



# Meeting the healthcare needs of adults with a learning disability and autistic adults in prison

**Guidance on the design and delivery of prison healthcare for adults with a learning disability and autistic adults accessing healthcare services whilst in prison**

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## Equality and Health Inequalities Statement

Promoting equality and addressing health inequalities are at the heart of NHS England’s values. Throughout the development of the policies and processes cited in this document, we have:

- Given due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act, 2010) and those who do not share it; and
- Given regard to the need to reduce inequalities between patients in access to, and outcomes from healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities.

# 1. Introduction

This guidance is for healthcare commissioners, providers and staff operating within the adult prison estate to assist them with the planning and delivery of healthcare for adults with a learning disability and autistic people<sup>1</sup> accessing healthcare services in prison. Please see Appendix 3 for definitions.

The guidance is designed to support the implementation of the national prison healthcare service specifications and other relevant national strategies and standards. It also provides helpful background information and resources for prison healthcare commissioners and providers.

People with a learning disability are significantly more likely to experience health inequalities, including certain physical and mental health conditions, and are less likely and less able to access healthcare services.<sup>2</sup> Autistic people are also more likely to experience certain physical health problems,<sup>3</sup> problems accessing healthcare<sup>4</sup> and certain mental health conditions.<sup>5</sup>

The pandemic has both highlighted and exacerbated the health inequalities experienced by people with a learning disability and autistic people. There has been a higher rate of death from COVID-19 for people with a learning disability, at a younger age than the general population. The pandemic has had a disproportionate impact on people's mental health and wellbeing, particularly for autistic young people, as the restrictions put in place changed their routines and changed or limited the care and support they received.

The [NHS Long Term Plan](#) recognises the crucial role of healthcare services in helping people with a learning disability and autistic people lead longer, happier and healthier lives. The Government also recently published the new all-age [autism strategy](#). This national focus on people with a learning disability and autistic people brings expectations for all healthcare services, including those operating within the prison environment. Prison healthcare services have an important role and opportunity in reducing the health inequalities experienced by people with a learning disability and autistic people. Services need to be fully accessible to all, with robust

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<sup>1</sup> The term autism/autistic people is used throughout this document as shorthand for all autistic spectrum conditions, including Asperger's syndrome (unless otherwise stated).

<sup>2</sup> [www.ndti.org.uk/resources/publication/the-health-equality-framework-and-commissioning-guide1](http://www.ndti.org.uk/resources/publication/the-health-equality-framework-and-commissioning-guide1)

<sup>3</sup> [www.nhs.uk/conditions/autism/other-conditions/](http://www.nhs.uk/conditions/autism/other-conditions/)

<sup>4</sup> [www.ncbi.nlm.nih.gov/pmc/articles/PMC7373620/](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC7373620/)

<sup>5</sup> [www.ncbi.nlm.nih.gov/pmc/articles/PMC4860203/](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4860203/)

care pathways in place that form part of a whole-prison approach to meeting people's needs.

The vision for Integrated Care Systems (ICS) is the delivery of NHS care and improvements for patients as set out in the NHS Long Term Plan. The intention is to provide the right environment for the transformation of care and services to deliver maximum benefits for patients, with the triple aim of better health for everyone; better care for all patients; and efficient use of NHS resources, both for local systems and for the wider NHS.

The proposal, following the publication of the Integration and Innovation [White Paper](#) and pending changes, is that NHS England and NHS Improvement will retain accountability for Health and Justice commissioned services (which includes prison healthcare), with the option to jointly (co-)commission or delegate, if ICS systems and local pathways are established and effective.

Services providing prison healthcare will continue to operate under a suite of national guidance and the governance structures and service provision will be delivered to national specification requirements. However, pathways of care will be further enhanced and developed to meet the needs of the local population.

Some regions already have good pathways in place to improve care. Support for people with a learning disability and autistic people is provided at all relevant stages of the criminal justice system, forensic and community settings. The ICS developments will further enhance these pathways to ensure consistency of provision, equal access to services and 'parity of esteem' (whereby mental health is valued equally with physical health).

## 2. National expectations

The [NHS Long Term Plan](#) (2019) prioritises a reduction in health inequalities for people with a learning disability and autistic people. It endorses timely and appropriate health checks, better staff awareness of the relevant health inequalities and calls for improvements in the relevant community services.

A refresh of the [cross-Government autism strategy](#), which is a statutory requirement set out in the Autism Act (2010), was published in July 2021. As part of this work, partners from across health and justice settings are called upon to work

collaboratively to help ensure improvements in the support for, and wellbeing of, autistic people within the criminal justice system.

Also recently published is a [review of evidence on neurodiversity in the criminal justice system](#), by the respective criminal justice inspectorates. This review looked at current practices concerning the screening, support and training/programmes available for people with a learning disability and autistic people (as well as other neuro-diversities) and gives recommendations for both Government and local services.

NHS England and NHS Improvement's [prison health primary care service specification \(2020\)](#) and [prison health integrated mental health service specification \(2018\)](#) both include expectations concerning people with a learning disability and autistic people accessing services. These specifications have some overlapping outcomes and both make clear reference to the need for joined up, collaborative work between primary and secondary care health services on behalf of these groups of people.

The prison health primary care service specification includes the objective: "Patients with a learning disability, autistic people, people with acquired brain injury or other cognitive impairments/neuro-disabilities can fully access healthcare services and have their healthcare needs met". This objective includes specific outcomes for services that relate to the care of people with a learning disability and autistic people (see Appendix 1). Services should be familiar with the [primary care service specification](#), which includes this objective (page 35) and provides recommended actions and steps for the objective's outcomes.

The prison health integrated mental health service specification refers to people with a learning disability and related vulnerabilities (which includes autistic people) throughout. It states the [prison health] "integrated mental health team are expected to have a comprehensive understanding of people with a learning disability and other vulnerabilities."

It outlines specific areas the team will lead on regarding people with a learning disability ([see page 28 of the specification for full details](#)). This includes their role in identification, ensuring appropriate pathways, raising awareness, joint working with colleagues within the establishment, using accessible communication and health checks (such as Health Action Plans), as well as working closely with the primary care team to keep a register of people and sharing information, as appropriate.

## 3. Guiding principles

The following guiding principles, suggested by relevant stakeholders, relate to working with people with a learning disability and autistic people within prison healthcare settings.

**A rights-based approach to care:** Upholding a person's human rights and values throughout, including to fairness, equality, dignity, respect and autonomy.

**Person-centred care:** The wishes of a person with a learning disability or an autistic person need to be upheld and respected and kept firmly at the 'centre of things' which concern them. The person in question, plus the people closest to them (where possible and where this is the person's preference), needs to be involved in all relevant decision-making and planning.

**Early identification and appropriate support:** People with a possible learning disability or who may be autistic need to be identified as early as possible and appropriately supported to have equal access to services and equal opportunity to progress in prison. It is recommended that healthcare staff encourage people to disclose any conditions or needs, promoting the benefits of doing so.

**Informed workforce:** Care needs to be delivered by professionals and allied staff who are suitably competent and trained, well informed, well led, properly supervised and operating within clear quality and clinical governance frameworks for the safe and effective delivery of care to these groups of people.

**Working in partnership:** Close joint working between all types of healthcare services is imperative for a co-ordinated approach to meeting the health needs of people with a learning disability and autistic people. Similarly, healthcare services need to work closely with all other agencies and departments in the prison to develop the whole-prison approach required to meet the needs of this group of people.

In 2015, NHS England published a [model for community services](#) that are provided to people with a learning disability and autistic people who display behaviour that challenges, including behaviour that is attributable to a mental health condition. This model has five 'golden threads' to help uphold the human rights of people using services.

These can also be used to help design any provision for people with a learning disability and autistic people receiving healthcare within prison. These include:

- **quality of life** – people should be treated with dignity and respect
- **keeping people safe** – people should be supported to take positive risks while ensuring that they are protected from potential harm
- **choice and control** – people should have choice and control over their own health and care services; it is they who should make decisions about every aspect of their life
- **support and interventions** – people should receive support and interventions that are always provided in the least restrictive manner
- **equitable outcomes** – people should have comparable outcomes to those of the general population, from services addressing the determinants of health inequalities outlined in the [Health Equalities Framework](#).

## Mencap’s ‘Getting it right’ charter

Mencap, a charity working for people with a learning disability, worked with the respective royal colleges<sup>6</sup> to produce a charter for healthcare staff. It encourages staff to sign up to a pledge called [‘Getting it right’](#) for people with a learning disability. The values of the charter include:

- all people with a learning disability have an equal right to healthcare
- all healthcare professionals have a duty to make reasonable adjustments to the treatment they provide to people with a learning disability
- all healthcare professionals should provide a high standard of care and treatment and value the lives of people with a learning disability.

## The National Autistic Society’s ‘autism accreditation’ process: healthcare principles

Healthcare services based within those prisons undertaking the National Autistic Society’s [autism accreditation process](#) are expected to uphold the following recommended practices:

- **Commitment and consultation:** a commitment within the prison to improving support and outcomes for autistic people (including training) and consulting with autistic people.
- **Understanding the autistic person:** looking at whether information is gathered about the person and their healthcare needs; ensuring information is provided in a way which the person understands and that any co-morbid conditions are considered.

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<sup>6</sup> The respective Royal Colleges of Psychiatrists, Paediatrics and Child Health plus the Chartered Society of Physiotherapists and the College of Occupational Therapists.



- **Enabling the autistic person:** the ways autistic people are enabled to attend and engage with healthcare services; ensuring staff consider adaptations to the environment and enable autistic people to communicate their preferences and needs.
- **Positive outcomes for autistic people:** recording information about autistic people and using this to make reasonable adjustments and improvements to healthcare services and each person's experience of those services.

## 4. The role of healthcare services

It is important that people with a learning disability and autistic people in prison are known to healthcare. However, a person's learning disability or autism is not to be medicalised and does not require clinical treatment.

It is recommended that healthcare services plan how to meet the physical and mental health needs of these groups of people. This includes providing culturally appropriate services, promoting equality and addressing health inequalities, supporting people to be healthy, to communicate, to understand what is happening and to access and engage with services or any healthcare treatments.

