



Listen to families

Desk review of rights and legal tools

April 2024



About Communitatis Ltd

Communitatis Ltd is a strategic business consultancy that helps organisations to develop and implement strategies that address their key business challenges.

We facilitate and advise on the design, development, implementation and roll-out of strategies and operating models that are saleable, scalable and sustainable. By sharing knowledge and facilitating positive, sustainable change, we leave a far-reaching and valuable legacy for our clients.

Our ultimate aim is to enable boards and executive teams to achieve better organisational and systemic outcomes for the people and communities they work with.



1. Introduction

Carers and family members need to know how to navigate the prison healthcare system, where they stand in relation to it, and to be able to make informed decisions about how and when to challenge things that are not working, either for them or their loved one.

Against this backdrop, Pact's Listen to Families service is looking to develop a practical guide to prison healthcare. In order to inform its thinking on what this guide might look like, Pact has commissioned Communitatis Ltd to produce this summary of the legal tools and policy instruments that carers and family members of patients might find useful as they seek to ensure their loved ones' healthcare needs are met while they are in prison.

2. Desk review question

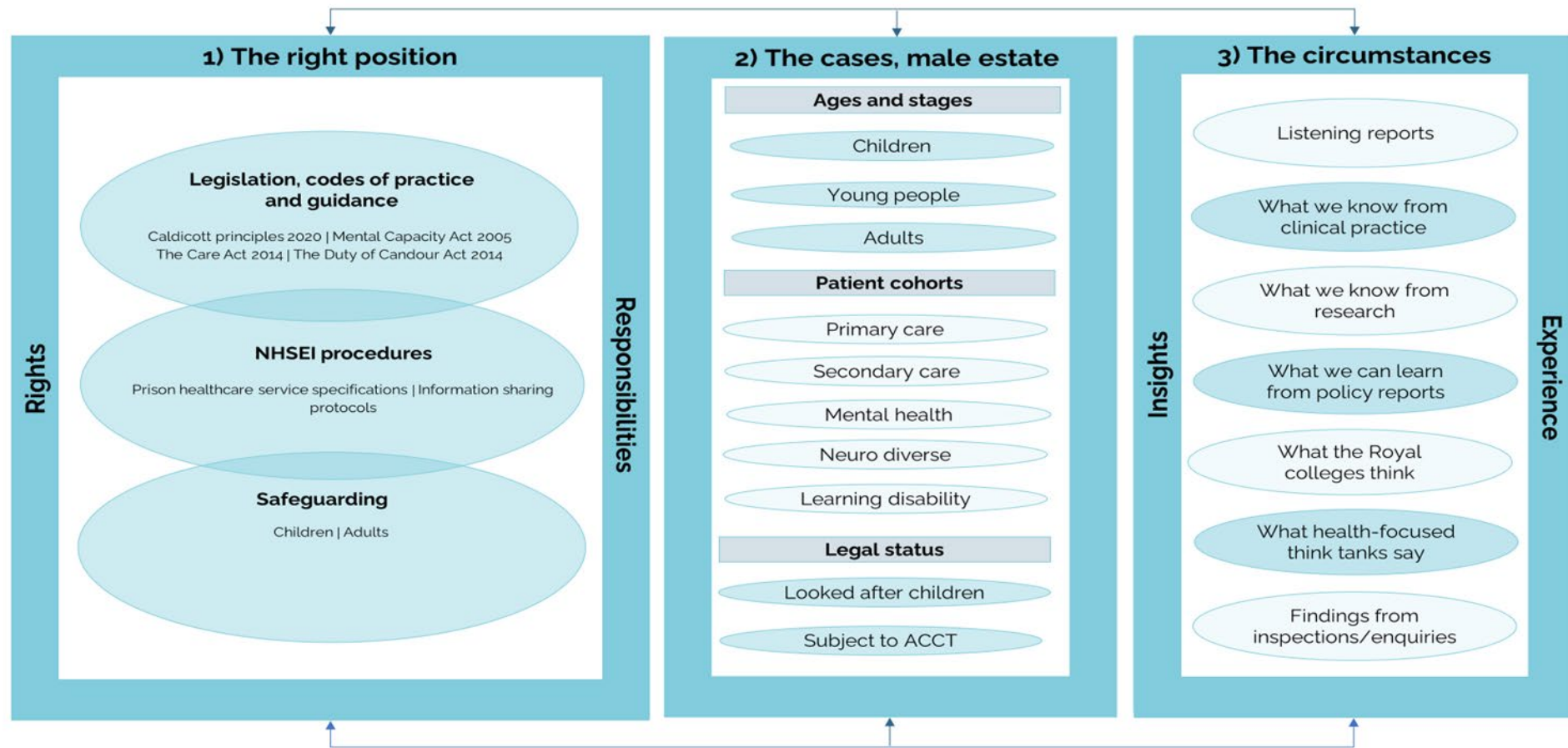
We chose a question from a relative and carer perspective to anchor our desk review:

