



UK Mission  
Geneva

31 October 2018

**Catalina Devandas-Aguilar**

Special Rapporteur on the rights of persons with disabilities

**Agnes Callamard**

Special Rapporteur on extrajudicial, summary or arbitrary executions

**Dainius Puras**

Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health

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**From the Deputy Permanent  
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Dear Ms Devandas-Aguilar, Ms Callamard and Mr Puras,

Thank you for your letter dated 20 August regarding alleged human rights violations against persons with disabilities within public health facilities in the United Kingdom. Our comments and observations on the points raised in your letter are provided within the attached annex.

The UK Government reiterates our strong support for the work of the UN Treaty Bodies, the Special Rapporteur mandate holders, and the Office of the High Commissioner for Human Rights.

The UK has a long-standing commitment to promoting and protecting human rights. Ensuring non-discriminatory behaviour by individuals delivering care to patients continues to be the focus of much Government scrutiny and attention – to help ensure fair and just treatment for all. As such, we want to offer reassurance that issues such as those raised in your letter are taken extremely seriously by the UK Government.

Yours sincerely,

A handwritten signature in blue ink, appearing to read 'Miriam Shearman'.

**Miriam Shearman**  
Chargé d'Affaires  
UK Mission, Geneva

## Annex

The UK Government supported the development of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and was one of the first countries to sign it. When developing its policies and programmes, the UK Government acts in line with its UNCRPD treaty obligations to ensure that all disabled people, including those with an intellectual (learning) disability, can take part in society and be treated with dignity and respect. For example, the implementation framework for the Scottish Government's 'Keys to Life' learning disability strategy contains four strategic outcomes which relate to the UNCRPD.

The rights and freedoms set out in Schedule 1 of the European Convention on Human Rights are incorporated into domestic law by The Human Rights Act 1998 (HRA) which sets out the fundamental rights and freedoms which everyone in the UK is entitled to. A number of these are relevant to the design and delivery of health and care services and these include the right to life; the right to be free from inhuman/degrading behaviour; the right to liberty and the right to respect for private and family life.

Pursuant to Section 6 of the HRA it is unlawful for a public authority to act in a way which is incompatible with a Convention right. Alongside this, the HRA places a duty on public bodies to take action to ensure that people's rights are respected. The Human Rights Act places a duty on officials to both respect human rights and to take action to ensure that people's rights are respected. This includes protecting people from known risk to their rights, such as the risk of abuse or loss of life, preventing discrimination and promoting inclusion and participation.

People with a learning disability should be able to expect high quality care across all services provided by the NHS or social care. They should receive treatment, care and support that is safe and personalised and have the same access to services as everybody else.

The Equality Act 2010 prohibits various forms of discrimination, harassment, and victimisation in respect of certain protected characteristics, including disability, in the context of the provision of services and the exercise of public functions in Great Britain. The Public Sector Equality Duty (PSED), introduced under section 149 of the Equality Act 2010, requires all public bodies in Great Britain to have regard to the need to eliminate discrimination and the need to advance equality of opportunity and foster good relations between persons who share a relevant protected characteristic and those who do not share it. Therefore, providers and commissioners of health and care services in England, Wales and Scotland must consider the needs of diverse communities, including those with a learning disability, when planning, commissioning and providing services. Government departments and Ministers in Great Britain must also have regard to the PSED when making policy decisions.

In terms of anti-discrimination legislation, in general the legislation that applies in Northern Ireland is different to that for the rest of the UK. The Northern Ireland Act 1998 established the devolved Northern Ireland Assembly and anti-discrimination legislation is devolved in Northern Ireland. Section 75 of the Northern Ireland Act 1998 places public authorities in Northern Ireland under a duty to have due regard to the need to promote equality of opportunity between persons with a disability and persons without. The Disability Discrimination Act 1995 (DDA) bans disability discrimination by service providers against service-users with disabilities and places a duty on service providers to make reasonable adjustments for people with disabilities to help them to overcome barriers in accessing and using services, including health and social care services.

In England, the Government has enshrined equality and human rights principles in the NHS Constitution, under which NHS organisations in England are required to provide high quality

comprehensive services based on clinical need, and which do not discriminate between patients on the basis of disability. The National Health Service Act 2006 requires the Secretary of State, NHS England and Clinical Commissioning Groups to have regard to the need to reduce inequalities between the people of England with respect to the benefits that they can obtain from the health service.