Healthcare services will need to screen people for a learning disability or autism when required. See Section 17 for more information. The appropriate reasonable adjustments (as per the [Equality Act](#)) should be provided for anyone with any impairment, behaviour or characteristic that impacts their everyday life, regardless of whether they have a confirmed diagnosis. These could include adapted forms of communication, Easy Reads, memory aids, extra time and support, and environmental changes, depending on the needs of an individual. Any known reasonable adjustments should be recorded in a person's health records and flagged.<sup>7</sup>

Healthcare services are expected to have specific learning disability and autism care pathways in place that cover screening, support, assessments and referrals. See Section 13 for more information. This also involves working closely with other agencies within the prison to ensure that people are appropriately supported as part of a prison-wide approach.

It is strongly recommended that services employ a full or part-time learning disability nurse/practitioner, whenever possible. See Section 5.1 for more information. The

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<sup>7</sup> <https://digital.nhs.uk/services/reasonable-adjustment-flag>

[prison health primary care service specification](#) recommends that all healthcare services nominate a learning disability and autism healthcare champion. This person would advocate for the needs of these groups of people. See Section 5.3 for more information. All healthcare staff are expected to have a basic awareness of learning disabilities and autism.

Services are advised to familiarise themselves with [Equal access, equal care; guidance for prison healthcare staff treating people with learning disabilities](#), which outlines all relevant community-based healthcare approaches and applies them to a prison healthcare setting.

Skills for Health have produced [core capability frameworks](#) for any staff working with people with a learning disability and autistic people. These describe the skills, knowledge and behaviours required when working with these groups of people. As part of this work, government has commissioned a programme of mandatory awareness training for all health and social care staff.<sup>8</sup>

## 5. Specialist roles within prison healthcare

### 5.1 Learning disability nurses/practitioners

Prison healthcare services need access to learning disability and autism expertise. It is strongly recommended that prisons employ a full or part-time learning disability nurse/practitioner, whenever possible, based within primary or secondary prison health services.

A learning disability practitioner takes a person-centred approach to supporting the health, wellbeing and social inclusion of people with a learning disability (and typically also autistic people).<sup>9</sup> With the support of their managers, practitioners can support other healthcare staff and the service to meet the healthcare needs of these groups of people.

Practitioners also typically have links with local community learning disability and autism services. They can advise or train other prison agencies, including on how to manage certain people, in particular those with behaviour that challenges. Some

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<sup>8</sup> [www.hee.nhs.uk/our-work/learning-disability/oliver-mcgowan-mandatory-training-learning-disability-autism](http://www.hee.nhs.uk/our-work/learning-disability/oliver-mcgowan-mandatory-training-learning-disability-autism)

<sup>9</sup> [www.healthcareers.nhs.uk/explore-roles/nursing/roles-nursing/learning-disability-nurse](http://www.healthcareers.nhs.uk/explore-roles/nursing/roles-nursing/learning-disability-nurse)

community providers also have learning disability nurse consultants that can provide more strategic guidance and expertise if required.

The skill set and helpful changes that a learning disability nurse/practitioner brings to a prison are also likely to benefit many others in that setting, specifically certain vulnerable groups such as neurodivergent individuals and people with communication difficulties.

Examples of activities that a clinical learning disability nurse/practitioner could undertake include:

- advising other healthcare staff on the latest specialist tools and interventions used in community healthcare settings, including health action planning
- ensuring the screening tools used by healthcare are credible
- raising awareness of the barriers to accessing healthcare services and other support services and helping to address these
- delivering awareness training in the health issues and inequalities people with a learning disability and autistic people often experience
- delivering general learning disability and autism awareness training to other prison agencies
- working with other prison agencies to gain the National Autistic Society's prison autism accreditation
- attending safer custody meetings, case conferences and other multidisciplinary meetings
- delivering communication training to healthcare services and potentially also prison wide
- advising healthcare and other agencies on communication adaptations for people to ensure information is accessible
- working directly with people to ensure they are being supported appropriately by all prison agencies and receiving adapted treatments for any specific physical or mental health issues, where appropriate/possible
- supporting other healthcare and prison staff to work with specific people with a learning disability and autistic people
- helping to ensure there is access to advocacy, where appropriate/possible
- contacting family members, carers and community support staff (with consent) to gain useful insights and background information that will be helpful in a person's care or treatment

- securing specialist expertise when required (e.g. for diagnostic assessments), via established local pathways.

There is a network of learning disability nurses, practitioners and nominated leads working within prison healthcare services, with an online platform that provides useful resources, a forum and also networking events. See Appendix 5 for more information.

## 5.2 Speech and language therapists

Speech and language therapists are in post in some prisons or can be brought in, as required. For any person in prison with communication needs they can assess the needs, produce support plans and help to deliver therapeutic interventions.<sup>10</sup> They can also advise other staff working with a person on how best to communicate and recommend useful tools and resources. People with a learning disability and autistic people in prison are likely to require assistance with their communication.

## 5.3 A learning disability and autism healthcare champion

The [prison health primary care service specification](#) recommends that services nominate a learning disability and autism healthcare champion. Champions advocate for the needs people with a learning disability and autistic people across all healthcare services in a prison and remind all staff and services of their responsibilities, both legal and those in the relevant service specifications.

Champions could be based in any healthcare team and one person could fulfil this role or it could be shared. Where a learning disability nurse/practitioner or a speech and language therapist is already employed, it is anticipated they would be best placed to take on the champion role.

Examples of activities a champion may be involved in include:

- promote the relevant outcomes of prison healthcare service specifications
- make healthcare settings more accessible for people with a learning disability
- make healthcare settings 'autism friendly'
- find resources, tools and templates and share these with the rest of healthcare
- check that Easy Read versions of all written materials are available
- promote communication guidance and tools

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<sup>10</sup> [www.rcslt.org/speech-and-language-therapy/where-slts-work/justice#section-2](http://www.rcslt.org/speech-and-language-therapy/where-slts-work/justice#section-2)

- work with partner agencies to agree a whole-prison approach concerning these groups of people, including an information-sharing agreement
- ensure healthcare services record all necessary information correctly
- keep a register of people with a learning disability (this is a [Quality and Outcomes Framework](#) (QOF) indicator requirement) and a register of autistic people
- check recorded information is being used correctly, such as in prompting the need for any relevant support or reasonable adjustments
- promote the Her Majesty's Prison and Probation Service (HMPPS) adapted offending behaviour programmes (for people with 'a learning disability or learning challenges') to offender managers.

The above actions and changes are likely to benefit many vulnerable people in prison, in particular those with communication needs, neurodivergent individuals and people struggling to access healthcare services, not just those with a learning disability and autistic people.

Learning disability and autism champions are advised to join the learning disability and autism prison practitioners' network. This network has an online platform with useful resources, a forum and also networking events. See Appendix 5 for more information.

## 6. Relevant national standards

. In 2018, NHS Improvement published national [learning disability improvement standards](#) for NHS trusts. The standards reiterate expectations arising from a range of statutes and national policies and require NHS trusts, whether they provide universal or specialist services, to put in place improvement measures to ensure that:

- people with a learning disability and autistic people's rights are respected and protected
- they are included and engaged as partners in their own care, as well as in the design and review of services
- they are supported by staff with the right knowledge, skills and values
- services deliver the objectives of the national learning disability and autism programme.

A [national benchmarking programme](#) has been commissioned so that trusts can implement improvement action plans, based on understanding their performance against a matched cohort of comparator trusts. This benchmarking triangulates corporate activity data with anonymised surveys of staff and patient experience. NHS trusts providing prison healthcare are expected to participate in this programme.

The NHS Long Term Plan requires that by 2023/24, all NHS commissioned care should meet the improvement standards and this includes all independent sector providers of prison healthcare.

The National Institute for Health and Care Excellence (NICE) has produced various [guidance concerning working with people with a learning disability](#). It has also produced sets of clear quality statements [regarding learning disabilities and challenging behaviour](#), quality statements [regarding learning disabilities and identifying and managing mental health problems](#) and also quality statements [regarding working with autistic people](#).

The Royal College of Psychiatrists' quality network for prison mental health services published the fifth edition of its [Standards for prison mental health services](#) in 2021. Many of the standards could apply to the care of people with a learning disability and autistic people. It also makes explicit reference to everyone "receiving a first and second stage health assessment that incorporates a mental health screen [which includes] questions and actions relating to their risk of self-harm and/or suicide, learning disabilities and neurodevelopmental disorders."

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

## 7. Quality assurance and governance

All prison healthcare providers will be expected to demonstrate how they have met the outcomes set out in the relevant prison health service specifications via regular contract review meetings with commissioners.

Some prisons/regions collect data and indicators of performance relating to the prevalence of people with a learning disability and other indicators such as monitoring the use of annual health checks. There are also plans to introduce the learning disability population indicator, based on [Quality and Outcomes Framework](#) definitions, to the national adult prison dashboard.

NHS trusts providing prison healthcare are currently required to participate in the learning disability improvement standards benchmarking programme; and there is an ambition to extend this to include independent sector providers of NHS commissioned care (see Section 6 for more information).

## 8. Safeguarding

Under the [Care Act](#) safeguarding needs to be applied when a local authority has reasonable cause to suspect that an adult:

- has needs for care and support (whether or not the local authority is meeting any of those needs)
- is experiencing, or is at risk of, abuse or neglect
- as a result of those care and support needs is unable to protect themselves from either the risk of, or the experience of, abuse or neglect.

All staff working in a custodial setting need to be aware of the relevant safeguarding policies and how they discharge these within this setting. The NHS has outlined its [safeguarding policies](#) and the Royal College of Nursing has produced [guidance on safeguarding roles and competencies](#). There is also [prison service instructions \(PSI\)](#) on adult safeguarding in prison and on safeguarding vulnerable adults.

It is recommended that prison healthcare teams have a strong working relationship with the prison safer custody teams, which lead on ensuring a safe environment for people identified as vulnerable in prison. See Appendix 2.5 for more information.

The level of vulnerability of a person with a learning disability or an autistic person depends on the nature and severity of their condition and their ability to cope. People with a learning disability and autistic people are more likely to suffer abuse and exploitation.

They may be made more vulnerable by the behaviour of other prisoners towards them or potentially by their reduced ability to understand, and therefore comply, with

prison rules and regulations. If an autistic person has a very fixed, literal understanding of the prison rules they may act to enforce a strict adherence to these, for themselves and potentially for others, which could increase their vulnerability should conflict situations arise.