“Our loved one is in custody and whilst they are there, we want to ensure they receive the best possible healthcare they need. So we want to understand, all things being equal: what can we assume to be *the right position* relating to these *cases* in these *circumstances* based on this law, this protocol or this procedure?”

Three key words/phrases in our desk review question acted as hooks upon which we could hang our desk review framework (see the next slide). These key words/phrases included:

- The right position
- Cases
- Circumstances.

3. Desk review framework



4. Patient consent, data protection and privacy

Pact's listening reports¹ show that relatives and carers question why the issue of consent is such a large barrier to their receiving information about a loved one's care.

The reports also show that relatives and carers are left wondering whether privacy and data protection are in fact genuine reasons for them not to be kept informed about the care their loved one is receiving as a patient in prison.

4. Patient consent, data protection and privacy

Our desk review shows that there is an extensive body of ethics, law, policy material and formal guidance in relation to confidentiality and information sharing in healthcare settings, including (but not limited to):

- The Caldicott Committee report on the review of patient identifiable information, 1997
- The Mental Capacity Act 2005, code of practice, updated 2016
- The NHS code of practice on confidentiality, 2010
- The General Medical Council (GMC) report on protecting children and young people: the responsibilities of all doctors, 2012
- The DoH report on information sharing and suicide prevention, 2014
- The GMC report on good practice in handling patient information, 2017
- The Royal College of Psychiatrists good psychiatric practice report on confidentiality and information sharing, 2017
- The Data Protection Act, 2018

4. Patient consent, data protection and privacy

Caldicott principles² (first introduced in 1997 following a review chaired by Dame Fiona Caldicott)

Principle 1	Justify the purpose(s) for using confidential information
Principle 2	Use confidential information only when it is necessary
Principle 3	Use the minimum necessary confidential information
Principle 4	Access to confidential information should be on a strict need-to-know basis
Principle 5	Everyone with access to confidential information should be aware of their responsibilities
Principle 6	Comply with the law: Every use of confidential information must be lawful
Principle 7	The duty to share information for individual care is as important as the duty to protect patient confidentiality
Principle 8	Inform patients and service users about how their confidential information is used

4. Patient consent, data protection and privacy³

Under common law, there is a duty of confidentiality. (i.e. when a patient shares information in confidence, it must not be disclosed without some form of legal authority or justification). In practice, this usually means the information cannot be disclosed without the patient's consent.

There are three types of consent:

1) Implied consent for individual care

Staff caring for a patient don't need the patient's consent to record information about their care/treatment. For medical/legal reasons health records do need to be kept. But the law requires all organisations to make information readily available to the patient that explains this. These records may be accessed by healthcare professionals involved in a patient's care without the patient having to explicitly say so. A patient may withdraw this consent, but this may result in the care/treatment being withdrawn.

2) Explicit consent beyond individual care

If confidential patient information is used for purposes beyond individual care, for example for a research project, it will normally be necessary for staff to obtain the patient's explicit consent. This is a very clear and specific statement of consent. It can be given in writing, verbally or through another form of communication such as sign language.

3) Consent exempted when in the public interest

Healthcare professionals have a duty to ask for consent to share information unless there is a compelling/justifiable reason for not doing so. Information may be shared without consent if this can be justified in the public interest, is required by law or where there is an overriding safeguarding or public protection concern.

5. The importance of information sharing⁴

Legal obligations

Organisations are legally obliged to be transparent with patients about how information is used and shared. They must have a privacy notice, which includes information about information sharing. This information should be transparent, and be made available in patient welcome packs, on notice boards and on the corporate website.

