service and purchasing of assessment services from other NHS or independent

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[5] Evidence-based recommendations to guide commissioning and clinical decision making that have been developed by independent committees of professional, research and lay experts, and consulted on by a wide range of stakeholders

[6] A tool to measure how well a service is performing, identify areas for improvement and to guide regulatory review oversight processes by the Care Quality Commission (CQC).

services. Clear, accurate, current and accessible information about the extent to which each service providing autism assessments complies with NICE guidance should be available to inform people's choices.

A significant amount of scientific research evidence about the assessment, diagnosis and support for autistic people has been published since NICE guidelines were last updated. Both this national framework and operational guidance refer to additional research that was not considered in the development of the autism NICE guidelines. These documents are not intended to replace NICE guidelines, but to supplement or extend some recommendations. Some NICE guidelines have had varied implementation. For instance, where NICE refers to the need for and composition of multidisciplinary teams it does not specify the precise sources and degrees of multidisciplinary input required for every assessment. These documents seek to add additional guidance to inform decision making in these areas. NICE guidelines remain the primary information source to justify resource allocation on interventions offered for autistic people after diagnosis.

It is the responsibility of individual clinicians, their respective professional bodies and people in commissioning roles to ensure public resources are spent on well evidenced services and not on un-evidenced or under-evidenced alternatives.

Together with the Innovation Agency, NHS England have produced a practical guide to support commissioners to interpret and use evidence.

Respectful

Words matter – a lot. The terms used to communicate with, and about, autistic people can influence people's attitudes about autism.

We recommend that autism assessment pathways use language that categorises autism in diagnostic, but not negative or deficit-based terms. Autism should not be referred to as a disease or illness. Using respectful, inclusive and destigmatising language is a priority. We have set out the language principles we have used in this document that we recommend others adopt in Table 1.

Table 1. Language principles guiding this document.

Do	Do not
Use consistent terminology to describe an autism diagnosis for everyone and add details about other diagnoses a person may have, such as an intellectual disability, if appropriate.	Use functioning level descriptors, such as, high-functioning, or low-functioning autism. These are not and never were diagnoses.

When possible, ask people what language they prefer to use and respect this preference.	Be rigid about the terminology you use to talk about autism or about autistic people.
When communicating with a person or to a group of people without knowing their terminology preferences, use the more widely preferred identity first language, for example, say “she is autistic” instead of the less preferred person-first language, for example, saying “she has autism”.	Correct a person’s terminology choice about themselves or their family members.
When appropriate, describe autism as a neurodevelopmental disorder or neurodevelopmental disability.	Refer to autism as a disease or an illness.
Use descriptive and clinically informative language about a person’s strengths and difficulties.	Use negative or value-laden language when describing a person’s diagnosis, such as, suffers from autism, or struggles with autism.
Use the language from the version of the International Statistical Classification of Diseases and Related Health Problems that is valid and current at the time at which a person is diagnosed.	Use assessment categories from earlier editions or international variants of diagnostic manuals, unless the person was diagnosed when the term was still in use.
Use descriptive names for teams, services or job titles, for example, autism assessment service, specialist autism team or autism team lead.	Use acronyms when naming or referring to teams, services or people’s job titles, such as, an ASD team or ASC assessment lead.

Delivered by an appropriately skilled multidisciplinary workforce

An important feature of an effective autism assessment pathway is that within every service, there needs to be an appropriately skilled multidisciplinary team that can deliver high-quality assessments. An appropriate clinical workforce includes:

- Good leadership. Each assessment service should be led by an appropriately qualified, skilled and experienced clinical service lead. Some services may have separate operational and clinical leadership.
- The right skill mix. The combination of skills represented in each autism assessment service should be determined by the clinical needs of the people who routinely present for assessment at that service. For example, the clinical professionals in any autism assessment service should, together, have experience and expertise in assessment of neurodevelopmental (including intellectual disability), language and communication, and behavioural and mental health conditions, as these are commonly differential or co-occurring conditions. The precise proportion of these skills required will depend on the service.
- Qualified staff. Clinical professionals should all meet the qualification, regulation and current professional registration requirements to practice by their respective professional bodies. Clinical professionals from a limited number of professional disciplines (for example, a paediatrician, psychiatrist, clinical psychologist) are qualified to conduct each component of an autism assessment. Clinical professionals from many clinical professions (for example, speech and language therapists, occupational therapists and some types of nurses) are qualified to conduct some but not all components of an autism assessment; they should conduct autism assessments as part of a multidisciplinary team where the team is collectively qualified to conduct all required components of the assessment, see the Operational Guidance and Appendix B for more detail. Some clinical professionals may have additional training and qualifications to practice at multi-professional consultant or multi-professional advanced clinical practice level to increase the number and diversity of professions represented in leadership roles. When these include training and assessed capability to conduct components of autism assessments, such as, for example, the autism credential, this may increase capability in relation to the components of assessment a professional can undertake. Some clinical professionals may have some additional non-clinical qualifications (for example diplomas, undergraduate or postgraduate degrees); this does not change their qualification to conduct each component of an autism assessment. Some components of assessment can be undertaken by staff under clinical supervision.
- Access to clinical supervision. The type, amount and level of clinical supervision for clinicians and unqualified staff should meet the requirements outlined by relevant professional bodies and training institutions. In service planning, supervising clinicians should be consulted about how much time they need for clinical supervision of both qualified and unqualified staff.
- A comprehensive workforce. Autism assessment services should identify the total number of clinical professionals and professionals under clinical supervision needed to deliver a high-quality, comprehensive assessment pathway with capacity to meet anticipated demand for the year ahead, to facilitate progress against wait time policy ambitions while delivering post-assessment support. This should include focused efforts to identify and address any issues with recruitment and retention.

- Administrative staff capacity that matches demand. The amount of administrative support should be such that there is capacity to manage tasks including, appointment scheduling, liaison with people and their family/carers, coordination of staff availability, room bookings, acquisition of any assessment tools that require purchasing, ongoing input with preparation of letters and outcome documentation, and data entry into electronic clinical records. Given the limited number of appropriately qualified clinicians available to recruit to longstanding clinical vacancies in autism services, these administrative tasks should not be completed by clinical staff.
- Informed referrers. 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. This training is in addition to the Oliver McGowan Mandatory Training on Learning Disability and Autism.
- Time to upskill non-specialist services. Autism assessment services are hubs of autism expertise. When feasible, these services should deliver training, consultation and liaison, and supervision, to increase the breadth and depth of knowledge about autism across the NHS. This could include, for example, how to identify possible autism, information about the local autism assessment offer, scenarios when an autism assessment referral may not be warranted, and tips about how to support an autistic person receiving treatment for another condition. This upskilling could increase collaborative working, foster opportunities for joint assessment or ensure people waiting for an autism assessment are not excluded from other services.
- Succession planning. Services should complete and maintain talent and succession plans in advance of roles becoming vacant, such as when staff go on extended periods of planned leave, are promoted, leave a service or retire. This should include identifying staff who may be ready for promotion and supporting their training and development to attain this. This may reduce instances of dropped capacity when positions are vacant for periods during lengthy recruitment processes.
- Attractive jobs. Services should work to ensure staff are actively supported, have fulfilling and varied roles and well-paced development opportunities, such as secondment and training, as this may help reduce common recruitment and retention challenges.

Another important consideration is that there is an appropriately skilled and trained workforce performing commissioning functions for the autism assessment offer. An advanced practice credential about supporting people with learning disabilities, including people with a learning disability who are autistic and a learning disability and autism version of the principles of commissioning for wellbeing are available.

A comprehensive, coherent offer

NHS and local authority organisations should ensure that, collectively, provision is available for people of all ages to have autism assessments, and for there to be support available pre-assessment and following a recent diagnosis of autism (21).

The autism assessment offer in any given ICS area can include different combinations of the following types of services:

- For children, community paediatric teams, such as in child development centres either from within the ICS or from another ICS.
- For children and young people, community child and young people's mental health service either from within the ICS or from another ICS.
- For adults, services providing autism assessments, described in NICE guidelines as a specialist autism team, either from within the ICS or from another ICS.
- Independent services.
- Voluntary, community, and social enterprise services.
- Educational organisations.

Change and uncertainty can be anxiety-provoking for many people, particularly autistic people. It is important that the experience from referral through to discharge from autism assessment services is as continuous and consistent as possible from the perspective of the person being assessed and their family/carers. For example, when feasible, professionals in contact with the person being assessed should remain consistent (that is, when possible, the same professional contacts them or responds to queries), information could be delivered about the stages and processes in the pathway at the outset and in a standardised format, consistent terminology is used throughout the process, and meetings could take place in the same location, or on the same day/time, if the person would prefer this.

Partnership working across an ICS is important to ensure that autism assessment services work efficiently alongside each other and other care and support available across the ICS. Pre-assessment and post-diagnostic support should be available either through statutory services, education, voluntary, community, or social enterprises or independent providers. Links should be strong between a range of local organisations. Contact details for general local health and social care services, education support, regional and national charities, third sector organisations and personalised approaches should be shared and widely available to ensure the maximum amount of support is available.

There are also specific mandated partnership working requirements in the Care Act 2014 that need to be adhered to. In particular, standard 4 of the commissioning for better outcomes route map (41) that supports the implementation of the Care Act 2014.

Accessible

Autism assessments are available to all, irrespective of gender, ethnicity and culture, disability, age, sexual orientation, religion, belief, gender reassignment, pregnancy and maternity or marital or civil partnership status (3).

Reasonable adjustments are required for some people referred to the autism assessment pathway to fulfil this duty to parity in provision. For example, people who have visual or hearing impairments, are minimally verbal, have sensory sensitivities, social communication difficulties, or have no fixed access to a postal address, may find certain modes of communication more difficult to navigate. This includes telephone calls, especially if these are unplanned, with unfamiliar people or involving important discussions. Additionally, some people may find travelling to clinic or being assessed in person overwhelming experiences. Therefore, a flexible approach should be adopted to service provision when feasible, balancing choice and accessibility needs with risk, clinical utility and resource available.

Some people referred for an autism assessment, or their family/carers, do not speak or read fluent English, or they may communicate using sign language. For an autism assessment to be accessible in these instances, an interpreter may be required for a clinical interview, behavioural observational assessment or assessments with family/carers, or the person may be seen by a national service specialising in sign language assessments. Additionally, services need to be accessible for interpreters and should be commissioned by the organisation’s interpreter service. If possible, providing continuity for people using the interpreter service is beneficial. Commonly used written resources should be translated into some languages that are common in a service. Asking family/carers to interpret or translate should be avoided, whenever possible.

Health literacy universal precautions

In England, 43% of adults do not have adequate literacy skills to routinely understand health information and 61% of adults do not have adequate numeracy skills in this regard (42). Variation in health literacy plays a powerful role in many health inequalities (43).

Embedding a universal precautions approach in autism assessment pathways avoids stigmatising people with low health literacy. Health literacy can be situational. People with proficient health literacy skills may sometimes have trouble understanding health information, especially when anxious or in an unfamiliar environment.

A universal precautions approach to health literacy should be adopted within the autism assessment pathway. This calls for health care services and professionals to assume that all patients and family/carers can have difficulty understanding information and accessing services. It helps address the negative impact of low health literacy on people and the health system. This means not automatically assuming that people and their family/carers are fully clear about what the pathway comprises, how to access this, what the assessment can entail and the range of potential outcomes. Pathways should therefore:

- Develop clear and accessible written materials, such as webpages, leaflets, or posters, to outline the autism assessment offer in the area, as well as describing the assessment pathway, assessment process and potential outcomes for the specific service, using the NHS standard for creating health content.
- Use multiple formats, like easy read, plain English, video or audio, to communicate important information to ensure certain groups (such as people with an intellectual disability or visual or hearing impairment) receive information in accessible formats, using the NHS accessible information standard.
- Reduce the complexity of the pathway and terminology used to describe it.
- Prepare accessible autism diagnostic reports.
- Educate staff working within the pathway about the importance of health literacy and adoption of a universal precautions approach.

Access is based on clinical need

A guiding NHS principle is that access to an NHS autism assessment is based on clinical need, not a person’s ability to pay (3). According to the Who pays framework, no necessary assessment, care or treatment should be refused or delayed because of uncertainty or ambiguity as to which NHS commissioner is responsible for funding a person’s healthcare provision (44). This includes when a person is accessing an autism assessment outside of the area where they normally reside.

Co-designed by clinicians and people who access the services

Partners in each ICB should listen to and act on the experience and aspirations of communities in the area. There is a statutory duty for ICBs to involve people and communities in developing plans for continual improvement of services (45).

Shared and current concept of autism diagnosis

Several frameworks have been produced to supplement NICE guidelines and support local decision makers in health and social care services, with planning, designing, procuring, and evaluating autism assessment services.

The Core Capabilities Framework for Supporting Autistic People (46) sets out the skills, knowledge and behaviours that professionals working in any health or social care setting need in order to best support people accessing these services.

Commissioning services for autistic people: A cross-system framework for commissioning social care, health and children's services for autistic people (47) outlines a suggested framework to support ICBs to consider what they should analyse, what actions they should undertake and who they should engage with, when making local commissioning decisions about health, education and social care services for autistic people. This states that four areas are important in relation to autism assessment services:

- the level of population needs, including any waiting lists,
- the mix of services already in place (for example, NHS, independent and community and voluntary sector),
- the gaps that are evident in current provision and
- what future input from partners within the ICS is likely to be.

Autism diagnostic criteria have undergone numerous revisions since the first descriptions, due to expanded diagnostic thresholds, more public recognition of possible autistic traits, improved sensitivity of assessment tools and an increase in people previously receiving other diagnoses being diagnosed as autistic (48–51). One result of evolving diagnostic criteria, clinical practices and public ideas about autism, is the potential variation in people's views about what an autism diagnosis is, and currently accepted best practice in assessment for autism. For an autism assessment pathway to function effectively there must be a high degree of trust between all agencies involved (that is, professionals involved in any assessment pathway should have similar and up-to-date conceptualisations of autism). This may mean working to bring different services together to foster shared understanding and to ensure outdated ideas or practices become obsolete.

Transparent

All the information that somebody may need to easily navigate the autism assessment pathway within any ICS should be clearly and transparently communicated in an accessible public forum. This could be, for example, a single webpage that lists, by name, every service that is currently part of an autism assessment offer within an ICS geography, as well as whether there is a single point of access. A summary of the information that should be made publicly available can be found in the identification and referral section of the operational guidance. This information can be shared in other locations, for example, printed leaflets or cards linking to online content could be shared with professionals who may refer people into an autism assessment pathway or be linked in other online locations, such as the local offer.

To facilitate informed patient choice and to minimise inappropriate referrals, inclusion and exclusion criteria for each service forming part of the autism assessment offer must be clear, including age cut-offs, geographic cut-offs and eligibility based on any other existing co-occurring conditions, for example, moderate intellectual disability.

Details should be clearly communicated about who can make a referral to each service, and what information this must contain. This should also detail the process by which a referral can be made, for example, with a (template) letter or completion of an online form.

When possible, the inclusion criteria, referral mechanisms and information required in the referral process should be standardised across all services that comprise the autism assessment offer, so as to reduce the need to collect the same information more than once if a person is seen by more than one autism assessment service, for example, if they are referred onward.

Subsequent stages of the autism assessment pathway should be adequately detailed, so that the person and their family/carers, and professionals working in other settings, have clarity about what will happen, how, the likely timeframe and the potential outcomes.

Details should be provided about what is offered by each service in the autism assessment offer**,** for example, if pre-assessment and post-assessment support is available in one service but not another, this should be clearly communicated. Additionally, information should be freely and clearly accessible about the local rules used to inform decision making for people who may seek different stages of their pathway in different services, for example, if a person is diagnosed by one service, they should be able to identify whether they can access post-assessment support at another service. This information should be available to referrers and can inform patient choice decisions.

Be described in, and informed by, national statistical data

The national strategy for autistic children, young people and adults (4) sets a goal for “demonstrable progress on reducing diagnosis waiting times and improving diagnostic pathways”. Progress towards these goals will be measured through national statistics.

Regular statistical digests are published by NHS Digital[7] about services providing autism assessments (25,52). These reports draw on statistics of mental health service activity collected through the Mental Health Services Dataset (MHSDS). All NHS-funded mental health service providers, including independent sector providers, are required to report details of all NHS-funded mental healthcare activity, including autism assessments, through this collection.

Published data about autism diagnosis services report the numbers and progress of referrals to mental health providers where the primary reason for referral is recorded as ‘suspected autistic spectrum disorder’ (MHSDS table MHS101). Further relevant elements of these records are the start and end dates recorded in

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[7] NHS Digital merged with NHS England in February 2023. While previous statistical digests have been published by NHS Digital, and will be referenced as being authored by NHS Digital, future reports will be produced by NHS England.

the referral table, the records of clinical contacts (table MHS202) including the dates on which these occur, and diagnoses assigned following the referral and assessment (tables MHS604 and MHS605). Additional data relating to autism diagnosis that may be collected, includes the professional groups and occupation codes of professional staff involved (tables and MHS901) and coded standardised assessments (tables MHS606 or MHS607)

Referral rates vary widely between areas of the country, with 20% of ICB areas showing no diagnosis service activity. A further group of providers report no diagnoses of any kind made in the context of autism assessment services. A dashboard has been prepared showing currently available data for services and commissioner areas. Local services and commissioners can request access on the FutureNHS Collaboration Platform to ensure the accuracy of their data and to compare activity with other providers locally and nationally.

This approach was designed to cover the adult services described in the 2014 autism strategy. It does not cover autism assessments of children in child development or paediatric services that do not report activity through the MHSDS. Work is ongoing to identify ways to document relevant aspects of these services through the Community Services Data Set and other approaches in relation to hospital-based paediatric services.

How to commission an autism assessment service

Accountability for the commissioning of assessment services resides with the ICB, although it may transfer the commissioning responsibility to another organisation. Organisations new to commissioning with transferred responsibility may need to access support, guidance and information from organisations with more commissioning experience. We have used a model commissioning cycle to help people in commissioning roles to apply the principles of effective autism assessment services at each stage of the cycle. Figure 1 is a schematic diagram of an example of a commissioning cycle.

Figure 1. This diagram shows the continuous cycle of activity required to commission services, care and support (53)**.**

Strategic Planning

Assessing needs

To plan service capacity, each ICB will need to establish how many people from the population it covers are likely to need an autism assessment during each commissioning cycle. Population health management tools are useful for assessing need and should be used to provide good quality information with which to make informed commissioning decisions. Some considerations for assessing local demand are outlined in the following sections.

Autism assessment provision is needed throughout the lifespan

The traits that characterise autism emerge during the pre-school years, yet diagnoses given before 2 years of age are less stable than those given after this age (54). Autism is also a lifelong condition. For some people, autism is identified and diagnosed very early in life. However, autistic traits can be subtle and awareness of these is variable, meaning that for some people, traits are not identified or assessed until well into adulthood (55,56).

Capacity is needed for at least 1,300-2,300 people per 100,000 to be assessed for possible autism at least once in their lifetime

Autism is common; the incidence of autism in England is estimated to be approximately 1 - 1.7% of the population (57,58). This incidence means 1,000 - 1,700 people per 100,000 population in every age cohort is estimated to be autistic. Determining assessment capacity requires further consideration. Not everyone who is referred to or assessed by an autism assessment service will be diagnosed as autistic. In two studies, 68% and 84% of adults assessed for possible autism were diagnosed as autistic, respectively (59,60). For children and young people's assessment services approximately 66% of children referred were diagnosed as autistic, and about 75% of those who were assessed were diagnosed as autistic (61). There are also several scenarios when somebody has an autism assessment on more than one occasion. For example, the outcome was not clear when they were first assessed or they were referred for a second opinion, so needs should also be assessed based on some people requiring more than one assessment. Therefore, to reduce wait times in accordance with national policy commitments, a minimum capacity is needed for at least 1.5 – 2.6% of the population to be referred to an autism assessment service and for at least 1.3 – 2.3% of the population to be assessed for autism.

In each planning round, the total likely assessment need for the year ahead should be estimated alongside a breakdown of needs by age group/service type

People in commissioning roles should estimate the likely need for autism assessments (including based on information about waiting lists from every service in their autism offer locality), to inform commissioning decisions. Additionally, information may be used from national autism waiting time statistics and NHS England's dashboard to understand trends in national or neighbouring areas. Information about the range, distribution and mean wait times, as well as any differences for specific groups of people, may also be available in information used to manage contracts with services.

Furthermore, people in commissioning roles should consider historical rates of diagnosis at different ages to inform strategic decisions about the apportioning of local resource to services for autism assessment for people of different ages and with different levels of ability.

Reviewing service provisions

People in commissioning roles are expected to have accurate, current and reliable information about all providers of autism assessment services available in their area. This applies to NHS, independent, or voluntary, community and social enterprise sector organisations. Services should be reviewed with respect to the extent to which NICE clinical guidelines are applied, a Care Quality Commission (CQC) review of services has been undertaken whether services are performing well relative to national and local advisory and statutory guidance. A service self-declaring that it is compliant with NICE guidelines, or a single CQC review, is not sufficient to determine if a service is having a positive impact on the whole autism assessment offer. Additionally, owing to the lack of available evidence at the time that NICE guidelines were last updated, these do not mention telehealth assessment; therefore, providers using telehealth in autism assessment should have quality and safety checks in addition to any claims of NICE compliance.

People in commissioning roles should work with all autism assessment services and wider organisational partners to understand if any autism assessment services contributing to the autism assessment offer may have a detrimental unintended consequence elsewhere in the system. An example is when a service's assessment decisions and diagnostic outcomes are not widely trusted by other services in the area, as this can result in services committing substantial resource re-confirming assessment decisions that, when combined with the cost of the initial assessments, represents a false economy. Another example is that if one service has narrow eligibility criteria, it may disproportionately increase the waiting times for people who meet the exclusion criteria, thereby increasing inequality.

Changes within a service should be considered in terms of its impact on the wider assessment offer. For example, expanding the remit of a service to include a period of psychoeducation, without a corresponding increase in resource, will reduce the number of assessments conducted and increase waiting times.

Reviewing service provision involves:

- Ensuring there is a full understanding of all providers from all sectors in the assessment pathway and what they can offer.
- Working with a diverse range of people with lived experience to fully understand what they want and need from an autism assessment service.
- Making sure that everyone involved in the development of an autism assessment offer is aware of gaps in provision and works together to establish how these can be addressed within the resource available.
- Working with the local authority/authorities to review market position statements and wider market development, and identifying how autism assessment services can be influenced.

It is for every ICB to determine need for its population, so as to commission and procure accordingly. ICBs are also responsible for delivering a range of other services and transformation programmes. A key element of the role of the ICB is to consider assessment of need alongside review of available service provision, and to agree how to prioritise resources so that as much as possible can be provided for the local population.

Deciding priorities

Once need has been assessed, agreeing the priorities in meeting needs with all relevant stakeholders is vital. This should involve identifying gaps in provision, for example, if there are groups of people for whom there is currently no provision, or if there are groups of people for whom the amount of provision currently available is mismatched with demand. The mutually agreed priorities should then inform the subsequent stages in the commissioning cycle.

The local authority/authorities should also be involved to make sure that any wider support is taken into consideration. This should form part of a local area's planning on the use of personalised approaches as set out in NHS England's guidance on personal health budgets. This may include, for example, considering if social prescribing and personal health budgets could help in the provision of pre-assessment and post-assessment support. Similarly, this could include agreeing processes for responding to requests for an assessment with a personal health budget. This process should balance the need to meet a person's legal rights with the need to protect the autism assessment offer from negative unintended consequences, for example, untrusted assessment decisions or overwhelming services with good reputations.

Procuring services

Provision of autism assessment services could include a range of providers from the NHS, independent sector and voluntary and community sector. People in a commissioning role are expected to work across the ICS with a range of providers, including people who use services being designed. An explanatory note is available in relation to the application of the procurement, patient choice and competition regulations in the context of the new health and care arrangements, since 1 July 2022.

Designing services

The accountable ICB needs to ensure that professionals in a commissioning role work with partners so that services are designed and delivered in line with agreed priorities. This could involve re-shaping service design and delivery, or developing and procuring new services within the autism assessment offer. For example, re-shaping may be required to improve the reported experiences of the person being assessed and their family/carers, to re-distribute capacity, or to enable providers to deliver support in addition to an assessment outcome decision.

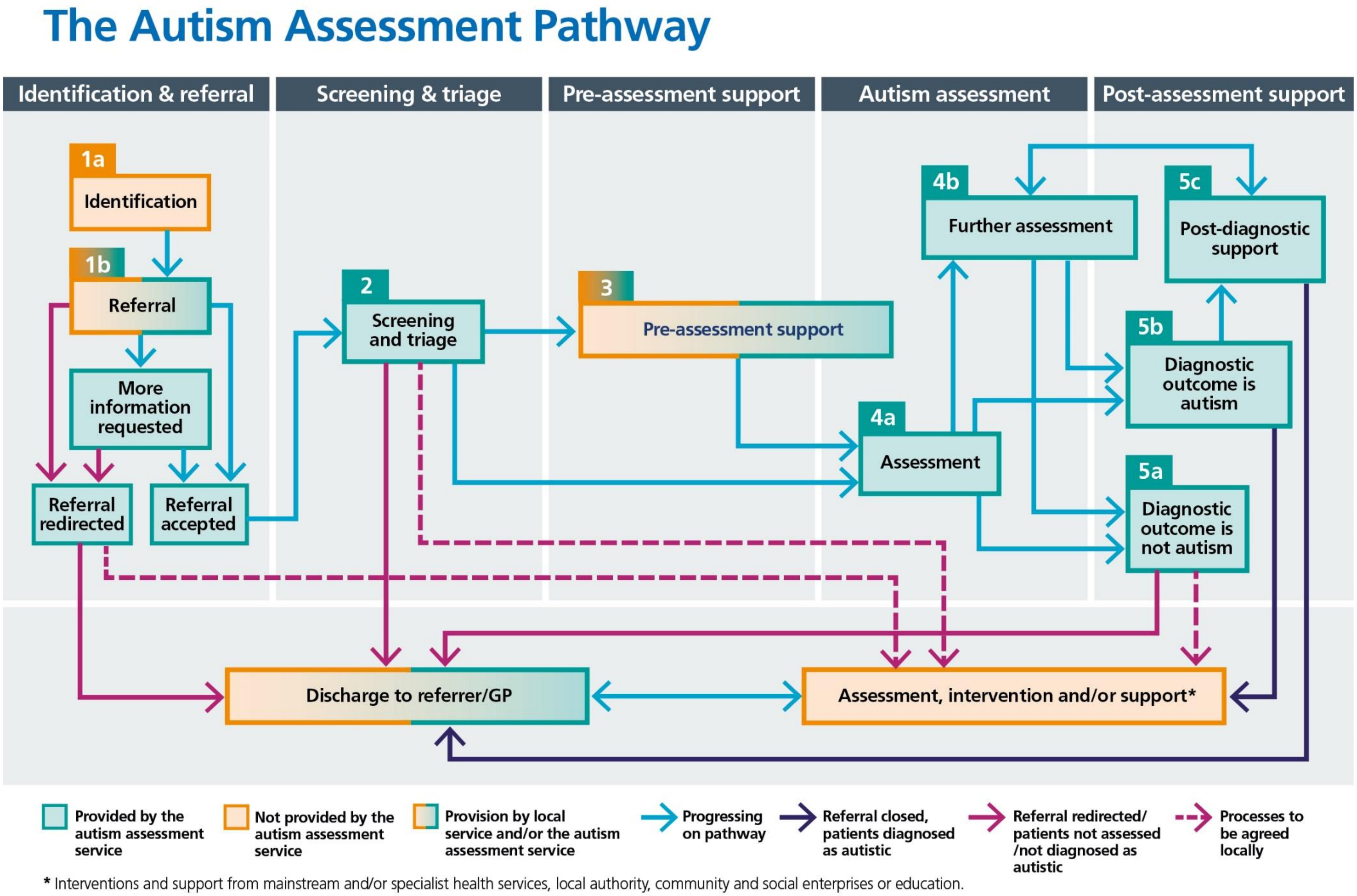
Shaping structure of supply

Once people in a commissioning role decide on what provision needs to be commissioned, they should develop clear and detailed specifications in co-production with people, family/carers and clinicians that set out precisely what is required from providers.