## 9. Mental capacity

The term mental capacity, as defined in the [Mental Capacity Act](#), means being able to successfully make your own decisions. If someone is lacking mental capacity because of a disability or illness, such as a learning disability, they will need to be supported in line with the guidance. The Act provides a [detailed explanation](#) of when and how a person may be found to lack mental capacity. The five principles of the Act are:-

1. A person must be assumed to have capacity unless it is established that he lacks capacity.
2. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
4. Any act done, or decision made, under this Act for, or on behalf of, a person who lacks capacity must be done, or made, in his best interests.
5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

There is a presumption of capacity within the Act. Whether someone is lacking capacity should be ascertained on a case-by-case basis and for each decision that needs to be taken. People's capacity may change over time. If a lack of capacity is established, it is still important to involve the person as far as possible in decisions. Each decision has to be in the person's best interest, taking into the account the person's view, values and culture.

It is a legal requirement that a person lacking capacity should be provided with an independent mental capacity advocate to support decision-making.<sup>11</sup> The local

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<sup>11</sup> [www.scie.org.uk/mca/imca](http://www.scie.org.uk/mca/imca)



authority has a legal duty to provide an advocate if a person does not have family or friends who can advocate for them.

It should not be assumed that a person with a learning disability in prison lacks the capacity to make decisions. People with a learning disability have as much right to make decisions for themselves as anyone else when they have the capacity to do so.

Staff need to make every effort to encourage and give people all practical help to make decisions for themselves, before treating someone as not able to make their own decisions. For example, accessible information should be provided and other reasonable adjustments made to help people understand information.

If a person in prison does not have the capacity to make well-informed decisions about their personal health, they may not make contact with healthcare services and/or look after themselves. Staff therefore need to be aware of new people arriving into prison not engaging with healthcare.

Prison healthcare services need appropriate policies, procedures, training and guidance in place regarding the Mental Capacity Act. It is recommended that senior managers champion the implementation of the conditions of the Act. Useful resources can be found [online](#).

## 10. Legal requirements and inspection criteria

Several acts make specific requirements that apply to the care of people with a learning disability and autistic people. These include the Mental Health Act (2007), the Autism Act (2009), the Mental Capacity Act (2005), the Health and Social Care Act (2012), the Equality Act (2010) and the Human Rights Act (1998).

Healthcare staff also need to be aware of the Care Act (2014) and how social care referrals and delivery have been agreed locally between the prison and the local authority. See Appendix 2.1 for more information.

Both Her Majesty's Inspectorate of Prisons (HMIP) and the Care Quality Commission (CQC) have clear expectations concerning the treatment of people with a learning disability and autistic people in prison and in prison healthcare settings.

HM Inspectorate of prisons and HM Inspectorate of Probation, in 2015, jointly inspected the treatment of offenders with a learning disability and autistic people in prison custody and in the community (on probation). Their [report](#) provides detailed insight into the experiences of these groups of people, including of the use of healthcare services, plus recommendations for all services.

The CQC has carried out a [thematic review](#) of social care provision in prisons, including that for people with a learning disability and autistic people.

## 11. Equivalence and addressing health inequalities

People in prison need to receive the same quality of, and access to, healthcare as people in the community, both in terms of the range, quality and standard of interventions available to meet their needs. This [definition of equivalence](#) has been agreed by the relevant government agencies:

“Equivalence is the principle which informs the decisions of the National Prison Healthcare Board, so that member agencies’ statutory and strategic objectives and responsibilities to arrange services are met, with the aim of ensuring that people detained in prisons in England are afforded provision of, and access to, appropriate services or treatment (based on assessed population need and in line with current national or evidence-based guidelines) and that this is considered to be at least consistent in range and quality (availability, accessibility and acceptability) with that available to the wider community. This is in order to achieve equitable health outcomes and to reduce health inequalities between people in prison and in the wider community.”

The NHS England guidance [Equal access, equal care](#) outlines the healthcare provision that people with a learning disability should receive in the community and applies this to prison healthcare settings.

# 12. Care planning and specialist interventions

## 12.1 Care plans

All people with care plans need to be involved in planning their care and supported appropriately to do so, if required.

It is recommended that everyone receiving healthcare in prison has a care plan, recorded on 'SystemOne'. Services may wish to consider making a copy of a person's care plan available to them, taking into account any risk or data protection issues. This should be in a format that is accessible to the person in question.

Health action plans are commonly used in the community for people with a learning disability. These are patient-led, easy to understand, plans that explain the things a person must do to get, or stay, well. People with a learning disability who also have complex mental health needs may need an accessible version of the care programme approach plan. This information needs to be integrated with any other care plans in place and to include clear goals and treatment decisions in line with [NICE guidance](#) concerning people with a learning disability who also have mental health problems.

People with a learning disability serving a sentence longer than a year will also need an annual health check, as outlined in the [prison health primary care service specification \(2020\)](#). These checks are offered to all people (aged 14 and above) with a learning disability in the community, via their GP. NHS England and NHS Improvement and Autistica have commissioned [research](#) that will be used to create a health check for autistic adults for use in primary care (NHS General Practice).

[NICE guidance](#) recommends that autistic people have a personalised plan that is developed and implemented in a partnership between them, their family/carers (if appropriate) and the local autism team.

Prison healthcare staff can also find out whether a person already has a plan in place which can be adapted to the prison setting. Alternatively they can develop a new plan. See useful resources in Appendix 5.

Joint care planning with other health and social care services, both those in the prison and in the community, is recommended. It is also recommended that

healthcare services attend any relevant multidisciplinary case conferences, both inside and outside the prison, to help ensure joined-up working in meeting the requirements of a person's care plan.

Healthcare services may want to check whether a person's personal emergency evacuation plan (PEEP) adequately takes into account their learning disability or autism. The PEEP assessment is prison-led and identifies support needs for prisoners with disabilities in the event of an evacuation.

## 12.2 Specialist interventions

Some people with a learning disability and autistic people may require specialist interventions to address identified needs that cannot be met by either in-house primary or secondary health services or any reasonable adjustments or support provided by the prison service.

Examples of such interventions include speech and language therapy (where a therapist is not already contracted to the prison) and specialist mental health or other health treatment programmes that are adapted specifically for people with a learning disability or autistic people.

Commissioned care packages need to be in accordance with any locally developed learning disability or autism pathways and comply with evidence-based practices. The care delivered should follow a clear, patient-centred care plan, with goals and outcomes.

If a person requires specialist interventions (as confirmed by the prison consultant psychiatrist/psychologist), these need to be separately commissioned by the NHS England Health & Justice regional/ICS commissioner and provided by an external specialist. See Section 17.3 for information on commissioning responsibilities.

# 13. Designing specific pathways

It is recommended that prison healthcare services develop care pathways for people with a learning disability and autistic people accessing healthcare. These need to cover all relevant options and stages from screening, assessments and care to resettlement.

Pathways need to include actions for commissioners and providers plus all relevant signposting to other agencies or other relevant pathways. They should be informed by national clinical guidance.

It is recommended that pathways include occasions when a person's transfer from prison to a secure hospital is being considered, referencing [relevant guidance concerning who this is appropriate for](#) and also guidance on [how this should happen in practice](#) plus other considerations, such as whether a [Care \(Education\) and Treatment Review \(C\(E\)TR\)](#) would be helpful. There are [cited local examples](#) (page 113) of C(E)TRs being used successfully in youth offender institutes for people with a learning disability and autistic people.

[NICE guidance on autism diagnosis and management](#) states that local care pathways should be developed to promote the implementation of key principles of good care, that these should be integrated so that there are no barriers to movement between different levels of the pathway, and that they should be outcome focused (including measures of quality, service user experience and harm).

The Health & Justice regional/ICS commissioning team will need specific commissioning pathways for these groups of people. Commissioners need to collaborate with local authorities and the local health economy, including NHS trusts and potentially local clinical commissioning groups (CCGs)/ICSs regarding potential collaborative commissioning opportunities. This ensures that any necessary commissioning activity is pre-planned and relationships are established with specialist providers in advance.

Pathways should help all agencies involved to be clear about their role and it is recommended that contracts are put in place to support role agreements (where necessary) for the different points on the pathway, thereby facilitating easier referrals and joined-up working.

## 14. Taking the setting into account: making reasonable adjustments

It is recommended that staff consider the appropriateness of the setting/surroundings for people with a learning disability and autistic people. Healthcare

settings need to be accessible, easy to use and navigate as well as 'autism-friendly'. In practice, this means people can understand the service, book appointments (or be supported to do so), understand any communication or signage and ultimately feel comfortable about being assessed by healthcare and receiving any necessary healthcare treatments.

People with lived experience of using healthcare booking systems in prison have reported struggling with both new digital systems and with paper-based appointment systems, which often require a written form to be completed and are not in Easy Read format.

Autistic people will often significantly benefit from a calm and quiet space when accessing healthcare services. This may enable them to function and interact more easily in such a setting. Staff may need to accommodate a person's environmental or sensory needs; for example, reducing the light intensity and having a quiet place for someone to wait to help reduce stressful triggers.

Prisons that decide to apply for the National Autistic Society's autism accreditation need to demonstrate that their environment is suitable or that reasonable adjustments are in place to accommodate the typical preferences and needs of autistic people.

The highly-structured, routine-based environment within a prison, plus the addition of 'autism friendly' changes to a prison environment, may mean autistic people cope well when in prison and therefore their needs could be overlooked. They may require extra support from all agencies to prepare them for leaving prison or during periods of change or transfer between areas/establishments.

## 15. Medicines optimisation

Medicines optimisation within prison healthcare services follows the principles described in [professional guidance](#) and is led by the prison's pharmacy team. Background information is provided in the respective prison healthcare care service specifications.

Any adjustments or support required for people with a learning disability and autistic people, to enable the safe self-administration of medicines, needs to be routinely available as part of commissioned primary care and pharmacy services. These include:

- adjustments to the style of communication or environment for medicines-related consultations that facilitate involving the person in decision-making about medicines choices and outcomes<sup>12</sup>
- provision of compliance aids, such as monitored dosage systems and medicines reminder charts
- information leaflets or labelling adjustments that enable the person to fully understand what the medicines are for, when to take them and who to contact about their medicines
- planning medicines supply and continuity of access that results in adherence support being available once the person leaves prison
- engaging with the person's carers and providing them with information about the medicines and support needed.