In Scotland, mental health and incapacity legislation is based on rights and principles. It promotes patients' rights and provides safeguards which include that any function should be carried out for the maximum benefit of the patient, with the minimum necessary restriction on the freedom of the patient and having regard to the views of the patient and includes:

- equality - all powers under the Mental Health (Care and Treatment) (Scotland) Act 2003 should be exercised without any direct or indirect discrimination.
- non-discrimination – people with a mental disorder should, wherever possible, retain the same rights and entitlements as those with other health needs.
- respect for diversity – service users should receive care, treatment and support in a manner that accords respect for their individual qualities, abilities and diverse backgrounds.
- participation – service users should be fully involved, so far as they are able, in all aspects of their assessment, care, treatment and support; they should be provided with all the information and support necessary to enable them to participate fully; information should be provided in a way which makes it most likely to be understood.

Your letter raises a number of direct questions, which are addressed below.

**1. Please provide any additional information and/or comment(s) you may have on the above-mentioned allegations.**

As highlighted above, the UK Government has taken steps to improve the lives of people with a learning disability and realise the vision of everyone being treated with dignity and respect by health and care services and enjoying the same rights as everybody else.

Within England, the Government and NHS England have committed specifically to reducing health inequalities for people with learning disabilities and have established national programmes to improve treatment and outcomes. The [Government's Mandate to NHS England](#)<sup>1</sup> 2018-19 sets an objective for the NHS to close the health gap between people with mental health problems, learning disabilities and autism and the population as a whole.

As highlighted above, the 10-year '[Keys to Life](#)'<sup>2</sup> strategy in Scotland is designed to support people with a learning disability with a focus on improving health practice and outcomes so that people's human rights are respected and upheld. Between 2014 and 2016, the Care Inspectorate, which is the independent scrutiny and improvement body for social care and social work in Scotland, undertook an inspection of care services in Scotland to assess the extent to which care services supported the four strategic outcomes in 'Keys to Life', as well putting into practice the learning from Winterbourne View.

The Scottish Government are working on a new iteration of the implementation strategy of Keys to Life to be published at the end of the year. The next phase of The Keys to Life strategy will adopt a whole life and whole population approach and be closely aligned with the disability action plan - A

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<sup>1</sup> <https://www.gov.uk/government/publications/nhs-mandate-2018-to-2019>

<sup>2</sup> <https://keystolife.info/>

Fairer Scotland for Disabled People. There will be a greater focus on children and young people in the strategy.

During 2017, the Welsh Government undertook a comprehensive review of its learning disability policies across health, social care, education, transport and housing services. This stems from the Welsh Government's commitment to improve the lives of all citizens in Wales and to address inequalities where they exist.

Three key features of the Welsh Government's Programme for Government are:

- Delivering quality health and care services,
- Promoting good health and well-being, and
- Building healthier communities and better environments.

The review resulted in twenty-four outcome focussed recommendations and prioritised the reduction of health inequalities, increasing community integration, and improving planning and funding systems. The recommendations from the review have now been embedded in the Welsh Government's Learning Disability - Improving Lives Programme and will be implemented over the next two years.

In June this year, the Welsh Government published its long-term plan for health and social care '[A Healthier Wales](#)'<sup>3</sup>. This provides a blueprint to build and strengthen services for people with a learning disability and their families and carers, ensuring the seamless delivery of services focused around the needs of the individual and encouraging good practice to be shared consistently across Wales.

The Improving Lives Programme will focus on improving services in five key areas including health and social care:

- Social Care – making sure everyone who needs it has access to good quality care and support which is focused on their needs;
- Health – through reasonable adjustments to mainstream services and access to specialist services when needed, and making sure people with a learning disability receive the annual health checks they are entitled to and health boards ensure they meet the needs of people with a learning disability when in hospital.

In Northern Ireland, the [Physical and Sensory Disability Strategy and Action Plan](#)<sup>4</sup> was developed to help achieve and improve outcomes, services and support for people in Northern Ireland who have a physical, communication or sensory disability. It's intended to provide the strategic direction for the further development of services for disabled people. The strategy addresses the needs of all age groups, regardless of the cause of their disability. In accordance with the articles and principles of the Convention, it promotes; dignity and respect for individual differences, social inclusion and acceptance of the individual by society, independence and life opportunities, informed choices, anti-discrimination in service provision and equality of opportunity and access to services and facilities.