The autism assessment pathway is considered to have five stages, shown in **Figure 2** and outlined below:

1. identification and referral
2. screening and triage
3. pre-assessment support
4. autism assessment

5. post-assessment support



* Interventions and support from mainstream and/or specialist health services, local authority, community and social enterprises or education.

Figure 2. The five stages of the autism assessment pathway

Planning capacity and managing demand

People in a commissioning role need to give regard to the capacity required to meet the assessed demand. This includes planning across a range of providers including NHS services, voluntary and community organisations and the independent sector. In the points below, we have provided some information that may be helpful when doing this.

Autism assessment demand capacity modelling needs to continuously plan for changing demand.

When planning capacity to meet predicted demand for an autism assessment offer, attention must be given to historical diagnostic rates of specific groups in each area to correct for historical inequalities. There has been significant variation in the incidence of autism across sex, age, ethnicity, socioeconomic status, English language fluency and geographical location (62).

There has been exponential increase in demand for autism assessment in the twenty-year period between 1998 and 2018. In this period, there has been a 787% increase in recorded incidence of autism diagnoses in a sample of GP records in the UK (63). There was a sharp rise throughout the 1990s that appeared to plateau in the 2000s (64,65), before increasing again in the 2010s, with the most pronounced rise among females, adults and people without a co-occurring intellectual disability (63).

Plan capacity by recognising that autism assessment is time consuming.

Autism assessment capacity modelling should recognise that autism assessment, by its nature, is time intensive. One UK-based survey of autism assessment teams for children put a conservative median estimate of time required per person assessed at 13 hours of clinician time (66). Capacity modelling should also reflect that the time taken to assess for autism is variable from person to person depending on a range of factors, such as gathering information about differential or co-occurring conditions, or a person’s history. Capacity planning should therefore estimate the proportion of referrals for whom a standard or an enhanced assessment may be warranted. There should be flexibility in resource allocation such that a clinician can increase the time needed to assess a person or request input from another member of the multidisciplinary team if required.

Planning capacity for post-assessment support improves autistic people’s mental health and may reduce the amount of mental health capacity required.

Newly diagnosed autistic people and their family/carers can experience an adjustment period and may take time to come to terms with their diagnosis (19,67). Brief packages of support delivered shortly after diagnosis are found to improve autistic people’s mental health (68). Post-assessment support can help people form positive autistic identities, connect with the autistic community, and understand their diagnosis. This can also involve practical advice and sharing of high-quality information to protect people against widespread autism misinformation.

Autism assessment pathways must respect a person's right to choose about interventions.

For a person to be diagnosed as autistic, a clinician must determine they have significant difficulties in their life. Some autistic people and some family/carers want safe and effective interventions to improve some skills and abilities that overlap with diagnostic criteria, such as language and communication (11). Some autistic people view being autistic as a positive or neutral part of their identity that does not require intervention. Pathways should be designed to respect the person's choice in relation to intervention. Capacity should be planned with flexibility, so that it can respond to differing proportions of people seeking interventions at different times.

Assessment services must be delivered by specialist multidisciplinary teams

Assessment of autism involves consideration of differential diagnosis, whereby other possible conditions that could explain traits and difficulties presented, need to be diagnosed or ruled out. To comply with clinical guidelines, assessments must be conducted by clinical professionals who are members of a multidisciplinary team, clinicians from certain professional disciplines may conduct single clinician assessments if they judge that a consensus decision is not required (2,39). The multidisciplinary team requires the capabilities to efficiently gather information, interpret wide and varied sources of information, navigate subjective and divided interpretations, and work efficiently with other services when joint working is appropriate, such that decisions about diagnostic outcomes are consistently arrived at with a high degree of confidence. Assessment involves a degree of subjectivity, especially when a person is on the borderline of the diagnostic boundary, or when co-occurring diagnoses are present (69). Each service within an autism assessment offer needs to be confident in the diagnostic decisions made by other services. Therefore, shared specifications should be used to determine an appropriate multidisciplinary team configuration, including a protocol for which clinicians are able to make final diagnostic decisions.

Monitoring and Evaluating

Supporting patient choice

Patient choice is an important part of the NHS Constitution. This recognises the right for all patients to make informed choices about the services commissioned by the NHS and information to support decisions about these choices. In addition, Schedule 2M of the NHS Standard Contract, which is the development plan for personalised care, should be used to set out actions for people in commissioning roles or providers, to ensure that people have choice about how their autism assessment, if clinically indicated, is delivered.

People commissioning local autism services should note that they will need to:

- Provide information about the healthcare services available, locally and nationally.
- Offer easily accessible, reliable and relevant information in a form people can understand and provide support to use it.

- Set out the national determined choices available; including when there are legal rights, ensuring these are considered and built into the pathways, and are explained in NHS Choice Framework.

Managing performance

People in a commissioning role need to review and monitor the whole autism assessment market in their area in terms of how providers are performing. This should include assessing performance against current or past contracts. The clinical quality of a service should be assessed, for instance, compliance with the NICE clinical guidelines, as well as this framework and associated operational guidance. CQC regulation reports should be reviewed. For services not registered with the CQC, other sources of information should be used to determine if there is parity of regulation to CQC, and if not, a process should be determined to ensure this is communicated to prospective patients. Patient and family/carer satisfaction and value for money should also be considered.

All the above performance metrics should be appraised holistically. Prioritising a single performance metric may be at the detriment of other metrics. That is, one provider prioritising, for example, wait times could have a negative effect on, for example, adherence to clinical guidelines, quality or patient experience. This may have knock on effects elsewhere in the autism assessment offer, for example, if one provider's decisions are routinely not trusted because of low fidelity to clinical guidelines, this can result in additional resource from other providers to review a diagnostic decision.

Seeking public and patient views

People and their family/carers have the right to provide feedback on their thoughts and experiences of accessing the autism assessment offer. There should be a regular mechanism by which feedback is reviewed and used by decision makers throughout the commissioning pathway. **Table 2** outlines several ways to involve people to ensure that the autism assessment offer reflects what is needed in the area.

Table 2. Involving people and families.

Ways to involve people and families	Resources
Meet as an autism strategy group to make local decisions about service provision informed by NICE guidelines, with representation from different stakeholder groups	NICE guidelines
Employ people with lived experience to work with you	Employing experts by experience

Set up a co-production group or commission local groups to help shape and monitor services	Co-production resources
Run focus groups that enable people to share their views and experiences about the service and act on concerns and complaints in services	Making meetings accessible Information about Ask, Listen, Do

Appendices

Appendix A. How we developed this guidance

Authors who contributed towards the framework and operational guidance.

- Dr Janine Robinson – National Speciality Adviser (National autism programme, NHS England)
- Dr Lou Thomas – Research Manager, Autism (National autism programme, NHS England)
- Daisy Wilson McNeal – Research officer, Autism (National autism programme, NHS England)
- Di Domenico – Independent Commissioning Consultant
- Dr Debbie Spain – Clinical Senior Manager (National autism programme, NHS England)
- Dr Lorcan Kenny – National Research Lead, Autism (National autism programme, NHS England)
- Sheriden McKiniry – Senior Programme Manager (National autism programme, NHS England)
- Rhona Savy Westrip – Programme Manager (National autism programme, NHS England)

Research evidence

Table 3. Research commissioned by NHS England to inform the development of this framework and operational guidance.

Title	Organisation(s)	Output(s)
A Realist Evaluation of autism service delivery: Which diagnostic pathways work best, for whom, when, and at what cost?	• Sussex Community NHS Foundation Trust • Newcastle University • University of Kent • Cambridge and Peterborough NHS Trust • Council for Disabled Children • Autistica	• Unpublished report for NHS England • Journal article in BMJ Open (70)

Post-diagnostic psychoeducation for recently diagnosed autistic adults	- University of York	- NHS England commissioned report, [available on University of York website]()
Post-diagnostic psychoeducation for recently diagnosed autistic teenagers	- Autistica - King's College London	- Unpublished report for NHS England
"Stepped Up" Care models after immediate post-diagnostic support	- University of Manchester	- Unpublished report for NHS England - Journal article in The Lancet Child & Adolescent Health (71)
Assessments of needs during autism diagnosis	- University of Bath	- Unpublished report for NHS England
Ensuring best principles in telehealth for provision of mental and physical health care for autistic people	- Autistica - University College London	- Journal article in Autism (72)
Use of digital technology in autism assessment	- King's College London	- Unpublished report for NHS England - Journal article in Frontiers in Psychiatry (27) - Journal article in JMIR Mental Health (73)
Use of stigma intervention for parents of children recently diagnosed as autistic	- University of Bedfordshire	- Unpublished report for NHS England

Additionally, the authors reviewed peer-reviewed literature, national policies, clinical guidelines and statutory guidance when preparing this framework.

External stakeholders

External stakeholders who contributed to the development of this framework and operational guidance by participating in consultation groups or providing comments on previous drafts are listed below, in alphabetical order.

- Sandy Bering – Strategic Lead Clinical Commissioner (Greater Manchester Integrated Care Board)
- Diana Boyd – Family Carer Advisor
- Professor Tony Charman – Professor of Clinical Child Psychology and Consultant Clinical Psychologist (King's College London, and South London and Maudsley NHS Foundation Trust)
- Dr Laura Crane – Associate Professor (University College London)
- Dr Conor Davidson – Consultant Psychiatrist and Royal College of Psychiatrists Autism Champion (Leeds and York Partnership NHS Foundation Trust and the Royal College of Psychiatrists)
- Dr Sophie Doswell – Consultant Clinical Psychologist (South London and Maudsley NHS Foundation Trust)
- Dr William Farr – Senior Research Fellow and Lecturer in Child Development (Sussex Community NHS Foundation Trust and the University of Cambridge)
- Professor Jonathon Green – Professor of Child and Adolescent Psychiatry (University of Manchester)
- Georgia Harper – Policy Manager (Autistica)
- Mark Humble – Commissioning and Development Manager (North of England Commissioning Support Unit)
- Sarah Jackson – Consultant Nurse, Associate Director of Nursing, Autism Clinical Pathway Lead, and Trainee Approved Clinician (Specialist Services Network, Lancashire and South Cumbria NHS Foundation Trust)
- David Keaveney-Sheath – Senior Strategic Case Manager, Adults and Autism (NHS England South East England)
- Dr Lesley Kilshaw – Clinical Autism Lead (NHS England Midlands)
- Dr Mark Lovell – Consultant Child and Adolescent Intellectual Disability Psychiatrist (Tees Esk and Wear Valley NHS Foundation Trust)
- Dr Ian Male – Consultant Community Paediatrician, and Honorary Senior Lecturer and Workforce Officer (Sussex Community NHS Trust, and Brighton and Sussex Medical School)
- Adam Micklethwaite – Director (Autism Alliance)

- Professor Mark Mon-Williams – Professor of Psychology and Director of Research Centre (Centre for Applied Education Research, Bradford Institute of Health Research)
- Joseph Nettleton Burrows – Policy and Public Affairs Manager (National Autistic Society)
- Professor Jeremy Parr – Professor of Paediatric Neurodisability (Newcastle University, Newcastle Tyne and Wear NHS Foundation Trust, and Cumbria Northumberland Tyne and Wear NHS Foundation Trust)
- Dr Venkat Reddy – Neurodevelopmental Paediatrician and Clinical Director (Royal College of Paediatrics and Child Health)
- Professor Jacqui Rodgers – Professor of Psychology and Mental Health (Newcastle University)
- Professor Ashok Roy – Clinical Advisor in Learning Disability and Autism, and Consultant Psychiatrist and Associate Medical Director (Health Education England, and Coventry and Warwickshire Partnership NHS Trust)
- Dr Marion Rutherford – Speech and Language Therapist, and (Scottish) National Autism Implementation Team (NAIT) Lead (Queen Margaret University, Scotland)
- Professor Andrew Whitehouse – Professor of Autism (Telethon Kids Institute and the University of Western Australia)

Appendix B. Roles in an autism assessment team

Table 4. Qualified clinical professionals in an autism assessment team

Discipline	Role	Activities					
		Single clinician assessment	Conduct triage	Conduct clinical interview	Conduct standardised assessments	Consensus MDT assessment	Pre- and post-assessment support and liaison
Medical	Paediatrician[a]	✓	✓	✓	✓	✓	✓
	Psychiatrist	✓	✓	✓	✓	✓	✓
Nursing [b]	Children's nurse[a]	✗	✓	✗	✓	✓	✓
	Learning disability nurse[b]	✗	✓	✓	✓	✓	✓
	Mental health nurse[b]	✗	✓	✓	✓	✓	✓
	Health visitor[a]	✗	✓	✗	✓	✓	✓
Psychology[c]	Clinical psychologist	✓	✓	✓	✓	✓	✓
	Educational psychologist[a]	✗	✓	✗	✓	✓	✓
	Forensic psychologist	✗	✓	✓	✓	✓	✓
	Counselling psychologist	✗	✓	✓	✓	✓	✓
Allied Health	Speech and language therapist[b]	✗	✓	✗	✓	✓	✓
	Occupational therapist[b]	✗	✓	✗	✓	✓	✓
	Physiotherapist[d]	✗	✗	✗	✗	✓	✗

[a] In children and young people's services

[b] Professionals practicing at multi-professional advanced clinical practice or consultant level may undertake some additional leadership roles within autism assessment services or within the ICB

[c] Some Practitioner Psychologist titles are regulated. This means it is a legal requirement to have certain qualifications or experience to undertake certain roles and use certain titles. The qualified psychologist roles in an autism assessment service are regulated more information about understanding the regulation of psychologists is available here

[d] Physiotherapists are sometimes part of the team in a child development centre and may conduct some movement/co-ordination assessments for children receiving a general developmental assessment, but would not otherwise be involved in the assessment of autism

Table 5. Unqualified and non-clinical roles that may be in an autism assessment service or team

Discipline	Roles	Conduct a single clinician assessment	Conduct triage	Conduct a clinical interview	Conduct standardised assessments	Participate in consensus MDT assessment	Pre- and post-assessment support and liaison
Medical	Trainee psychiatrist	✕	supervised	supervised	supervised	✓	supervised
	Trainee paediatrician[a]	✕	supervised	supervised	supervised	✓	supervised
Nursing [b]	Trainee children's nurse[a]	✕	supervised	supervised	supervised	✓	supervised
	Trainee learning disability nurse	✕	supervised	supervised	supervised	✓	supervised
	Trainee mental health nurse	✕	supervised	supervised	supervised	✓	supervised
	Trainee health visitor[a]	✕	supervised	supervised	supervised	✓	supervised
Psychology	Trainee clinical psychologist	✕	supervised	supervised	supervised	✓	supervised

	Trainee educational psychologist[a]	✗	supervised	supervised	supervised	✓	supervised
	Trainee forensic psychologist	✗	supervised	supervised	supervised	✓	supervised
	Trainee counselling psychologist	✗	supervised	supervised	supervised	✓	supervised
	Assistant psychologist	✗	supervised	✗	supervised	✓	supervised
	Clinical associate in psychology	✗	supervised	✗	supervised	✓	supervised
Allied Health	Trainee speech and language therapist	✗	✗	✗	✗	✓	supervised
	Trainee occupational therapist	✗	✗	✗	✗	✓	supervised
	Trainee physiotherapist[c]	✗	✗	✗	✗	✓	✗
Other	Social worker	✗	✗	✗	✓	✓	✓
	Nursery nurse[a]	✗	✗	✗	✓	✓	✓
	Teacher[a]	✗	✗	✗	✗	✓	✓
	Special Educational Needs Coordinator[a]	✗	✗	✗	✗	✓	✓
	Neurodevelopmental /autism assessment practitioner[b]	✗	✗	✗	supervised	✓	supervised
	Autism peer support worker	✗	✗	✗	✗	✗	supervised

[a] In children and young people's services

[b] This is a job description used in some services for staff employed to conduct components of autism assessments. People in these roles should always operate under the supervision of a fully qualified clinician, including people with clinical

qualifications or professional registrations not listed in Table 5, for example, psychotherapists, counsellors, social workers and teachers.

Appendix C. Glossary

Table 6. This shows the abbreviations and definitions used throughout this document.

Abbreviation	Definition
ADHD	Attention deficit/hyperactivity disorder
ASD	Autism spectrum disorder
CQC	Care Quality Commission
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, fifth edition
ICB	Integrated Care Board
ICD-11	International Statistical Classification of Diseases and Related Health Problems, eleventh edition
ICP	Integrated Care Partnership
ICS	Integrated Care System
MHSDS	Mental Health Services Dataset
NICE	The National Institute for Health and Care Excellence

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Operational guidance to deliver improved outcomes in all-age autism assessment pathways

Guidance for integrated care boards

Version 1.0

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Equality and health inequalities statement

This operational guidance sets out the principles that should underpin the planning, design and delivery of an autism assessment pathway that works for everyone irrespective of where they live, their background, age, ethnicity, sex, gender, sexuality, disability, or health conditions. Implementation of this operational guidance will include taking actions to reduce known sources of health inequality that exist in access to, or experiences of, an autism assessment across England.

Contents

Overview

This operational guidance sits alongside the national framework to deliver improved outcomes in all-age autism assessment pathways. It provides an overview of common roles and responsibilities that autism assessment services have. These include conducting autism assessments, as well as providing training, consultation and liaison, and supervision, to a range of local and regional services and organisations.

Part 1 of this operational guidance outlines key components of the autism assessment pathway. These are underpinned by ten key principles that should guide decision making about the design, procurement, delivery and evaluation of all services that comprise the autism assessment offer within the area, notably that this is:

1. ethical
2. evidence based
3. respectful
4. delivered by an appropriately skilled multidisciplinary workforce
5. a comprehensive, coherent offer
6. accessible to everyone
7. co-designed by clinicians and people who access the services
8. based on shared and current conceptualisation of autism
9. transparent
10. described in, and informed by, national statistical data.

Part 2 of this operational guidance outlines considerations for conducting autism assessments that differ from standard service delivery, such as using telehealth or seeing people who are in hospital or a forensic setting.

Part 3 focuses on the provision of autism-relevant training, consultation and liaison, and supervision.

For more information about the design, procurement, delivery and evaluation of accessible and effective autism assessment services, please refer to the national framework, which should be read in conjunction with this operational guidance. The national framework document outlines a brief overview of the most relevant policy context, general principles underpinning autism assessment service and how to apply these principles when commissioning.

Part 1. The autism assessment pathway

Five stages of the autism assessment pathway

People and their family/carers seek an autism assessment for a range of reasons. Confirmation of an autism diagnosis can be a validating experience (1–3) and facilitate access to services and support (4). Establishing if a person is not autistic is also important as it offers the opportunity for them to be referred into an alternative pathway, receive signposting to support or be directed to social prescribing link workers, depending on need.

Autism assessments routinely take place in different services, including child development centres, neurodevelopmental assessment teams and autism assessment services. In this guideline, and based on extensive stakeholder engagement, the autism assessment pathway (that is, from the point at which possible traits are identified and a referral for an autism assessment is first considered, through to discharge after an assessment has taken place) is seen to comprise five distinct stages, specifically:

1. identification and referral
2. screening and triage
3. pre-assessment support
4. autism assessment
5. post-assessment support

Some services solely provide an autism assessment (stages 1, 2 and 4), whereas other services also provide pre- and post-assessment support (stages 1 to 5). For many people, sequential delivery of each stage of the autism assessment pathway is ideal. This recognises that people and their family/carers can benefit from signposting and support before and after the autism assessment, rather than simply focusing on the assessment element of the pathway (3,5–7). At the same time, there should be flexibility in service provision. For example, it is important to consider the needs, preferences and other time or work commitments of people, as well as their family/carers, a proportion of whom may themselves be autistic.

Importantly, the autism assessment pathway should be viewed in the context of other services (including health, social care and education) that a person or their family/carers may be receiving or could benefit from. This is because referral for an autism assessment does not preclude input from other services if there are identified needs that warrant support.

The five stages of the autism assessment pathway are outlined in Figure 1. It is recommended that a range of stakeholders in each Integrated Care System (ICS) and Integrated Care Board (ICB) collaboratively develop accessible autism assessment services for people of all ages and all abilities residing in that area. See Appendix B for a list of suggested stakeholders.

Reach, acceptability and effectiveness of these pathways should be evaluated periodically, including through service evaluation, audit or research, as well as feedback, concerns or complaints received. This should involve particular focus on any gaps in provision, such as for people who are approaching transitions (for example, from children and young people's services to adult services), and people who are members of marginalised groups, have atypical presentations, and people with additional needs (for example, an intellectual disability, or visual or hearing impairment). Consideration should also be given to gaps between different services, including adult mental health and learning disability services, to ensure that people do not fall between service eligibility criteria.

Personalisation

There may be opportunities to use personalised approaches throughout the autism assessment pathway. More information on the comprehensive model for universal personalised care can be found in the national framework and on the NHS England website.

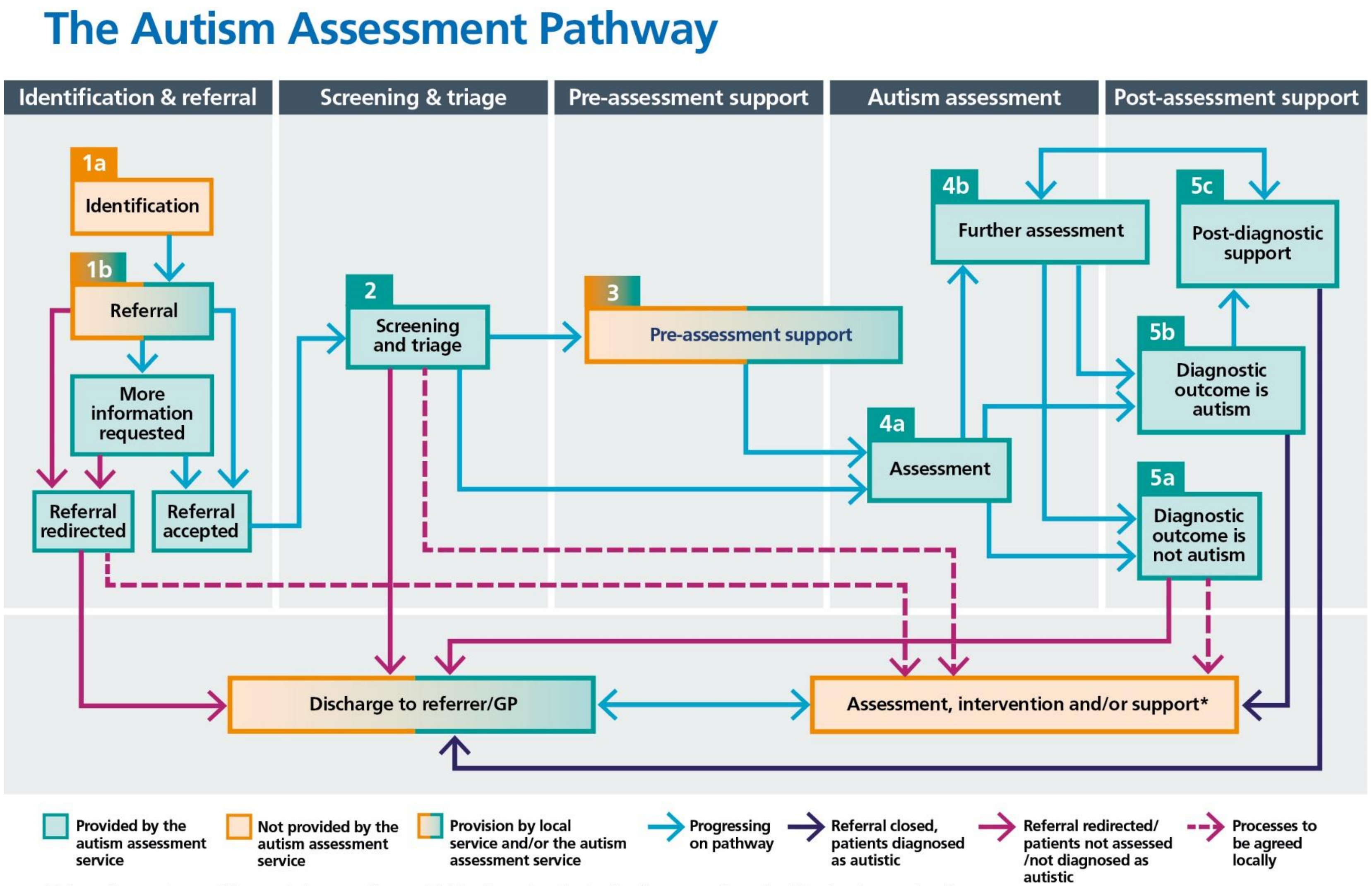
Two elements of universal personalised care may be especially relevant to the autism assessment process. Firstly, social prescribing link workers can offer signposting to local services and support networks when someone is early in the pathway and may provide continuity of care throughout a person's journey on the assessment pathway, including when onward referrals are made. It is important link workers are appropriately skilled and trained to best support autistic and possibly autistic people (8). Social prescribing link workers form part of local personalised care offers across ICBs.

Secondly, decision making can be used to ensure that the person understands the risks, benefits and possible consequences of different care and support options. NICE has developed a shared decision making learning package to support healthcare professionals develop skills and knowledge to apply the clinical guideline on shared decision making (9).

Consent

In places throughout this document, we refer to the person's consent, for example to taking part in the assessment, or to involving others in that process or sharing information that would otherwise be confidential. That consent is essential if they have capacity to make those decisions (as should be presumed if they are over 16, unless established otherwise, per the Mental Capacity Act 2005), or if they are under 16 years but are “Gillick competent” (that is, they have sufficient maturity and understanding to make those decisions). Where the person is a child who does not yet have Gillick competence to make those decisions for themselves, the decision may be made by the exercise of parental responsibility, where this is in the best interests of the child.

For someone over 16 who lacks capacity for the relevant decisions, the decision must be made in the person’s best interests, per the Mental Capacity Act.



* Interventions and support from mainstream and/or specialist health services, local authority, community and social enterprises or education.

Figure 1. The five stages of the autism assessment pathway

Stage 1: Identification and referral

The first stage of the autism assessment pathway involves identification of potential autistic traits and subsequent referral for an assessment. While autism is a neurodevelopmental disorder of childhood onset, the possibility that a person is autistic can become evident at any age. It may be that people self-identify traits they associate with autism, or these may be observed by family/carers, professionals, friends or colleagues (6,7,10–13). A formal referral for an autism assessment may be sought when traits are first identified or when there are concerns about the impact these appear to have. Importantly, perceived stigma around an autism diagnosis or cultural stigma may present concerns to people or their family/carers, potentially serving to delay obtaining a referral (14–17). Cultural factors such as differences in knowledge, awareness and descriptions of autism may also contribute to delays (18–20).

Services can minimise the impact of these factors by ensuring referrers have up to date information that is clear and accessible to inform discussion with people and their family/carers, such as regarding the options for accessing an autism assessment within the area and what this may involve. While the latter screening and triage stage is a fact-finding process (stage 2), initial conversations with a referrer can also focus on preparing the person and their family/carers about possible outcomes of a referral and an autism assessment. Information should be tailored to the needs of different groups, including people of all ages, some of whom may have a possible or confirmed intellectual disability.

Identification

There can be a significant lag between the identification of possible autistic traits, a referral being made, and the autism assessment taking place (5,7). This is partly because some people and their family/carers experience barriers and bottlenecks at this early stage of the autism assessment pathway (21,22). See Appendix C for examples of barriers. This can result in a delay in people and their family/carers obtaining the right support when they need it. Consequently, routes into the autism assessment pathway need to be transparent and easy to access, irrespective of age or ability.