Public Health England says that everyday about 30,000 to 35,000 adults with a learning disability are taking psychotropic medicines even though they do not have the health conditions these medicines are designed to treat.<sup>13</sup>

NICE has produced [guidance on the use of psychotropic medicines](#) for people with a learning disability and autistic people who also have behaviour that challenges and [guidance on managing people with a learning disability and behaviour that challenges](#), which also covers medication.

[STOMP](#) stands for 'stopping over medication of people with a learning disability and autistic people'. This is a national project involving many different organisations that are helping to stop the overuse of these medicines. The aims of STOMP are to:

- encourage people to have regular check-ups about their medicines
- make sure doctors and other healthcare professionals involve people, families and support staff in decisions about medicines
- inform everyone about non-drug therapies and practical ways of supporting people so they are less likely to need as much medicine, if any.

Healthcare services operating within one of the 3 prisons that also have therapeutic communities (TC+) for people with a learning disability would benefit from a close working relationship with the TC+ service. This will help enable a more co-ordinated approach between therapeutic and medicine-based interventions. Changing a

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<sup>12</sup> [www.nice.org.uk/Guidance/CG76](http://www.nice.org.uk/Guidance/CG76)

<sup>13</sup> [www.england.nhs.uk/learning-disabilities/improving-health/stomp/](http://www.england.nhs.uk/learning-disabilities/improving-health/stomp/)

person's medication is likely to affect the extent to which they can take part in certain therapies delivered by the TC+.

The same co-ordinated approach is recommended where a prison has a dedicated learning disability or autism unit and also with prison programmes and psychology departments.

## 16. Working with partner agencies

Different prison agencies are responsible for different aspects of the welfare of people with a learning disability and autistic people. All agencies working in a prison have a responsibility to provide the appropriate reasonable adjustments for a person, in accordance with the Equality Act (2010). All need to work together to develop a prison-wide approach to supporting people with a learning disability and autistic people in prison. See Appendix 2 for more information.

Other stakeholders that healthcare may contact (with consent) include community health and social care services. Such services may have useful information to share. People need to be registered with a local GP. Healthcare staff may also consider contacting a person's family, carer or community support workers (with consent) as they often have extremely useful insights and background information.

### 16.1 Specialist local strategy groups

The [NICE autism guidance](#) recommends that communities have specific strategy groups that bring all relevant partner agencies together to take responsibility for developing, managing and evaluating local pathways, with clear policy and protocols for how these operate. The Social Care Institute for Excellence's Commissioning services for autistic people<sup>14</sup> states the need for autism pathways and also for CCGs (or, moving forward, for ICSs) to work in partnership with their local prison healthcare providers and commissioners.

Given the unique setting and different commissioning arrangements within prison healthcare, NHS England Health & Justice regional/ICS commissioners may consider creating their own strategic learning disability and autism partnership group, inviting all relevant stakeholder agencies from prison(s), external specialists and local learning disability/autism commissioning agencies for the regional/local area.

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<sup>14</sup> Awaiting publication: 2021



The group could develop a care strategy and an action plan. It could agree clear commissioning strategies for diagnostic assessments, specialist interventions and referral mechanisms and processes. It could help develop care pathways and commissioning pathways and would be dependent on effective partnership working via strategic partnerships with other local commissioners, i.e. CCGs/ICSs/local authorities, as well as local specialist providers.

## 17. Screening and diagnostic assessment

Healthcare services need to have credible and reliable learning disability and autism screening tools, as required. The standard healthcare reception screen delivered to all people arriving in prison includes questions that can trigger the need for a learning disability or autism screen. Also, any mental health screening that takes place needs to take into account how mental health issues may present differently if a person has a learning disability or is autistic.

If a person screens positive for a learning disability, autism or both, services need to carry out in-depth assessments of their support needs and relevant background checks. Healthcare services need to agree to share information with other prison agencies also doing screens, to help reduce the amount of repeat screening. Services will require pathways outlining the actions to take after a person screens positive for a learning disability or autism. See Section 13 for more information.

Healthcare services will need to judge the appropriateness of seeking a formal diagnostic assessment when someone screens positive. The guidance below details the relevant considerations and responsibilities.

Screening tool results are not always correct. Mistakes can be made and people may wrongly screen positive or negative. The purpose of a screening tool and any outcomes will need to be communicated in a way that the person in question can fully understand also bearing in mind consent issues, as appropriate.

There is currently no screening tool for autism designed for use specifically in the adult prison population. This reinforces the need for awareness training, training in the use of screening tools and background checks and assessments of a person's needs and abilities.

If a person arrives in prison with a diagnosis of a learning disability or autism, even if they received this when they were under 18, this diagnosis remains valid and no additional screening or diagnostic assessments are required.

To note: All agencies in prison need to implement appropriate reasonable adjustments for anyone with any impairment, behaviour or characteristic that impacts their everyday life, regardless of what screening or diagnostic assessment has or has not taken place.

## 17.1 Screening tools commonly used in prison healthcare

A credible screening tool is one that has been validated with an offender population or similarly researched and tested. Examples of screening tools validated for a learning disability in prison include the [Learning Disability Screening Questionnaire \(LDSQ\)](#), the [Hayes Ability Screening Index \(HASI\)](#) and the [Do-It Profiler](#).

For adults with possible autism and who do not have a moderate or severe learning disability, the [NICE guidance](#) recommends GPs in the community use the [AQ-10 screening tool](#). There is also an AQ-20 available (containing 20 rather than 10 questions) and an AQ-50. This tool is currently used by some prison healthcare services. However, the tool's author notes that it was not designed for the offender/forensic population. One [study](#) found the AQ-10 was poor at identifying adults in the community and NICE is currently reviewing its recommendations.

It is recommended that healthcare services carry out more rigorous autism assessment and background checks. Three [autism assessments](#) are often used instead of/as well as the AQ-10. These are called the 'empathy quotient', the 'friendship quotient' and the 'relationship quotient'.

Most people with a learning disability in prison are classed as having a 'mild' learning disability. However, if a person has a moderate or severe learning disability and possible autism, the [NICE guidance](#) (chapter 1.2.4) recommends a specific assessment to determine next steps.

If English is not a person's first language and/or they are a foreign national, services may wish to use a 'non-verbal' screening tool for a learning disability, such as the [HASI non-verbal](#), which helps overcome potentially misleading responses to questions about reading, writing, culture and communication. Links to all these tools can be found in Appendix 5. A licence is necessary for some tools.

Some prison healthcare services opt to use the screening tools endorsed by their local learning disability/autism teams to facilitate easier referrals post-custody or where there is some form of co-commissioning arrangement in place with the local service.

## 17.2 Screening tools often used by other prison agencies

The Do-It Profiler screens for a learning disability, specific learning difficulties, ADHD and other needs. It also screens for symptoms associated with possible autism and other related social and communication needs. Where this tool is in place, it is typically administered by prison education or in some cases as part of prison induction but could be used by healthcare.

All people arriving in prison currently undertake the [Basic Custody Screening Tool](#) (as part of the prison induction process), which includes some questions relating to learning disabilities. Level 3 of the OASys<sup>15</sup> process includes a validated learning disability screening tool. This can also be administered separately from the rest of OASys, at any stage, by a person's offender manager.

Prison governors commission education providers to screen a percentage of prisoners for both a learning disability and learning difficulties on reception, regardless of whether they choose to access education. This includes screening for behaviours that may indicate possible autism.

All Prison Education Framework (PEF) providers undertake this screening to the level commissioned by the prison governor. The details of the screening tool to be used are included in the PEF specification (schedule C16). See Appendix 2.2 for more information.

## 17.3 Diagnostic assessments for a learning disability or autism

Services should not wait for, or require, a formal diagnosis of a learning disability or autism to provide the healthcare, support and reasonable adjustments a person may require when accessing or receiving healthcare in prison. The exception to this is where the consultant psychiatrist/psychologist identifies an individual's need for

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<sup>15</sup> Available via the HMPPS Intranet

specialist clinical interventions that may require a suspected diagnosis or diagnosis confirmation.

It is ultimately the decision of the consultant psychiatrist/psychologist whether a diagnostic assessment (and any potential subsequent interventions) is required. They will meet the person in question, consider all factors and determine if diagnosis in prison is clinically indicated. The psychiatrist/psychologist should have all relevant information regarding any screening, needs assessments and background checks undertaken. Alternative local arrangements concerning who is responsible for this decision would need to be agreed with the psychiatrist in advance.

The decision to commission an external provider to carry out an assessment (and any potential subsequent interventions) also requires the consent of the relevant responsible commissioner and sign off via local finance governance processes.

For people leaving prison, a formal diagnosis can sometimes facilitate access to certain community care or specialist services and support. It can also provide a more in-depth understanding of a person's condition, their presentation and specific needs. A person may have all their support needs met by the prison regime along with any reasonable adjustments, yet the decision still be made to pursue a diagnostic assessment to support their transition from prison back into the community (with their consent).

Another consideration is the time a person has before they are discharged from prison versus the time it may take to source and undertake a diagnostic assessment, which often involves various assessments, background checks and family/carer interviews.

Identifying whether a person may be autistic requires a specialist skill set. It cannot be based solely on the judgement of a healthcare practitioner. The consultant psychiatrist/psychologist will assess a person, review all information and may refer to [NICE's list of considerations](#) for deciding when an assessment is appropriate.

Some autistic people have been misdiagnosed as having a personality disorder and placed on the wrong care pathway. Autistic people who present as articulate and intelligent are often mistakenly presumed to have similarly high levels of social functioning. Also, autistic women may present quite differently to autistic men. These and other considerations reinforce the need for any decisions to be based on as much information as possible, to be person-specific and ultimately to be made by a clinician with expertise in this area.

It is the role of the prison consultant psychiatrist/psychologist to consider all relevant factors on a case-by-case basis to determine the need for a diagnostic assessment.

There may be occasions when criminal justice agencies request a formal learning disability or autism diagnosis for a person; for example, as part of the parole process to enable access to specialist services/units/courses or to inform certain reports. In such instances, healthcare services may first wish to check whether the outcome of a screening test plus other background checks and assessments of need would be sufficient.