As the specific cases outlined in your letter demonstrate, steps were taken to investigate and review the deaths of the individuals concerned to identify and address any failures in services across health and social care. For example, the Government's response to the Confidential Inquiry into the Premature Deaths of People with Learning Disabilities (CIPOLD), which was established to investigate the avoidable or premature deaths of people with learning disabilities through a series of

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<sup>3</sup> <https://gov.wales/topics/health/publications/healthier-wales/?lang=en>

<sup>4</sup> <https://www.health-ni.gov.uk/publications/physical-and-sensory-disability-strategy-and-action-plan>

retrospective reviews of deaths in south-west England, recommended the establishment of a national learning disability mortality review to better understand the circumstances leading to a death and whether such deaths could potentially be avoided in the future through improvements to health and care services. The Learning Disabilities Mortality Review (LeDeR) Programme was established as a result and this continues to identify actions to tackle the inequality which exists in life expectancy of people with a learning disability, and those without. The Government has recently [responded to the second annual report of the LeDeR Programme](#)<sup>5</sup>, setting out a plan of action for each of the recommendations made in the report.

Where abuse and neglect of people with a learning disability has been identified, there are existing means of recourse available to take action against the individuals and organisations concerned. For example, the abuse that took place at Winterbourne View resulted in criminal convictions for a number of staff, as well as their removal from the register to practice. The Serious Case Review on Winterbourne View also showed a wider catalogue of failings at all levels both from the operating company and across the wider system which has resulted in changes in policy and practice in England. The Transforming Care Programme was established as a response to the findings from the investigation into the Winterbourne View case and this is seeking to reduce the number of people with a learning disability who are placed in inpatient services; reduce the length of time those admitted spend there, as well enhancing the quality of support in both hospital and community settings. Furthermore, the priority attached to improving care for people with a learning disability is reflected in the inclusion of learning disability as a clinical priority in the forthcoming NHS Long-Term Plan, which will set the ambitions to improve health services in England over the next decade.

The Scottish government has launched a [10-year strategy for mental health](#)<sup>6</sup>, which places human rights as a key theme. Part of the strategy is a review which will consider whether the provisions of the Mental Health (Care and Treatment) (Scotland) Act 2003 fulfils the needs of people with learning disability and autism. In England, an independent review of the Mental Health Act 1983 is also considering specific issues in relation to learning disabilities and autism, including how to avoid detention, and whether learning disabilities and autism should continue to be within the scope of the Act.

**2. Please provide details, and where available, the results, of any further investigations, including judicial or other inquiries, and prosecutions carried out in relation to premature deaths of persons with intellectual disabilities in the National Health Service, including changes introduced in health care services, as well as remedies and redress provided to the families of the victims.**

Attached, at **Annex A**, is a detailed timeline setting out the requested information.

In Scotland, a Ministerial review is currently underway, under section 37 of the Mental Health (Scotland) Act 2015, of the arrangements for investigating the deaths of patients who, at the time of death, were detained in or voluntarily admitted to hospital for the purposes of receiving treatment for mental disorder. The review is due to conclude by 24 December 2018.

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<sup>5</sup> <https://www.gov.uk/government/publications/government-response-to-the-learning-disabilities-mortality-review-leder-programme-2nd-annual-report>

<sup>6</sup> <https://www.gov.scot/Publications/2017/03/1750>

**3. Please provide the details on what measures have been taken to prevent, detect, report and address all forms of omission or abuse perpetrated against persons with intellectual disabilities in the National Health Service.**

England, Scotland, Wales and Northern Ireland each have their own health and care regulatory bodies to ensure that health and social care organisations are meeting relevant standards of safety and quality. If organisations fail to meet those standards, the regulatory bodies have a number of enforcement powers. These powers vary between the regulators but include the suspension or cancellation of registration, fixed penalty notices, the use of special measures and, in the most serious cases, bringing criminal prosecutions.

Acting on recommendations made in the national response to Winterbourne View and the The Mid-Staffordshire NHS Foundation Trust Public Inquiry (the Francis Inquiry), the Care Quality Commission (CQC), the health and care regulator for England, introduced new fundamental standards of safety and quality for all health and adult social care providers in England . [The fundamental standards](#)<sup>7</sup>, are the standards which must be met by health and social care providers in order to achieve or maintain their registration with the CQC. The fundamental standards are:

- Care and treatment must be appropriate and reflect service users' needs and preferences.
- Service users must be treated with dignity and respect.
- Care and treatment must only be provided with consent.
- Care and treatment must be provided in a safe way.
- Service users must be protected from abuse and improper treatment.
- Service users' nutritional and hydration needs must be met.
- All premises and equipment used must be clean, secure, suitable and used properly.
- Complaints must be appropriately investigated and appropriate action taken in response.