Facilitating sensitive conversations about a possible autism assessment

Discussions with professionals involved in a person’s care and support, for example, a GP or teacher, are often the first step in the process for requesting a referral for an autism assessment (23). Some people feel comfortable talking about why they would like to have this, but others may not. It may be difficult for them to articulate their thoughts, or they may find the professionals they approach dismissive and unsupportive (12,15).

Therefore, initial conversations with people and their family/carers should be conducted sensitively and with compassion (15), focusing on aspects including:

- Ensuring they have time to talk about possible autistic traits that have been identified and potential impact on day-to-day functioning. Offering a longer appointment than usual or follow up meetings may be appropriate.

- Broadly clarifying the range of difficulties or needs the person experiences – and the order of priority – to establish whether an autism assessment or referral for another type of assessment is necessary (for example, of mental health or intellectual ability). This can include clarifying if the priority areas of need or difficulties identified are the same for the person and their family/carers, or distinct.

- Identifying the drivers for, potential advantages with and any concerns about having an autism assessment.

- Considering any cultural differences that may make it difficult for some people and their family/carers to seek or accept a referral, such as perceived stigma about autism specifically or healthcare use more generally.

- Noting any contextual factors that may influence a referral being made (for example, for people and their family/carers who are from travelling communities or who have no current fixed abode).

- Making a plan to address needs and risks in the short term, if necessary.

The outcome of these initial discussions should be formally noted in the clinical records, including whether the person would like to proceed with a referral. This can help with continuity of care, for example if the person discusses this with a different clinician at a follow up appointment.

Referral

Some people and their family/carers report that information about the autism assessment pathway is inaccessible (6). There can be a lack of clarity about who can make a referral, when, how, and what will happen next. Understandably, this can be distressing for people and their family/carers and contributes to delay in obtaining support.

For each ICS, the following information should be publicly available and proactively shared across multiple locations, for example, social media and local authority publications, as well as all service provider websites:

- Accurate and up-to-date information about the autism assessment offer in each area, including details for services providing autism assessments (including name, address, contact details, general remit, eligibility criteria, referral process and documentation).

- An indication of waiting times for an autism assessment at each service.

- Information on Legal Rights to Choice of provider and team, and information to facilitate informed choice including waiting times, quality of assessment that would facilitate access to local services and any known limitations as a result of accessing an external pathway.

Suggested actions for the ICB:

- Check that people of all ages can access an autism assessment in the area.
- Address gaps in autism assessment provision for particular groups (for example, people with an intellectual disability, or people in inpatient NHS or independent hospitals or services, at residential schools and colleges, or in prison).
- Decide at an ICS level whether standardised referral processes across services have merit (for example, single point of access, an online form, shared templates).
- Develop protocols for how people and their family/carers can access pre- and post-assessment support if seen for an autism assessment by an external provider, including independent providers.
- Indicate what types of autism-relevant training is available for professionals working across services in the ICS.
- Identify who holds responsibility for periodically evaluating that information listed remains up to date.

A transparent referral process

People and family/carers report they would like to know more about the potential reasons for choosing to proceed with an autism assessment (or not), the process for referral, which services can provide this, and any differences in this according to age or ability. They want to know what the main components of the autism assessment pathway are and what they can expect as potential outcomes (7,24). From the outset, conversations about expectations are essential to encourage the person and their family/carers to approach the process as an assessment for autism, rather than anticipating a specific assessment outcome. At the point of referral, people should be made aware of their rights to choose a provider and provided with accurate and up-to-date information to inform these choices. This may include average wait time and where opportunities to access local pre- and post- assessment support after an assessment differs by service.

Autism assessment services have responsibility for providing referrers, people and family/carers with accurate and detailed information about the autism assessment pathway; ideally, this information is co-produced. This should be available in multiple formats. This can include leaflets (for example, placed at GP practices, mental health and learning disability services, and in education settings as part of the Special Educational Needs and Disabilities (SEND) agenda), and on the internet (for example, websites for health and social care services, and parent groups such as Parent Carer Forums). This should also be tailored for different audiences, including young people, adults and family/carers. Translation into other languages may be appropriate for people who use English as a second language. Similarly, easy read versions and plain English versions can be more accessible for some. Referral processes should be accessible, with services addressing possible barriers, including literacy levels and access to technology.

Developing easier routes into the autism assessment pathway

Referral routes for an autism assessment can vary according to the person's age and availability of services. In some areas, the GP can refer directly to autism assessment services. However, there can be stipulations about what assessments or input are needed after possible autistic traits have been identified, but before a formal referral for an autism assessment is made. For example, people may first need to be seen for a more general assessment of difficulties, functioning or mental health, such as by a clinician in secondary care. Alternatively, people or family/carers may be asked to complete autism screening questionnaires, the scores of which may be used to help determine whether onward referral is deemed appropriate.

People and their family/carers may experience stress or distress in learning how to navigate these processes. While some areas may adopt an 'all age, no wrong door' referral system, good practice would be for each ICB area to have one accessible source of information about autism assessment services for all ages and the routes to these.

Additionally, it is sometimes suggested that family/carers of children and young people attend classes or courses focused on training in parenting skills while waiting for an autism assessment. This can delay input for children and young people. The research evidence for training in parenting skills in this context is limited (25,26), and the potential harm to family/carers by recommending they attend these courses is rarely considered (27).

There is some evidence for the success of parent mediated interventions (that may be delivered in a course format) targeting communication skills in young children, with improvements found in parent/carer and child interaction (28). Recommending interventions is appropriate only if clinically indicated. It should be based on the need for support, and not tied to the autism assessment pathway. However, parents should not be excluded from receiving support on the basis that their child is waiting for an autism assessment if they could derive benefit from this.

Taken together, decisions to delay referral for an autism assessment must be underpinned by a clinical rationale.

Making a referral for an autism assessment

Referrals for an autism assessment are usually made by professionals working in health services, social care and in education, or by professionals in the criminal justice system. Table 1 shows a summary of these settings and the roles of professionals who commonly instigate referrals. Some areas also accept self-referrals or referrals from family/carers.

Table 1. Examples of professionals who may make referrals for autism assessments, and the setting in which they may work.

Setting	Professional
Health	- GPs - Paediatricians - Psychiatrists - Nurses - Clinical, counselling or forensic psychologists - Occupational therapists - Speech and language therapists - Health visitors
Social care	- Social workers - Occupational therapists - Speech and language therapists
Education	- Educational psychologists - Speech and language therapists - Special Educational Needs Co-ordinators - Teachers at schools or colleges - Nursery teachers
Criminal justice	- Probation officers - Professionals working in court - Forensic psychologists

A joint referral from two or more professionals who know the person enhances the specificity of this. For example, this could be contributed to by the GP and either the Special Educational Needs Co-ordinator (SENCo) or the clinical psychologist offering intervention at that time. When joint referrals are made, clarity is needed about which professional and service has primary responsibility for the person while they are on the waiting list for an autism assessment, and for actioning onward referrals and recommendations.

Self-referrals for an autism assessment, and direct referrals from family/carers, are less common in NHS services. If autism assessment services accept these, there must be operational protocols about what information is needed so that appropriateness (that is, eligibility for the service) can be clinically evaluated. There also needs to be an agreement that the person’s GP be kept informed about the referral and outcome to ensure continuity of care. Careful consideration must be given to factors such as which professional and service has responsibility for ongoing risk management and can initiate further referrals if indicated at subsequent stages of the autism assessment pathway. If the person is formally referred by a professional, for example, they may be more easily signposted to other services during and after the autism assessment.

Preparing a detailed referral letter

Some autism assessment services require a general referral letter while others have a standardised referral form. The latter can reduce duplication and effort on the part of people and their family/carers. Submission of referrals via an online portal can be particularly efficient.

Referrals should be comprehensive and, at the very least, summarise:

- Past and current clinical information (including about possible autistic traits and any other physical or mental health-related symptoms).
- Concerns, as described by the person and family/carers, and order of priority, whether these differ between the person and their family/carers, and how these concerns are currently being managed.
- Contextual factors (such as about who the person lives with, any dependents, their day-to-day activities).
- If known, information about adverse childhood experiences.
- Identified risks to or from self/others, including a risk management plan.
- Any requirements for adapting the autism assessment pathway if known (for example, as the person has an intellectual disability).

A referral should indicate whether the person has been referred for assessment for another developmental condition, including Attention Deficit Hyperactivity Disorder (ADHD) or possible intellectual disability. See Appendix D for a summary of suggested focal points for inclusion in an autism assessment referral.

The more detailed a referral is, the more informed the decision making can be regarding eligibility for an autism assessment and any adaptations the person or family/carers may benefit from along the autism assessment pathway. This can reduce inefficiencies at this initial stage, such as undue administrative and clinical time addressing inappropriate referrals and retrieving missing information. However, it is important that referrals are not declined based on omitted information that is not crucial for the referral, as this can cause unnecessary delay and frustration.

Information that may be relevant to include in a referral for children and young people:

- Clarity about whether the child or young person met developmental milestones at the expected age or whether there were any noted delays.
- Details about the education settings the child or young person attends and the current year or stage of education that they are in or specifying if they are not currently in education settings.
- A copy of the current Education, Health and Care Plan, plans put in place at SEN Support, or details of other access requirements at education settings, or other services if the child or young person is not in education.
- Whether the child or young person is due to move education settings within the following calendar year.
- A summary of concerns raised by teachers, along with examples of strengths and difficulties observed within the classroom and less structured education settings contexts (for example, break times, after school clubs).
- Details of any assessments conducted by professionals such as an educational psychologist, a speech and language therapist, an occupational therapist.
- An overview of any additional support the child or young person has or is receiving (for example, one to one support in lessons, referral for additional classes), including details of teachers and SENCo to input into the process and as points of contact post-assessment.
- If any siblings or parents have been diagnosed with a developmental condition or are awaiting an autism assessment.
- Whether the child or young person has some understanding of autism and the purpose of the assessment.

Information that may be relevant to include in a referral for adults:

- Age on leaving education.
- Any notable difficulties in education (for example, dropping out of education settings or university).
- A summary of the person’s independent living skills or requirement for social care or support.
- Any noted concerns in the context of employment (for example, a history of difficulties within the workplace).
- A description of the person’s current social circumstances.
- The person’s expectations of the autism assessment.
- Information about who is able to provide additional information, such as a parent or partner.

Information that may be relevant to include in a referral for people approaching transition:

- The age at which people are discharged from the service they may be referred to.
- If and how referrals can be transferred from services for children and young people to an adult service, without the person being placed at the bottom of the waiting list (that is, they should not wait disproportionately longer if their referral is transferred to an adult service).
- If and how referrals can be transferred to a service in another area if the young person moves from the family home for university.
- Which service will keep the person and their family/carers updated about the potential transfer of a referral to adult services.

Stage 2: Screening and triage

Streamlined and accessible referral processes help to ensure that the second stage of the autism assessment pathway – screening and triage – is efficient and effective at identifying people who are eligible for the service and will potentially benefit from an autism assessment. This process should also identify what components will be included in the assessment (such as via a differentiated pathway). Equally, timely decisions about people who are not eligible or are more likely to benefit from assessment by another service is essential for facilitating onward referral or signposting to another service.

Different services use the terms screening and triage interchangeably, or to refer to distinct aspects of the autism assessment pathway. Some services use these steps to determine eligibility for an autism assessment. This means some people may not be offered input beyond triage if this does not appear to be clinically indicated.

Each autism assessment service should, therefore, define screening and triage processes as per commissioning agreements (for example, what the service is commissioned to provide, for whom, in what circumstances and with any additional requirements noted, such as for children and young people approaching transition age). Additionally, there should be clarity about when screening and triage take place (for example, the number of days from the point of receipt of a referral), and the range of potential outcomes from these processes. This information should be available for people and family/carers.

Screening

Screening processes require input from administrative staff and clinicians. On receipt, referrals are usually reviewed in the first instance by administrative staff against pre-agreed eligibility criteria for the service, such as the age of the person and whether they live in the relevant catchment area, unless the referral has been made through Patient Choice. The sensitivity and specificity of these criteria or checklists should be evaluated periodically, for example, in relation to conversion rates (the proportion of people diagnosed with autism relative to the total number of people seen for an autism assessment). The criteria should also be reviewed if commissioning arrangements for the service change, or if there are changes to eligibility criteria for other autism assessment services in the area that may impact on the flow of referrals elsewhere.

Screening necessitates clinical input to determine if an autism assessment is appropriate based on the referral letter/form, with or without additional information being obtained in the interim. The focus here is on ascertaining whether the person may have traits indicative of autism, which is why comprehensive and detailed information is required.

A further aspect of screening involves noting any reasons why the referral cannot be accepted, for example because the person does not meet the age criteria for the service. Alternatively, a person may have specific additional diagnoses or difficulties that are outside the remit of the autism assessment service. Decisions to decline a referral are ordinarily made by senior clinicians responsible for screening these or the multidisciplinary team (MDT). In either instance, the referral should be promptly returned to the referrer or forwarded on to a more appropriate service if this is possible (depending on relevant service level agreements).

Some areas may have comparable processes for reviewing referrals across children, young people and adult services. This can make it simpler and more efficient for referrals to be passed on, such as in the instance a person is referred for an autism assessment during the transition period from children and young people to adult services.

In some instances, screening can take substantial time. For example, if the referral lacks information required to make a decision about appropriateness for the service, or when there is evidence of clinical complexity. Autism assessment services may choose to conduct audits periodically on the amount of time and input required at this stage, and by whom (for example, by administrative staff and clinicians), including the processing of clearly inappropriate referrals. Sharing information about the screening process with people in a commissioning role can highlight whether there are adequate resources available for this stage of the autism assessment pathway.

Triage

Triage helps autism assessment services to better understand a person’s presenting needs and difficulties, gather comprehensive information about possible autistic traits and traits suggestive of other conditions (for example, anxiety or ADHD), and potentially ascertain what the autism assessment should comprise.

Different approaches to triage

Triage can comprise one or more standardised or semi-structured methods, including:

- paper-based questionnaires or forms
- review of relevant correspondence (such as from health, social care, education, or the criminal justice system)
- meeting with the person, their family/carers, partners or friends
- liaising with professionals the person is in contact with or has recently been in contact with.

Any paper-based methods of triage should be accessible for people and family/carers, such as translated in other languages, easy read or Plain English versions if the service is an all-ability service, and age appropriate. Questionnaires, for example, are potentially easily completed online, but there should be options for people and family/carers to receive and return hard copies in the post if they prefer.

For more information about different types of triage, see Appendix E.

People and their family/carers may also be supported with triage in some areas by local authority, voluntary, community and social enterprises or education.

Clinical decision making after screening and triage

Information gathered by screening and triage processes should ideally be evaluated within ten working days. In some services, a senior or more experienced clinician who has reviewed paper-based information or met the person decides what the outcome of screening and triage is. Other services hold meetings – attended by the MDT – to discuss the information obtained and to form a consensus view about whether an autism assessment is indicated. Another option is for the decision-making approach to vary. For example, people who have more complexity or atypicality in presentation are discussed at dedicated MDT referrals/triage meetings and single clinicians reach a decision for people who appear, at triage, to present with less complexity.

Setting up an internal audit system, whereby clinicians discuss a proportion of decisions they have made with the MDT, their clinical supervisor or a peer can contribute to standardisation in practice. Additionally, a peer supervision process can be developed across autism assessment services within the area, to enhance parity in clinical decision making and provision.

The decision to progress to an autism assessment should be made based on the available information, while balancing the impact of any gaps. For example, there may be no one identified to complete an informant-based questionnaire about childhood or to support the autism assessment. However, this should not preclude the person having this if the available information suggests this is clinically indicated. Alternatively, a person may have a high score on an autism self-report screening questionnaire, yet in-person triage with an experienced or senior clinician, along with information from family/carers and clinical records, may indicate autism is highly unlikely. In this instance, it may be that the person is discharged without being seen for an autism assessment (that is, they are discharged back to the referrer as the information gathered until that point indicates they do not need an autism assessment). Conversely, differential or co-occurring diagnoses can obscure the (underlying) clinical presentation. Decisions to discharge people at this stage of the autism assessment pathway should therefore be discussed with the MDT and include appraisal of all the information available about the person.

Outcomes of screening and triage

A fundamental aim of screening and triage is to establish what the next clinical step is for the person, with regards to proceeding through the autism assessment pathway (that is, whether an autism assessment is indicated, at this time, with or without additional input or support from another service).

The most common outcomes following screening and triage are listed below.

- Discharge the person from the service if they are not considered to require an autism assessment. Signposting the person to other services may be appropriate.

- Recommend a ‘wait and see’ (or ‘watch and wait’) approach with the option of review or re-referral in the future. There should be an agreement about when this period will end, how the person can be seen for review (that is, will they need a re-referral or stay open to the autism assessment service) and who will provide a written summary of traits or difficulties for the referrer during this interim period. The person should maintain their place on the waiting list, so that they are not disadvantaged if there is a ‘watch and wait’ period.

- Recommend the person is offered assessment or intervention by another service to address acute symptoms or difficulties they present with that appear to take priority over an autism assessment (for example, psychotic symptoms or hypomania). Review by the autism assessment service (further screening or triage) takes place either after an agreed period or when symptoms or difficulties have been adequately addressed, to facilitate the person’s participation in the autism assessment. The person should maintain their place on the waiting list, so that they are not disadvantaged by the need for more urgent support by another service.

- Recommend the person is referred to a national specialist service for an autism assessment (for example, when the constellation or complexity of needs and difficulties warrants more specialist input).

- Offer the person an autism assessment without recommendations for interim input by another service. This may be tailored to their specific needs or difficulties and may also involve jointly conducting the assessment with clinicians based at another service, such as an ADHD or secondary care mental health service.

- Offer the person an autism assessment with recommendations for interim input by another service. Recommendations could include intervention for mental health symptoms (for example, low mood, anxiety), or ongoing assessment and support of special educational needs and disability within an education context. The autism assessment may be tailored to the person’s specific needs or difficulties. This may also involve jointly conducting the assessment with clinicians working at another service, such as an ADHD assessment or secondary care mental health service. Information about actioned recommendations should be shared with the autism assessment service while the person is on the waiting list.

Communicating screening and triage outcomes

A summary of the information gleaned at screening and triage should be communicated to people, their family/carers and professionals at different times, such as after this has been obtained or after the autism assessment has been completed. Services may adopt different approaches to this stage. Feedback can be summarised succinctly (for example, an overview of scores on self- and informant-report standardised questionnaires), or described comprehensively (for example, in depth description of responses to questions posed during an appointment with the person). All information should be presented in a manner and format that is accessible to the person, their family/carers and professionals.

The amount and detail of information shared at this stage also potentially depends on the outcome and next steps. Recommendations for interim or alternative assessment, or intervention by other services should be explicitly outlined, including clarification about what processes are already in place and which professional or service is being asked to make onward referrals or to assess the person.

Addressing concerns about screening and triage outcomes

Sometimes a person is discharged from the service without being seen for an autism assessment. They or their family/carers may feel disappointed about this outcome or concerned about how their perceived needs will be met. Similarly, professionals working in health, social care or in education may disagree with the clinical opinion. This means there should be an option for the person, their family/carers or professionals to discuss screening and triage outcomes. Discussion should include the rationale for how and why particular clinical conclusions have been reached (that is, what information was used to inform decision making), with emphasis on signposting to other services when feasible.

Expediting referrals

There are likely to be instances when people on the waiting list – whether already in receipt of support or not – are deemed to require an expedited (faster) assessment. Autism assessment services should outline the process for requesting an expedited assessment, criteria for reviewing these requests (such as an MDT discussion about new/current concerns) and the possible outcomes (for example, agreeing or declining the request). Criteria employed to support expediting of referrals may vary between services. Therefore, consistency and transparency are essential for ensuring parity in decision making. It may be that children and young people and adult services within the area develop shared criteria that are reviewed periodically.

Information that may be relevant when screening and triaging referrals for children and young people include:

- Using age-appropriate self-report questionnaires of autistic traits and traits of other conditions.
- Reviewing the My Personal Child Health Record and any medical correspondence from very early years.
- Asking for copies of reports from education settings, reports by educational psychologists, SENCOs and Education, Health, and Care Plans.
- Asking teachers to complete informant-rated screening questionnaires or to provide more general information.
- Establishing if there are other informants who can contribute information (for example, grandparents, childminders, nannies).
- Seeking information from support providers, for example if the person is a ‘Looked After Child'.

Information that may be relevant when screening and triaging referrals for adults include:

- Establishing if there are others who can contribute to the assessment as an informant for childhood and adult years (e.g., family, friends, partners) and the period during which they have been in contact.
- Obtaining information about further and higher education, such as end of year reports.
- Reviewing any correspondence relating to employment, such as occupational health reports.

Information that may be relevant when screening and triaging referrals for people approaching transition include:

- Seeking consent to share information gathered at a children and young person's service with an adult service, rather than the person and family/carers needing to re-start the process.
- Determining what data sharing arrangements are in place if the person is moving to another area.
- Considering whether the person will need to complete additional screening questionnaires if they step up into an adult service.

Stage 3: Pre-assessment support

There is often a gap between screening and triage and the autism assessment taking place. This may be due to waiting times, preference, or clinical factors (for example, if the person is experiencing significant mental health symptoms) that warrant being addressed first. Pre-assessment support is described as important by people and their family/carers but has traditionally seldom been available.

Keeping people and their family/carers informed about their autism assessment pathway

People, and where consent allows, their family/carers and professionals they are in contact with should be updated about the estimated waiting time for the assessment regularly (for example, every three months). There should, however, be an opt out option for the person if they do not wish to receive these updates.

Updates should:

- Highlight the reason for the waiting time (for example, due to demand for the service or that the person requires prior assessment or intervention elsewhere).

- Indicate the approximate waiting time at that point.

- Provide contact details for a professional working at the service (for example, an administrator or clinician) who they can contact if they have questions while they are waiting, or if they need to advise about a change in circumstances (for example, a new home address or telephone number).

- Specify which service to contact if the person or family/carers become more acutely concerned about risk or acuity of presenting symptoms or difficulties.

- Confirm the next steps to be taken by the autism assessment service and how and when this will happen.

- Correspondence should be copied to the referrer so that they know when the autism assessment is likely to take place.

Providing resources for people and family/carers while they wait

Some people or their family/carers require support or input from health or social care services or education while the person is waiting for the autism assessment.

Needs identified can be related to possible autism (for example, social communication difficulties, problems with managing change and transition) or broader issues (for example, anxiety, disrupted sleep). Similarly, family/carers can benefit from signposting, advice or support at this time, in relation to supporting their child, other family members and in terms of their own wellbeing.

Needs and difficulties may have been highlighted in the initial referral letter/form or during screening and triage processes. For health-related needs, the referrer or local primary or secondary care services must not omit providing assessment or interventions relevant to the person’s needs while they are waiting for an autism assessment. Clarity about a possible autism diagnosis, in almost all instances, does not negate input for current needs, symptoms or difficulties that appear linked to physical or mental health. If a person’s needs are particularly complex, a link worker or equivalent can provide helpful oversight and coordination between services.

The autism assessment service may share resources or offer input while people are on the waiting list. This can include:

- Contact details for general local health and social care services, education support, voluntary, community and social enterprises, and social prescribing.

- Information about what will happen at the autism assessment and how, potential outcomes and a list of answers to frequently asked questions about the autism assessment pathway and process.

- General psychoeducational information about autism, such as what autism is and is not. This may include tips and strategies for addressing the possible impact of autistic traits.

- General psychoeducational information and evidence-based tips and strategies about symptoms and conditions commonly experienced by people referred for an autism assessment (including autistic and non-autistic people), such as low mood, general or specific anxiety, or disrupted sleep.

- General information and evidence-based tips and strategies for family/carers, such as around reducing stress and enhancing wellbeing.

- Peer support sessions or groups. Peer support sessions can include support from people or family/carers of people who have been through the autism assessment pathway.

- Information can be provided in written, audio-visual formats or via group approaches and should be accessible for people and their family/carers using the service (for example, translations, different versions for people with all abilities, and of different ages). Information should also be conveyed using an autism-informed approach (29), such as combining prose and images.

Education support – delivered outside of the autism assessment service

Some children and young people will benefit from support within an education setting while awaiting an autism assessment. Support for children in these settings should not be dependent on an autism diagnosis; education staff are expected to work collaboratively with external professionals and family/carers to ensure good quality support is in place when needed. Education settings are required to plan support in response to a child or young person’s individual profile of SEND through reasonable adjustments, SEND support or through an Education, Health and Care Plan (EHCP).

This should include how schools, while waiting for an assessment, can a) identify special educational needs linked to possible autism, and b) meet those needs. It could also include training and advice for schools, colleges and universities on the likely presentation of traits and needs of people while they are on the waiting list and how students can be supported.

Autism assessment services should provide information about a point of contact for queries while the person and family/carers are waiting, keep education settings informed of the anticipated waiting time for an assessment and signpost to other sources of advice and support when possible.

Informing professionals about pre-assessment support

Referrers and local services should be informed about any provision of resources or input to people while they are on the waiting list for an autism assessment. This may be via a template checklist or letter, or a more comprehensive letter for people or family/carers who have been offered more specific pre-assessment support.

Clinical records should be updated in a timely way, to reflect what resources or input has been offered to the person and their family/carers, when, and by which professionals. Scores on any outcome measures administered should also be provided.

Factors that may be relevant for pre-assessment support for children and young people include:

- Providing age-appropriate information for children and young people, and parallel information for family/carers.
- Considering the age and developmental stage mix of children and young people attending for group interventions.
- Providing clarity for family/carers about differences between parent-mediated interventions and training in parenting skills. Any interventions offered to family/carers should be delivered based on an emerging or robust evidence-base.
- Offering family/carers information about how to access support in education settings and in further or higher education.
- Signposting family/carers to social care support and options for breaks from caring.
- Undertaking stakeholder engagement to clarify what resources and sources of support for family/carers would like.

Factors that may be relevant for pre-assessment support for adults include:

- Providing information about access to support in higher education and at work.
- Putting together a list of links to different benefits and financial support options, with some supporting notes about completing application forms.
- Considering the age and life stage mix of adults attending for group interventions.
- Running group interventions at times people working full time will also be able to access.
- Giving examples of anonymised communication passports that adults may wish to edit for their own use.
- Undertaking stakeholder engagement to clarify what resources and sources of support family/carers would like.

Factors that may be relevant for pre-assessment support for people approaching transition include:

- Setting up protocols that outline which service (that is, the children and young people or adult service) will provide pre-assessment support if the young person is due to transition to adult services while awaiting an autism service.
- Providing information about adult services and adult-focused third sector organisations within the local area.
- Developing written resources, podcasts or blogs about cohesive transitions.
- Clarifying, for family/carers, the age at which young people transition to adult medical, mental health and neurodevelopmental services in the local area. For example, for some services this will be at aged 18, at others this may be at 21. Listing contact details for adult services commonly accessed by people seen by the autism assessment service.
- The GP becoming the coordinator of care from the age of 18 years, unless there are additional provisions available.

Stage 4: Autism assessment

Following screening and triage, people are either discharged from autism assessment services, offered a review appointment after a specified period to determine whether an assessment is clinically indicated (a ‘watch and wait’ approach) or placed on the waiting list for an autism assessment.

Clear aims for the autism assessment

An autism assessment has several aims. Broadly, these are to:

- Establish whether autistic traits are currently present, appear to have been lifelong and have contributed to impairment in different areas of daily life. For example, in education, occupation and social relationships (30).
- Screen for or assess common differential (that is, alternative) or co-occurring diagnoses.
- Understand the person’s strengths and goals, as well as their current needs and difficulties.
- Consider whether further medical, psychological, cognitive, sensory, skills-based or functional assessment is warranted and, if so, which service is best placed to provide this.
- Reach a clinical conclusion about whether the person is autistic and communicate this.
- Provide written recommendations to address current difficulties and needs, and to maximise well-being.