To note: If a person has related social care needs that warrant a separate social care assessment and care package, they should be referred by healthcare (or any other prison agency) to the respective social care provider. This is a separate process to obtaining a learning disability or autism diagnosis. Obtaining confirmation of a diagnosis should not be used as a barrier to receiving a social care needs assessment or the provision of any care required.

### **Delivering a diagnostic assessment for a learning disability**

A diagnostic assessment for a learning disability will typically include an assessment of a person's social skills and emotional behaviours, as well as an 'IQ' test using the Wechsler Adult Intelligence Scale (WAIS) or potentially other tools; for example, non-verbal assessment tools, where required, or assessments of adaptive behaviour, such as the adaptive behaviour assessment system (ABAS). Diagnostic assessments will be carried out by a psychiatrist/psychologist trained in these assessments.

If a member of the prison healthcare integrated mental health service is qualified to carry out a diagnostic assessment, and an assessment is deemed appropriate, then this member of staff can carry out the assessment in-house.

Where no member of staff is qualified to carry out such an assessment, then an external specialist would need to be sourced by the healthcare provider and/or commissioner and separately commissioned to carry out the assessment. This would typically be via the local mental health trust or other local specialist provider with which the healthcare service has an established relationship; the details of the pathway to obtaining an assessment would be established locally. An external specialist may also be called in to provide any necessary specialist interventions, if required.

Some prison healthcare services may have an established relationship with the community learning disability team local to the prison which includes collaborative commissioning arrangements for assessments and interventions.

## **Delivering a diagnostic assessment for autism**

There are several autism diagnostic tools. These typically involve a series of questions about a person's developmental history from when they were a young child, i.e. about language, interactions, play and cognition, and also current observations of the person. Any diagnostic assessments in prison will be carried out by a psychiatrist/psychologist trained in specific diagnostic tools.

Most diagnostic assessment tools require knowledge of early developmental history. This can be difficult to obtain in adulthood or in criminal justice settings where autism may be suspected but access to someone who knows the person's early history may not be possible. The Diagnostic Interview for Social and Communication Disorders (DISCO) explores all current aspects of an individual's behaviour, skills and difficulties. It enables the clinician to base their conclusions on the current behavioural patterns, which are recognised as typical of the way an autistic person sees the world.

If a member of the prison healthcare integrated mental health service is qualified to carry out a diagnostic assessment, and an assessment has been deemed appropriate, then this member of staff can carry out the assessment in-house. However, given the specialist nature of autism diagnostic assessments most integrated mental health teams do not include a practitioner with this specific training.

Where no member of staff is qualified to carry out such an assessment, then an external specialist would need to be sourced by the healthcare provider and/or the regional/ICS commissioner and commissioned to carry out the assessment. This would typically be via the local mental health trust or other local specialist provider with which the healthcare service has an established relationship; the details of the pathway to obtaining an assessment would be established locally. An external specialist may also be called in to provide any necessary specialist interventions, if required.

Some prison healthcare services may have a relationship with the autism team/pathway local to the prison that includes collaborative commissioning or other arrangements with their local services for assessments and interventions. Such arrangements would mean that people awaiting diagnostic assessments are subject to the local pathway referral wait times and these can be lengthy in some areas.

Prison healthcare providers and commissioners therefore need to consider all factors and local circumstances when designing their pathways.

Some autism specialists may be reluctant to assess people in prison settings. The National Autistic Society has produced a [directory of diagnostic services](#) that can complete autism assessments, including those that work in forensic settings.<sup>16</sup>

The Social Care Institute for Excellence's Commissioning services for autistic people<sup>17</sup> should also help inform this process, as appropriate. This sets out the need for local autism pathways and CCGs (or, going forward, ICSs) to work in partnership with their local prison healthcare providers and commissioners on behalf of the needs of these groups of people.

## **Identifying the responsible commissioner for diagnostic assessments**

The commissioner responsible for commissioning/funding a specialist diagnostic assessment and/or subsequent specialist interventions depends on the circumstances and justification for the requested diagnosis confirmation. To correctly identify the responsible commissioner, please refer to NHS England's [Who pays? Determining responsibility for NHS payments to providers](#).

Where there is an identified or suspected unmet clinical need warranting a diagnostic assessment and no qualified diagnosticians within prison healthcare (which would be more likely for an autism assessment than a learning disability assessment), then the responsible commissioner is the NHS England Health & Justice regional commissioning team.

The commissioner will assess any referral requests requiring funding, taking into account all factors, and secure best value options that support a patient-centred model and is based on the best healthcare outcomes for the person in question. It is the responsibility of the prison healthcare provider, working with the commissioner, to source the appropriate specialist provider to carry out the assessment and to make the appropriate clinical referral.

If there are local collaborative commissioning arrangements in place between an NHS England Health & Justice regional commissioning team and the local ICS/provider collaborative commissioning team, then this commissioning route can be taken. If there are no such arrangements, then it is for the NHS England Health &

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<sup>16</sup> Search for the word 'forensic' under 'assessments' - for all listings in the directory.

<sup>17</sup> Awaiting publication: 2021

Justice regional commissioning team to commission (as responsible commissioner for people in prison).

Whether there are collaborative commissioning arrangements in place or NHS England directly commissions these services, funding for specialist assessments and/or any specialist interventions will be obtained in line with NHS England's [standing financial instructions](#) and procurement policy.<sup>18</sup> The [NHS Continuing Healthcare Framework](#) is also a route commissioners may use to fund specialist care, as is the [individual funding request process](#) where exceptionality can be demonstrated.

Should a request for a diagnostic assessment originate from a criminal justice agency, the prison healthcare services need to be made aware of it, and the person in question, to enable staff to advise and signpost those requesting the assessment to the appropriate specialists and provide any necessary support to the person.

It may be that the screening and background information healthcare alone can provide is sufficient detail for agencies requesting diagnosis confirmation. If it is not, however, then the person in question needs to also be seen by the consultant psychiatrist/psychologist. If no clinical indications warrant a diagnosis in prison, then the commissioning/funding responsibility for that case would sit solely with the prison service/agency requesting the assessment.

The parole board may request a diagnostic assessment if they believe it will help their task of assessing a person's potential risk of harm to the public and therefore whether they can safely be released on licence. Such a request would be the commissioning/funding responsibility of the prison service.

The same would apply if a diagnosis were sought via education, perhaps to allow access to educational interventions or programmes, although education providers may have trained expertise to draw on and their own screening and assessment processes in place, in line with the Prison Education Framework (PEF) specification. See Appendix 2.2.

If the consultant psychiatrist/psychologist does find clinical indications that warrant a diagnostic assessment these, in addition to the reasons put forward by the prison agency, will mean the prison healthcare and prison service may wish to explore co-commissioning funding arrangements for that person's diagnostic assessment.

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<sup>18</sup> Available upon request from NHS England and NHS Improvement



# 18. Information sharing

The personal information about those using healthcare needs to be kept safe and secure. Practitioners should also be able to confidently and appropriately share information. This helps ensure the right support for people can be put in place. It enables agencies to share concerns and information on support needs (in prison and during resettlement) and to avoid situations that may cause distress or trigger challenging behaviour, and may help reduce the need for repeated screening by different agencies.

Healthcare practitioners should be familiar with [Confidentiality: the NHS Code of Practice](#) and have undertaken mandatory information governance training. Staff need to be aware of what information is appropriate to share under which conditions and when consent is, and is not, necessary. The Social Care Institute for Excellence outlines [seven golden rules for information sharing](#). The General Medical Council has [guidance on handling patient information](#) and guidance is also provided within the Nursing and Midwifery Council's ['Code' of professional standards](#).

The [national information sharing protocol](#) between the prison and health services, designed to regulate the sharing of specific personal sensitive data, can be incorporated into local information sharing agreements.

It is recommended that any information sharing agreements include the actions to take after a positive screen for a learning disability or autism undertaken by other agencies (screening can take place via prison reception and education; see Appendix 2 for more information).

Information sharing is vital when a person with a learning disability or an autistic person moves between prison establishments or transitions from the children and young people secure estate to the adult prison estate. Giving the receiving service prior information will help smooth the transition and allow it to prepare any required reasonable adjustments and avoid potential challenging behaviour that could result from a stressful, uncoordinated transfer to the new establishment.

The death of a person with a learning disability or an autistic person in prison should be reported to the relevant local [LeDeR programme](#), which reviews the deaths of these groups of people.

Ensuring comprehensive record keeping is key. Additional information about a person's learning disability or autism (plus any related needs or reasonable

adjustments) can be added to their [summary care record](#) which can be viewed by other healthcare providers. The NHS 'Spine' now includes a [reasonable adjustments flag](#) to enable health and care professionals across the NHS to record, share and view a person's required reasonable adjustments.

It is important that any information sharing agreements take into account the different IT systems in place, plus any other potential barriers to sharing information.

# Appendix 1: Relevant outcomes from the primary care service specification

The primary care service specification includes the following objective: “Patients with a learning disability, autistic people, people with acquired brain injury or other cognitive impairment/neuro-disabilities can fully access healthcare services and have their healthcare needs met”.

This objective includes specific outcomes, most of which apply to the care of people with a learning disability and autistic people. The relevant outcomes are listed below. The full [service specification](#) (page 35) includes further detail, including a list of recommended actions for each outcomes.

- Individuals with a learning disability [and/or] autism can fully access all types of healthcare services in prison.
- Individuals are at the centre of their own care.
- Individuals understand how healthcare can help them, plus understand any health conditions/treatments and how to take medications.
- Individuals experience improvements in health conditions and feel supported to make healthy choices.
- Individuals are able to fully communicate when using healthcare.
- Services can identify individuals with a possible learning disability [and/or] autism.
- A nominated learning disability and autism healthcare champion (or existing learning disability nurse) is in post to promote this agenda.
- All healthcare services have a joined-up approach regarding meeting the needs of these people.
- Services have access to expertise concerning individual cases and awareness training.
- The standard of healthcare provided is equal to that delivered to these populations in the community.
- Healthcare services work to address related health inequalities for these populations.
- Individuals are medicated appropriately and supported to use any medication.
- All relevant guidance, standards and laws are adhered to.