The United Kingdom also operates a system of professional regulation, whereby twelve organisations oversee the health and social care professions by regulating individual professionals. They do this by setting standards of behaviour, education and ethics that health and care professionals must meet, and by dealing with concerns about professionals who are unfit to practise owing to poor health, misconduct or poor performance. Professional regulators register health care professionals who are fit to practise in the United Kingdom and can remove professionals from the register and prevent them from practising where they consider this to be in the best interests of public safety.

Each professional regulator has a 'fitness to practise' process for handling complaints about health and care professionals. The most serious cases are referred to formal hearings in front of fitness to practise committees. The Professional Standards Authority, which oversees the professional regulators, will review final decisions made by the fitness to practise committees and refer these fitness to practice panel decisions to court where it believes they are unduly lenient and do not protect the public.

Section 43 of the Care Act 2014 introduced new safeguarding arrangements for adults in England. Under the Act, local authorities must:

- lead a multi-agency local adult safeguarding system that seeks to prevent abuse and neglect and stop it quickly when it happens;

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<sup>7</sup> <https://www.cqc.org.uk/what-we-do/how-we-do-our-job/fundamental-standards>

- make enquiries, or request others to make them, when they think an adult with care and support needs may be at risk of abuse or neglect and they need to find out what action may be needed;
- establish Safeguarding Adults Boards, including the local authority, NHS and police, which will develop, share and implement a joint safeguarding strategy;
- carry out Safeguarding Adults Reviews when someone with care and support needs dies as a result of neglect or abuse and there is a concern that the local authority or its partners could have done more to protect them;
- arrange for an independent advocate to represent and support a person who is the subject of a safeguarding enquiry or review, if required.

The Social Services and Well-being (Wales) Act 2014 introduced strengthened arrangements for safeguarding adults. This includes:

- establishing Safeguarding Adult Boards in Wales, on a statutory basis;
- introducing the 'duty to report' where there is reasonable cause to suspect that a person is an adult at risk
- establishing the National Independent Safeguarding Board, which must make an annual report to Welsh Ministers on the adequacy and effectiveness of arrangements to safeguard children and adults in Wales, and make recommendations as to how those arrangements could be improved.

To contribute to improvements in the quality of health and social care for people with learning disabilities in England, the Learning Disabilities Mortality Review (LeDeR) programme has been established to support local areas in England to carry out local reviews of deaths of people with learning disabilities. The Programme has developed a review process for the deaths of people with learning disabilities and provides support to local areas to take forward the lessons learned in the reviews to make improvements to service provision. LeDeR reviews do not hold any individual or organisation to account. They support local agencies to identify and learn from any potentially avoidable factors that may have contributed to an individual's death.

Pursuant to sections 20 and 21 of the Criminal Justice and Courts Act 2015, it is a criminal offence for a care worker or care provider to 'ill-treat or wilfully neglect' an individual in their care. Sections 20 and 21 of the Act came into force on 13 April 2015 as a response to number of hospital and care home abuse scandals and especially in relation to the abuse of the vulnerable adults and the elderly. Under section 20 of this Act, it is an offence for an individual who is paid to provide health or social care (other than excluded health care) to ill-treat or wilfully to neglect that individual. Section 21 applies to 'care providers', as defined in section 21 (2) and means that the care provider is criminally responsible if:

- a) an individual who has the care of another individual as part of the care provider's arrangements i.e. an employee ill-treats or wilfully neglect that individual;
- b) the care provider's activities are managed or organised in a way which amounts to a gross breach of a duty of care to the ill-treated or neglected individual and were it not for this breach the ill-treatment or wilful neglect would not have occurred or would have been less likely to occur.

The definition of 'wilful' is taken from case-law and is defined as intentional, or reckless and can be said to reflect a "couldn't care less attitude" towards those that care is provided.

The Mental Capacity Act 2005 introduced the criminal offences of ill treatment and wilful neglect of a person who lacks capacity to make relevant decisions in England and Wales. These offences apply to anyone caring for a person who lacks capacity, including healthcare and social care staff in hospital or care homes and those providing care in a person's home. Similar provisions exist in the Mental Capacity Act (Northern Ireland) 2016, which was enacted by the Northern Ireland Assembly in 2016 but is not yet commenced. When commenced the Act will provide a statutory framework for acts in relation to care, treatment and personal welfare for those who are 16 and over and lack capacity to consent.