People, their family/carers and professionals should be aware of these aims prior to this stage in the autism assessment pathway – ideally at the point of referral, as well as in public-facing materials about the service (for example, documented in leaflets in written and diagrammatic form and on the organisation’s website). They should also know how information they provide will be used within correspondence (that is, in interim letters or an assessment report), if there will be opportunities to comment on the report before the final draft is shared with the referrer and other professionals involved, and what steps they can take if they do not agree with the assessment outcome or recommendations.

Additionally, the triage stage of the process may have provided the person and their family/carers with an opportunity to meet with clinicians and find out more about what the autism assessment could comprise.

The parameters of the assessment must be explicit, including which structured, semi-structured and unstructured measures may be used in the autism assessment (for example, autism assessment tools, or questionnaires), other neurodevelopmental and mental health conditions that will be screened for and assessed, and common outcomes from the assessment.

The National Institute for Health and Care Excellence (NICE) clinical guidelines (31–33) and Quality Standards (34) set out evidence for good practice in autism assessments. This includes which professionals may be involved and the recommended autism assessment tools and processes employed.

A multidisciplinary team approach to autism assessment

The workforce configuration of autism assessment services differs between settings. At a minimum, this should comprise an MDT, with substantial collective experience and expertise in assessing both autism and the range of neurodevelopmental and mental health conditions that can commonly be differential or co-occur with autism (33).

Owing to the nature of core training, paediatricians, psychiatrists and clinical psychologists are well placed to conduct autism assessments and reach diagnostic opinions, both independently, and as part of an MDT (22). Clinicians from other professional disciplines often undertake components of the assessment, but do not tend to routinely conduct these as sole practitioners see Tables 4 and 5 in the framework for more information about which professionals perform which roles in autism assessment teams.

Some clinical professionals may have additional training and qualifications to practise at multi-professional consultant or at multi-professional advanced clinical practice level to increase the number and diversity of professions represented in leadership roles. When these include training and assessed capability to conduct components of autism assessments, such as, for example, the autism credential, this may increase capability in relation to assessment components a professional can undertake. Some clinical professionals may have some additional non-clinical qualifications (for example diplomas, undergraduate or postgraduate degrees in research or other non-applied areas), this does not change their qualification to conduct each component of clinical autism assessment. Some components of assessment can be undertaken by staff under clinical supervision.

See Table 5 in the national framework to understand who can perform which roles in an assessment.

Given the possibility of clinical complexity and differential co-occurring diagnoses, it is not advisable for non-clinically trained professionals to conduct autism assessments independently (for example, research assistants, teachers), but they may make helpful contributions to aspects of the assessment or post-assessment support offered.

A differentiated approach to autism assessment based on clinical presentation and need

Based on information gathered from screening and triage, autism assessment planning should consider which components to include alongside the clinical interview. Planning should consider assessment tools, possible further assessments and which professional disciplines should be involved. The assessment can be differentiated in two main ways: standard or enhanced.

A standard autism assessment

- An assessment conducted by one or two clinicians (for example, a consultant psychiatrist and a mental health nurse or trainee psychologist).
- This may be indicated when information attained at screening and triage suggests an autism diagnosis is probable with no evidence of likely mental health considerations for the person. Furthermore, the circumstances may lend themselves to a straightforward process of gathering developmental and corroborative information. For example, the person is able to participate in the regular assessment format (including the clinical interview) and family/carers are available for interview.
- Consistent with NICE guidelines (31,32) the assessment should include, at a minimum, a clinical interview, behavioural observation, integration of developmental and corroborative information and consideration of possible differential and co-occurring diagnoses not identified at triage (especially when there has been a delay between initial referral, triage and main assessment).

An enhanced autism assessment

- An assessment conducted by two or more clinicians.
- This may be indicated when the screening and triage information suggests an autism diagnosis is possible but there is the possibility of other health considerations (for example, differential or co-occurring diagnoses). The circumstances may not lend themselves to a straightforward process of gathering developmental and corroborative information, such as parents being unavailable for interview or the person not being able to participate in the regular assessment format, such as the clinical interview.
- Consistent with NICE guidelines (31,32) assessment should include, at a minimum, a clinical interview, behavioural observation, integration of developmental and corroborative information, use of validated assessment tools, a broader assessment of clinical presentation (such as estimated intellectual functioning or sensory processing) and additional liaison with referrers and other involved service(s). Siblings, partners or friends may provide corroborative information.

Components of a good clinical assessment

The components of an autism assessment can vary according to the age and developmental stage of the person. As noted previously, the early indications from triage may direct the nature and breadth of the assessment, but not always. This means the autism assessment service should facilitate flexibility as needed, including having the option to incorporate additional components into the assessment, when clinically indicated.

The autism assessment must include a clinical interview with the person, conducted by a clinician with a medical background or a qualified mental health professional (for example, clinical psychologist or mental health nurse)(31,32). This is distinct from an assessment with family/carers or conversations with siblings (for example, developmental history taking or asking for descriptions of current concerns). This is also distinct from semi-structured behavioural observation assessments that specifically focus on traits associated with autism (for example, the Autism Diagnostic Observation Schedule – 2; ADOS-2 (35)). The clinical interview is pivotal for putting into context scores obtained on standardised questionnaires that may be used for screening or triage, or scores on semi-structured assessment tools. This also helps to address the question as to whether the person may have differential or co-occurring diagnoses; crucial for formulation and reaching clinical conclusions.

Themes for discussion at a clinical interview with the person include:

- Reason(s) for referral and the person’s, their family/carers and referrer’s expectations of the assessment
- the impact of past and current traits associated with autism (according to the International Classification of Diseases, eleventh edition; ICD-11 (30), or the Diagnostic and Statistical Manual of Mental Disorders, fifth edition; DSM-5 (36)), and any modifiers for these
- current concerns, and the onset and trajectory of these
- developmental history
- information about what life was like growing up
- general day-to-day functioning
- education and occupation
- hobbies and passions
- needs and difficulties
- strengths, resilience factors and personal (coping) resources
- social circumstances, friendships and relationships
- physical and mental health and emotional wellbeing
- mental state assessment
- risk (to self/others including self-harm and suicidal ideation, and from others).

The assessment must include screening or assessment of common differential or co-occurring diagnoses, as part of the clinical interview conducted by a clinician with a medical background or a qualified mental health professional. This includes consideration of other neurodevelopmental conditions such as ADHD and intellectual disability, mental health conditions (including mood disorders, anxiety disorders, obsessive compulsive disorder and related disorders, disordered eating, traumatic stress) and attachment-based difficulties.

The person and family/carers may also complete screening questionnaires about mental health and wellbeing. In this instance, responses should be followed up if clinically indicated. This is because it is important to ascertain whether low or high scores on questionnaires are consistent with information gathered during screening, triage and the autism assessment from the person. Information about other potential neurodevelopmental traits or mental health symptoms is crucial for developing a formulation and thereby the diagnostic opinion, as well as informing recommendations for post-assessment support or intervention.

Some services incorporate behavioural observation assessments (for example, the ADOS-2 (35)). These should be conducted by appropriately trained professionals, ideally with expertise in mental health and development. There must be clinical oversight if the professionals conducting these are not clinicians, and they should have regular supervision. These assessments may take place in clinic, at education settings or at home and can be structured, semi-structured or unstructured.

Importantly, behavioural observation assessments do not replace the need for a clinical interview. This is because scores cannot be meaningfully interpreted without the contextual information gathered during a clinical interview (scores below and above the indicative threshold suggested for autism may be due to the presence of autistic traits, differential diagnosis, or both autistic traits and co-occurring conditions).

Any deviations in the administration of standardised and licensed assessments (for example, conducting the ADOS-2 online) should be reported in the outcome documentation (for example, what adaptations were introduced, which, if any, activities or tasks were omitted or added), with clarity about how this may be relevant for any clinical conclusions reached.

Corroborative information is important for reaching clinical conclusions. This should be sought when feasible, and the person has consented to this. This may be obtained using a standardised semi-structured assessment (for example, the Autism Diagnostic Interview – Revised (ADI-R (ADI-R; 37)) or an unstructured interview. Some services gather this information as part of the triage process, whereas other services may do this as part of the autism assessment. It can be more challenging with older adults as parental information may not be readily available or may be less reliable owing to time passed since childhood.

As with behavioural observation assessments, interviews conducted with family/carers, such as the ADI-R, do not replace the need for a clinical interview that asks the person directly about their experiences growing up. Additionally, developmental information obtained in semi-structured assessments needs to be considered alongside all other information gathered, to discern whether scores below or above the threshold are attributable to the presence of autistic traits, differential diagnosis, or a combination of autistic traits and co-occurring conditions. Other information, such as from siblings, partners, close friends or professionals the person is in contact with, should be gathered when possible.

Development of service or area-wide templates for systematic gathering and recording of information can be useful for ensuring that key focal points for an autism assessment are addressed before or during Stage 4 of the autism assessment pathway. Using a consistent template for an area also makes it easier to transfer information, for example, if people have had a triage at a children and young people service, but are likely to transition to an adult service for the autism assessment.

Formulating a view about diagnosis

Clinical formulation of individual presentation, developmental patterns, strengths and needs, resources and difficulties, contributes to the clinical conclusions and provides the first step to generic and focused post-assessment support. Formulation is based on the integration of information gathered from a clinical interview, behavioural observation, developmental and corroborative accounts, clinical and educational records and liaison with other professionals. It must be viewed as more than just the scores on any given screening questionnaires or assessment tools.

At times, it may be necessary to consider all the information available and, on balance, to agree that the scores on standardised assessments do not present an accurate picture of the person. In other words, while specific assessment tools tapping traits associated with autism may yield scores above or below the indicative threshold suggested for autism, this remains a clinical decision – that is, made by clinicians on the basis of all available information and in light of their clinical experience.

Consensus diagnosis meetings provide opportunities to:

- present information gathered about a person.
- identify potential gaps in information before completing the assessment and determine how this can be best obtained.
- consider multidisciplinary perspectives about the formulation, including views about whether the person is autistic.
- outline recommendations to be shared with the person.

Communicating the assessment outcome clearly

The lead clinician or clinical team (depending on the protocol of the autism assessment service) shares the outcome with the person and their family/carers (as appropriate). Consideration needs to be given regarding the nature and format of this feedback to ensure this is accessible and clear, and that recipients can feel confident in the outcome, irrespective of what this is.

Some young people and adults participating in the assessment process may be expecting an autism diagnosis. Parents may be hoping for an autism diagnosis if they believe this is essential for securing necessary services to meet their child's needs (38). Sharing the assessment outcome is never neutral, whether expected or not (3,6,11,13,39). A lengthy wait for assessments can make the outcome more important to people and their family/carers. If the standard protocol for the service includes sharing the outcome at the end of the main assessment appointment (usually involving a clinical interview), due time and attention should be given to this aspect of the process; this should not be rushed.

The following considerations are needed for the sharing the outcome of the autism assessment verbally:

- The person may benefit from more than one appointment to discuss this, whether diagnosed as autistic or not.
- Feedback may need to be offered face-to-face, even if the main assessment took place via a telehealth platform, particularly if the person or family/carers have difficulty understanding or accepting the outcome.
- Consider the skill set that clinicians require to share the formulation and assessment outcome.
- Feedback should be provided by a lead clinician or qualified clinician who participated in the assessment process and is known to the person and their family/carers.
- Local protocols for providing feedback can be developed in consultation with people and family/carers to ensure this is shared in a personalised manner.
- Check consent (from earlier consent processes) and current wishes for sharing the outcome with others, including the referrer or professionals in other contexts.[1]
- Signpost people and their family/carers to information concerning their rights if an autism diagnosis is made, such as information to help someone understand how their diagnosis help them to seek reasonable adjustments in the workplace under the Equality Act 2010.
- Inform people and their family/carers that details of the assessment and the discussion will also be provided in writing.

The following considerations are needed for sharing the outcome of the autism assessment in written form:

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[1] Consider that some information may be shared with GPs via local recording and reporting processes, such as System One, and the person and their family/carers should be made aware of this. See earlier section about consent.

- Develop local protocols for efficient and effective written communication of the assessment outcome and recommendations.

- Agree on integral components of each document. See 66Appendix G for the core components of an autism assessment report.

- Determine an optimal time within which to complete the autism assessment documentation and share with the person and their family/carers.

- Consider the option of a staged process of sharing the documentation (brief statement with headlines and evidence prepared within one week of the outcome, followed by a more detailed report including recommendations and next steps. Further documents might be provided at a later stage depending on the post-assessment support offered.[2]

- Establish local systems to support the integration of clinical notes and electronic patient records to reduce duplication when producing outcome documentation.

- Where multiple authors contribute to the document, consider using shared documents to enable clinical professionals to work concurrently, rather than waiting for sections to be completed independently.

- When possible and sufficient administrative resources are available, consider dictation of letters and statements.

- Develop templates for assessment statements, reports and letters.

- Consider relevant recipients – documents may need to be available in the future so that a copy can be held by the person, family/carers or Primary Care, irrespective of who the referrer is.

- Consider privacy rules and sharing information, such as when reporting information about extended family members who are not part of the autism assessment process.

- Include, when appropriate, the comments and contributions of the person in the process, outcome and recommendations.

Recording assessment outcomes in clinical records

Clinicians are responsible for recording the assessment outcome in the clinical records system. This is essential for maintaining contemporaneous and accurate information about a person and ensures other health professionals in contact with them are aware of the diagnosis.

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[2] The function of the brief statement is to provide evidence of the diagnostic outcome and how this was reached. This also serves the purpose of a short statement that can be used by the person or family/carers for a wide range of purposes without the need to share the detailed clinical report that contains highly personal information.

This is also an important step in the submission of regional recording and coding of the referrals for autism assessment, waiting times and assessment outcomes that are monitored nationally via the Mental Health Services Data Set (MHSDS) and Community Services Data Set (CSDS) respectively.

Specific considerations for conducting an autism assessment with children and young people can include:

- Offering flexibility around appointment times to accommodate days and times spent in education and family/carer commitments.
- Considering the age and developmental stage of the person and which semi-structured assessment measures are appropriate to their needs.
- Recognising that good practice for autism assessments in children and young people includes assessment/observation in at least two settings, such as clinic and education setting, irrespective of the service (child development centres or children and young people mental health services).
- Facilitating opportunities for parents/carers to speak with clinicians independently of the child or young person, if appropriate.
- Offering information about diagnosis in an accessible way for both children and young people and family/carers.
- Making recommendations about which service may be able to update the assessment report over time, to reflect any changes in strengths and needs.

Specific considerations for conducting an autism assessment with adults can include:

- Identifying whether there are informants who can take part in the autism assessment, to provide, for example, developmental or corroborative information.
- Offering flexibility around appointment times to accommodate higher education, work, or care commitments the person may have.
- Providing a shorter assessment letter that the person can share with an employer if they wish to.

Specific considerations for conducting an autism assessment with people approaching transition can include:

- Considering the age and developmental stage of the person and which semi-structured assessment measures are appropriate to their needs.
- Considering joint autism assessments between the children and young people, and adult services.
- Developing protocols for sharing information between services if the person is due to transition to adult services after screening and triage processes have taken place at a children and young people service.

Stage 5: Post-assessment support

Receiving or not receiving an autism diagnosis can mean different things to different people. Some people experience a sense of validation. For others, the clinical assessment conclusion can come as a surprise and feel unsettling or upsetting, at least initially. Family/carers and partners can similarly experience a range of emotions about this. Members of a family can have shared or unique responses; not all will feel able to have open and in-depth conversations about this (3,6,11,13,39). Therefore, having time to talk through the assessment outcome (and formulation) and to ask questions is important.

Some people and their family/carers can benefit from further support or intervention after an autism assessment. Post-assessment input can be offered by health, social care, education and voluntary, community and social enterprises. Some people benefit from short-term support by one service, while others may require several types of input either sequentially or concurrently.

Autism assessment services can be well placed to provide targeted interventions for autistic people and signposting for people who are not diagnosed as autistic.

Offering post-assessment support for people who are not autistic

Some people seen for an autism assessment are not diagnosed as autistic. Whether they receive an alternative (differential) diagnosis can depend on factors including:

- The skill set of the clinicians who assess the person (for example, whether they have the training and expertise required to assess other conditions).
- The scope of the assessment (that is, whether other conditions have been sufficiently investigated in order to be able to reach a firm clinical conclusion).

- Commissioning arrangements (for example, whether the service is commissioned to provide clinical conclusions about diagnoses other than autism).

Signposting and referral for further assessment or support

Many people who are not diagnosed as autistic may benefit from further signposting and provision of resources, support or intervention after being seen for an autism assessment. If these are available, it can be useful to share a list of resources, pertaining to health, social care, education, occupation or third sector organisations, locally and nationally. Some people who are not diagnosed as autistic will require a referral for further assessment or support by another team (for example, specific mental health service, an ADHD service). To avoid unnecessary delays, there should be a standardised policy about which service can make onward referrals. For example, this could be the GP, or a clinician at a mental health service, who may be better placed to make referrals or has a gatekeeping function within referral pathways. Assessment outcome documentation can be a useful appendix to any further referrals.

Offering post-assessment support for autistic people

Post-assessment support for autistic people can comprise:

- further assessment
- enhanced understanding of strengths
- development of a passport or self-disclosure tools
- signposting and provision of resources
- individual or group psychoeducational interventions focused on autism
- individual or group psychosocial interventions focused on mental health and emotional wellbeing
- individual or group interventions for family/carers
- peer support and mentorship
- personalised care and recommendations for social prescribing
- crisis intervention
- liaison with other services.

Further assessment

During the autism assessment, it may become evident that the person presents with needs that have not been sufficiently investigated, but that are likely to benefit from greater understanding and support. This can include specific difficulties, such as in relation to speech and language, sensory processing or functional skills. Alternatively, a more global assessment of the person's needs can lead to tailored recommendations for education, occupation and independent living. While these focal points are slightly aside from clarifying whether a person is autistic, they can inform more individualised support offered by health and social care services or within education settings.

Enhanced understanding of strengths

While people are often referred to health services based on presenting needs (including for an autism assessment), it is paramount to also understand a person's strengths, resilience factors and personal (coping) resources. This can be a focus of individual and group-based post-assessment support.

Development of a passport or self-disclosure tools

Some autistic people benefit from having a health passport (summarising preferences and needs relating to health and health care), an autism passport (summarising preferences and needs relating to autism) or self-disclosure tools (for example, assessment statements or a summary of key information they would like to share with others, including professionals).

The amount and type of information people choose to document varies, as can the format and layout. Some autistic people prefer to compile this alone, whereas others may like support to develop these as part of a post-assessment support offer. These are not static documents. Autistic people and family/carers should be encouraged to update these as appropriate (such as, if the person would like to share this with new people or in a new context, or as preferences and needs change over time).

Signposting and provision of resources

Many autistic people and family/carers find it useful to have access to resources about:

- psychoeducation[3] about autism
- recognising and regulating emotions
- understanding and improving mental health conditions
- strategies for improving eating
- strategies for enhancing sleep
- health and social care provision in the local area (including acute and general services, and how these can be accessed)
- employment rights

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[3] Psychoeducation is the provision of a focused programme of information-sharing and advice for diagnosed individuals, families and carers.

- third sector organisations.

This list of topics is indicative rather than exhaustive. Provision and signposting of the most clinically helpful services will depend, to some extent, on the age of people seen and available services within the area.

Resources are more commonly provided in written form (for example, leaflets, posters and worksheets), but complementing these with podcasts or workshops can be helpful. The input of autistic people and family/carers into resource development is key, including ensuring that there are versions tailored according to age, ability and additional needs (for example, dyslexia).

Individual or group psychoeducational interventions focused on autism

Research suggests that access to psychoeducational interventions following an autism diagnosis can be beneficial and contribute to improved understanding and acceptance of autism, and improved mental health (40). These sessions can be delivered in groups or individually and may involve input from autistic people who have previously gone through the autism assessment pathway.

Overall, psychoeducational interventions – delivered individually or via groups – should aim to:

- normalise and validate experiences
- support a person's understanding about autism, what this means to them and their autism identity
- reduce perceived stigma and build confidence.

Individual or group psychosocial interventions focused on mental health and emotional wellbeing

A substantial proportion of autistic people experience one or more co-occurring mental health conditions, including anxiety disorders and depression (41–44). They can benefit from (adapted) evidence-based psychosocial interventions. The autism assessment service may offer time-limited individual or group psychosocial interventions to target mental health and emotional wellbeing. This does not, however, replace the remit of primary and secondary mental health and psychological therapies services that are expected to make reasonable adjustments to routine care, so this is more accessible for autistic people.

Locally, there should be clarity about which service will provide psychosocial interventions, to whom (that is, the eligibility criteria) and what the referral process is.

Individual or group interventions for family/carers

Family/carers can benefit from individual and group interventions after people have received an autism diagnosis. These groups may occur alongside parallel groups for autistic people or separately and may be for family/carers of children and young people as well as adults. While more research into these types of interventions is required, initial evidence (25,26,45) demonstrates feasibility, effectiveness and acceptability for interventions designed to:

- increase knowledge and understanding of autism and associated conditions
- validate experiences and reduce perceived stigma
- improve emotional wellbeing and self-efficacy
- enhance communication, interaction and relationships between parents/carers and their autistic child
- teach skills and strategies flexibly for supporting an autistic child.

General principles for developing and delivering individual and group interventions

Some general principles underpin provision of individual/group psychoeducation and psychosocial interventions for autistic people and family/carers.

Intervention design should:

- Involve co-production – autistic people and family/carers who have used this or a similar service should be invited to contribute to decision-making about what interventions are offered, as well as developing materials.
- Be evidence-based – there is emerging evidence for varied interventions for autistic people and family/carers. Novel interventions offered should be underpinned by a clinical rationale.
- Have clear parameters – interventions offered by autism assessment services are intended to complement, rather than replace or replicate those offered within mental health or other settings.
- Emphasise strengths – a focus on strengths and unique abilities is key.
- Reduce perceived stigma – interventions should seek to normalise and validate experiences and reduce perceived stigma.
- Be accessible – the needs and abilities of autistic people and family/carers vary. Interventions should accommodate different requirements (for example, with parallel materials developed for autistic people with and without an intellectual disability).
- Demonstrate cultural sensitivity – interventions should be accessible to the people living in the local area. Resources may require translation into other languages and may need to consider cultural norms for different groups.

The following factors are important for intervention delivery:

- Location – some people may wish to attend sessions in person, and others may prefer to use telehealth. Sometimes, a hybrid of in-person and telehealth sessions may be suitable. If clinically appropriate, autistic people and their family/carers should choose which they prefer; see the personalised care section in the national framework document for more information about choice.

- Mode of delivery – some autistic people and family/carers will prefer to be offered sessions individually, and others may wish to attend a group session. Developing a process for assessing eligibility for individual versus group interventions can help to ensure parity in provision while balancing available resources.

- Duration of sessions – some autistic people benefit from having a longer time to process information. Others may experience attentional impairments, such as those associated with ADHD. It can be helpful to build in regular breaks and to provide a summary of information discussed or contemporaneous notes that people can refer to between sessions.

- Clinical considerations – potential delivery of post-assessment support involves clinical considerations around issues, such as whether the person seems able to engage in the intervention at that time and whether there are any known risks to self or others that could influence participation or engagement in individual or group sessions.

- Audit and service evaluation – the accessibility, feasibility, acceptability and effectiveness of post-assessment support options should be regularly audited or evaluated. This can include summary and analysis of routinely collected information (for example, any systematic differences in characteristics of people or family/carers who decline to attend versus those who participate) and qualitative exploration of the views and experiences of people who have had post-assessment support, as well as the clinicians who delivered this. Providing autistic people with answers to frequently asked questions or worries about interventions (for example, “what will happen in a session?”, “will I have to speak in a group?”, “what if I change my mind and want to come to a group rather than having sessions individually?”) can be useful.

Further assessment and individual and group interventions can result in internal referrals and waiting lists. It is important to let people and their family/carers, professionals based in other settings and colleagues within the service know about these processes and the likely waiting time for input. It is also crucial that referrers and the GP are aware of the parameters of ongoing work by the autism assessment service. For example, this does not replace the need for risk assessment and management by local health services, or requests for referral for psychological therapy.

Peer support and mentorship

Peer support roles are becoming more commonplace in mental health services, and these are intended to be paid positions. Health Education England (HEE) has been developing a new Autism Peer Support Worker role. To this end, HEE has commissioned the development of a framework of core skills and capabilities required by Autism Peer Support Workers. Training will be provided for these roles to enable people with lived experience of autism to provide support to other autistic people who are experiencing health difficulties. Peer support (carers) could also be provided to family/carers of autistic people. The training and implementation of these roles will be piloted in 2023.

Crisis intervention and prevention

According to the Building the Right Support national plan (46), autistic people who are experiencing a mental health crisis, who are at risk of admission to hospital or who are admitted to hospital have a right to have a Care (Education) and Treatment Review. They should also be placed on the Dynamic Support Register if they are in or at risk of admission to a mental health inpatient setting. Key working services are also available in every area funded through the NHS Long Term Plan (4).

Some people seen for an autism assessment may potentially be eligible for input under the Building the Right Support national plan. In this instance, there should be clarity about which service will make the referral to the person in a commissioning role (that is, the referrer, a mental health team, or the autism assessment service).

In some instances, the autism assessment service may be asked to attend a Care (Education) and Treatment Review if the autism assessment has been completed very recently and, for example, the outcome documentation has not yet been finalised and circulated. Within this forum, there should be clarity about the remit and parameters of each professional and service involved. For example, it may be that post-assessment support can be postponed until such time that the person is able to attend this.

Liaising with other services after the assessment

Following the autism assessment, it may be beneficial for a designated clinician to offer information, consultation or feedback to external professionals involved in providing ongoing care, further assessment or education to the person. The person and family/carers may also be involved in this. Regular meetings between services offering autism assessments and other services should be arranged to ensure people and their family/carers are supported through the respective pathways, especially at times of transition.

Supporting people who relocate prior to or during delivery of post-assessment support

Some people and their family/carers may move out of the area prior to post-assessment support being fully delivered. The autism assessment service should provide clarity about whether it can honour the offer of post-assessment support in this instance and for what time period this extends to (for example, if a person moves abroad for an extended period). Conversely, the service should operationalise whether it can provide post-assessment support to autistic people and their family/carers if the diagnosis was made by another NHS service or independent provider.

Specific considerations for developing post-diagnostic support for children and young people diagnosed as autistic can include:

- Considering the age and developmental stage mix of children and young people attending group interventions.
- Running group interventions at times that fit with the education settings day and other childcare responsibilities family/carers may have.
- Providing a quiet space for family/carers to use while their child is attending individual or group interventions.
- Offering family/carers adjunctive post-diagnostic support sessions.

Specific considerations for developing post-diagnostic support for people approaching transition diagnosed as autistic can include:

- Setting up protocols that outline which service will provide post-diagnostic support if the young person is due to transition to adult services before this has been offered (that is, the children and young people or adult service).
- Noting any differences in eligibility criteria for post-diagnostic support for children and young people and adults, across services.
- Developing resources focused on issues relating to transitions (for example, coping with exam stress, starting university, moving out of the family home).

Specific considerations for developing post-diagnostic support for adults diagnosed as autistic can include:

- Considering the age and life stage mix of adults attending group interventions.
- Providing clarity about the remit and parameters of group interventions.
- Running group interventions at times that fit with higher education and occupational responsibilities adults may have.
- Developing a protocol regarding whether group interventions can be offered via telehealth, and if so, what the eligibility criteria for this are.

Discharge from the services providing autism assessments

Discharge from the service conducting the autism assessment takes place after the clinical assessment conclusions have been reached and the letter has been sent, or after post-assessment support or intervention have been delivered. People may be discharged back to the care of the professional who initially referred them for an autism assessment (for example, the community psychiatrist), or to the GP if they are no longer open to the referring service.

Sometimes it can be useful to give a verbal handover to the referrer or other services and any professionals involved in the person’s care and support.