Organisations must also be able to answer patients' further questions about information sharing and signpost patients to someone who can help e.g. the organisation's Caldicott Guardian (a senior person responsible for protecting the confidentiality of people's health and care information and making sure it is used properly).

5. The importance of information sharing

Healthcare professionals

Sharing information with patients' relatives and carers is seen as a good thing, and it is often regarded as being crucial to the ongoing well-being of all parties. Relatives often know the patient best, have known them the longest, and may be the only constant support in a patient's life. Meanwhile, the well-being of the relative or carer can be greatly improved if they are encouraged to feel part of a supportive team, with ready access to up-to-date information.

Yet there are barriers to information sharing, with concerns often being linked to lack of training or confidence when dealing with complex issues around confidentiality, and insufficient time or resources to liaise with relatives and carers whilst also meeting all the needs of their patients.

5. The importance of information sharing

Sharing information with patients' relatives and carers requires *explicit* consent

Different organisations/professionals handle the matter of consent in different ways. Some practitioners prefer to check back with the patient prior to each interaction with the relative or carer, whereas others will go by the latest note on record. The way this is dealt with will be addressed via the policies and procedures of the relevant healthcare provider. Either way, NHS guidance states that healthcare practitioners should have early discussions with the patient to establish what information they wish to be shared, with whom, and in what circumstances. The patient's wishes should be noted on the patient's record. Patients are free to withdraw or change their consent to information sharing about them at any time.

5. The importance of information sharing

This usually requires *informed consent*

As a general rule, where the patient withholds consent or lacks capacity, confidential information can only be disclosed in exceptional situations, i.e. where the patient's or other's health or well-being is under serious risk, or where there is a public interest/legal reason for disclosure without consent.

GMC guidance⁵ states that if a patient who has capacity to make the decision refuses permission for information to be shared with a particular person or group of people, it may be appropriate to encourage the patient to reconsider that decision if sharing the information may be beneficial to the patient's care and support. However, at the end of the day, the practitioner must abide by the patient's wishes, unless disclosure would be justified in the public interest.

5. The importance of information sharing

Relatives or carers can share information about a patient with a healthcare practitioner even if this can't be reciprocated

Anyone close to the patient can discuss their concerns about the patient's health with a healthcare practitioner, and the practitioner should not refuse to listen to those concerns. Listening to what a third party has to say about a patient does not in itself breach patient confidentiality.

That said, the practitioner will not be able to guarantee:

- a) That they will not tell the patient about the conversation;
- b) That they will not share the information with the patient or other healthcare staff; or
- c) That the patient may not be able to identify the source of the information, even if their identity is withheld.

5. The importance of information sharing

Assessment, Care in Custody and Teamwork (ACCT)⁶

ACCT is used to support people at risk of self-harm and suicide within HM Prison Service.

The ACCT case review is the vehicle used to identify potential sources of support for a prisoner (this is anyone they can turn to in order to help keep them safe). This may include staff members, peer supporters, or outside supporters e.g. a relative or carer. Supporters are invited to engage in the ACCT process as long as the prisoner consents to their involvement and it complies with guidance relating to safeguarding, public protection and maintaining security.

If consent is not given by the prisoner to involve identified sources of support, or if the sources of support do not meet the criteria as set out in the guidance relating to safeguarding, public protection and maintaining security, then the decision not to involve them must be fully documented and explained.

6. Equivalence

Pact's listening reports raised key questions about equivalence, including:

- **Delays:** Loved ones facing long delays in receiving healthcare, treatment, medication, and test results
- **Poor communication:** Relatives/carers being kept in the dark about what is going on
- **Missed appointments:** Long-awaited hospital appointments and operations being missed
- **Lack of respect:** Relatives and carers being seen as the enemy, being fobbed off and being lied to.

6. Equivalence

A plethora of legal tools and policy instruments point to the fact that prison healthcare services should be delivering standards of care and health outcomes for prisoners that are at least equivalent to that of the general population.