Other processes, such as criminal or civil proceedings or disciplinary procedures within individual organisations, may also apply in any cases of neglect or abuse.

In Scotland, all patients receiving care or treatment are entitled to receive high-quality person-centred care in a safe setting, and the vast majority of mental health care and treatment across Scotland is provided with care and compassion. Section 315 of the Mental Health (Care and Treatment) (Scotland) Act 2003 provides for an offence which applies where a person is ill-treated or wilfully neglected in the course of the provision of their care or treatment. On investigation of a complaint, the police will decide if there is sufficient evidence to submit a report to the Procurator Fiscal.

The Scottish Government is committed to ensuring that the criminal justice system is able to hold individuals and organisations to account where they are responsible for serious and deliberate neglect or ill-treatment in the course of providing care. The Health (Tobacco, Nicotine etc. and Care) (Scotland) Act 2016 ("the 2016 Act"), introduced new offences relating to the ill-treatment or wilful neglect of adults receiving health care or social care (including mental health care or treatment). The 2016 Act also introduces two offences: one for care workers; and one in respect of organisations, which will allow neglect or ill-treatment that has resulted from organisational failings to be dealt with effectively.

#### **4. Please explain what measures have been taken to inform and raise awareness among persons with intellectual disabilities and their families on how to identify and facilitate their access to complaint and reporting mechanisms against inadequate access to healthcare or discrimination within the National Health Service**

The NHS complaints system within the United Kingdom is designed to ensure that making a complaint is as straightforward as possible by providing support to complainants throughout the process where needed. Where an NHS patient is unhappy with the healthcare they have received, they, or someone on their behalf and with their consent, can use the NHS complaints procedure. Relevant healthcare providers are required to ensure that patients and their representatives are aware of how to do this.

In England, Regulation 5(2) of the Local Authority Social Services and National Health Service Complaints (England) Regulations 2009, specifically allows for a complaint to be made by a representative of the complainant if they are unable to make the complaint themselves for example because of:

- Physical incapacity;
- Lack of capacity within the meaning of the Mental Capacity Act 2005; or
- Has requested the representative to act on their behalf



If the complaint cannot be resolved locally the complainant is able to ask the relevant Ombudsman to investigate the case, with England, Wales, Scotland and Northern Ireland each having their own Ombudsmen. Following an investigation, the Ombudsman may recommend that an organisation:

- Provides a written apology
- Reviews a decision or changes a process
- Puts in place a procedure they should have had
- Complies with their complaints process

In cases of poor care and abuse, or alleged poor care or abuse, individuals may report this to the relevant regulator – England, Scotland, Wales and Northern Ireland each has its own regulatory bodies - which will use the information when inspecting health and social care services to make sure that they are meeting the relevant standards of quality and safety.

In England, the Department of Health and Social Care has sought to improve the information available locally for NHS patients on how to complain, including by publishing [a national advice guide](#)<sup>8</sup>, providing templates for posters on every hospital ward and, through Healthwatch England, which was established to provide a collective voice for people who use health and social care services, working with Citizens Advice, has ensured that there is accurate information online about how to complain.

Additionally, the Parliamentary and Health Service Ombudsman in England has provided [information, including information in easy read format](#)<sup>9</sup>, for people with a learning disability on how to make a complaint about NHS services.

The [Ask Listen Do project](#)<sup>10</sup> has been established by NHS England to support organisations to learn from and improve the experiences of people with a learning disability, autism or both, their families and carers when giving feedback, raising a concern or making a complaint. Resources have been developed to support good practice in organisations across health, education and social care, and guidance for people, families and carers so that they feel empowered and confident to speak up.

From August 2016, all NHS and publicly funded adult social care providers across England have been legally required, under section 250 of the Health and Social Care Act 2012, to have regard to the Accessible Information Standard. The Standard sets out a specific consistent approach to identifying, recording, flagging, sharing and meeting the communication needs of patients, service users, carers, and parents with a disability, impairment or sensory loss. As such, health and publicly funded social care providers should support individuals with information and communication needs to provide feedback on their experience of services.

Since April 2013, individual local authorities in England have had a statutory duty to commission independent advocacy services to provide support for people making, or thinking of making, a complaint about their NHS care or treatment. The arrangements for advocacy arrangements will vary between local authority areas. Complainants will be advised to contact their local Healthwatch or local authority for information on how this service is provided in their area.