- Essential information is recorded, kept and shared appropriately.
- Healthcare forms part of a whole-prison approach to meeting the needs of individuals with a learning disability [and/or] autism.
- Healthcare work with prison safeguarding to help ensure vulnerable and at-risk individuals are kept safe.
- Services are co-ordinated with external healthcare providers concerning an individual's care and support needs including, with patient consent, supporting HMPPS to access families and gain their input concerning an individual's healthcare needs.
- Healthcare help prepare individuals for resettlement and ensure continuity of care after leaving a prison.
- Healthcare works with prison social care providers, the community learning disability team, local autism pathway, the forensic learning disability team/lead within the local transforming care partnership through the local sustainability and transformation partnerships (STPs) or integrated care partnerships (ICP).

## Appendix 2: The role and responsibilities of other prison-based agencies

Each service within a prison has its respective responsibilities and duties concerning people with a learning disability and autistic people. Healthcare services need to be aware of the ways in which other agencies support people, to provide a more co-ordinated, streamlined approach with time and resources focused appropriately, and duplication or unnecessary overlap avoided.

This approach requires robust information sharing, joined-up working and pathways of support/referral between all agencies supporting the same people. This Appendix summarises the roles, duties and responsibilities of other prison services and agencies.

### A2.1 Social care providers and peer support schemes

The [Care Act](#) states that the delivery of care in prisons is the responsibility of the local authority in which the prison is situated. The local authority needs to ensure arrangements are made for care and support assessments for people in prison and

provide care and support for people with eligible needs. For people who do not meet the national eligibility threshold for care and support, the local authority should offer advice and information and may also offer services, such as items of daily living equipment, that help prevent, reduce or delay such needs arising. This includes people with a learning disability and autistic people in prison who have specific care and support needs.

However, a person with a learning disability or who is autistic does not automatically warrant the need for social care intervention. The Act describes 'care needs' as falling into the following domains. Local authorities should consider each of them within the context of the prison environment:

- a. **Managing and maintaining nutrition:** whether the adult has access to food and drink to maintain nutrition, and that they can prepare and consume the food and drink.
- b. **Maintaining personal hygiene:** for example, the adult's ability to wash themselves and launder their clothes.
- c. **Managing toilet needs:** the adult's ability to access and use a toilet and manage their toilet needs.
- d. **Being appropriately clothed:** the adult's ability to dress themselves and to be appropriately dressed, for instance in relation to the weather, to maintain their health.
- e. **Being able to make use of the home safely:** the adult's ability to move around their home safely; for example include getting up steps, using kitchen facilities or accessing the bathroom. This should include the immediate environment around the home, such as the ability to climb steps to access the property.
- f. **Maintaining a habitable home environment:** whether the condition of the adult's home is sufficiently clean and maintained to be safe. A habitable home is safe and has essential amenities. An adult may require support to sustain their occupancy of the home and to maintain amenities, such as water, electricity and gas.
- g. **Developing and maintaining family or other personal relationships:** whether the adult is lonely or isolated, either because their needs either prevent them from maintaining the personal relationships they have or from developing new relationships.
- h. **Accessing and engaging in work, training, education or volunteering:** whether the adult has an opportunity to apply themselves and contribute to

society through work, training, education or volunteering, subject to their wishes in this regard. This includes the physical access to any facility and support required to participate in the relevant activity.

- i. **Making use of necessary facilities or services in the local community including public transport and recreational facilities or services:** the adult's ability to get around in the community safely and their ability to use such facilities as public transport, shops or recreational facilities. Local authorities do not have responsibility for providing NHS services such as patient transport but they should consider need for support when the adult is attending healthcare appointments.
- j. **Carrying out any caring responsibilities the adult has for a child** any parenting or other caring responsibilities the person has. The adult may, for example, be a step parent with caring responsibilities for their spouse's children.

Each partnered local authority and prison need to have a local agreement concerning how social care is to be delivered. This arrangement is typically governed by the prison, rather than the prison healthcare services. The [prison service instruction \(PSI\) on adult social care](#) outlines how the Act is applied in prisons and the ways social care can be delivered. The Act includes the duty to promote integration between health and social care services as being as applicable in prisons as it is in the community.

Some people with a learning disability and autistic people will be referred to the local authority for a social care assessment, resulting in recommendations concerning how the prison establishment can meet a person's identified care needs. This will potentially involve social care practitioners working with the person (depending on the severity of their care needs). In some establishments, peer/'buddy' schemes are also used to deliver (non-intimate) care. There is a [PSI on prisoners assisting prisoners](#), including the provision of care and support.

The CQC and HMIP have conducted a [thematic inspection on social care in prisons](#), which included inspection of the care given to people with a learning disability and their care needs.

Anyone in the prison can refer a person for a social care assessment, including self-referrals. Healthcare services need to inform their local authority of anyone they believe has care and support needs. Any referral requires the person's consent, unless the person lacks the capacity to refuse or is experiencing or at risk of abuse or neglect. If the local authority determines that the person has eligible care and support

needs, then they have a duty to meet those needs if the person wishes them to. A person's social care needs should be recorded on the P-NOMIS IT system (which includes a social care 'flag').

All adults in custody should expect care and support equivalent to that received by someone in the community. This principle of equivalence of care is the basis of the policy intent of the Act. This is crucial for ensuring that people in need of care and support achieve the outcomes that matter to them and that will support them to live as independently as possible after their detention. It will also contribute to the effectiveness of rehabilitation and improve community safety.

Some people will have needs that do not qualify them for social care services while they are in prison because the prison regime meets those needs as a matter of course. However, on returning to the community they may not manage as well and therefore healthcare professionals will need to consider the need for a further social care needs assessment referral as part of resettlement planning.

## A2.2 Education providers

### Education, Health and Care plans

[Education, Health and Care \(EHC\) plans](#) have replaced Statements of Special Educational Needs (SEN). Children and young people, up to 25 years old, may have an EHC plan. Therefore, it is quite possible that people within the adult prison estate already have an EHC plan in place.

This information will be held by a person's home local authority and, in some circumstances, by prison education providers (although there is currently no requirement for EHC plans to be acted on within the adult or young adult estate, only in the youth custody service). An EHC plan may provide important information for healthcare – a person's assessment of need, existing diagnoses and the reasonable adjustments they require.

An EHC plan includes:

- the views, interests and aspirations of the person and their parent/carer
- an outline of the person's special educational need
- outcomes covering education, health and social care
- the special educational provision needed to support a person
- the name and type of their current education setting
- resource attached to the plan

- personal budget information, if applicable.

## **Role of specialist education needs co-ordinators in education**

Education providers employ specialist education needs co-ordinators (SENCoS) who are responsible for assessing, planning and monitoring the progress of people with 'special educational needs' (in the context of their education provision). This role includes liaising with partner agencies within the prison, including healthcare, that are also working with any learners that the SENCo is supporting.

## **Education screening programme for learning disabilities and learning difficulties**

Adult prison education reforms in England mean that prison governors commission education providers to screen a percentage of sentenced prisoners for learning disabilities or learning difficulties (LDD) on reception, regardless of whether or not they choose to access education. This includes screening for behaviours that may indicate autism.

All Prison Education Framework (PEF) providers need to undertake this screening to the level commissioned by the prison governor. This screening information is potentially very valuable to other agencies (including healthcare) within the prison. It is important that a prison-wide approach to LDD screening and information sharing is co-ordinated, both for system efficiency and to avoid the stress of repeat screening and assessments.

Where the screening results are positive and indicate the likelihood of a learning disability or possible autism, arrangements need to be put in place to ensure this information is shared with healthcare services (with consent) to allow a more detailed assessment of a person's needs and, if required, a diagnostic assessment. Where screening results indicate the likelihood of a learning difficulty (for example, dyslexia), this information may be shared with other service providers throughout the prison (with consent), particularly if they will be providing written material for the person in question.

The PEF provider will organise more detailed assessments if required. If a person with an LDD decides to take up the prison's offer of education, the PEF provider should ensure the right suite of adaptations and additional learning support are put in place. Regarding the education of people with a learning disability and autistic people this may mean involving a SENCo.

The PEF LDD schedule C16 document outlines how LDD screening should take place. Where a PEF provider has screened a person in prison, the results are



recorded on the prison learning data collection system (called Curious) as well as within a person's digital personal learning plan, along with details of additional learning support in place for people accessing education programmes.

The Ministry of Justice (MoJ) and Her Majesty's Prison and Probation Service (HMPPS) officials are working to ensure the data systems used facilitate data sharing, in compliance with data protection law. They are working to establish an effective way to share relevant information with healthcare and others. The MoJ is also planning to collect data on LDD and autism as part of the new education contracts. It is recommended that any information from a learning disability or autism screen conducted via healthcare that may be useful to PEF providers is shared with education at an appropriate level of disclosure and with the person's consent.

Actions for healthcare are:

- speak to your education provider about this programme of screening
- agree what information you would like from education after a positive LDD screen
- agree how and to whom in healthcare this information is sent
- agree with your education provider what information you have consent to share and how and to whom this information is to be sent to education
- ensure that the responsible senior prison managers are made aware that such conversations are taking place, via the governor.

## A2.3 Prison officers, key workers and offender managers

Prison staff have a common law duty of care to people in prison. They have duties under the [Equality Act](#) to provide reasonable adjustments, as required. There is also a [prison service instruction](#) (PSI) on the application of this Act in prison.

Officers should have a basic level of understanding concerning how someone with a learning disability or an autistic person may present and the ways they may need to be supported, via Prison Officer Entrance Level Training (POELT). Where an officer has concerns about a person, they would be expected to contact healthcare (for an assessment of the person's needs and/or to seek advice on the best ways to manage them).

Prison staff may also be asked to take part in multidisciplinary meetings about certain people, especially where challenging behaviour is present. It is recommended they

share any information or useful approaches they find helpful with other relevant agencies so a person can be fully supported in all areas of prison life.

HMPPS has introduced the 'key worker' scheme in the male closed estate. Every prison officer supports five or six prisoners on a one-to-one basis. This approach allows for a more personalised approach that people with a learning disability and autistic people often require.

Resettlement in, and preparing to return to, the community is a crucial time for people with a learning disability and autistic people. Those employed by the prison service to support people with the resettlement process will need to give these groups of people additional considerations: securing housing, benefits and travel, as well as ensuring they understand all the information given to them and what is expected of them.