Yet as Pact's listening reports, as well as those produced by the House of Commons health and social care committee⁷ would attest, the prison healthcare system is beset by problems relating to:

- Missed appointments
- Barriers to access to primary care services
- Significant challenges in relation to resources and the workforce
- Insufficient and inadequate involvement of family members and carers.

6. Equivalence: International law

UN International Covenant on Economic Social and Cultural Rights (ICESCR) 1966, Article 1211

The right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

UN General Assembly Resolution 37/194, 1982

...those charged with the medical care of prisoners and detainees have a duty to provide them with protection of their physical and mental health and treatment of disease of the same quality and standard as is afforded to those who are not imprisoned or detained.

The UN 'Basic Principles for the Treatment of Prisoners', General Assembly resolution 45/111, 1990

Prisoners shall have access to the health services available in the country without discrimination on the grounds of their legal situation.

UN International Covenant on Civil and Political Rights (ICCPR) 1996, General Comment 2112

Persons deprived of their liberty enjoy all the rights set forth in the Covenant, subject to the restrictions that are unavoidable in a closed environment.

Committee of Ministers, Council of Europe, 1998: Recommendations for delivery of healthcare in prisons which abide by ethical principles:

Paragraph 13, recommendation No. R(98)7 concerning the ethical and organisational aspects of healthcare in prison: Medical confidentiality should be guaranteed and respected with the same rigour as in the population as a whole.

Paragraph 20:

Clinical decisions and any other assessments regarding the health of detained persons should be governed only by medical criteria. Healthcare personnel should operate with complete independence within the bounds of their qualifications and competence.

UN Standard Minimum Rules for the Treatment of Prisoners 70/175 (the Nelson Mandela Rules), 2015: Rule 1

All prisoners shall be treated with the respect due to their inherent dignity and value as human beings. No prisoner shall be subjected to, and all prisoners shall be protected from, torture and other cruel, inhuman, or degrading treatment or punishment, for which no circumstances whatsoever may be invoked as a justification. The safety and security of prisoners, staff, service providers and visitors shall be ensured at all times.

6. Equivalence: UK law

Case law

R (on the application of Nathan Brooks) v (1) Secretary of State for Justice (2) Isle of Wight Primary Care Trust, 2010

The High Court held that:

Prisoners are entitled, in so far as is possible, to the same attention as would be provided to any person under the terms of the National Health Service.

The judge added:

"There are, of course, some constraints which are inevitable because of security considerations..."

The role of the Care Quality Commission (CQC)

Responsibility (working with Her Majesty's Inspectorate of Prisons) to ensure that detainees are safeguarded against ill treatment and receive the same quality of care as the rest of the population.

Other potential legal mechanisms

- Personal injury claims caused by a breach of duty on the part of a healthcare provider
- Clinical negligence claims resulting from failures or errors in medical care
- Human Rights Act claim where the patient claims their medical treatment was so bad that it amounted to inhuman or degrading treatment (article 3 of the European Convention – the threshold for inhuman/degrading treatment is high)
- Judicial review: typically, a challenge to the refusal of treatment by prison healthcare
- Coroner's inquest: An investigation into the prisoner's death and the care received in prison is one of the circumstances relevant to the death.

6. Equivalence: Duty of candour

Duty of Candour Act 2014

The concept of duty of candour was first introduced in the Francis Report following the enquiry into failings at Mid Staffordshire Hospital in 2013. Under this legislation, enacted in 2014, duty of candour became a legal duty for NHS organisations. Failure by these organisations in relation to this duty is treated as a crime.

In 2015, this duty was extended to all health service bodies including the NHS, adult social care, primary medical and dental care, and independent healthcare providers. From that point onwards, if any of these agencies fails to notify and apologise to patients for incidents that have caused them harm, it will be treated as a criminal offence.

The CQC regulates whether these organisations are adhering to the duty.

6. Equivalence: Duty of candour

Duty of candour: Key principles	
1. Openness	Enabling questions, concerns and complaints to be raised freely without fear
2. Transparency	Allowing the truth about performance and outcomes to be shared with staff, patients, the public and regulators
3. Candour	Any patient harmed by the provision of a healthcare service is informed of the fact and an appropriate remedy is offered, regardless of whether a complaint has been made or a question asked about it
Apply to:	<p>Any 'notifiable patient safety incident' should be reported i.e. any unintended/unexpected incident if it causes, or is expected to cause:</p> <ul style="list-style-type: none"> • Death or severe harm, if it relates to the incident rather than the disease • Moderate harm, i.e. harm that is significant in that it requires a moderate increase in treatment and harm that is significant but not necessarily permanent • Prolonged psychological harm for a minimum of 28 continuous days.