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<sup>8</sup> <https://www.nhs.uk/using-the-nhs/about-the-nhs/how-to-complain-to-the-nhs/>

<sup>9</sup> <https://www.ombudsman.org.uk/making-complaint/before-you-come-to-us/complain-change/information-for-people-learning-disability-Easy-Read>

<sup>10</sup> <https://www.england.nhs.uk/learning-disabilities/about/ask-listen-do/>

In addition, most hospitals in England have a Patient Advice and Liaison Service (PALS), which is part of the NHS, and offers confidential advice, support and information on health-related matters providing a point of contact for patients, their families and their carers.

In Scotland, there is an independent Mental Health Tribunal, which grants and reviews orders for compulsory treatment. The independent Mental Welfare Commission (MWC) monitors the use of Scottish mental health law, including compulsory treatment. The MWC also has the power to intervene in particular cases if there is evidence of improper care, treatment or practices.

Anyone discharging a function under the Mental Health (Care and Treatment) (Scotland) Act 2003 must have regard to the present and past wishes and feelings of the patient have regard to the importance of the patient participating as fully as possible in the discharge of the function and to the importance of providing the information and support necessary to the patient to participate.

The Scottish Government is clear that access to independent advocacy is a key part of ensuring that people have their voices heard in discussions about their health and wellbeing. The Scottish Government has continued to make funding available to both NHS Boards and the Scottish Independent Advocacy Alliance so that people are supported to understand their choices and make their own decisions. Individual patient care and treatment is the responsibility of the NHS and its clinicians however all patients have the right to complain to the NHS who themselves have a duty to make public their complaints procedures. In addition, Citizens Advice Bureau offers a useful service to NHS patients and carers in relation to providing support to make a complaint.

#### **5. Please provide information and details on any measures taken regarding accountability mechanisms to address the concerns identified in the various reports in the National Health Service**

The Department of Health and Social Care holds NHS England to account for improving health services for people with a learning disability through the NHS Mandate, which specifies the objectives for the health service which NHS England should seek to achieve. This includes an expectation to reduce the health gap between people with mental health problems, learning disabilities and autism and the population as a whole, and to provide support for them to live full, healthy and independent lives.

NHS England is legally required to seek to achieve the objectives set out in the Mandate and progress is monitored through regular updates to the Department of Health and Social Care and through the Secretary of State for Health and Social Care's quarterly accountability meetings. The Secretary of State also publishes an annual assessment, which summarises how well NHS England has achieved its objectives.

In response to the CQC's report, '[Learning, candour and accountability: A review of the way NHS trusts review and investigate the deaths of patients in England](https://www.cqc.org.uk/sites/default/files/20161213-learning-candour-accountability-full-report.pdf)'<sup>11</sup>, a Learning from Deaths Programme Board has been established to provide oversight of progress made against the recommendations in the CQC's report. A key objective of the national Learning from Deaths Programme is to ensure greater scrutiny of care for people with a learning disability and mental health needs, in all healthcare settings to reduce premature mortality. This is being taken forward through the Learning Disability Mortality Review (LeDeR) programme. As highlighted above, Transforming Care is a programme of work to improve health outcomes and quality of life for people with a learning disability and/or autism with behaviour that challenges, including those with a mental health condition and was established in response to the abuse revealed at Winterbourne View. In 2017, a new assurance programme was

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<sup>11</sup> <https://www.cqc.org.uk/sites/default/files/20161213-learning-candour-accountability-full-report.pdf>

established for the programme. Transforming Care Assurance Meetings (TCAM) are held quarterly for key delivery partners of the Transforming Care programme to hold them to account for delivery of the programme's objectives and to provide information about progress and risks to delivery. Meetings are informed by a new dashboard of key metrics and measures to assess progress of the programme.

Additionally, meetings of TCAM are preceded by meetings of the Transforming Care Assurance Stakeholder Roundtable meeting (TCASR). These involve a selection of representative groups, self-advocates and carer and family representatives and its purpose is to compile views from the ground and identify key areas and concerns to be raised with delivery partners.

**6. Please provide information on measures that will be taken to implement the recommendations contained in the LeDeR report of May 2018.**

[The UK Government's response to the national recommendations of the second annual LeDeR report](https://www.gov.uk/government/publications/government-response-to-the-learning-disabilities-mortality-review-leder-programme-2nd-annual-report)<sup>12</sup> was published on the 12<sup>th</sup> September 2018.