Sending a formal discharge letter is standard practice for all people seen for an autism assessment, whether or not they are diagnosed as autistic, unless this has already been documented in the assessment outcome letter. This should include the following information at a minimum:

- Updated personal information if there have been any recent changes (for example, to the person’s name, contact details).
- A concise summary of what input the service conducting the autism assessment has provided and when (for example, seen for an autism assessment, attended a post-assessment group).
- A statement indicating the clinical assessment conclusions.

- An outline of any pertinent clinical issues that warrant short-term consideration or input by the referrer or GP (for example, relating to risk).
- A list of requests for other professionals to action, if needed (for example, please refer for further occupational therapy input or a medication review).
- Clarity about the date the person is being discharged from the service.

People and their family/carers should be made aware of the discharge date and what this means for them in terms of any further contact (for example, whether they will be asked to provide anonymous feedback about their experiences). They should also be made aware of which service or professional they should contact if they have questions about the assessment outcome or further assessment or intervention.

Clinical records should be updated to reflect the date the person is discharged and by whom promptly.

Part 2. Common variations in how the autism assessment is conducted

Many people will have a standard or enhanced autism assessment at a local autism assessment service, but some people will have a different experience. For example, they may be assessed jointly with another service or require adaptations to usual practice.

There should be eligibility criteria for different types of autism assessment by each service. This information should be communicated to people and their family/carers as part of the identification and referral, or screening and triage stages of the autism assessment pathway.

Telehealth

The COVID-19 pandemic impacted service provision across the NHS. Many autism assessment services introduced telehealth to conduct components of, or the entirety of an autism assessment.

Telehealth refers to digital healthcare practices for the purpose of delivering health-related services and information, using methods including video calling, telephone services (voice- or text-based) and apps or web portals. There is preliminary empirical support for using this approach in terms of autism assessments and primary care interventions for autistic people from research studies conducted before and during the pandemic (47–49).

At the time of preparing this document in early 2023, COVID-19 restrictions have been lifted. However, there continues to be variation in routine service provision by autism assessment services across England, with some working exclusively in person, some exclusively offering telehealth assessment and others using a mix of both.

In 2021, the autism team at NHS England commissioned Autistica to produce a briefing report outlining considerations for using telehealth methods in healthcare delivery for autistic people (50). Autism assessment services via telehealth methods should consider the following.

- Telehealth autism assessments should be conducted in accordance with current organisational policy and guidance (for example, using the approved e-platform, and ensuring security settings are switched on during an appointment to limit the possibility of anyone else joining the meeting).
- Clinical and risk issues permitting (see below), people and their family/carers should be able to indicate their preference for being seen in person, via telehealth or with a hybrid approach. For example, people and their family/carers could provide this detail, including their email address, as part of the referral or screening and triage process.
- People and their family/carers should be provided with an information sheet about telehealth (for example, at the point of referral, or at screening and triage). This may be developed by the autism assessment service or the organisation more generally and outline:
    - issues for people and family/carers to think about in terms of the range of advantages and considerations with having the autism assessment via telehealth (such as, no need to travel, but a lack of privacy at home)
    - what happens during in-person and telehealth assessments, so that people and family/carers can effectively ‘walk through’ the process before making a decision about which to opt for
    - practicalities associated with using telehealth (for example, how to log on to the platform and access the meeting link)
    - answers to troubleshooting questions (including who to contact if the meeting link is not working)
    - environmental considerations (for example, optimal set up for the appointment such as being in a quiet location, with privacy, good internet access)
    - clinical considerations (such as what to do if the person or family/carers become highly distressed or agitated during a telehealth appointment).
- Ideally, telehealth should be accessible to everyone on a waiting list for an autism assessment and their family/carers, if this is clinically appropriate, and including people who do not have access to internet-enabled devices or require an interpreter service.
- Each autism assessment service or all services doing so collectively in the area offering at least some autism assessments via telehealth, should develop clinical guidelines indicating:

    - reasons for offering people an in-person versus telehealth autism assessment, or giving the option for either (for example, some people may present with significant mental health issues or risk or systemic factors within the home that seem to clinically warrant an in-person appointment)
    - an outline of factors that suggest people should be seen in person rather than via telehealth after they have attended for a first appointment or if new information comes to light
    - any additional considerations for assessment and management of risk or safeguarding when seeing people and family/carers off site
    - how to manage unanticipated situations that could occur during a telehealth appointment (such as if the internet connection fails, or the person discloses imminent risk)
    - if and how post-assessment interventions require adaptation if they are delivered via telehealth as opposed to in person.
- Use of telehealth methods of service delivery should be evaluated regularly by the autism assessment service to establish factors, including what is working well or not, or whether any specific sub-groups of people are waiting disproportionately longer for the autism assessment or post-assessment support (for example, due to digital poverty or substantial risk).

Joint assessments with clinicians from another service

Sometimes, the autism assessment is conducted by clinicians from the autism assessment service in collaboration with clinicians working in another service (such as mental health, learning disability or ADHD assessment services). This might be because the person is well known to the other team and there is consensus that a joint assessment by both services will be clinically appropriate and, potentially, an efficient use of resources. Alternatively, it may be that the person has several areas of need, and concurrent assessment by two services could result in a more complete formulation/clinical assessment conclusion and better support for the person. In this event, it is useful for the clinicians involved in the process to meet prior to the autism assessment commencing. This is an opportunity to:

- Share relevant background and contextual information about the person.

- Consider whether there is a need to embed reasonable adjustments or adaptations into the assessment process, so that this is more tailored for the person's needs or preferences (for example, in relation to previously identified sensory sensitivities, use of communication aids, attentional impairments).

- Clarify what, if any, components of the autism assessment have already been conducted, when, by whom and the outcomes.

- Establish which MDT clinicians are best placed to conduct the assessment based on the person's identified difficulties or needs (for example, including a clinician with a medical background or a speech and language therapist).

- Identify focal points for the joint assessment, which methods will be used (for example, autism assessment tools) and who will have responsibility for administering these.

- Decide about practicalities such as which service will arrange appointments, who will coordinate preparation of the assessment letter and upload information to the clinical records, and how post-assessment support will be organised.

Working jointly in this way can reduce the likelihood of people falling through gaps between services, such as when a person with a borderline or mild intellectual disability is not eligible to access a Learning Disability service, but whose needs may not readily be met by autism assessment services to people who do not have an intellectual disability.

Assessment of people in mental health inpatient settings

Some people may be admitted to a mental health or forensic ward at the time they are due to be offered an autism assessment. They may be admitted on a voluntary basis or detained under the Mental Health Act 1983.

Ideally, autism assessment services should be informed in advance if there has been a change in the person’s mental health or emotional well-being or risk, such that they are deemed to require an inpatient admission. Furthermore, if the person has been admitted to an establishment far from home, clarity will be needed about whether they will be seen by the initial autism assessment service that they were referred to or if a local autism assessment service may offer this instead. The referrer should also be kept up to date.

The appropriateness of undertaking an autism assessment when people are in hospital depends on several factors, including:

- clinical symptomatology (for example, what mental health symptoms they are experiencing, acuity of these and degree of impairment)

- current circumstances (for example, how settled the person is)

- engagement (for example, whether the person will be able to participate in all the components of an autism assessment if there are factors that substantially impact attention, concentration or memory)

- level of distress (for example, whether conducting an autism assessment will increase the person’s level of distress, even if unintentional)

- risk (for example, imminent risk to self, very high risk to others)

- timing (that is, considerations, advantages and disadvantages with conducting the autism assessment now versus waiting until the person is less symptomatic)

- potential imminent utility of outcomes (for example, that an autism diagnosis would mean the person is eligible to have a Care (Education) and Treatment Review, can be placed on the Dynamic Support Register)

- the likelihood that the range of factors highlighted above will impact on completion of the autism assessment and the possibility of drawing meaningful clinical conclusions about diagnosis.

Decisions to proceed with, or delay, the autism assessment should be discussed with the person, their family/carers if appropriate, and informed by discussions with the referrer, the clinical team providing inpatient care and potentially other professionals who are involved.

If a decision is made to delay the autism assessment, there should be agreement about when this decision will be reviewed and by whom (that is, which professionals), what factors are deemed to need to change so that this can proceed (for example, what a reduction in mental health symptoms looks like, what the threshold is for attention and concentration capability in order for the person to engage with the process) and who will be measuring these factors and updating professionals in the system, including the referrer.

If a decision is made to proceed with the autism assessment while the person is in hospital, this is likely to require some additional planning beyond the standard and enhanced autism assessments taking place in the community. Factors to consider include identifying:

- What information has been obtained during the hospital admission that is relevant to review prior to commencing (for example, initial assessment by the psychiatrist, assessments or progress notes by MDT clinicians).

- Which MDT clinicians from services conducting autism assessments are best placed to be involved in the process (for example, a psychiatrist or clinical psychologist).

- Which professionals in the clinical team providing inpatient care may be able to be involved in the process (for example, gathering information about particular themes, supporting completion of self-report screening questionnaires).

- Who (which professional from which service) will discuss the autism assessment with the person and assess capacity to participate in this, as well as liaising with family/carers if appropriate.

- How to set up assessment appointments in a way that suits the person and the ward (for example, what time of day and which days of the week do not interfere with the person’s structured activities and are easier for the ward to accommodate, including environmental adjustments for sensory differences).

- What caveats there are to undertaking the autism assessment at that time (for example, if the person becomes floridly unwell, or risk substantially increases).

- When, how and to whom the clinical assessment conclusions should be communicated.
- Which service will provide post-assessment support relevant to the outcome.

A summary of discussions and decisions made should be recorded on the clinical records.

Outreach assessments

Some people may have moved out of the catchment area for the autism assessment service between the point of referral and the autism assessment taking place. For example, they may reside in a residential education setting, residential social care setting or have been admitted to a specialist inpatient service in another area. Ideally, the service providing the autism assessment will be kept updated about any changes in contact details for people on the waiting list and clinical factors relevant for decision making about optimal times to do the autism assessment, and what this should comprise (for example, the skill set of clinicians meeting the person).

Depending on commissioning agreements, some services will provide outreach autism assessments, with clinicians visiting the person if they are unable to come to in-person appointments and telehealth is not viable. The reasons for and remit of outreach autism assessments should be explicit for referrers, people and their family/carers.

Assessment of people with additional needs

Depending on commissioning agreements and autism and wider service pathway arrangements, autism assessment services may accept referrals based on clear criteria, such as people who do not have additional needs (including intellectual disability). When autism is considered a possible diagnosis for a person with a known intellectual disability, the appropriate learning disability service should be well placed to conduct the autism assessment. MDT professionals should have knowledge and expertise of assessment of features of autism in the context of features and behaviours consistent with an intellectual disability. Screening and assessment tools appropriate for a person’s cognitive and communication differences should be available and used routinely. Communication aides should be employed as needed, to support the inclusion of the person in the process. Careful gathering of corroborative information from family/carers is essential for forming a comprehensive a picture of the person and their strengths, needs and aspirations as possible.

There are some instances when a person does not meet the formal criteria for an intellectual disability, but the referral should be made or transferred to the learning disability team. For example, if cognitive testing indicates a highly mixed cognitive profile with borderline intellectual disability in verbal or non-verbal domains, or functional assessment suggests their needs would be better understood and supported by the expertise available in the learning disability service.

Alternatively, a joint assessment with the learning disability service may be indicated. Post-assessment support and psychoeducation will likely need tailoring to the person’s needs as the standard group psychoeducation programme on offer may not be appropriate.

Assessment of people in residential education settings

In some instances, children and young people in residential special education settings (who should all be in receipt of an Education, Health and Care Plan (EHCP)) may be identified as needing an autism assessment while they are placed in residential education settings. While circumstances and presentation may be complex, a clear clinical rationale must be provided if an autism assessment is not conducted at this time, such as the child or young person is due to relocate or return home and the process cannot be completed during this time. A request for an autism assessment or annual review would follow the same process as for any child or young person in the community.

The period for which the child or young person is resident (38-52 weeks) may have an impact on their legal status. Some children and young people will be looked after under different sections of The Children Act 1989, in which case parental responsibility may be shared between parent carers and the local authority. When children have a looked after status – either under s.20, s.31 (or other section of the Children Act 1989) the local authority will have other responsibilities as a corporate parent. Consideration needs to be given as to who holds the legal responsibility to make decisions for the child or young person. However, the child or young person should be involved in decision making and the referral process for an autism assessment.

The needs of children and young people in these settings are likely to be complex and an enhanced assessment should be conducted with close collaboration between clinical, educational and support staff to reach a diagnostic outcome and comprehensive formulation of the child or young person’s strengths and needs.

However, some young people may not wish to proceed with an assessment or may be reluctant to involve their parents or carers[4]. Care must be taken to provide information that is accessible and transparent with respect to the purpose of the assessment, the process and likely outcomes. If a child or young person is diagnosed as autistic, their EHCP plan and any other relevant plan (such as Looked After Child) should be revised to ensure it reflects the diagnosis and recommendations for care and support.

If a diagnosis of autism is made, post-diagnostic support and intervention should address needs across education and residential domains, potentially including consultation for education, therapeutic and residential staff in supporting the child or young person. Reasonable adjustments and consideration of transitions would be as relevant as for children and young people in the community.

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[4] See earlier section about consent.

Assessment of people in the criminal justice system

Some children, young people and adults are identified as needing an autism assessment while they are in secure and detained settings. Such settings include prisons, secure facilities for children and young people and immigration removal centres.

The national framework and operational guidance may be helpful to consider when commissioning and delivering autism assessment pathways. However, there is already guidance from NHS England best practice guidance concerning meeting the healthcare needs of adults with a learning disability or autistic people in prison (51) and best practice guidance for those accessing Liaison and Diversion services (52). In all guidance, the importance of identification, screening, assessments, appropriate support, pathways and partnership working is emphasised.

The Ministry of Justice published an action plan to address the issues raised by a 2021 Inspectorate report on neurodiversity in the criminal justice system (53).

Assessment of people by national specialist services

Many people are seen by an autism assessment service in the area within which they live. However, for a proportion of people, referral to a national specialist service may be considered appropriate. This may be for several reasons. For example, there may be no existing autism assessment service that the person can access in their area. Alternatively, the person may present with a high level of clinical complexity and a more in-depth assessment of autism, and differential and co-occurring diagnoses is being sought. On some occasions, it may be that the person has previously had an autism assessment but there is no clear assessment outcome due to clinical complexity, and therefore, an opinion from another service is deemed pragmatic.

Routes to a national specialist service can vary (such as, whether a GP or clinician working in secondary care setting can instigate the referral and whether the person needs to have already had an autism assessment in the area they live).

Information about the autism assessment pathway for people, their family/carers and professionals should outline the process for making referrals for an autism assessment to a national specialist service. This should include whether the person will first need to be seen by an autism assessment service in the area they live and whether they need to be open to a specific health service concurrently (for example a secondary care mental health service).

Referrals to national specialist services should be detailed and include copies of any correspondence reports from health and social care services or education settings that may be relevant for informing decisions about whether the national specialist service accepts the referral and the subsequent autism assessment. National specialist services may not have access to the same clinical records, and so the referrer or professional who knows the person well may need to amalgamate relevant information.

There should also be clarity about which service has responsibility for risk assessment and management while the person is awaiting an autism assessment. There should also be clarity about which professional or service will be expected to action any outcomes or recommendations following the autism assessment (such as for referring for or overseeing further assessment or post-assessment support).

Second opinion referrals

Some professionals, or people or their family/carers, may seek a second or even third opinion, to clarify whether a person meets diagnostic criteria for autism, with or without co-occurring conditions.

Second opinions may be sought when a person or their family/carers disagree with the existing clinical assessment conclusion(s), or when there is clinical uncertainty about initial clinical assessment conclusion (for example, that this was made some time ago, or the person had symptoms from another condition that substantially impacted their clinical presentation). Further opinion about possible autism diagnosis may also be sought at a different point in time (for example, some years after an initial autism assessment, and if the person's autistic traits have become more apparent). It is important that the rationale for seeking a second opinion is clarified for each person.

ICBs should have a local policy regarding second opinion autism assessments, focusing on issues including:

- Operationalisation of criteria used to decide whether to accept or decline second opinion autism assessments.
- Whether people can be seen by a second clinician at the service that conducted the initial autism assessment.
- Whether it is helpful to have reciprocal agreements with other services in the area, as part of the autism assessment offer, that may be able to provide a second opinion assessment.
- The process of referring people to a service outside their local area or to a national/specialist service and for what reasons.
- The rationale and protocols for removing diagnoses (such as an autism diagnosis being queried during an inpatient admission, or a previous diagnosis of personality disorder being queried when a new diagnosis of autism is made).

In instances when a second opinion autism assessment is offered or there is a question about removing an existing autism diagnosis, the clinician(s) should have access to previous correspondence, including the original autism report as well as the write up of specific methods of assessment (for example, of autism assessment tools).

Consideration is needed regarding which clinicians will conduct the assessment (that is, representing which professional disciplines, with what level of experience or seniority, and expertise in autism). As with all autism assessments, there should be emphasis on gathering sufficient current, contextual, developmental and historic information, in order for clinicians to be able to develop a clinical formulation and reach a decision about autism diagnosis. Completion of self-report screening questionnaires or standalone behavioural observation assessments is insufficient. The parameters of the assessment should be clear for people, their family/carers and professionals (that is, what the specific remit of the appointments is, and that the outcome may not be different from the previous clinical assessment conclusions).

Assessments by independent providers

Sometimes, independent providers are commissioned to conduct autism assessments, either as part of a block contract or per person (for example, through referrals where patients have exercised their legal rights to choice of provider/team). Independent providers may be based in the local area, regionally or nationally. People, their family/carers may also seek and self-fund an independent assessment.

Issues that inform decision making about whether to commission an independent provider include the following:

- Parity of provision – service provision should be comparable to the local NHS offer with respect to quality standards, flexibility and experience for people and their family/carers.

- Parity of regulation – at present some providers of autism assessments are registered with the CQC and others, especially independent sector providers, are not. While that remains the case, ICBs commissioning autism assessments should consider the extent to which any provider that is not CQC registered can offer reassurance that this will not be to the detriment of the person assessed, and the way in which this distinction and its implications will be communicated to the person and their family/carers as appropriate.

- Accessibility – the service should be accessible to all people who could potentially be referred from the area.

- MDT representation – some autism assessments require input from different professional disciplines (for example, psychiatry, psychology and occupational therapy, see Second opinion referrals for more information). The clinicians best placed to see a person for the autism assessment may be known at the point of referral. Alternatively, this may become more apparent during the screening and triage stages, or once the assessment has commenced. Services need an MDT workforce, with options for different clinicians to become involved, as indicated. At least one clinician conducting the autism assessment should be a mental health professional (for example, psychiatrist, clinical psychologist, mental health nurse), given the high possibility that people may have differential or co-occurring diagnoses.

- Differentiated pathway – components of the autism assessment can vary slightly, depending on the needs and difficulties of each person. For example, some people will need to meet one experienced clinician, whereas others will benefit from seeing several clinicians. The service should be flexible and be able to offer the components of the assessment that are relevant to each person.

- Location of assessment – some services offer in-person appointments, whereas others use telehealth, or a hybrid approach of both methods. There is preliminary evidence of feasibility and reliability of telehealth autism assessments (49,54). However, there is insufficient research to date indicating what the optimum components of telehealth appointments are (for example, in terms of structure, process and methods of assessment) and whether this is a sufficient approach for all people (that is, does it affect the rate of false negative and false positive diagnoses when compared with in-person appointments). Additionally, telehealth may not be feasible for some people and their family/carers, due to factors including digital poverty, risk or safeguarding issues, or personal preference. The service, therefore, should be able to offer in-person appointments if these are clinically indicated or this is the person's preference.

- Components of assessment – the autism assessment should include a clinical interview with the person, augmented with information obtained in other ways such as observation in education settings for children and young people. Use of screening questionnaires and assessment tools (such as the ADOS-2 and ADI-R) are insufficient on their own. Assessments must include core components outlined in the Components of a good clinical assessment section of this document.

- Conversion rates – the proportion of people diagnosed as autistic following an autism assessment, versus those who are not, differs between services. Conversion rates should be made available to those in a commissioning role and the local or regional NHS services that provide autism assessments. These should be considered alongside the conversion rates for other services in the area and would be expected to be broadly comparable.

- Outcome documentation – assessment documentation should be shared in a timely way with people attending for the appointment, their family/carers and professionals involved in the person's care and support.

- Post-assessment support – evidence indicates that many people diagnosed as autistic benefit from post-assessment support (40,55). This can include signposting and interventions, offered individually or in groups, in person or via telehealth. To promote parity of provision, comparable post-assessment support should be offered that is similar to other services in the area.

- Audit and service evaluation – evaluation of services provided is key to ensuring that people and their family/carers are offered high quality, accessible and effective care. Services should conduct regular audit and service evaluation and findings should be shared with those in a commissioning role.

People and their family/carers should be informed at the outset of the autism assessment pathway, as to whether there are any implications of accessing an assessment via an independent provider, rather than an NHS service. For example, whether the person and their family/carers will have access to local support while waiting for an assessment (that is, pre-assessment support) and post-assessment support.

Part 3. Training, consultation and liaison, and supervision

Autism assessment services also offer support to professionals working with autistic people and people who may be autistic. General types of support include autism-relevant training, consultation and liaison, and supervision.

Training

In some areas, autism assessment services organise autism-relevant training for other professionals, including MDT trainees and students. Doing this can enhance the knowledge, skills and confidence of professionals working in mainstream services, so that they can work more effectively with autistic and possibly autistic (but not yet assessed) people. National Frameworks are available to support staff and managers in considering the core competencies required when working with autistic people (22).

The type of training delivered will depend on the requirements of other services, the professional skill mix of clinicians in the autism assessment service, as well as time and resources. Working jointly with other autism assessment services to develop a local area training offer can help to reduce duplication.

Training can be formal or informal, and generic or bespoke. This must also fit with the organisation's training strategy and policy and may take place alongside the Oliver McGowan Mandatory Training on Learning Disability and Autism. Ideally, training materials are co-produced and delivered by autistic people and family/carers.

Key considerations regarding training delivery are:

- Determining whether the autism assessment service is the right service to deliver this.

- Having clarity about the purpose of the training, and who (which professional disciplines and level of experience) will attend this.

- Providing the trainers with access to up-to-date research and clinical guidelines so that this can be embedded in teaching materials.

- Delivering training to professionals from different services concurrently, if appropriate.
- Identifying the learning outcomes and objectives in advance.
- Considering the appropriateness of training relating to autistic people of all ages, with the needs of young people and family/carers being different to those of adults.
- Choosing methods of training delivery that are accessible, efficient and effective (for example, delivering training online).
- Evaluating outcomes before and after training.
- Ensuring there is scope for training attendees to offer qualitative feedback.
- Maintaining a log of training requests and sessions delivered to avoid duplication.
- Providing the necessary training and support for professionals, and autistic people and family/carers so that they can contribute to the design, delivery and evaluation of training provision.

Consultation and liaison

Colleagues working in mainstream and specialist services can benefit from consultation and liaison with clinicians working at the service conducting autism assessments. For example, to discuss the possible needs of autistic people, and people with possible autism who are awaiting an autism assessment, who are accessing other services (for example, adjustments to sensory environments or accounting for communication preferences). Consultation is one way that clinicians working in non-autism services can become more knowledgeable, skilled up and confident to work with autistic people.

Key considerations regarding provision of consultation and liaison are:

- Clarifying what the aims of this are, what outcomes are expected, and for whom.
- Establishing which clinicians (that is, representing which professional disciplines) are best placed to provide this.
- Obtaining the person’s consent for this to go ahead.
- Deciding who can attend.
- Documenting a summary of the discussion, aims, outcomes and action points in the clinical records, including ensuring there is clarity about which service holds clinical responsibility for the person.

- Obtaining quantitative and qualitative feedback about the process.

Clinical supervision

All professionals using standardised assessment tools should only do so after they have completed relevant training and gained sufficient experience to be signed off to administer using these.

Professional and accrediting bodies for each of the clinical disciplines (for example, General Medical Council, Health and Care Professions Council, Nursing and Midwifery Council) provide guidance on the key characteristics of effective supervision for professionals registered with the Health and Care Professions Council (56). This includes how often meetings should take place, the level of seniority and clinical experience of supervisors and requirements for them to be signed off as competent in this role.

In some autism assessment services, the supervisor will have the same professional background as the supervisee. When this is not possible, it is important that the supervisee can access supervision that will allow them to continue meeting requirements for revalidation of their professional pin number.

Some autism services provide a combination of individual, group and peer clinical supervision. Each of these forums have merit. Combined group or peer supervision with clinicians working at similar services in the area can also be a useful means for exploring issues pertinent to the area. Formal terms of reference and clear governance are essential to ensure the agreed remit and scope of supervision and discussion groups are clear and confidentiality is maintained in relation to any clinical discussions. Local and regional discussions may highlight common areas of concern and identify learning needs across services and professional disciplines.

While professionals in autism assessment services may be well placed to offer supervision and training to practitioners working in generic and specialist services (mental and physical health settings), highly specialist knowledge and skills will be in evidence within certain teams where autism co-occurs with mental health conditions, for example, psychosis and opportunities for shared learning should be facilitated.

Appendices

Appendix A. Glossary

Table 2. This shows the abbreviations and definitions used throughout this document.

Abbreviation	Definition
ADHD	Attention deficit hyperactivity disorder
ADI-R	Autism Diagnostic Interview – Revised
ADOS-2	Autism Diagnostic Observation Schedule-2
CSDS	Community Services Dataset
DISCO	Diagnostic Interview for Social and Communication Disorders
DSM-5	Diagnostic and Statistical Manual for Mental Disorders, fifth edition
EHCP	Education, Health, and Care Plan
GP	General Practitioner
HEE	Health Education England
ICD-11	International Classification of Diseases and Related Health Problems, eleventh edition
ICS/ICB	Integrated Care System and Integrated Care Board
MDT	Multidisciplinary team

MHSDS	Mental Health Services Dataset
NICE	The National Institute of Health and Care Excellence
SENCO	Special Educational Needs Coordinator
SEND	Special Educational Needs and Disabilities
SPA	Single point of access

Appendix B. Suggested autism assessment services development stakeholders (ICS and ICB)

- Representatives from the ICB and ICS
- Operational managers, service leads and MDT clinicians for autism assessment services and allied primary, secondary and tertiary developmental and mental health services
- Operational managers, service leads and multidisciplinary team clinicians from primary and secondary medical health services, including General Practitioners, paediatricians and health visitors
- Transition workers
- Operational managers and service leads working in the criminal justice system and forensic services
- Autistic people and family/carers
- Representatives from third sector organisations providing advice or support to people who may access the autism assessment pathway
- Operational managers and service leads who have responsibility for social care support
- Educational psychologists, SENCOs, Local Authority SEND Leads, teachers and representatives leading on the SEND agenda

Appendix C. Examples of common barriers to assessment

Table 3. This shows examples of barriers to accessing the initial stages of the autism assessment pathway, split by type of barrier.

Category	Barriers to accessing initial stages of the autism assessment pathway
Service-related	• Fragmented and inflexible services. • Lack of clarity about which service provides autism assessments. • The need for review by multiple people. • Long waiting times.
Professional-related	• Mainstream professionals' lack of knowledge or understanding of autism and its heterogeneity. • Inaccurate or biased preconceptions about autism. • Lack of support to proceed with an autism assessment. • Diagnostic overshadowing.
Family/carer-related	• Perceived stigma associated with autism. • Lack of knowledge or understanding of autism. • Difficulties knowing where and how to access help. • Negative previous experiences with professionals, and apprehension about approaching them again.

Appendix D. Information to be included in a referral letter

Referrals for an autism assessment can include the following information, when known:

- Full name of the person, and the name they prefer to be called if this is different (for example, Steven Jones, preferred name Steve).

- Their date of birth and age.

- Gender and preferred pronouns.