6. Equivalence in practice

The Royal College of General Practitioners (RCGP)

In their guidance document,⁸ the RCGP reaffirmed its commitment to the delivery of healthcare in the health and justice system to prisoners and detainees that is of the *highest possible standard*. The document also highlighted what is stated in international, European and UK law, namely that healthcare provision in secure environments should be of an 'equivalent' standard to that which is provided in the wider community. However, the RCGP acknowledged that there is no resource setting out how equivalent care should be defined, measured or compared within the secure setting to that in the wider community, and acknowledged that this has implications for the way healthcare is delivered inside prisons.

Meanwhile, the RCGP highlighted that, ultimately, the goal of providing 'equivalent' care requires partnership working between the healthcare providers and security authorities and where possible, by integration with community services – all within the context of maintaining patient confidentiality.

6. Equivalence in practice

RGCP Equivalence principles

- Statutory, strategic and ethical objectives must be met by the health and justice organisations
- People detained in secure environments must be afforded provision of or access to appropriate services or treatment (based on assessed need and in line with current national or evidence-based guidelines)
- These services and treatment are considered to be at least consistent in range and quality (availability, accessibility and acceptability) with that available to the wider community in order to achieve equitable health outcomes
- Equivalence does *not mean* that healthcare in secure environments is *the same as* that provided in the community.

6. Equivalence in practice

NHSE Health and justice framework for integration 2022-25⁹

12 commitments

1. Putting the patient voice at the centre of everything we do.
2. Working in partnership to commission high quality care.
3. Supporting people with neurodiversity and complex health needs.
4. Providing evidence-based treatment as alternatives to custodial sentences.
5. Improving the health and well-being of vulnerable children.
6. Improving the health and well-being of people in custody.
7. Ensuring good mental health for adults in custody.
8. Reducing early and avoidable deaths.
9. Connecting people leaving custody to health services on release.
10. Improving the health of people detained in immigration removal centres.
11. Improving quality through learning and technology.
12. Ensuring an inclusive and representative workforce.

7. Mental Capacity Act (MCA) 2005

MCA provides a legal framework for the care, treatment and support of people who lack capacity to make decisions for themselves or are unable to manage their own affairs. Whilst the MCA's focus is on an individual being at the centre of decision making, the framework fully supports the involvement of loved ones. So person-centred care and family/carer involvement are both underpinned by the MCA.

There are some tensions between personalised approaches to care and wider family/carer involvement. Under the terms of the MCA, personal care plans can only be implemented or shared with others if the person gives consent where they have the capacity to do so. But the MCA framework recognises that involving other people who are part of the person's life generally leads to better outcomes, and tapping into a person's existing support networks leads to better information gathering, assessment and support.

Person centred care is also a key theme that runs through the Care Act 2014, particularly in relation to the concept of 'Making Safeguarding Personal' – a person-centred, outcome focused approach to adult safeguarding.

8. Children and young people (CYP) in the secure estate

Key legislation:

UN Convention on the Rights of the Child:

"Every child has the right to the enjoyment of the highest attainable standard of health."

Children Act 1989, Sections 20 and 31: Looked after children:

- Are in LA care for more than 24 hours
- Are in LA care until they are adopted or until they turn 18
- Continue to be supported by the LA until they turn 21
- Sometimes, though not always, remain 'looked after' whilst in custody and on release

Safeguarding children: The 'golden thread' embedded in the ethos of the CYP estate

- Safety and welfare are at the heart of all processes and procedures
- Preventing harm and abuse and promoting individual well-being are at the heart of everyone's role
- Parents, relatives and carers are usually notified about a safeguarding matter unless there's a compelling reason not to
- Staff do not need consent to share personal information if it is for the purpose of protecting or safeguarding a child or other individual in relation to neglect or harm, or to protect their physical, mental, or emotional well-being

Duty of Candour Act 2014 (see above)

Mental Capacity Act 2005 (see above)

The Caldicott Principles 2020 (see above)

Gillick Competence (1983 judgment, Gillick v DoH)

Children under 18 can consent to their own treatment if they are believed to have enough intelligence, competence and understanding to fully appreciate what is involved in their treatment.