The MoJ has produced a toolkit for prison and probation services to help ensure that the service provided and the environment it is provided in are suitable for people with a learning disability or learning challenges (LDC).<sup>19</sup> This has been developed with frontline staff and recommends simple actions for services, including joint working and planning with healthcare services within the prison.

## A2.4 Prison psychology and specialist services

Prisons may employ in-house psychologists. The expectation is that healthcare services will work closely with them to develop coordinated, prison-wide learning disability and autism pathways of care and support.

Various offending behaviour programmes has been adapted for people with an IQ of 80 or below and needs associated with their social and adaptive functioning. The target audience is referred to as people with LDC. Governors and offender managers/supervisors should be aware of these programmes; however, some of the newer programmes may be less well known and could be brought to their attention. For example, the HMPPS suite of programmes written specifically for people with LDC, called 'New Me' programmes, are designed to help address unhelpful patterns of thinking and behaviour that lead men to offend. For more information, contact [Interventions\\_businessenquiries@noms.gsi.gov.uk](mailto:Interventions_businessenquiries@noms.gsi.gov.uk)

Three prisons in England<sup>20</sup> have a therapeutic community (TC+) for people with LDC. These are separate bedded units in a group-based setting and provide a long-term,

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<sup>19</sup> This can be found on the HMPPS Intranet.

<sup>20</sup> HMP Gartree, HMP Grendon and HMP Dovegate.

residential, offending behaviour intervention for community members. The approach supports prisoners with a learning disability and/or an IQ under 80 to access therapy.

TC+ services encourage community members to address offence-related risk and associated personality and psychological problems. TC+ services deliver a core treatment model suitable for sentenced prisoners with a wide range of offending needs and they accept referrals from other prisons. These services are co-commissioned by HMPPS and NHS England.

Some prisons have dedicated wings/areas for people with a learning disability, autistic people or related vulnerabilities. The Mulberry unit at HMP Wakefield is for prisoners with a diagnosis, or a likely diagnosis, of autism and whose clinically relevant traits mean they are unable to reside in the main prison and/or meaningfully engage with any identified progression pathway. It is broadly accepted that the men in the Mulberry unit will have a variety of complex and challenging psychological, behavioural and emotional demands and co-morbid mental health needs requiring a bespoke specialist service.

The Mulberry unit offers an alternative environment in which these particularly complex men are offered the opportunity to develop an understanding of their condition(s), its symptoms and resultant behaviours, and, with support, develop ways of managing these with a view to progressing to the main prison and/or identifying specialist service provision with the relevant health partners. In turn, this unit offers them equality of opportunity in terms of managing and reducing risk and progressing through their prison sentence. It is anticipated that a prisoner will remain in the Mulberry unit for a maximum 18–24 months, dependent on individual need. The unit accepts referrals from any prison/source (with consent).

## A2.5 Safer custody staff

Adult safeguarding in prisons means keeping people in prison safe and protecting them from abuse and neglect. Prison staff have a common law duty of care towards people in prison, which includes taking appropriate action to protect them. Prisons have a range of processes in place to ensure that this duty is met. Such processes also help ensure that any people in prison unable to protect themselves, due to their care and support requirements, are provided with a level of protection that is equivalent to that provided in the community. Safer custody teams work towards creating a safe, decent and secure environment for everyone in prison.

The [PSI on managing prisoner safety \(64/2011\)](#) outlines the desired outcomes of having safer custody teams:

- identify, manage and support prisoners and detainees who are at risk of harm to self or others, and from others
- reduce incidents of self-harm and deaths in custody
- manage and reduce violence, deal effectively with perpetrators and support victims
- support effective multidisciplinary case management and sharing of information to reduce incidents of harm
- ensure staff, prisoners and visitors affected by incidents of harm are supported appropriately
- ensure appropriate responses to and investigations of incidents, which promote learning to prevent future occurrences and improve local delivery of safer custody services.

Any staff working in a custodial setting with people with a learning disability and autistic people need to be alert to safeguarding concerns within that setting but also indications that a person may have experienced events prior to coming into prison and is at risk of their repeat on return to the community (and that therefore require investigation).

People in prison with a learning disability or autistic people can be at higher risk of violence, abuse or various types of exploitation from others due to their higher level of vulnerability. They may also find the prison environment particularly challenging, partly for this reason, which can have an adverse impact on mental wellbeing and increase the risk of self-harm. It is therefore essential that healthcare services work with the safer custody team to help them minimise and manage the related risks and keep people in prison safe.

It is recommended that prison healthcare teams establish an effective and appropriate channel of communication with the safer custody team to highlight and discuss the appropriate, safe management of any vulnerable people in prison. This may include sharing information concerning any support needs or reasonable adjustments, as well as communicating with a person's family and/or carers to obtain information (with consent), and sharing any other information that can inform good practice and the safe management of people with a learning disability and autistic people in prison.

Healthcare may also need to share information such as relevant aspects of care plans, Care in Custody and Teamwork (ACCT) case reviews for vulnerable people in prison at risk of self-harm or suicide, and Challenge, Support and Intervention Plan CSIP case reviews for people in prison who present a risk of violence towards others.

It is good practice for the safer custody team to keep a register of all vulnerable people in prison.

## Appendix 3: Definitions

While people who have a certain diagnosis or label will share common behaviours, everyone is unique and may act, react or present in different ways. This includes how people may react to a prison environment, including the demands of prison life and its routines. However, the nature of both a learning disability and autism is such that a person with either or both of these conditions and who is residing in a prison is likely to be more vulnerable because of their condition(s).

To note: Some practitioners now use the collective term 'neurodevelopmental disorders/disabilities or neurodivergent conditions' to refer to learning disabilities, autism, attention deficit hyperactivity disorder (ADHD) and other conditions that affect the development of the nervous system and therefore brain function.

Please refer to the resources in Appendix 5 for more detailed guidance on how best to support and manage people with a learning disability and autistic people.

**A learning disability** includes the presence of:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with
- a reduced ability to cope independently (impaired social functioning)
- which started before adulthood, with a lasting effect on development.<sup>21</sup>

This definition encompasses people with a broad range of disabilities. The presence of a low 'intelligence quotient' (IQ), typically below 70, is also often used as an indicating factor. However, an assessment of social functioning and communication skills must also be taken into account when determining need. Many people with a learning disability also have physical and/or sensory impairments. Please refer to the NHS England guidance, [Equal access, equal care](#), for more detail, including examples of the types of activities people with a learning disability may struggle with.

The term learning disability is not to be confused with a **learning difficulty** (or 'specific learning difficulty') which is used to refer to specific problems in processing

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<sup>21</sup>[Valuing people: a new strategy for learning disabilities in the 21st century](#) (Department of Health, 2007).

information that substantially affect a person's ability to learn rather than the characteristics outlined in the above definition. However, some services or people may use the term learning difficulty when referring to a learning disability, so it is advisable to seek clarification.

Some practitioners also use the term **intellectual disability** to mean a learning disability. Labels can be de-humanising and it is important to remember that people with a learning disability are people first and all are unique in their needs.

**Autism** is also a lifelong, developmental disability. It affects how a person communicates with, and relates to, other people and how they experience the world around them. The characteristics of autism vary from one person to another, but for a diagnosis to be made, a person will usually be assessed as having had persistent difficulties with social communication and social interaction and also restricted and repetitive patterns of behaviours, activities or interests since early childhood, to the extent that these limit and impair everyday functioning. Autism is not classed as a learning disability in itself. However, about 20-30% of people with a learning disability are also autistic.<sup>22</sup>

**Asperger's syndrome** is on the continuum of autism spectrum conditions. However, this label is less commonly used as a diagnostic term. People with Asperger's syndrome have the same difficulties described above but no clinically significant delays in language, cognitive development or the development of age-appropriate self-help skills, adaptive behaviour and curiosity about the environment in childhood.

**Pathological demand avoidance** is increasingly, but not universally, accepted as a behaviour profile that is seen in some people on the autism spectrum. People with a demand avoidant profile share difficulties with others on the autistic spectrum in social communication, social interaction and restricted and repetitive patterns of behaviours, activities or interests. However, they are driven to avoid everyday demands and expectations to an extreme extent. While relatively uncommon, it has implications for the way a person is best supported. They are unlikely to follow instructions or obey rules, and if required to do so this often results in panic and 'disobedient' behaviour, which can cause serious problems in a secure environment setting.

**Fetal alcohol spectrum disorders** are conditions that can result from prenatal alcohol exposure. The most severe form is known as fetal alcohol syndrome, whereby people can present as having a learning disability. Problems may include an

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<sup>22</sup> [Emerson E, Baines S \(2010\) The estimated prevalence of autism among adults with learning disabilities in England](#)

abnormal appearance, short height, low body weight, small head size, poor coordination, low intelligence, behaviour problems, and problems with hearing or seeing. People affected are more likely to have trouble in school and with alcohol or other drugs, and legal problems, and participate in high-risk behaviors.

## Appendix 4: Prevalence

A [report](#) by the Learning Disability Observatory estimated that 2.16% of the adult population of England has a learning disability. Average estimates and research findings regarding the number of adults with a learning disability in the prison population range between 1% and 7%, depending on the type of prison, the location and the research and screening methods used.

[Mottram et al \(2007\)](#) compared prevalence of a learning disability using three different screening tools in a local prison, a women's prison and a young offender institution. Using the 'Valuing People' definition, 6.7% of adults were found to have a learning disability, and 25.4% were 'borderline' cases. Such cases would not be eligible for services in the community. However, people found to have a borderline learning disability (sometimes referred to as 'learning challenges') are likely to struggle with similar needs and benefit from certain reasonable adjustments.

The [Coates review](#) into education in prison states that one-third of prisoners self-identified as having a learning disability and/or learning difficulty and this appears to be broadly consistent with data held by HM Prison and Probation Services (HMPPS).

HMPPS has adapted a suite of offending behaviour programmes so that they are available to people with a borderline learning disability (the courses are designed for people with an IQ of 80 or below). The prison service also encourages prisons to provide reasonable adjustments based on the assessed need of the person, rather than a label or diagnosis.