- Current contact details and the person's preferred mode of contact (for example, letter, telephone, email).

- A summary of past and current developmental, medical and mental health diagnoses.

- A list of pending medical, mental health or developmental assessments or investigations.
- An overview of current and past treatment for developmental, physical or mental health conditions, including what treatment was offered and a summary of the treatment response.
- Copies of relevant developmental or mental health letters or reports written by other professionals.
- Reason for the referral, including examples of autistic traits, symptoms or behaviours the person has, or others have noticed and the context(s) within which these manifest (for example, only at home or at home, education settings and social situations).
- Scores of any developmental or mental health screening questionnaires or standardised tests used.
- Clarity about whether any risks have been identified at the time the referral is made, including directly or indirectly to the person or to others. If there are known risks, a copy of the risk assessment and crisis safety plan should be provided
- Any past or current contact with the criminal justice system.
- Information relevant to the practicalities of arranging an autism assessment, such as whether the person is agoraphobic, has access to the internet or is due to move home.
- Clarity about whether the person has additional needs (for example, an intellectual disability, visual or hearing impairment) that may require adaptations to an autism assessment.
- A note about whether there are any known impending transitions or changes (for example, parents separating or divorcing, a house move).
- A statement indicating whether the person is aware the referral has been made and has consented to this. If the person is not aware of this or they have not provided consent, the rationale for making the referral should be clearly documented.

Appendix E. Triage

Standardised screening strategies

- Self-report questionnaires are completed by the person. These may screen for autistic traits, traits of other developmental conditions (for example, ADHD), mental health symptoms (for example, low mood, anxiety, emotion regulation), or the impact of current difficulties on daily functioning. Care must be taken in the interpretation of questionnaires, particularly where people may have speech and language or literacy difficulties.

- Informant-report questionnaires are completed by someone who knows the person well now, or knew them well as a child, such as family/carers, a partner or a professional. These may screen for traits associated with autism or other developmental conditions, mental health symptoms, as well as general behavioural difficulties and the impact of these for the person and possibly others around them. For children and young people these may be completed by professionals in education settings such as colleges. For some adults, it may be difficult to identify reliable informants to provide developmental and personal information. Also, care must be taken to obtain up-to-date written consent prior to contacting informants, and to protect confidentiality in the process of gathering third-party information.

Semi-structured screening questionnaire developed in-house by the autism assessment service

- Some services develop a document to collect information from the person, their family/carers or significant others in their lives (such as a partner) and professionals the person is currently in contact with or has been recently. Ideally, these documents are developed in collaboration or consultation with people who use the service and their family/carers, to ensure these are structured and phrased meaningfully.

- It can be advantageous for autism assessment services within the area to collect similar information or to use the same document (with age and stage relevant additions and omissions). This makes it easier for referrals to be passed between services (for example, in the case of people transitioning from children and young people to adult services). It also limits the need for the same information to be sought on repeated occasions.

- These questionnaires commonly collate factual historical information (for example, about mother’s health during pregnancy, age at which developmental milestones were met), family context (for example, health and wellbeing of family members), schooling (for example, details about attendance, additional support provided) and health and wellbeing history (for example, art therapy or access to community support).

Review of correspondence relating to medical and mental health history

- Some people have had regular or substantial contact with medical or mental health services, in the past or at the time of the referral for an autism assessment.

- At the very least, a summary of the history should accompany the referral letter. Review of correspondence is integral to screening, particularly letters and reports that summarise history, treatment plans and progress.

Review of correspondence relating to contact with other developmental services

- Some people may have been seen by other developmental services, including ADHD assessment services or services for people with an intellectual disability.

- Correspondence from these appointments, such as an overview of what the assessment comprised, test results (for example, IQ and functional ability scores) and overall clinical assessment conclusions, is highly informative. This can reduce the likelihood of repeating tests unnecessarily.

Information about contact with the criminal justice system

- Some people may have had past or current contact with the criminal justice system, either as a victim or perpetrator of a crime (or alleged crime).

- Review of information relating to cautions and convictions is important, as this can inform decision making about risk and vulnerability.

In-person triage

Some services offer people an initial triage appointment. The purpose can vary. For example, this can be an opportunity to more formally determine whether an autism assessment is clinically indicated, or to gather general information that can be used to inform the autism assessment. People and their family/carers should know what the aims and possible outcomes of the appointment are.

Meeting with family/carers, partners or friends

Significant others (typically family/carers of adults) are sometimes invited to attend an appointment as part of the triage process, most commonly to provide background information about childhood history and development, and additional context (for example, the person's current difficulties from their perspective). Consent to speak to someone else should normally be obtained from the person. If consent is not granted, but others are contacted nevertheless, the rationale for doing so should be documented in the clinical records. Family and carers of children and young people under the age of 16 should be included in triage and assessment since they have parental responsibility.

Some services use validated standardised semi-structured interviews to gather information, whereas others develop a bespoke interview. As with other forms of triage, reasons for offering this appointment, and how the information will be used, should be clear from the outset.

Liaison with professionals the person is in contact with

When feasible, and consent-permitting, it can be useful to speak with professionals who are currently or have recently been in contact with the person, such as professionals working in health and social care, education, the criminal justice system or third sector organisations. This can help to clarify information about parameters of their involvement, approaches or interventions offered, to or the effectiveness of these and anticipated next steps.

Appendix F. Data reporting

Autism assessment services are an important element of the Government's National Strategy for Autistic Children, Young People, and Adults (21). This emphasises a focus on ensuring 'demonstrable progress on reducing diagnosis waiting times and improving assessment pathways for children, young people and adults across the country'. For adults and children and young people referred for assessment to mental health services, this will be monitored through the monthly submissions mental health care providers make to the MHSDS. For children and young people assessed through paediatric services it is likely that it will be monitored mainly through submissions to the CSDS.

At present referrals to autism diagnosis services in mental health services are identified through the Primary Reason for Referral specified in MHSDS table MHS101. This should be coded '25 – Suspected Autistic Spectrum Disorder'. This code should not be used for any other referrals. If a person has been referred to the provider for another reason, but clinicians initially assessing them consider an autism assessment is appropriate, a second referral should be made for this.

Contacts between clinical staff and the referred person are normally recorded in the Care Contacts (MHS201) and Care Activity (MHS202) tables. The clinical discipline and grade of staff undertaking contacts is of interest. This should be recorded in the Staff Details (MHS901) table and providers should ensure that links between this and the Care Activity table, through the Care Professional Local Identifier field, are intact.

During the course of an assessment, an autism diagnosis or other diagnoses may be made. These should be recorded in the Primary Diagnosis (MHS604) and Secondary Diagnosis (MHS605) tables.

The Referral Request Received Date and Service Discharge Date in the Referrals table, along with the dates of contacts and of recording of diagnoses provide the basis for assessment of waiting times.

Further work is currently under way:

- To develop additional Systematized Nomenclature of Medicine to record the method of termination of autism diagnosis assessments, structured tools used in the assessment process, whether the process was conducted face to face or through tele-consultation, whether an autism diagnosis made was the first the person has received, and the outcome of the assessment. The last is needed in part to allow recording of the negative clinical conclusion that a person is not autistic.

- To assess the developments needed in the CSDS to allow similar monitoring of autism assessments undertaken by paediatric services.

Appendix G. Core components of autism assessment report

Core components of an autism assessment report:

- reason and background to referral
- dates seen and format (face-to-face, telehealth or hybrid)
- professionals involved
- sources of information, including parents, teachers, partners, employers etc.
- screening tools used and results
- autism assessment tools
- assessment system, for example, ICD-11 or DSM-5
- summary of current functioning
- summary of health and wellbeing, including risk
- summary of developmental and personal history
- assessment formulation
- consideration of the impact of strengths and needs
- recommendations and next steps.

Core components of brief autism assessment statement (optional):

- reason and background to referral
- dates seen and format (face-to-face, telehealth or hybrid)
- professionals involved
- sources of information, including parents, teachers, partners, employers etc.
- screening tools used and results
- autism assessment tools
- assessment system, for example, ICD-11 or DSM-5
- summary assessment formulation

- reference to recommendations and next steps:
- including Equality Act 2010
- reasonable adjustments
- disclosure.

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A national framework to deliver improved outcomes in all-age autism assessment pathways: guidance for integrated care boards

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Content

Equality and health inequalities statement

This national framework sets out the principles that should underpin the planning, design and delivery of an autism assessment pathway that works for everyone irrespective of where they live, their background, age, ethnicity, sex, gender, sexuality, disability, or health conditions. Implementation of this national framework will include taking actions to reduce known sources of health inequality that exist in access to, or experiences of, an autism assessment across England.

Foreword

Demand for autism assessments has risen rapidly over the past 20 years. Investment in autism assessment capacity has not kept pace with this growth; demand now far exceeds available capacity. Waiting lists for autism assessments across England have reached unsustainable levels. In July 2022, NHS Digital reported there were more than 125,000 people waiting for assessment by mental health services; an increase of 34% from October 2021 (1). These data show that most people wait longer, often much longer, than the three-months recommended in clinical guidelines for an autism assessment to begin (2) and the 18-week maximum waiting time for treatment to begin, as set out in the NHS Constitution (https://www.gov.uk/government/publications/the-nhs-constitution-for-england) (3). As demand continues to grow and capacity has remained stable or has dropped, the demand-capacity gap continues to widen.

In addition to long wait times, improvement in other areas of the autism assessment pathway is also needed. This includes improving the quality of information and support provided during and after assessment, increasing the ease and efficiency with which people transition through stages of the pathway and reducing people's uncertainty about the process. We know services are working extraordinarily hard to keep pace with rising demand, but on account of the demand-capacity gap, the ability to provide timely assessment and support for people is not often currently possible. Strategic action is needed.

The Autism Act 2009 (https://www.legislation.gov.uk/ukpga/2009/15/contents) set a statutory duty on NHS organisations and local authorities to provide appropriate services to assess autism in adults and to support autistic adults post-diagnosis. In 2019, the NHS Long Term Plan (https://www.longtermplan.nhs.uk/) committed to reducing autism assessment waiting times and delivering packages of post-assessment support for children. In 2021, the National strategy for autistic children, young people and adults (https://www.gov.uk/government/publications/national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026) (4) expanded upon this ambition, by committing to timely access to diagnosis and demonstrably improved autism assessment pathways for people of all ages by 2026.

We recognise that achieving these policy ambitions requires a multifaceted response, that should include increasing the supply of a specialist workforce, ensuring that resource allocation to autism assessment services is sufficient to close the demand-capacity gap, while adhering to best practice clinical guidelines and deploying existing resources as effectively and efficiently as possible. Increasing workforce supply and resource allocation to autism assessment services are outside of the scope of this work but should remain a focus in efforts to achieve national policy ambitions.

With respect to effective and efficient use of existing resource, we have developed two documents to support integrated care boards (ICB) in England. We anticipate ICBs will use these documents to work with other organisations that may provide some of the autism assessment offer in their integrated care system (ICS) footprint. We have produced this national framework that sets out general principles to be applied during the commissioning cycle for an autism assessment offer in each area of the country. We have also produced operational guidance (https://www.england.nhs.uk/long-read/operational-guidance-to-deliver-improved-outcomes-in-all-age-autism-assessment-pathways-guidance-for-integrated-care-boards/) that places these general principles in operational context in terms of how they can be applied in each area.

Both documents have been created with input from clinical, lived experience, scientific, commissioning and service management experts. Both documents incorporate relevant, evidence-based recommendations from NICE guidance.

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Brief introduction to autism diagnosis

Autism spectrum disorder (referred to as autism in this national framework and the operational guidance (https://www.england.nhs.uk/long-read/operational-guidance-to-deliver-improved-outcomes-in-all-age-autism-assessment-pathways-guidance-for-integrated-care-boards/)) is the official name of a diagnosis within a broader category called neurodevelopmental disorders in the International Statistical Classification of Diseases, eleventh edition (ICD-11; 5) [1]. The ICD is the only assessment manual that officially applies in the NHS in England. This global assessment standard states that for a person to be diagnosed as autistic, all the following criteria must apply:

- "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. [2]
- 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" (5)

ICD-11 was endorsed by the World Health Organisation in February 2022 but does not have a mandatory implementation date. This means that each health service around the world that uses the ICD manual sets its own timeline for adoption. In the NHS in England, there is, as yet, no definitive date for the ICD-11 to be mandated; the tenth edition of the ICD (6) remains the mandated information standard for use about diagnosis while clinical records systems are updated to reflect the eleventh edition. 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. (https://nhsengland.kahootz.com/t_c_home/view?objectID=36254864)

Autism is also a diagnosis described in the Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5; 7). 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 diagnostic criteria are referred to in clinical guidelines. Also, some standardised assessment tools used in England were designed using DSM-5 criteria or criteria from the previous edition. Additionally, some services used DSM-5 criteria while awaiting publication of the latest edition of the ICD. For consistency across the NHS, ICD-11 criteria should be used for the primary description of autism, but assessment tools based on DSM criteria and health record codes based on ICD-10 can still be used.

There are no diagnostic biomarkers for autism. This means there are no objective biological tests or scans used in confirming or refuting an autism diagnosis [3]. Autism is therefore a clinical diagnosis; diagnosis is based on expert clinical judgement about whether a person's observable behaviour and their own or another person's report about their developmental history and behaviours meet the clinical threshold for each of the above criteria.

None of the individual autism diagnostic criteria are exclusive to autism; that is, there is considerable overlap in diagnostic features of several communication, neurodevelopmental and mental health conditions (8). Autism also co-occurs with other conditions more often than it occurs as a sole diagnosis (9,10). For these reasons, consideration of differential, that is, alternative or co-occurring diagnoses, is necessary as part of an autism assessment to establish whether a person's behaviour is explained by none, one, or more than one of a range of possible diagnosable conditions. Autism should not be assessed without also considering the possibility of differential or co-occurring diagnoses.

The purpose of an autism diagnosis

Autism is not an illness or disease, and autistic traits are not a universally agreed intervention target for every autistic person. However, an autism diagnosis can serve several important purposes as set out below. This is why universal, equitable and timely access to autism assessment in every ICB is important.

Firstly, an autism diagnosis is important in the context of healthcare. While not the case for all, many autistic people do seek interventions that are safe and effective for improving particular skills and abilities that overlap with diagnostic traits, for example, language and communication (11). A diagnosis enables clinicians to recommend interventions that have been tested for safety, acceptability, efficacy and effectiveness with people meeting the same diagnostic criteria as the person they are supporting; a critical tenet of evidence-based care. This may be, for example, interventions with an autistic person (12), or parents (13), to improve communication, behavioural or well-being outcomes.

Secondly, an autism diagnosis is a mechanism to ensure reasonable adjustments are made in general physical health or mental health services (14,15). A diagnosis is often vital in clinical formulation and treatment planning for co-occurring conditions. For example, some common mental health interventions are known to be less effective or can require adaptations for autistic people (16). For example, cognitive behavioural therapy for anxiety or depression (17) or intervention for feeding and eating disorders (18).

Thirdly, clarity about autism diagnosis can be validating for many people in their day-to-day lives. For example, this can help with the development of a positive autistic self-identity and foster connections with the autistic community (19).

Fourthly, an autism diagnosis can help facilitate access to some forms of statutory protection beyond the healthcare context. For example, an autism diagnosis may be considered when a person seeks an Education, Health and Care Plan, a legal document setting the support children and young people receive. The Equality Act 2010 (https://www.gov.uk/guidance/equality-act-2010-guidance) can be a source of protection for people with a disability, the definition of disability according to the Act is available here (https://www.gov.uk/government/publications/equality-act-guidance/disability-equality-act-2010-guidance-on-matters-to-be-taken-into-account-in-determining-questions-relating-to-the-definition-of-disability-html). Further, autistic people have been shown to be better able to advocate for reasonable adjustments in the workplace if they have clarity about an autism diagnosis (20). Additionally, according to the statutory guidance (21) of the Autism Act 2009, autistic adults are entitled to a care assessment under the Care Act 2014 (https://www.legislation.gov.uk/ukpga/2014/23/contents) and, in some cases, an assessment report may be considered in assessing a person's support needs.

For an undiagnosed autistic person access to personal understanding, healthcare, education, social care, reasonable adjustments in the workplace, statutory protection from discrimination, or benefits may be withheld. For these reasons, it is important that ICBs do not restrict or withhold access to an autism diagnosis, for example, because locally a decision has been taken by health to conduct only a needs-based assessment. Barriers to a diagnosis increase a person's risk for poor outcomes in life, for example, late diagnosed autistic adults commonly experience multiple forms of abuse (22) and can experience poorer mental health, suicidality or hospital admission (23,24). As a result, autistic people, and especially people without an intellectual disability, represent a significant proportion of the mental health inpatient population in England (25).

An autism diagnosis should always be made by clinical professionals in a health service. Delayed or unequal access to autism assessment can result in missed opportunities for support from education, social care, voluntary, community and social enterprise. In turn, this can increase the likelihood that people require restrictive and costly hospital care (23,24). That is, while broad and timely access to an autism diagnosis is costly to the health service, narrow and delayed access may be more costly still.

Definitions of terms used

- **Suspected or possible autism**: an administrative term used to denote when a person is identified as having traits and difficulties suggestive of autism, that warrant formal assessment.
- **Autism assessment**: an assessment that takes place to determine if a person with suspected or possible autism meets the diagnostic criteria for autism (that is, is autistic). It is essential that the assessment of autism is not undertaken in isolation from screening or assessment of other conditions that may be the cause of, contribute to, or be associated with traits and difficulties identified; often referred to as differential or co-occurring diagnoses.
- **Autism assessment service**: any service commissioned to conduct autism assessments, as described above, when these represent a significant proportion of the service's activity. Some autism assessments take place in services that do not routinely conduct autism assessments, such as, by secondary care mental health services, in an inpatient ward or during contact with the criminal justice system. This national framework and the operational guidance (https://www.england.nhs.uk/long-read/operational-guidance-to-deliver-improved-outcomes-in-all-age-autism-assessment-pathways-guidance-for-integrated-care-boards/) were not developed with these services in mind. However, any service that conducts autism assessments should consider the principles of service design and delivery in both documents. This term is used to refer to a range of services with a variety of local naming conventions, including child development centres, social-communication teams, community paediatrics, neurodevelopmental assessment teams, children and young people's mental health services, services providing autism assessments or independent services.
- **Autism assessment offer**: the overall NHS autism assessment capacity in each area when capacity for all autism assessment services is considered collectively. Services contributing capacity towards the autism assessment offer may be a combination of NHS services and independent providers.
- **Autism assessment pathway**: the journey a person takes from the moment they are identified as potentially warranting an autism assessment until the point at which they are discharged from an autism assessment service. Discharge can take place, for example, after there has been a screening and triage process that suggests a full assessment is not clinically indicated, after the autism assessment has been conducted and the person is given an assessment outcome, or after post-assessment support has been delivered. See Figure 2 for a graphical schematic depiction of the pathway.
- **Standard autism assessment**: an autism assessment conducted by a single clinician, or two or more clinicians, appropriately qualified to diagnose or rule out possible autism (see Table 4). The assessment includes at a minimum, a clinical interview, behavioural observation, integration of developmental and corroborative information and consideration of possible differential and co-occurring diagnoses not identified at triage (especially when there has been a delay between initial referral, triage and main assessment).
- **Enhanced autism assessment**: an autism assessment conducted by two or more clinicians, appropriately qualified to diagnose or rule out possible autism. The assessment includes at a minimum, a clinical interview, behavioural observation, integration of developmental and corroborative information, use of validated assessment tools, a broader assessment of clinical presentation (such as estimated intellectual functioning or sensory processing) and additional liaison with referrers and other involved service(s). Siblings, partners or friends may provide corroborative information.
- **Clinician or clinical professional**: a health professional who has graduate or postgraduate qualifications in a health or related discipline, as well as current registration or accreditation with one of the following professional bodies: the General Medical Council, Health and Care Professions Council [4] or Nursing and Midwifery Council. Registration with a professional body does not, by definition, equip an individual to be competent in autism assessment, without appropriate skills and training in autism assessment and diagnosis.
- **Staff under clinical supervision**: people who may work directly with people being assessed by an autism assessment team and their family/carer under the supervision of a clinical professional, but who do not themselves have a clinical qualification or accreditation with professional bodies listed above. This includes, for example, assistant psychologists and staff in training.
- **Autism assessment team**: the multidisciplinary team that works in an autism assessment service. Professionals in an autism assessment team must collectively have skills to assess autistic traits and differential and co-occurring diagnoses. The National Institute for Health and Care Excellence (NICE) recommends professionals who should be represented in teams for children and young people under 19 years of age, and teams for adults. For a more detailed breakdown of autism assessment team membership see Appendix B (https://www.england.nhs.uk/long-read/a-national-framework-to-deliver-improved-outcomes-in-all-age-autism-assessment-pathways-guidance-for-integrated-care-boards/#appendix-b-roles-in-an-autism-assessment-team).
- **Autism assessment tool**: a standardised assessment tool that has been designed and carefully tested to provide clinical professionals with information that can inform their decision about whether somebody is autistic. While these tools provide useful information, they are not diagnostic on their own and must be interpreted by clinical professionals. These include questionnaires, structured observational assessments, and developmentally focused interviews.
- **Pre- and post-assessment support**: any support that a person or their family/carer is offered while they are on the autism assessment pathway. This includes providing people with high-quality, accurate and timely information throughout the process such as communication about the assessment process, updates about what will happen and when, and where and how to get practical support. This may include signposting or facilitating introductions to other services within or beyond health. Post-assessment support can include signposting to sources of help for other

conditions or provision of support around accepting and understanding an autism diagnosis. This phrase can be used to include evidence-based interventions, but also includes other broader forms of educational or informational support.

The impact of COVID-19 on autism assessment services

The impact of the COVID-19 pandemic on autism assessment services was acute and prolonged; some autism services were suspended entirely, or capacity was profoundly reduced for periods throughout 2020 (26). Some services were disrupted due to staff redeployment to the COVID-19 response effort, or to facilitate services to rapidly change their protocols and procedures, such as using telehealth methods, social distancing and personal protective equipment, or to adhere to COVID-19 lockdowns (27). Additionally, autistic people and those supporting them reported exacerbations of pre-pandemic health and educational inequalities (28, 29). This suggests that people referred for autism assessment may be more likely to also have unmet social care, mental health or educational needs than was typical pre-pandemic.

The purpose of the national framework and operational guidance

Despite successive policy commitments to improve the quality and increase capacity of autism assessment services in England, gaps remain in setting out actions that need to be taken to achieve these improvements. Here, we set out two interrelated pieces of guidance to address this gap.

We have developed a national framework to deliver improved outcomes in all-age autism assessment pathways. It has three sections:

- a brief overview of the most relevant policy context
- general principles underpinning autism assessment services
- how to apply these principles during a commissioning cycle.

Additionally, we have developed operational guidance to deliver improved outcomes in all-age autism assessment pathways. The operational guidance (https://www.england.nhs.uk/long-read/operational-guidance-to-deliver-improved-outcomes-in-all-age-autism-assessment-pathways-guidance-for-integrated-care-boards/) outlines detailed information about how to deliver individual autism assessment services and how these should be configured to form an overall autism assessment offer in each area of England. This guidance is designed to help areas ensure that every person referred for an autism assessment experiences an efficient, high-quality pathway, with clarity about what will happen and confidence in the diagnostic outcomes. The guidance is comprised of three sections:

- specifications for the five stages of the autism assessment pathway
- common variations in how the autism assessment is conducted
- non-clinical tasks commonly undertaken by autism assessment services.

Together, these documents are intended to help people in commissioning, clinical, management, lived experience and administrative roles, to make decisions to deliver high quality all-age autism assessment pathways. Specifically, these documents are designed to be used to:

- Reduce the number of referrals to autism assessment services that are declined on account of insufficient information being provided.
- Reduce the number of people referred to autism assessment services when a referral is not warranted, for example, when there is no reason to suspect possible autism or when a referral to a different service would be more appropriate.
- Increase satisfaction of people referred for an autism assessment, including those who are not assessed and those who are not diagnosed as autistic, and by their family/carers, irrespective of their age, ability, or background.
- Increase confidence in decisions among all stakeholders, including the person assessed, their family/carers and all organisations that the decision is relevant to.
- Reduce the number of people who are referred to and assessed by multiple services for different conditions, especially when duplicated assessment occurs and when a single service has the capability required to conduct all the assessments that are clinically indicated.
- Increase the proportion of people who receive packages of support while awaiting assessment and soon after receiving a diagnosis.
- Maximise resource spent on well evidenced support and minimise the amount of resource allocated on un-evidenced or under-evidenced interventions.
- Ensure that autism assessment services offer attractive career options by having varied and stimulating roles for all relevant clinical professionals, to aid workforce recruitment and retention.

This national framework does not intend to:

- facilitate the complete elimination of autism assessment waiting times
- establish a single service to assess for all neurodevelopmental conditions (commonly referred to as neurodevelopmental services)
- replace existing clinical guidelines

- address models of ongoing intervention and care, beyond the immediate post-assessment period.

For more information about how both the national framework and operational guidance (https://www.england.nhs.uk/long-read/operational-guidance-to-deliver-improved-outcomes-in-all-age-autism-assessment-pathways-guidance-for-integrated-care-boards/) were developed, including the evidence considered and stakeholders consulted, see Appendix A.

A brief overview of policies and laws relevant to autism assessment service delivery is provided below.

Building the Right Support (2015)

The Building the Right Support national plan (https://www.england.nhs.uk/learning-disabilities/natplan/) (30) and national service model (https://www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdf) (31) were developed to support the NHS and local authorities to reduce the number of autistic people and people with an intellectual disability in mental health hospitals, by increasing the provision of support in their local community.

The NHS Long Term Plan (2019)

The NHS Long Term Plan (https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/) set out a 10-year vision for improving the NHS in England, including, for the first-time, recognising autism as a national priority. The commitments in the Long Term Plan outline a vision for changes needed in the whole NHS by 2029 to best support autistic people to lead happier, healthier, and longer lives, including:

- “Reduce waiting times for specialist services”
- “Achieving timely diagnostic assessments in line with best practice guidelines”
- “Together with local authority children’s social care and education services as well as expert charities, we will jointly develop packages to support children with autism or other neurodevelopmental disorders”.

The national strategy for autistic children, young people, and adults (2021)

The national strategy for autistic children, young people and adults: 2021 to 2026 (https://www.gov.uk/government/publications/national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026) (4) committed to ‘demonstrable improvements’ in reducing waiting times and improving assessment pathways across all age groups and across the country. Additionally, an autism strategy implementation plan (https://www.gov.uk/government/publications/national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026/autism-strategy-implementation-plan-2021-to-2022-annex-a) was published for 2021 to 2022 (32).

Requirements of the Autism Act 2009 are that the national autism strategy is kept under review and that there is always associated statutory guidance in place setting out what local authorities, NHS organisations, and NHS Trusts must do to implement the current autism strategy and to deliver on the requirements of the Act.

The Health and Care Act 2022

The Health and Care Act 2022 (https://www.legislation.gov.uk/ukpga/2022/31/) represented a landmark re-organisation of health and care services in England with the establishment of integrated care systems (ICSs (https://www.england.nhs.uk/integratedcare/)) across England.

ICSs are partnerships of organisations that come together to plan and deliver joined up health and care services across the ICS footprint. They are designed to improve health outcomes for their population and create efficiencies by making it easier for local authorities and NHS organisations to collaborate. Within an ICS, an ICB is the statutory NHS organisation, superseding Clinical Commissioning Groups, that develop a plan for meeting the health needs of the population, managing the NHS component of the budget required to achieve that plan and arranging for the provision of health services.

Personalised care

The Long Term Plan stated that personalised care, whereby people get more control over their own health and more personalised care when they need it, will become business as usual in the health and care system (33). Guidance about how to achieve this by 2023/2024 has also been published (34). Further information is available on the NHS England website (https://www.england.nhs.uk/personalisedcare/) and in the Finance, Commissioning and Contracting Handbook for the NHS England Comprehensive Model for Personalised Care (https://www.england.nhs.uk/publication/finance-commissioning-and-contracting-handbook/).