If a child passes the Gillick test, he or she is considered 'Gillick competent' to consent to that medical treatment or intervention. As with adults, this consent is only valid if given voluntarily and not under undue influence or pressure from anyone else.

If a child does not pass the Gillick test, then the consent of a person with parental responsibility (or sometimes the courts) is needed in order to proceed with the treatment.

8. Children and young people (CYP) in the secure estate

Key procedural documents:

NHSE Commissioning guidance¹⁰

Nine principles:

- Improved outcomes for children
- Needs of children being met through the continued implementation of the framework for integrated care (secure stairs: consistent, trauma-informed, evidence-based care)
- Continual quality improvement
- Promoting change and improving life chances
- Compliance with healthcare standards for children and young people in secure settings
- Young people expected to be healthier (measurable improvements) when leaving detention than on arrival
- Concerted focus on safeguarding
- Improving the quality of data collection and sharing between partners
- Development of public health services in the CYP secure estate

Royal College of Paediatrics and Child Health (RCPCH):¹¹ Healthcare standards for children and young people in secure settings:

This document reaffirms the commitment to equivalence and highlights the interplay between privacy, confidentiality and information sharing. It emphasises the focus on consistent, high-quality individualised care planning and continuity of care, and sets out expectations in relation to proficiency and cultural competence on issues such as learning difficulties, disabilities, autism, and speech, language and communication issues.

It encourages ongoing feedback from parents/guardians, relatives and carers, requires timely and proactive handling of complaints, calls for a range of evidence-based neurodevelopmental supports and interventions based on individual needs, and emphasises the need for individualised care and support in relation to:

- Suicide risk
- Self-harm
- Serious mental health conditions

9. Neurodiversity in the secure estate

Joint criminal justice inspectorate report on neurodiversity in the criminal justice system, 2021¹²

Four key themes/lines of enquiry (all within the context of the impact of Covid-19):

- Screening to identify neurodivergence
- Adjustments to support neurodivergent needs
- Programmes and interventions
- Training and support for staff.

Key recommendations

- Co-ordinated, cross-government approach needed (MoJ, Home Office, DHSC, DfE and Welsh Government)
- Common screening tool for universal use within CJS supported by an information sharing protocol
- Systematic data collection to inform needs analysis and service planning
- Awareness-raising and specialist training
- Adjustments to be made across CJS focused on anticipated needs
- Criminal justice agencies working together, and with third sector organisations in a coordinated way.

9. Neurodiversity in the secure estate

Joint criminal justice inspectorate report on neurodiversity in the criminal justice system, 2021

Government response, September 2023¹³

- Cross-government operational-level working group formed in January 2023, meeting four times a year
- Third sector roundtables and lived experience forums hosted
- Engagement with stakeholders to understand the needs of women and racialised communities
- 100+ neurodiversity support managers recruited (prisons and probation)
- Spaces being created to address sensory and mental health requirements for patients with complex needs
- Easy-read versions of key prison documents being produced, e.g. induction handbooks
- Neurodiversity training being embedded into staff induction processes.

Future focus on:

- Further identifying support gaps
- Understanding barriers to diagnosis
- Embedding cross-boundary working
- Reviewing training needs in light of race and gender differences.

10. Disability in the secure estate: Key legislation

Equality Act 2010

Prisons must comply with the Act, which protects the rights of both detainees and staff.

The Act protects people's rights against discrimination on the grounds of (without limitation):

- Disability
- Race
- Age
- Religion
- Gender
- Sexual orientation

Requires adjustments in relation to:

- Hearing loss
- Communication and learning difficulties
- Visual impairment
- Limited mobility
- Neurodivergence

Types of discrimination

- **Direct:** Discriminates against an individual because of their disability and treats the person less favourably than a non-disabled person
- **Indirect:** A person or public body discriminates against an individual if they apply a provision, criterion or practice that is discriminatory in relation to the disability (e.g. not making reasonable adjustments)

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