The Government's response highlights the action that is already underway to address the concerns raised in the LeDeR report and planned new actions.

**7. Please provide information on any measures taken to raise the awareness and provide training to personnel and care givers within the National Health Service directly providing services to persons with intellectual disabilities**

In England, it is the responsibility of individual employers to ensure that their staff are appropriately trained and competent to fulfil the responsibilities of the role. Regulation 18 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 require that any person employed by a service regulated by the CQC must receive the support, training, professional development, supervision and appraisal as necessary to enable them to carry out the duties they are employed to perform.

To support a consistent approach to learning disability education and training in England, the Department of Health commissioned and funded Skills for Health, Skills for Care and Health Education England to develop a Learning Disabilities Core Skills Education and Training Framework. Published in July 2016, the Framework, which sets out the essential skills and knowledge needed for all staff working with people with learning disabilities in health and social care settings, is structured in three tiers, or levels of training, to reflect the different levels of knowledge specific roles would require:

- Tier 1 - for roles that require general awareness of learning disabilities;
- Tier 2 - for roles that will have some regular contact with people (children, young people and adults) with a learning disability, and;
- Tier 3 - for those staff directly providing care and support for people (children, young people and adults) with a learning disability.

The Department of Health and Social Care has also commissioned Health Education England to develop an Autism Core Skills and Competency Framework to set out the knowledge, skills and behaviours needed for safe and effective practice when providing care to an individual on the Autism spectrum. It is anticipated that the Framework will be published in Spring 2019

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<sup>12</sup> <https://www.gov.uk/government/publications/government-response-to-the-learning-disabilities-mortality-review-leder-programme-2nd-annual-report>.

In April 2015, the Department of Health introduced the Care Certificate for health and care support workers in England, which sets out the fundamental skills, knowledge and behaviours that are required to provide safe and effective care. Comprising of 15 standards, which include a standard covering awareness of learning disability, mental health and dementia, the Care Certificate provides assurance to employers, patients and service users that employees who hold the certificate have been trained to a specific set of standards and know how to act with compassion and respect.

Whilst the Care Certificate is not mandatory, all new health care assistants and social care support workers are expected to attain the Care Certificate within their first twelve weeks of employment. As part of its inspection regime, the CQC expects to see that those who employ health care support workers and adult social care support workers demonstrating that staff have, or are working towards, the skills set out in the Care Certificate, or an equivalent, as the benchmark for staff induction.

In June 2018, NHS Improvement published, for guidance, [Learning Disability Improvement Standards](#)<sup>13</sup> for NHS Trusts in England to help ensure that Trusts monitor and review the care they provide to people with a learning disability, autism or both. One of the four standards is aimed at ensuring that trusts provide ongoing training to their staff on how to deliver care to people with learning disabilities, autism or both who use their services. The CQC is working with NHS Improvement to consider how they can encourage trusts to adopt and work to the standards.

As part of the Government's response to the LeDeR report, the Department of Health and Social Care and its partner organisations, have committed to a series of actions to increase uptake of learning disability training. The key action is to consult on proposals for mandatory learning disability awareness training for NHS staff. This will be completed by the end of March 2019. Additionally, actions include:

- Reminding health and social care providers and employers of their responsibilities in terms of training and promote use of the Learning Disabilities Core Skills Education and Training Framework.
- The development of a Tier 1 awareness training package, developed in conjunction with experts by experience (people with learning disabilities who use services and their carers).
- An audit of learning disability training provision.
- A skills and training audit of the social care workforce based on the Learning Disabilities Core Skills Education and Training Framework

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<sup>13</sup> <https://improvement.nhs.uk/resources/learning-disability-improvement-standards-nhs-trusts/>