About 1% of the general population are on the autistic spectrum, (with 2% of males being autistic and 0.3% of females). However, the number of autistic females is thought to be under-diagnosed, as they are frequently missed or misdiagnosed, often because of misconceptions about autistic females<sup>23</sup> and possibly due to autistic females presenting slightly differently to males.

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<sup>23</sup> Lai M-C, et al (2015). [Identifying the lost generation of adults with autism spectrum conditions.](#) *Lancet Psychiatry* 2(11), 1013–1027

The percentage of autistic people is thought to be slightly higher in the criminal justice system than the community. However, there are currently no comprehensive prevalence studies on this group of people. In 2016, HMP/YOI Feltham found they had a static population of 4.6% autistic people.<sup>24</sup>

Estimates vary concerning the percentage of people in the general population who are autistic and have a learning disability.<sup>25</sup> However, it is common for the two conditions to co-exist.

## Appendix 5: Resources

Below is a list of recommended guidance, tools and reports to help inform service development and delivery (this list is not exhaustive):

### National strategies, reviews and reports

- [The Bradley Review](#), Lord Bradley's review of people with mental health problems or learning disabilities in the criminal justice system (2009)
- [Various documents](#) relating to the NHS England Transforming Care programme
- [National strategy for Autistic children, young people and adults: 2021 to 2026](#) (cross Government strategy, 2021)
- A [review of evidence report on neurodiversity in the criminal justice system](#) (by the respective criminal justice Inspectorates, 2021).
- [The Autism Strategy](#) (cross Government strategy, 2014) and [guidance \(superseded by the 2021 national strategy listed above\)](#)
- [Valuing people: A new strategy for people with learning disabilities in the 21st century](#) (Government White Paper, 2001)
- [Health Equalities Framework](#); an outcomes framework based on the determinants of health inequalities (NDTI et al, 2013)
- [A joint inspection of the treatment of offenders with learning disabilities within the criminal justice system - phase two In custody and the community](#) (HMIP, 2015)
- [Social care in prisons in England and Wales: a thematic inspection](#) (CQC and HMIP, 2018)

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<sup>24</sup> The National Autistic Society; obtained as part of their Autism Accreditation process.

<sup>25</sup> [www.autism.org.uk/about/what-is/myths-facts-stats.aspx](http://www.autism.org.uk/about/what-is/myths-facts-stats.aspx)



## Clinical guidelines

- NICE sets of [guidance](#) relating to people with learning disabilities. These include:
  - Quality standards on working with people with learning disabilities who also have mental health problems
  - Quality standards on working with people with learning disabilities who also have behaviour that challenges
  - Guidance on working with older people with learning disabilities,
  - Guidance on working with people with dementia and learning disabilities,
  - Guidance on working with people with learning disabilities and mental health problems
  - Guidance on working with people with learning disabilities and behaviour that challenges (including additional guidance on the use of psychotropic medicines for this group of people).
- NICE sets of [guidance](#) relating to people with autism. These include:
  - Autistic spectrum disorder in adults: diagnosis and management guidance
  - Autism spectrum disorder in under 19s: recognition, referral and diagnosis
  - Autism spectrum disorder in under 19s: support and management
  - [Quality standard on people with autism](#)
- [Health of the Nation Outcome Scales for People with Learning Disabilities](#)
- [Prison healthcare service specification: Integrated Mental Health Services](#) (NHS England, 2018)
- [Prison healthcare primary care service specification](#) (NHS England, 2020)
- [Prison to hospital transfer guidance](#) (NHS England, 2021)
- [Core capabilities frameworks: supporting people with autism/learning disabilities: the skills required when supporting autistic people and/or people with a learning disability for those working in any sector and all staff working across health and social care](#) (Skills for Health, 2019)

## Delivering and commissioning healthcare guidance and tools

- [Equal access, equal care: Guidance for prison healthcare staff treating patients with learning disabilities](#) (NHS England, 2015)
- Royal College of Nursing's [The needs of people with learning disabilities](#). This is an introduction to this topic for new nurses
- [Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition:](#)

[Service model for commissioners of health and social care services](#) (NHS England, 2015)

- Skills for Health's [Core capabilities framework for supporting people with learning disabilities](#)
- Royal College of Nursing's [Adult safeguarding: Roles and competencies for healthcare staff](#)
- NHS England's [suite of resources](#) covering reasonable adjustments, annual health checks, premature deaths, stopping the over medication of people with learning disabilities and autistic people, and much more
- Royal College of GP's [Step-by-step toolkit for annual health checks](#) for GPs and nurses
- [STOMP: Stopping the over-medication of people with learning disabilities and autistic people](#) (NHS England, 2017)
- Royal College of GP's [One-stop shop toolkit on autism for primary care professionals](#)
- Mencap's '[Treat me well](#)', a campaign to change the way NHS staff treat people with learning disabilities in hospital
- [Care and Treatment Reviews \(CTRs\) various guidance](#) (NHS England)
- [Guidance on delivering health action plans](#)
- [Examples of health action plans used in prison healthcare services \(select healthcare in prisons\)](#)
- [Guidance on delivering annual health checks](#)
- [Quality and Outcomes Framework \(QOF\) indicators guidance](#)
- [Guidance on reasonable adjustments for people with learning disabilities who have various health conditions](#). This includes annual health check guidance, oral care, weight management, substance misuse issues and guidance on pharmacy-based reasonable adjustments, as well as other conditions.
- Health Education England's [Working in community settings with people with learning disabilities and autistic people who are at risk of coming into contact with the criminal justice system](#) (on the NHS learning Hub)

## Screening tools for a possible learning disability or autism

- [The Learning Disability Screening Questionnaire](#) (LDSQ)<sup>26,27</sup>
- [The HASI tool](#) (for screening a learning disability)<sup>28</sup>

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<sup>26</sup> [https://drkmckenzie.files.wordpress.com/2014/03/lds\\_q\\_forensic\\_authors\\_version.pdf](https://drkmckenzie.files.wordpress.com/2014/03/lds_q_forensic_authors_version.pdf)

<sup>27</sup> [k.mckenzie@northumbria.ac.uk](mailto:k.mckenzie@northumbria.ac.uk) (email the owner to use)

<sup>28</sup> [susan.hayes@sydney.edu.au](mailto:susan.hayes@sydney.edu.au) (email the owner to use)

- [The HASI non-verbal](#) (for screening a learning disability with foreign nationals)
- [The AQ10 by ARC](#) ( free tools for screening for autism: adult and adolescent versions)
- The [Do-It Profiler](#) (for a learning disability and difficulties plus other needs). This is already used in some prisons via education so check before purchasing

## Guidance for people working in the criminal justice system

- Department of Health's [Positive practice, positive outcomes: A handbook for professionals in the criminal justice system working with offenders with a learning disability](#)
- The [National Autistic Society](#) has lots of information online concerning the different stages of the criminal justice system
- The Prison Reform Trust online [guidance on people with a learning disability and autistic people](#) for use by magistrates and judges
- The Foundation for People with Learning Disabilities series of [factsheets](#) to help the criminal justice system. These include information on making decisions (capacity), making appointments, communication, spotting a learning disability, making Easy Read and more
- HMPPS toolkit for prison and probation staff on people with a learning disability and learning difficulties. It is available on the HMPPS Intranet.
- The Prison Reform Trust suite of documents as part of its previous '[No One Knows](#)' project about people with a learning disability or difficulties in the criminal justice system

## Communication guidance

- [The Accessible Information Standard](#) (NHS England, 2016)
- [Guide to implementing the Accessible Information Standard](#), with communication guidance (NHS England, 2016)
- Easy Read leaflets for most health conditions (via the [Easy Health website](#) and the [Foundation for People with Learning Disabilities website](#))
- Examples of Easy Read documents used in the criminal justice system via the [KeyRing website](#)
- The [Books Beyond Words series](#) (including 'You're in Prison' and others)
- The Advocates Gateway [range of communication tools for use in court settings](#) (for people with a learning disability or autistic people), much of which could be useful in prison situations

- Royal College of Speech and Language Therapists [information on people in the criminal justice system and various approaches for communication difficulties](#)
- Royal College of Speech and Language Therapists [Five good communication standards: Reasonable adjustments to communication that individuals with learning disability and/or autism should expect in specialist hospital and residential settings](#)

## Relevant prison service instructions (PSIs)

- Healthcare staff may wish to familiarise themselves with the [relevant PSIs](#) that prison staff work to. These include:
  - PSI 17/2015 Prisoners Assisting Other Prisoners
  - PSI 05/2014 Safeguarding of Children and Vulnerable Adults
  - PSI 16/2015 Adult Safeguarding in Prison
  - PSI 49/2011 2019
  - PSI 32/2011 Ensuring Equality
  - PSI 15/2015 Adult Social Care
  - PSI 04/2012 Enablers of Services in Prisons (for positive relationships with providers plus information sharing)

## Training and awareness

- Various national and regional awareness training programmes run periodically. Below are some national examples. You may wish to check for local examples also.
  - [National Autistic Society, criminal justice projects](#)
  - [KeyRing Living Support Networks, criminal justice projects](#)
  - [The Foundation for People with Learning Disabilities](#)
  - [Respond](#) Trauma informed training
  - [‘The Box’](#) online training course on people with a range of communication difficulties, designed for criminal justice professionals
  - [Level 2 accreditation in Understanding Autism](#) (available for prison staff via education providers and via the POA)
  - The [‘SPELL framework’](#) for understanding and responding to the needs of people with autism, developed by NAS and the Tizard Centre
- It is recommended that where learning disability nurses are in post they provide awareness training for colleagues. Many of the resources listed in this Appendix can be used as part of a training course or services can buy in

pre-written written materials such as [Pavilion: Working with people with learning disabilities and offending behaviour, a training guide](#)

## Useful networks and groups

- There is a network for learning disability/autism practitioners and champions working in prisons (and secure children's homes), overseen by NHS England and NHS Improvement. This includes a private online platform where members can share resources and practices, ask questions, etc. as well as annual network meetings. To join or for more information, please contact [Neisha.Betts@nhs.net](mailto:Neisha.Betts@nhs.net)
- The National Autistic Society has a [newsletter](#) on issues regarding people with a learning disability or autism in the criminal justice system
- There are various forums and networks that can be found online that focus on people with a learning disability or autism in a general healthcare and/or community services context (that is, not specifically on criminal justice issues)

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