Universal personalised care is defined by six components.

- **Shared decision making** – people are supported to understand the care, treatment and support options available, as well as the risks, benefits and consequences of each option and to use this information to decide on their preferred

course of action.
- **Personalised care and support planning** – this is about focusing on what matters to the person and their skills and strengths, as well as their clinical and support needs. It leads to a single plan, owned by the person and accessible to the people supporting them.
- **Enabling choice** – the NHS Constitution for England (https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england) (3) recognises patients' right to make informed choices about the services commissioned by the NHS and information to support making decisions about these choices.
- **Social prescribing and community-based support** – this enables all local agencies to refer people to a social prescribing link worker to connect them into community-based support, building on what matters to the person and their family/carers, as identified through shared decision making, personalised care and support planning, and making the most of community and informal support.
- **Supported self-management** – this refers to increasing the knowledge, skills and confidence a person has in managing their own health and care, referred to as patient activation. This is done through putting in place interventions such as health coaching, self-management education and peer support.
- **Personal health budgets** – this is an amount of money to support a person's identified health and wellbeing needs, planned and agreed between them and their local ICB. This may lead to integrated personal budgets for people with both health and social care needs.

Criminal justice

NHS England's health and justice and specialised commissioning teams are responsible for commissioning healthcare for people across a wide range of secure and detained settings including prisons, secure facilities and immigration removal centres. This national framework and operational guidance (https://www.england.nhs.uk/long-read/operational-guidance-to-deliver-improved-outcomes-in-all-age-autism-assessment-pathways-guidance-for-integrated-care-boards/) should be considered in the context of existing guidance from these teams about healthcare in these contexts. This includes, for example, meeting the healthcare needs of adults with a learning disability and autistic adults in prison (https://www.england.nhs.uk/publication/meeting-the-healthcare-needs-of-adults-with-a-learning-disability-and-autistic-adults-in-prison/) (35) and provision for people with a known or suspected learning disability, autism or both (https://www.england.nhs.uk/wp-content/uploads/2020/01/Learning-disability-and-autism.pdf) in liaison and diversion services (36).

In response to an inspectorate report on neurodiversity in the criminal justice system (https://www.justiceinspectorates.gov.uk/hmicfrs/publications/neurodiversity-in-the-criminal-justice-system/) (37) the Ministry of Justice has published a neurodiversity in the criminal justice system action plan (https://www.gov.uk/government/publications/a-response-to-the-criminal-justice-joint-inspection-neurodiversity-in-the-criminal-justice-system-action-plan), this includes a focus on identification and diagnosis.

Principles that guide commissioning of an autism assessment service

Here we set out 10 principles that should guide all decision making by anyone planning, designing, procuring, delivering, and evaluating an autism assessment offer. These principles are that an autism assessment offer should always be:

1. ethical
2. evidence based
3. respectful
4. delivered by an appropriately skilled multidisciplinary workforce
5. a comprehensive, coherent offer
6. accessible
7. co-designed by clinicians and people who access the services
8. based on shared and current conceptualisation of autism
9. transparent
10. described in, and informed by, national statistical data.

These principles are set out in the sections below.

Ethical

Autism assessment pathways, from the outset (that is, from the time potential autistic traits are identified, up until discharge from an autism assessment service), should not cause harm to people. This fundamental principle should guide decision making at every level to ensure services design and delivery is ethical. Ethical considerations should be made on several grounds.

Firstly, consider if actions taken by an autism assessment service have the potential to harm someone who is referred for assessment by that service. This may be, for example, considering how service level exclusion criteria or the sharing of inaccurate or potentially harmful information with someone before, during or after an assessment, could potentially cause harm.

Secondly, consider if actions taken by people performing commissioning functions are appropriately protecting people from risk. This could include, for example, taking appropriate precautions to ensure an ICB is satisfied each service that contributes to the autism assessment offer in each area is appropriately regulated, or when a service is not registered with the Care Quality Commission, that the ICB is satisfied with the steps taken to appraise that service and communicate what this means to prospective patients. Additionally, if a service routinely produces assessment decisions that are not trusted by other providers, consider the potential for this to cause harm both to the person assessed and to the wider autism assessment offer in the area. This may result in another service re-validating a decision incurring additional resource and questioning the decision may be distressing for the person who was assessed.

Thirdly, consider if activities commissioned or delivered represent value for public funds. This may be, for example, considering if an intervention or process within the autism assessment offer has evidence to demonstrate it is the most effective means of achieving its intended outcome. When evidence is found of superior cost effectiveness to an existing practice, it should be replaced.

Finally, consider if claims made by autism assessment services are well founded. Any intervention delivered by an autism assessment service that claims to lead to a potential therapeutic benefit, such as, an improvement in a skill or a reduction in a symptom should have evidence of efficacy and effectiveness and have been tested for potential adverse outcomes. It is not ethical for services to claim an intervention produces therapeutic benefits when scientific and clinical consensus have not yet been established.

Evidence based

For the NHS to achieve its founding principles to provide the highest standard of excellence and best value for taxpayers' money, care must be designed and delivered based on the best, currently available evidence.

NICE has published three clinical guidelines [5] that, together, describe how health and social care services should be delivered to identify, assess for and care for people diagnosed as autistic. The autism NICE clinical guidelines were also instrumental in the development of a NICE quality standard for autism [6]. The NICE autism publications are:

- Clinical guideline 128 (https://www.nice.org.uk/guidance/cg128): Autism spectrum disorder in under 19s: recognition, referral and diagnosis (2)
- Clinical guideline 170 (https://www.nice.org.uk/guidance/cg170): Autism spectrum disorder in under 19s: support and management (38)
- Clinical guideline 142 (https://www.nice.org.uk/guidance/cg142): Autism spectrum disorder in adults: diagnosis and management (39)
- Quality standard 51 (https://www.nice.org.uk/guidance/qs51): Autism (40)

NICE guidelines remain the primary source of information to inform decisions about how to apply evidence to service design and delivery. Compliance with NICE guidelines should always inform decision making about design and delivery of a service and purchasing of assessment services from other NHS or independent services. Clear, accurate, current and accessible information about the extent to which each service providing autism assessments complies with NICE guidance should be available to inform people's choices.

A significant amount of scientific research evidence about the assessment, diagnosis and support for autistic people has been published since NICE guidelines were last updated. Both this national framework and operational guidance (https://www.england.nhs.uk/long-read/operational-guidance-to-deliver-improved-outcomes-in-all-age-autism-assessment-pathways-guidance-for-integrated-care-boards/) refer to additional research that was not considered in the development of the autism NICE guidelines. These documents are not intended to replace NICE guidelines, but to supplement or extend some recommendations. Some NICE guidelines have had varied implementation. For instance, where NICE refers to the need for and composition of multidisciplinary teams it does not specify the precise sources and degrees of multidisciplinary input required for every assessment. These documents seek to add additional guidance to inform decision making in these areas. NICE guidelines remain the primary information source to justify resource allocation on interventions offered for autistic people after diagnosis.

It is the responsibility of individual clinicians, their respective professional bodies and people in commissioning roles to ensure public resources are spent on well evidenced services and not on un-evidenced or under-evidenced alternatives.

Together with the Innovation Agency, NHS England have produced a practical guide to support commissioners to interpret and use evidence (https://www.innovationagencynwc.nhs.uk/evaluation-and-evidence).

Respectful

Words matter – a lot. The terms used to communicate with, and about, autistic people can influence people's attitudes about autism.

We recommend that autism assessment pathways use language that categorises autism in diagnostic, but not negative or deficit-based terms. Autism should not be referred to as a disease or illness. Using respectful, inclusive and destigmatising language is a priority. We have set out the language principles we have used in this document that we recommend others adopt in Table 1.

Table 1. Language principles guiding this document.

Do	Do not
Use consistent terminology to describe an autism diagnosis for everyone and add details about other diagnoses a person may have, such as an intellectual disability, if appropriate.	Use functioning level descriptors, such as, high-functioning, or low-functioning autism. These are not and never were diagnoses.
When possible, ask people what language they prefer to use and respect this preference.	Be rigid about the terminology you use to talk about autism or about autistic people.
When communicating with a person or to a group of people without knowing their terminology preferences, use the more widely preferred identity first language, for example, say “she is autistic” instead of the less preferred person-first language, for example, saying “she has autism”.	Correct a person’s terminology choice about themselves or their family members.
When appropriate, describe autism as a neurodevelopmental disorder or neurodevelopmental disability.	Refer to autism as a disease or an illness.
Use descriptive and clinically informative language about a person’s strengths and difficulties.	Use negative or value-laden language when describing a person’s diagnosis, such as, suffers from autism, or struggles with autism.
Use the language from the version of the International Statistical Classification of Diseases and Related Health Problems that is valid and current at the time at which a person is diagnosed.	Use assessment categories from earlier editions or international variants of diagnostic manuals, unless the person was diagnosed when the term was still in use.
Use descriptive names for teams, services or job titles, for example, autism assessment service, specialist autism team or autism team lead.	Use acronyms when naming or referring to teams, services or people’s job titles, such as, an ASD team or ASC assessment lead.

Delivered by an appropriately skilled multidisciplinary workforce

An important feature of an effective autism assessment pathway is that within every service, there needs to be an appropriately skilled multidisciplinary team that can deliver high-quality assessments. An appropriate clinical workforce includes:

- **Good leadership.** Each assessment service should be led by an appropriately qualified, skilled and experienced clinical service lead. Some services may have separate operational and clinical leadership.
- **The right skill mix.** The combination of skills represented in each autism assessment service should be determined by the clinical needs of the people who routinely present for assessment at that service. For example, the clinical professionals in any autism assessment service should, together, have experience and expertise in assessment of neurodevelopmental (including intellectual disability), language and communication, and behavioural and mental health conditions, as these are commonly differential or co-occurring conditions. The precise proportion of these skills required will depend on the service.

- **Qualified staff.** Clinical professionals should all meet the qualification, regulation and current professional registration requirements to practice by their respective professional bodies. Clinical professionals from a limited number of professional disciplines (for example, a paediatrician, psychiatrist, clinical psychologist) are qualified to conduct each component of an autism assessment. Clinical professionals from many clinical professions (for example, speech and language therapists, occupational therapists and some types of nurses) are qualified to conduct some but not all components of an autism assessment; they should conduct autism assessments as part of a multidisciplinary team where the team is collectively qualified to conduct all required components of the assessment, see the operational guidance (https://www.england.nhs.uk/long-read/operational-guidance-to-deliver-improved-outcomes-in-all-age-autism-assessment-pathways-guidance-for-integrated-care-boards/) and Appendix B (https://www.england.nhs.uk/long-read/a-national-framework-to-deliver-improved-outcomes-in-all-age-autism-assessment-pathways-guidance-for-integrated-care-boards/#appendix-b-roles-in-an-autism-assessment-team) for more detail. Some clinical professionals may have additional training and qualifications to practice at multi-professional consultant or multi-professional advanced clinical practice level to increase the number and diversity of professions represented in leadership roles. When these include training and assessed capability to conduct components of autism assessments, such as, for example, the autism credential, this may increase capability in relation to the components of assessment a professional can undertake. Some clinical professionals may have some additional non-clinical qualifications (for example diplomas, undergraduate or postgraduate degrees); this does not change their qualification to conduct each component of an autism assessment. Some components of assessment can be undertaken by staff under clinical supervision.
- **Access to clinical supervision.** The type, amount and level of clinical supervision for clinicians and unqualified staff should meet the requirements outlined by relevant professional bodies and training institutions. In service planning, supervising clinicians should be consulted about how much time they need for clinical supervision of both qualified and unqualified staff.
- **A comprehensive workforce.** Autism assessment services should identify the total number of clinical professionals and professionals under clinical supervision needed to deliver a high-quality, comprehensive assessment pathway with capacity to meet anticipated demand for the year ahead, to facilitate progress against wait time policy ambitions while delivering post-assessment support. This should include focused efforts to identify and address any issues with recruitment and retention.
- **Administrative staff capacity that matches demand.** The amount of administrative support should be such that there is capacity to manage tasks including, appointment scheduling, liaison with people and their family/carers, coordination of staff availability, room bookings, acquisition of any assessment tools that require purchasing, ongoing input with preparation of letters and outcome documentation, and data entry into electronic clinical records. Given the limited number of appropriately qualified clinicians available to recruit to longstanding clinical vacancies in autism services, these administrative tasks should not be completed by clinical staff.
- **Informed referrers.** 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. This training is in addition to the Oliver McGowan Mandatory Training on Learning Disability and Autism. (https://www.hee.nhs.uk/our-work/learning-disability/current-projects/oliver-mcgowan-mandatory-training-learning-disability-autism)
- **Time to upskill non-specialist services.** Autism assessment services are hubs of autism expertise. When feasible, these services should deliver training, consultation and liaison, and supervision, to increase the breadth and depth of knowledge about autism across the NHS. This could include, for example, how to identify possible autism, information about the local autism assessment offer, scenarios when an autism assessment referral may not be warranted, and tips about how to support an autistic person receiving treatment for another condition. This upskilling could increase collaborative working, foster opportunities for joint assessment or ensure people waiting for an autism assessment are not excluded from other services.
- **Succession planning.** Services should complete and maintain talent and succession plans in advance of roles becoming vacant, such as when staff go on extended periods of planned leave, are promoted, leave a service or retire. This should include identifying staff who may be ready for promotion and supporting their training and development to attain this. This may reduce instances of dropped capacity when positions are vacant for periods during lengthy recruitment processes.
- **Attractive jobs.** Services should work to ensure staff are actively supported, have fulfilling and varied roles and well-paced development opportunities, such as secondment and training, as this may help reduce common recruitment and retention challenges.

Another important consideration is that there is an appropriately skilled and trained workforce performing commissioning functions for the autism assessment offer. An advanced practice credential about supporting people with learning disabilities, including people with a learning disability who are autistic (https://acppld.csp.org.uk/news/2021-01-08-advanced-clinical-practice-working-people-who-have-learning-disability-andor-autism) and a learning disability and autism version of the principles of commissioning for wellbeing (https://www.skillsforcare.org.uk/Developing-your-workforce/Qualifications/Level-5-Commissioning-for-Wellbeing-Qualification.aspx) are available.

A comprehensive, coherent offer

NHS and local authority organisations should ensure that, collectively, provision is available for people of all ages to have autism assessments, and for there to be support available pre-assessment and following a recent diagnosis of autism (21).

The autism assessment offer in any given ICS area can include different combinations of the following types of services:

- For children, community paediatric teams, such as in child development centres either from within the ICS or from another ICS.
- For children and young people, community child and young people's mental health service either from within the ICS or from another ICS.
- For adults, services providing autism assessments, described in NICE guidelines as a specialist autism team, either from within the ICS or from another ICS.
- Independent services.
- Voluntary, community, and social enterprise services.
- Educational organisations.

Change and uncertainty can be anxiety-provoking for many people, particularly autistic people. It is important that the experience from referral through to discharge from autism assessment services is as continuous and consistent as possible from the perspective of the person being assessed and their family/carers. For example, when feasible, professionals in contact with the person being assessed should remain consistent (that is, when possible, the same professional contacts them or responds to queries), information could be delivered about the stages and processes in the pathway at the outset and in a standardised format, consistent terminology is used throughout the process, and meetings could take place in the same location, or on the same day/time, if the person would prefer this.

Partnership working across an ICS is important to ensure that autism assessment services work efficiently alongside each other and other care and support available across the ICS. Pre-assessment and post-diagnostic support should be available either through statutory services, education, voluntary, community, or social enterprises or independent providers. Links should be strong between a range of local organisations. Contact details for general local health and social care services, education support, regional and national charities, third sector organisations and personalised approaches should be shared and widely available to ensure the maximum amount of support is available.

There are also specific mandated partnership working requirements in the Care Act 2014 that need to be adhered to. In particular, standard 4 of the commissioning for better outcomes route map (https://www.adass.org.uk/policy-documents-commissioning-for-better-outcomes) (41) that supports the implementation of the Care Act 2014.

Accessible

Autism assessments are available to all, irrespective of gender, ethnicity and culture, disability, age, sexual orientation, religion, belief, gender reassignment, pregnancy and maternity or marital or civil partnership status (3).

Reasonable adjustments are required for some people referred to the autism assessment pathway to fulfil this duty to parity in provision. For example, people who have visual or hearing impairments, are minimally verbal, have sensory sensitivities, social communication difficulties, or have no fixed access to a postal address, may find certain modes of communication more difficult to navigate. This includes telephone calls, especially if these are unplanned, with unfamiliar people or involving important discussions. Additionally, some people may find travelling to clinic or being assessed in person overwhelming experiences. Therefore, a flexible approach should be adopted to service provision when feasible, balancing choice and accessibility needs with risk, clinical utility and resource available.

Some people referred for an autism assessment, or their family/carers, do not speak or read fluent English, or they may communicate using sign language. For an autism assessment to be accessible in these instances, an interpreter may be required for a clinical interview, behavioural observational assessment or assessments with family/carers, or the person may be seen by a national service specialising in sign language assessments. Additionally, services need to be accessible for interpreters and should be commissioned by the organisation's interpreter service. If possible, providing continuity for people using the interpreter service is beneficial. Commonly used written resources should be translated into some languages that are common in a service. Asking family/carers to interpret or translate should be avoided, whenever possible.

Health literacy universal precautions

In England, 43% of adults do not have adequate literacy skills to routinely understand health information and 61% of adults do not have adequate numeracy skills in this regard (42). Variation in health literacy plays a powerful role in many health inequalities (43).

Embedding a universal precautions approach in autism assessment pathways avoids stigmatising people with low health literacy. Health literacy can be situational. People with proficient health literacy skills may sometimes have trouble understanding health information, especially when anxious or in an unfamiliar environment.

A universal precautions approach to health literacy should be adopted within the autism assessment pathway. This calls for health care services and professionals to assume that all patients and family/carers can have difficulty understanding information and accessing services. It helps address the negative impact of low health literacy on people and the health system. This means not automatically assuming that people and their family/carers are fully clear about what the pathway comprises, how to access this, what the assessment can entail and the range of potential outcomes. Pathways should therefore:

- Develop clear and accessible written materials, such as webpages, leaflets, or posters, to outline the autism assessment offer in the area, as well as describing the assessment pathway, assessment process and potential outcomes for the specific service, using the NHS standard (https://service-manual.nhs.uk/content/standard-for-creating-health-content) for creating health content.
- Use multiple formats, like easy read, plain English, video or audio, to communicate important information to ensure certain groups (such as people with an intellectual disability or visual or hearing impairment) receive information in accessible formats, using the NHS accessible information standard (https://www.england.nhs.uk/about/equality/equality-hub/patient-equalities-programme/equality-frameworks-and-information-standards/accessibleinfo/).
- Reduce the complexity of the pathway and terminology used to describe it.
- Prepare accessible autism diagnostic reports.
- Educate staff working within the pathway about the importance of health literacy and adoption of a universal precautions approach.

Access is based on clinical need

A guiding NHS principle is that access to an NHS autism assessment is based on clinical need, not a person's ability to pay (3). According to the Who pays framework (https://www.england.nhs.uk/publication/who-pays-determining-which-nhs-commissioner-is-responsible-for-commissioning-healthcare-services-and-making-payments-to-providers/), no necessary assessment, care or treatment should be refused or delayed because of uncertainty or ambiguity as to which NHS commissioner is responsible for funding a person's healthcare provision (44). This includes when a person is accessing an autism assessment outside of the area where they normally reside.

Co-designed by clinicians and people who access the services

Partners in each ICB should listen to and act on the experience and aspirations of communities in the area. There is a statutory duty for ICBs to involve people and communities in developing plans for continual improvement of services (45).

Shared and current concept of autism diagnosis

Several frameworks have been produced to supplement NICE guidelines and support local decision makers in health and social care services, with planning, designing, procuring, and evaluating autism assessment services.

The Core Capabilities Framework for Supporting Autistic People (https://www.skillsforhealth.org.uk/info-hub/learning-disability-and-autism-frameworks-2019/) (46) sets out the skills, knowledge and behaviours that professionals working in any health or social care setting need in order to best support people accessing these services.

Commissioning services for autistic people: A cross-system framework for commissioning social care, health and children's services for autistic people (https://www.skillsforcare.org.uk/resources/documents/Developing-your-workforce/Care-topics/Autism/Commissioning-autism-services/Commissioner-framework-main-FINAL-150621.pdf) (47) outlines a suggested framework to support ICBs to consider what they should analyse, what actions they should undertake and who they should engage with, when making local commissioning decisions about health, education and social care services for autistic people. This states that four areas are important in relation to autism assessment services:

- the level of population needs, including any waiting lists,
- the mix of services already in place (for example, NHS, independent and community and voluntary sector),
- the gaps that are evident in current provision and
- what future input from partners within the ICS is likely to be.

Autism diagnostic criteria have undergone numerous revisions since the first descriptions, due to expanded diagnostic thresholds, more public recognition of possible autistic traits, improved sensitivity of assessment tools and an increase in people previously receiving other diagnoses being diagnosed as autistic (48–51). One result of evolving diagnostic criteria, clinical practices and public ideas about autism, is the potential variation in people's views about what an autism diagnosis is, and currently accepted best practice in assessment for autism. For an autism assessment pathway to function effectively there must be a high degree of trust between all agencies involved (that is, professionals involved in any assessment pathway should have similar and up-to-date conceptualisations of autism). This may mean working to bring different services together to foster shared understanding and to ensure outdated ideas or practices become obsolete.

Transparent

All the information that somebody may need to easily navigate the autism assessment pathway within any ICS should be clearly and transparently communicated in an accessible public forum. This could be, for example, a single webpage that lists, by name, every service that is currently part of an autism assessment offer within an ICS geography, as well as whether there is a single point of access. A summary of the information that should be made publicly available can be found in the identification and referral section (https://www.england.nhs.uk/long-read/operational-guidance-to-deliver-improved-outcomes-in-all-age-autism-assessment-pathways-guidance-for-integrated-care-boards/#stage-1-identification-and-referral) of the operational guidance. This information can be shared in other locations, for example, printed leaflets or cards linking to online content could be shared with professionals who may refer people into an autism assessment pathway or be linked in other online locations, such as the local offer.

To facilitate informed patient choice and to minimise inappropriate referrals, inclusion and exclusion criteria for each service forming part of the autism assessment offer must be clear, including age cut-offs, geographic cut-offs and eligibility based on any other existing co-occurring conditions, for example, moderate intellectual disability.

Details should be clearly communicated about who can make a referral to each service, and what information this must contain. This should also detail the process by which a referral can be made, for example, with a (template) letter or completion of an online form.

When possible, the inclusion criteria, referral mechanisms and information required in the referral process should be standardised across all services that comprise the autism assessment offer, so as to reduce the need to collect the same information more than once if a person is seen by more than one autism assessment service, for example, if they are referred onward.

Subsequent stages of the autism assessment pathway should be adequately detailed, so that the person and their family/carers, and professionals working in other settings, have clarity about what will happen, how, the likely timeframe and the potential outcomes.

Details should be provided about what is offered by each service in the autism assessment offer, for example, if pre-assessment and post-assessment support is available in one service but not another, this should be clearly communicated. Additionally, information should be freely and clearly accessible about the local rules used to inform decision making for people who may seek different stages of their pathway in different services, for example, if a person is diagnosed by one service, they should be able to identify whether they can access post-assessment support at another service. This information should be available to referrers and can inform patient choice decisions.

Be described in, and informed by, national statistical data

The national strategy for autistic children, young people and adults (4) sets a goal for "demonstrable progress on reducing diagnosis waiting times and improving diagnostic pathways". Progress towards these goals will be measured through national statistics.

Regular statistical digests are published by NHS Digital [7] about services providing autism assessments (25,52). These reports draw on statistics of mental health service activity collected through the Mental Health Services Dataset (https://www.datadictionary.nhs.uk/data_sets/clinical_data_sets/mental_health_services_data_set.html#:~:text=The%20Ment (MHSDS). All NHS-funded mental health service providers, including independent sector providers, are required to report details of all NHS-funded mental healthcare activity, including autism assessments, through this collection.

Published data about autism diagnosis services (https://gbr01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fdigital.nhs.uk%2Fdata-and-information%2Fpublications%2Fstatistical%2Fautism-statistics&data=05%7C01%7Crhona.westrip1%40nhs.net%7Cc810fb1feeec411680d008db09f15f4d%7C37c354b285b047f5b report the numbers and progress of referrals to mental health providers where the primary reason for referral is recorded as 'suspected autistic spectrum disorder' (MHSDS table MHS101). Further relevant elements of these records are the start and end dates recorded in the referral table, the records of clinical contacts (table MHS202) including the dates on which these occur, and diagnoses assigned following the referral and assessment (tables MHS604 and MHS605). Additional data relating to autism diagnosis that may be collected, includes the professional groups and occupation codes of professional staff involved (tables and MHS901) and coded standardised assessments (tables MHS606 or MHS607)

Referral rates vary widely between areas of the country, with 20% of ICB areas showing no diagnosis service activity. A further group of providers report no diagnoses of any kind made in the context of autism assessment services. A dashboard has been prepared showing currently available data for services and commissioner areas. Local services and commissioners can request access on the FutureNHS Collaboration Platform (https://future.nhs.uk/NationalAutismStrategyDashboards/view?objectID=40119856) to ensure the accuracy of their data and to compare activity with other providers locally and nationally.

This approach was designed to cover the adult services described in the 2014 autism strategy (https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy). It does not cover autism assessments of children in child development or paediatric services that do not report activity through the MHSDS. Work is ongoing to identify ways to document relevant aspects of these services through the Community Services Data Set and other approaches in relation to hospital-based paediatric services.

How to commission an autism assessment service

Accountability for the commissioning of assessment services resides with the ICB, although it may transfer the commissioning responsibility to another organisation. Organisations new to commissioning with transferred responsibility may need to access support, guidance and information from organisations with more commissioning experience. We have used a model commissioning cycle to help people in commissioning roles to apply the principles of effective autism assessment services at each stage of the cycle. Figure 1 is a schematic diagram of an example of a commissioning cycle.

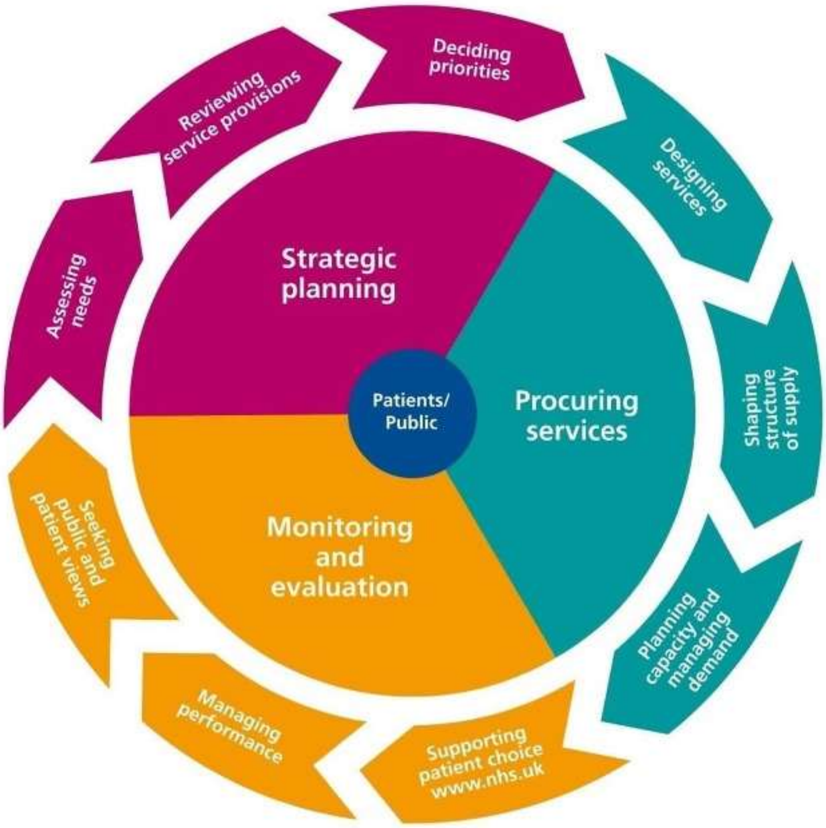


Figure 1. This diagram shows the continuous cycle of activity required to commission services, care and support (53).

Strategic planning

Assessing needs

To plan service capacity, each ICB will need to establish how many people from the population it covers are likely to need an autism assessment during each commissioning cycle. Population health management (https://www.england.nhs.uk/integratedcare/what-is-integrated-care/phm/) tools are useful for assessing need and should be used to provide good quality information with which to make informed commissioning decisions. Some considerations for assessing local demand are outlined in the following sections.

Autism assessment provision is needed throughout the lifespan

The traits that characterise autism emerge during the pre-school years, yet diagnoses given before 2 years of age are less stable than those given after this age (54). Autism is also a lifelong condition. For some people, autism is identified and diagnosed very early in life. However, autistic traits can be subtle and awareness of these is variable, meaning that for some people, traits are not identified or assessed until well into adulthood (55,56).

In each planning round, the total likely assessment need for the year ahead should be estimated alongside a breakdown of needs by age group/service type.

Autism is common; the prevalence of autism in England is estimated to be approximately 1 – 1.7% of the population (57,58). This prevalence means 1,000 – 1,700 people per 100,000 population in every age cohort is estimated to be autistic. Determining assessment capacity requires further consideration. Not everyone who is referred to or assessed by an autism assessment service will be diagnosed as autistic. In two studies, 68% and 84% of adults assessed for possible autism were diagnosed as autistic, respectively (59,60). For children and young people's assessment services approximately 66% of children referred were diagnosed as autistic, and about 75% of those who were assessed were diagnosed as autistic (61). There are also several scenarios when somebody has an autism assessment on more than one occasion. For example, the outcome was not clear when they were first assessed or they were referred for a second opinion, so needs should also be assessed based on some people requiring more than one assessment. Therefore, to reduce wait times in accordance with national policy commitments, a minimum capacity is needed for at least 1.5 – 2.6% of the population to be referred to an autism assessment service and for at least 1.3 – 2.3% of the population to be assessed for autism.

In each planning round, the total likely assessment need for the year ahead should be estimated alongside a breakdown of needs by age group/service type

People in commissioning roles should estimate the likely need for autism assessments (including based on information about waiting lists from every service in their autism offer locality), to inform commissioning decisions. Additionally, information may be used from national autism waiting time statistics and NHS England's dashboard to understand trends in national or neighbouring areas. Information about the range, distribution and mean wait times, as well as any differences for specific groups of people, may also be available in information used to manage contracts with services.

Furthermore, people in commissioning roles should consider historical rates of diagnosis at different ages to inform strategic decisions about the apportioning of local resource to services for autism assessment for people of different ages and with different levels of ability.

Reviewing service provisions

People in commissioning roles are expected to have accurate, current and reliable information about all providers of autism assessment services available in their area. This applies to NHS, independent, or voluntary, community and social enterprise sector organisations. Services should be reviewed with respect to the extent to which NICE clinical guidelines are applied, a Care Quality Commission (CQC) review of services has been undertaken whether services are performing well relative to national and local advisory and statutory guidance. A service self-declaring that it is compliant with NICE guidelines, or a single CQC review, is not sufficient to determine if a service is having a positive impact on the whole autism assessment offer. Additionally, owing to the lack of available evidence at the time that NICE guidelines were last updated, these do not mention telehealth assessment; therefore, providers using telehealth in autism assessment should have quality and safety checks in addition to any claims of NICE compliance.

People in commissioning roles should work with all autism assessment services and wider organisational partners to understand if any autism assessment services contributing to the autism assessment offer may have a detrimental unintended consequence elsewhere in the system. An example is when a service's assessment decisions and diagnostic outcomes are not widely trusted by other services in the area, as this can result in services committing substantial resource re-confirming assessment decisions that, when combined with the cost of the initial assessments, represents a false economy. Another example is that if one service has narrow eligibility criteria, it may disproportionately increase the waiting times for people who meet the exclusion criteria, thereby increasing inequality.

Changes within a service should be considered in terms of its impact on the wider assessment offer. For example, expanding the remit of a service to include a period of psychoeducation, without a corresponding increase in resource, will reduce the number of assessments conducted and increase waiting times.

Reviewing service provision involves:

- Ensuring there is a full understanding of all providers from all sectors in the assessment pathway and what they can offer.
- Working with a diverse range of people with lived experience to fully understand what they want and need from an autism assessment service.
- Making sure that everyone involved in the development of an autism assessment offer is aware of gaps in provision and works together to establish how these can be addressed within the resource available.

- Working with the local authority/authorities to review market position statements and wider market development, and identifying how autism assessment services can be influenced.

It is for every ICB to determine need for its population, so as to commission and procure accordingly. ICBs are also responsible for delivering a range of other services and transformation programmes. A key element of the role of the ICB is to consider assessment of need alongside review of available service provision, and to agree how to prioritise resources so that as much as possible can be provided for the local population.

Deciding priorities

Once need has been assessed, agreeing the priorities in meeting needs with all relevant stakeholders is vital. This should involve identifying gaps in provision, for example, if there are groups of people for whom there is currently no provision, or if there are groups of people for whom the amount of provision currently available is mismatched with demand. The mutually agreed priorities should then inform the subsequent stages in the commissioning cycle.

The local authority/authorities should also be involved to make sure that any wider support is taken into consideration. This should form part of a local area's planning on the use of personalised approaches as set out in NHS England's guidance on personal health budgets (https://www.england.nhs.uk/publication/guidance-on-the-legal-rights-to-have-personal-health-budgets-and-personal-wheelchair-budgets/). This may include, for example, considering if social prescribing and personal health budgets could help in the provision of pre-assessment and post-assessment support. Similarly, this could include agreeing processes for responding to requests for an assessment with a personal health budget. This process should balance the need to meet a person's legal rights with the need to protect the autism assessment offer from negative unintended consequences, for example, untrusted assessment decisions or overwhelming services with good reputations.

Procuring services

Provision of autism assessment services could include a range of providers from the NHS, independent sector and voluntary and community sector. People in a commissioning role are expected to work across the ICS with a range of providers, including people who use services being designed. An explanatory note is available in relation to the application of the procurement, patient choice and competition regulations (https://www.england.nhs.uk/procurement-patient-choice-and-competition-regulations/) in the context of the new health and care arrangements, since 1 July 2022.

Designing services

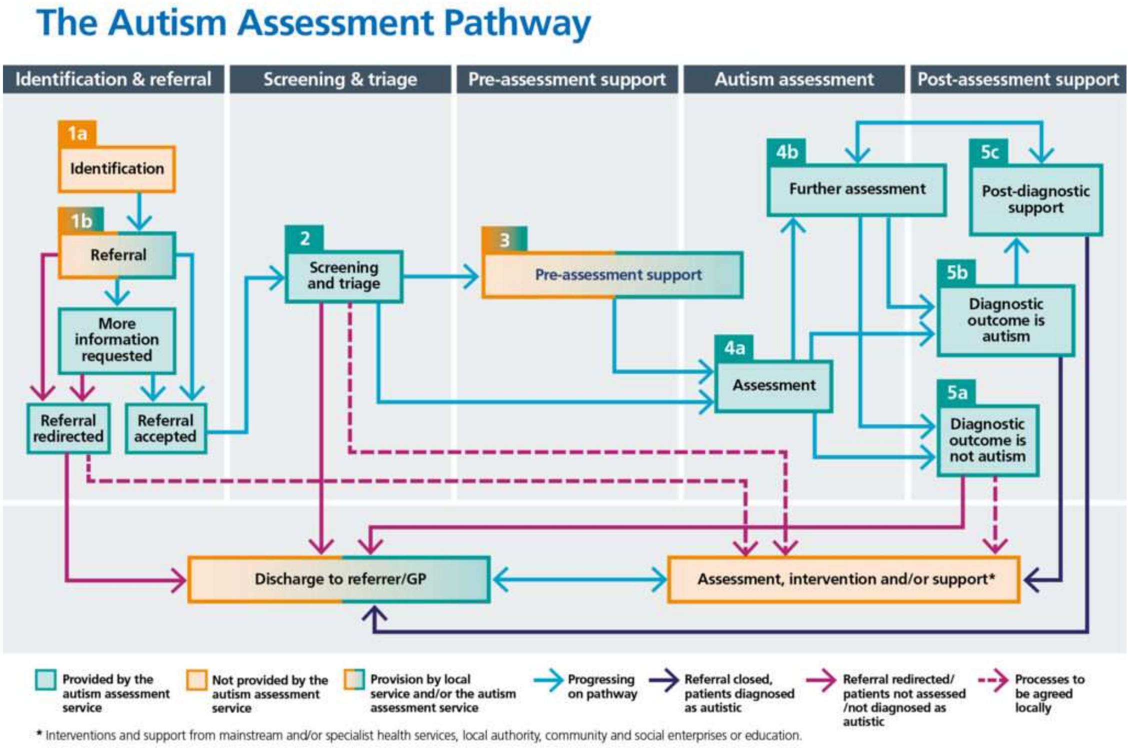
The accountable ICB needs to ensure that professionals in a commissioning role work with partners so that services are designed and delivered in line with agreed priorities. This could involve re-shaping service design and delivery, or developing and procuring new services within the autism assessment offer. For example, re-shaping may be required to improve the reported experiences of the person being assessed and their family/carers, to re-distribute capacity, or to enable providers to deliver support in addition to an assessment outcome decision.

Shaping structure of supply

Once people in a commissioning role decide on what provision needs to be commissioned, they should develop clear and detailed specifications in co-production with people, family/carers and clinicians that set out precisely what is required from providers.

The autism assessment pathway is considered to have five stages, shown in Figure 2 (https://www.england.nhs.uk/long-read/a-national-framework-to-deliver-improved-outcomes-in-all-age-autism-assessment-pathways-guidance-for-integrated-care-boards/#fig2) and outlined below:

1. identification and referral
2. screening and triage
3. pre-assessment support
4. autism assessment
5. post-assessment support



(https://www.england.nhs.uk/wp-content/uploads/2023/04/Autism-Pathway.jpg)

Figure 2. The five stages of the autism assessment pathway

Planning capacity and managing demand

People in a commissioning role need to give regard to the capacity required to meet the assessed demand. This includes planning across a range of providers including NHS services, voluntary and community organisations and the independent sector. In the points below, we have provided some information that may be helpful when doing this.

Autism assessment demand capacity modelling needs to continuously plan for changing demand.

When planning capacity to meet predicted demand for an autism assessment offer, attention must be given to historical diagnostic rates of specific groups in each area to correct for historical inequalities. There has been significant variation in the prevalence of autism across sex, age, ethnicity, socioeconomic status, English language fluency and geographical location (62).

There has been exponential increase in demand for autism assessment in the twenty-year period between 1998 and 2018. In this period, there has been a 787% increase in recorded prevalence of autism diagnoses in a sample of GP records in the UK (63). There was a sharp rise throughout the 1990s that appeared to plateau in the 2000s (64,65), before increasing again in the 2010s, with the most pronounced rise among females, adults and people without a co-occurring intellectual disability (63).

Plan capacity by recognising that autism assessment is time consuming.

Autism assessment capacity modelling should recognise that autism assessment, by its nature, is time intensive. One UK-based survey of autism assessment teams for children put a conservative median estimate of time required per person assessed at 13 hours of clinician time (66). Capacity modelling should also reflect that the time taken to assess for autism is variable from person to person depending on a range of factors, such as gathering information about differential or co-occurring conditions, or a person's history. Capacity planning should therefore estimate the proportion of referrals for whom a standard or an enhanced assessment may be warranted. There should be flexibility in resource allocation such that a clinician can increase the time needed to assess a person or request input from another member of the multidisciplinary team if required.

Planning capacity for post-assessment support improves autistic people's mental health and may reduce the amount of mental health capacity required.

Newly diagnosed autistic people and their family/carers can experience an adjustment period and may take time to come to terms with their diagnosis (19,67). Brief packages of support delivered shortly after diagnosis are found to improve autistic people's mental health (68). Post-assessment support can help people form positive autistic identities, connect with the autistic community, and understand their diagnosis. This can also involve practical advice and sharing of high-quality information to protect people against widespread autism misinformation.

Autism assessment pathways must respect a person's right to choose about interventions.

For a person to be diagnosed as autistic, a clinician must determine they have significant difficulties in their life. Some autistic people and some family/carers want safe and effective interventions to improve some skills and abilities that overlap with diagnostic criteria, such as language and communication (11). Some autistic people view being autistic as a positive or neutral part of their identity that does not require intervention. Pathways should be designed to respect the person's choice in relation to intervention. Capacity should be planned with flexibility, so that it can respond to differing proportions of people seeking interventions at different times.

Assessment services must be delivered by specialist multidisciplinary teams

Assessment of autism involves consideration of differential diagnosis, whereby other possible conditions that could explain traits and difficulties presented, need to be diagnosed or ruled out. To comply with clinical guidelines, assessments must be conducted by clinical professionals who are members of a multidisciplinary team, clinicians from certain professional disciplines may conduct single clinician assessments if they judge that a consensus decision is not required (2,39). The multidisciplinary team requires the capabilities to efficiently gather information, interpret wide and varied sources of information, navigate subjective and divided interpretations, and work efficiently with other services when joint working is appropriate, such that decisions about diagnostic outcomes are consistently arrived at with a high degree of confidence. Assessment involves a degree of subjectivity, especially when a person is on the borderline of the diagnostic boundary, or when co-occurring diagnoses are present (69). Each service within an autism assessment offer needs to be confident in the diagnostic decisions made by other services. Therefore, shared specifications should be used to determine an appropriate multidisciplinary team configuration, including a protocol for which clinicians are able to make final diagnostic decisions.

Monitoring and Evaluating

Supporting patient choice

Patient choice is an important part of the NHS Constitution (https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england). This recognises the right for all patients to make informed choices about the services commissioned by the NHS and information to support decisions about these choices. In addition, Schedule 2M of the NHS Standard Contract (https://www.england.nhs.uk/publication/full-length-nhs-standard-contract-2022-23-particulars-service-conditions-general-conditions/), which is the development plan for personalised care, should be used to set out actions for people in commissioning roles or providers, to ensure that people have choice about how their autism assessment, if clinically indicated, is delivered.

People commissioning local autism services should note that they will need to:

- Provide information about the healthcare services available, locally and nationally.
- Offer easily accessible, reliable and relevant information in a form people can understand and provide support to use it.
- Set out the national determined choices available; including when there are legal rights, ensuring these are considered and built into the pathways, and are explained in NHS Choice Framework (https://www.gov.uk/government/publications/the-nhs-choice-framework).

Managing performance

People in a commissioning role need to review and monitor the whole autism assessment market in their area in terms of how providers are performing. This should include assessing performance against current or past contracts. The clinical quality of a service should be assessed, for instance, compliance with the NICE clinical guidelines, as well as this framework and associated operational guidance (https://www.england.nhs.uk/long-read/operational-guidance-to-deliver-improved-outcomes-in-all-age-autism-assessment-pathways-guidance-for-integrated-care-boards/). CQC regulation reports should be reviewed. For services not registered with the CQC, other sources of information should be used to determine if there is parity of regulation to CQC, and if not, a process should be determined to ensure this is communicated to prospective patients. Patient and family/carer satisfaction and value for money should also be considered.

All the above performance metrics should be appraised holistically. Prioritising a single performance metric may be at the detriment of other metrics. That is, one provider prioritising, for example, wait times could have a negative effect on, for example, adherence to clinical guidelines, quality or patient experience. This may have knock on effects elsewhere in the autism assessment offer, for example, if one provider's decisions are routinely not trusted because of low fidelity to clinical guidelines, this can result in additional resource from other providers to review a diagnostic decision.

Seeking public and patient views

People and their family/carers have the right to provide feedback on their thoughts and experiences of accessing the autism assessment offer. There should be a regular mechanism by which feedback is reviewed and used by decision makers throughout the commissioning pathway. Table 2 outlines several ways to involve people to ensure that the autism assessment offer reflects what is needed in the area.

Table 2. Involving people and families.

Ways to involve people and families	Resources
Meet as an autism strategy group to make local decisions about service provision informed by NICE guidelines, with representation from different stakeholder groups	NICE guidelines (https://www.nice.org.uk/guidance/cg142)
Employ people with lived experience to work with you	Employing people with a learning disability, autistic people and family carers (https://www.england.nhs.uk/learning-disabilities/about/get-involved/involving-people/employing-people-with-a-learning-disability-autism-or-both-and-family-carers/)
Set up a co-production group or commission local groups to help shape and monitor services	Co-production resources (https://www.england.nhs.uk/learning-disabilities/about/get-involved/involving-people/making-information-and-the-words-we-use-accessible/)
Run focus groups that enable people to share their views and experiences about the service and act on concerns and complaints in services	Making meetings accessible (https://www.england.nhs.uk/learning-disabilities/about/get-involved/involving-people/making-meetings-accessible/) Information about Ask, Listen, Do (https://www.england.nhs.uk/learning-disabilities/about/ask-listen-do/)

Appendix A. How we developed this guidance

Authors who contributed towards the framework and operational guidance.

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Research evidence

Table 3. Research commissioned by NHS England to inform the development of this framework and operational guidance.

Title	Organisation(s)	Output(s)

A Realist Evaluation of autism service delivery: Which diagnostic pathways work best, for whom, when, and at what cost?	• Sussex Community NHS Foundation Trust Newcastle University • University of Kent • Cambridge and Peterborough NHS Trust • Council for Disabled Children • Autistica	• Unpublished report for NHS England • Journal article in BMJ Open (70)
Post-diagnostic psychoeducation for recently diagnosed autistic adults	• University of York	• NHS England commissioned report, available on University of York website (https://www.york.ac.uk/spru/projects/psychoeducation-autism-diagnosis/)
Post-diagnostic psychoeducation for recently diagnosed autistic teenagers	• Autistica • King’s College London	• Unpublished report for NHS England
“Stepped Up” Care models after immediate post-diagnostic support	• University of Manchester	• Unpublished report for NHS England • Journal article in The Lancet Child & Adolescent Health (71)
Assessments of needs during autism diagnosis	• University of Bath	• Unpublished report for NHS England
Ensuring best principles in telehealth for provision of mental and physical health care for autistic people	• Autistica • University College London	• Journal article in Autism (72)
Use of digital technology in autism assessment	• King’s College London	• Unpublished report for NHS England • Journal article in Frontiers in Psychiatry (27) • Journal article in JMIR Mental Health (73)
Use of stigma intervention for parents of children recently diagnosed as autistic	• University of Bedfordshire	• Unpublished report for NHS England

Additionally, the authors reviewed peer-reviewed literature, national policies, clinical guidelines and statutory guidance when preparing this framework.

Stakeholders

Stakeholders who contributed to the development of this framework and operational guidance by participating in consultation groups or providing comments on previous drafts are listed below, in alphabetical order.

- Sandy Bering – Strategic Lead Clinical Commissioner (Greater Manchester Integrated Care Board)
- Diana Boyd – Family Carer Advisor (NHS England)
- Professor Tony Charman – Professor of Clinical Child Psychology and Consultant Clinical Psychologist (King’s College London, and South London and Maudsley NHS Foundation Trust)
- Dr Laura Crane – Associate Professor (University College London)
- Dr Conor Davidson – Consultant Psychiatrist and Royal College of Psychiatrists Autism Champion (Leeds and York Partnership NHS Foundation Trust and the Royal College of Psychiatrists)
- Dr Sophie Doswell – Consultant Clinical Psychologist (South London and Maudsley NHS Foundation Trust)
- Dr William Farr – Senior Research Fellow and Lecturer in Child Development (Sussex Community NHS Foundation Trust and the University of Cambridge)
- Professor Jonathon Green – Professor of Child and Adolescent Psychiatry (University of Manchester)
- Georgia Harper – Policy Manager (Autistica)
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- Dr Ian Male – Consultant Community Paediatrician, and Honorary Senior Lecturer and Workforce Officer (Sussex Community NHS Trust, and Brighton and Sussex Medical School)
- Adam Micklethwaite – Director (Autism Alliance)
- Professor Mark Mon-Williams – Professor of Psychology and Director of Research Centre (Centre for Applied Education Research, Bradford Institute of Health Research)
- Joseph Nettleton Burrows – Policy and Public Affairs Manager (National Autistic Society)
- Professor Jeremy Parr – Professor of Paediatric Neurodisability (Newcastle University, Newcastle Tyne and Wear NHS Foundation Trust, and Cumbria Northumberland Tyne and Wear NHS Foundation Trust)
- Dr Venkat Reddy – Neurodevelopmental Paediatrician and Clinical Director (Royal College of Paediatrics and Child Health)
- Professor Jacqui Rodgers – Professor of Psychology and Mental Health (Newcastle University)
- Professor Ashok Roy – Clinical Advisor in Learning Disability and Autism, and Consultant Psychiatrist and Associate Medical Director (Health Education England, and Coventry and Warwickshire Partnership NHS Trust)
- Dr Marion Rutherford – Speech and Language Therapist, and (Scottish) National Autism Implementation Team (NAIT) Lead (Queen Margaret University, Scotland)
- Professor Andrew Whitehouse – Professor of Autism (Telethon Kids Institute and the University of Western Australia)
- Dr Karen Horridge – Visiting Professor of Childhood Disability and Development, University of Sunderland

Appendix B. Roles in an autism assessment team

Table 4. Qualified clinical professionals in an autism assessment team

Discipline	Roles	Single clinician assessment	Conduct triage	Conduct clinical interview	Conduct standardised assessments	Consensus MDT assessment	Pre- and post-assessment support and liaison
Medical	Paediatrician (a)	✓	✓	✓	✓	✓	✓
	Psychiatrist	✓	✓	✓	✓	✓	✓
Nursing (b)	Children’s nurse (a)	✕	✓	✕	✓	✓	✓
	Learning disability nurse (b)	✕	✓	✓	✓	✓	✓
	Mental health nurse (b)	✕	✓	✓	✓	✓	✓
	Health visitor (a)	✕	✓	✕	✓	✓	✓
Psychology (c)	Clinical psychologist	✓	✓	✓	✓	✓	✓
	Educational psychologist (a)	✕	✓	✕	✓	✓	✓
	Forensic psychologist	✕	✓	✓	✓	✓	✓
	Counselling psychologist	✕	✓	✓	✓	✓	✓
Allied Health	Speech and language therapist (b)	✕	✓	✕	✓	✓	✓
	Occupational therapist (b)	✕	✓	✕	✓	✓	✓
	Physiotherapist (d)	✕	✕	✕	✕	✓	✕
	[a] In children and young people’s services [b] Professionals practicing at multi-professional advanced clinical practice or consultant level may undertake some additional leadership roles within autism assessment services or within the ICB [c] Some Practitioner Psychologist titles are regulated. This means it is a legal requirement to have certain qualifications or experience to undertake certain roles and use certain titles. The qualified psychologist roles in an autism assessment service are regulated more information about understanding the regulation of psychologists is available here (https://www.hcpc-uk.org/news-and-events/blog/2023/understanding-the-regulation-of-psychologists/) [d] Physiotherapists are sometimes part of the team in a child development centre and may conduct some movement/co-ordination assessments for children receiving a general developmental assessment, but would not otherwise be involved in the assessment of autism						

Table 5. Unqualified and non-clinical roles that may be in an autism assessment service or team

Discipline	Roles	Conduct a single clinician assessment	Conduct triage	Conduct a clinical interview	Conduct standardised assessments	Participate in consensus MDT assessment	Pre- and post-assessment support and liaison
Medical	Trainee psychiatrist	✕	supervised	supervised	supervised	✓	supervised
	Trainee paediatrician (a)	✕	supervised	supervised	supervised	✓	supervised
Nursing (b)	Trainee children's nurse (a)	✕	supervised	supervised	supervised	✓	supervised
	Trainee learning disability nurse	✕	supervised	supervised	supervised	✓	supervised
	Trainee mental health nurse	✕	supervised	supervised	supervised	✓	supervised
	Trainee health visitor (a)	✕	supervised	supervised	supervised	✓	supervised
Psychology	Trainee clinical psychologist	✕	supervised	supervised	supervised	✓	supervised
	Trainee educational psychologist (a)	✕	supervised	supervised	supervised	✓	supervised
	Trainee forensic psychologist	✕	supervised	supervised	supervised	✓	supervised
	Trainee counselling psychologist	✕	supervised	supervised	supervised	✓	supervised
	Assistant psychologist	✕	supervised	✕	supervised	✓	supervised
	Clinical associate in psychology	✕	supervised	✕	supervised	✓	supervised
Allied Health	Trainee speech and language therapist	✕	✕	✕	✕	✓	supervised
	Trainee occupational therapist	✕	✕	✕	✕	✓	supervised
	Trainee physiotherapist (c)	✕	✕	✕	✕	✓	✕
Other	Social worker	✕	✕	✕	✓	✓	✓
	Nursery nurse (a)	✕	✕	✕	✓	✓	✓
	Teacher (a)	✕	✕	✕	✕	✓	✓
	Special Educational Needs Coordinator (a)	✕	✕	✕	✕	✓	✓
	Neurodevelopmental /autism assessment practitioner (b)	✕	✕	✕	supervised	✓	supervised
	Autism peer support worker	✕	✕	✕	✕	✕	supervised

[a] In children and young people's services

[b] This is a job description used in some services for staff employed to conduct components of autism assessments. People in these roles should always operate under the supervision of a fully qualified clinician, including people with clinical qualifications or professional registrations not listed in Table 5, for example, psychotherapists, counsellors, social workers and teachers.

[c] Physiotherapists are sometimes part of the team in a child development centre and may conduct some movement/co-ordination assessments for children receiving a general developmental assessment, but would not otherwise be involved in the assessment of autism.

Appendix C. Glossary

Table 6. This shows the abbreviations and definitions used throughout this document.

Abbreviation	Definition
ADHD	Attention deficit/hyperactivity disorder
ASD	Autism spectrum disorder
CQC	Care Quality Commission
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, fifth edition
ICB	Integrated Care Board
ICD-11	International Statistical Classification of Diseases and Related Health Problems, eleventh edition

ICP	Integrated Care Partnership
ICS	Integrated Care System
MHSDS	Mental Health Services Dataset
NICE	The National Institute for Health and Care Excellence

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Footnotes

[1] NHS England recognises that some autistic people dislike the presence of the word disorder in the official diagnostic category and that the terminology used is considered by some to be excessively negative. Nevertheless the ICD is the mandated diagnostic information standard in the NHS in England and the official diagnosis given by any clinical professional on behalf of the NHS must be as described, and named, in the ICD manual.

[2] This includes sensory sensitivity, including hypo- and hyper-sensitivity and sensory seeking behaviour.

[3] Genetic or other medical tests may be required to identify if a genetic syndrome or other medical condition explains some of the traits that led to a referral, but there are no diagnostic biomarkers for autism itself.

[4] The Health and Care Professions Council maintains a register of professionals who have designated titles that are protected by law. Professionals who would not be appropriate members of an autism assessment team are also included in the register, for example, sports and exercise psychologists or art therapists.

[5] Evidence-based recommendations to guide commissioning and clinical decision making that have been developed by independent committees of professional, research and lay experts, and consulted on by a wide range of stakeholders

[6] A tool to measure how well a service is performing, identify areas for improvement and to guide regulatory review oversight processes by the Care Quality Commission (CQC).

[7] NHS Digital merged with NHS England in February 2023. While previous statistical digests have been published by NHS Digital, and will be referenced as being authored by NHS Digital, future reports will be produced by NHS England.

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