## ANNEX A.

### TIMELINE FOR QUESTION TWO.

2007	Mencap publishes its report, ' <a href="#">Death by Indifference</a> ' <sup>14</sup> , which presented the stories of six people with a learning disability, who Mencap believed died unnecessarily due to institutional discrimination within the NHS.
2008	The report of Sir Jonathan Michael's ' <a href="#">Healthcare for All: an independent inquiry into access to healthcare for people with learning disabilities</a> ' <sup>15</sup> , was published. The inquiry was commissioned by the Department of Health (now Department of Health and Social Care)
2009	The Health Services and Parliamentary Ombudsman publishes, ' <a href="#">Six lives: the provision of public services to people with learning disabilities</a> ' <sup>16</sup> , it's report into the deaths of the people identified in the Mencap report.
2010-2013	<p>The Department of Health establishes and funds the <a href="#">Confidential Inquiry into the premature deaths of people with learning disabilities (CIPOLD)</a><sup>17</sup> from <b>April 2010 to March 2013</b>, in response to a recommendation in 'Healthcare for All'. This review investigates the avoidable or premature deaths of people with learning disabilities through a series of retrospective reviews.</p> <p><a href="#">The Government's response to CIPOLD</a><sup>18</sup> is published in <b>July 2013</b>, setting out the actions to be delivered by the Department, NHS England and Public Health England and other statutory organisations to address the Inquiry's recommendations. This included the establishment of a National Learning Disability Mortality Review Body.</p>
2011	<p><b>In May 2011</b>, an episode of BBC's Panorama programme, Undercover Care: The Abuse Exposed shows people with a learning disability and autism being abused in Winterbourne View, a hospital registered to detain people under the Mental Health Act run by Castlebeck Care Ltd in Bristol.</p> <p>The Care Quality Commission (CQC) announces an immediate programme of inspections of facilities run by Castlebeck in <b>May 2011</b>. The CQC also writes to Paul Burstow, the then Minister for Care Services, suggesting a programme of risk-based and random unannounced inspections of a sample of the 150 hospitals providing care for people with learning disabilities, which the Minister supports.</p> <p>A Serious Case Review of Winterbourne Review is announced by South Gloucestershire Council in <b>June 2011</b>.</p> <p>Paul Burstow announces a review into Winterbourne View as part of a wider lesson-learning exercise in <b>June 2011</b>.</p>

<sup>14</sup> <https://www.mencap.org.uk/sites/default/files/2016-06/DBIreport.pdf>

<sup>15</sup> [http://webarchive.nationalarchives.gov.uk/20130105064250/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_099255](http://webarchive.nationalarchives.gov.uk/20130105064250/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_099255)

<sup>16</sup> <https://www.gov.uk/government/publications/six-lives-the-provision-of-public-services-to-people-with-learning-difficulties-2008-to-2009>

<sup>17</sup> <http://www.bristol.ac.uk/cipold/>

<sup>18</sup> <https://www.gov.uk/government/publications/response-to-the-confidential-inquiry-into-learning-disability>

	<p>Winterbourne View closes on <b>24 June 2011</b>.</p> <p><b>In July 2011</b>, <a href="#">the CQC publishes its findings following an inspection of services at Winterbourne View</a>.<sup>19</sup> The report finds a “systemic failure to protect people at the hospital. The CQC also publishes the results of its review of all services run by Castlebeck. The report highlights serious concerns at four Castlebeck homes – Arden Vale in Coventry, Rose Villa in Bristol, Cedar Vale in Nottingham and Croxton Ledge in Melton Mowbray.</p> <p>Castlebeck announces the closure of Arden Vale on <b>17th August</b>, ahead of the conclusion of legal action by CQC. Rose Villa closes in the previous week.</p> <p>The CQC publishes its first five pilot reports from its targeted programme of 150 unannounced inspections of hospitals and care homes that care for people with learning disabilities in <b>December 2011</b>.</p> <p>The Department of Health asends update letters to the NHS and Local Authorities, about actions they are expected to take further to Winterbourne View in <b>December 2011</b>.</p>
<p><b>2012</b></p>	<p><b>In June 2012</b>, the <a href="#">interim report of the Review of Winterbourne View</a><sup>20</sup> is published, setting out 14 national actions to improve the care and support of people with learning disabilities or autism. These include:</p> <ul style="list-style-type: none"> <li>• Improving the capacity and capability of commissioning across health and care</li> <li>• Improving the quality of services which empower people with learning disabilities and their families to have choice and control</li> <li>• Clarifying roles and responsibilities and promoting better integration</li> <li>• Promoting innovation and reducing use</li> </ul> <p><a href="#">The CQC also publishes the report of its inspection of 150 learning disability services</a><sup>21</sup> <b>in June 2012</b>. Overall, the CQC found that nearly half the hospitals and care homes inspected did not meet the required standards and that some assessment and treatment services admitted people for disproportionately long spells of time and that discharge arrangements took too long to arrange. There was also an urgent need to reduce the use of restraint.</p> <p>David Nicholson, the then Chief Executive of the NHS, and David Behan, the then Director General of Social Care in the Department of Health write to NHS Bodies and Local Authorities in <b>July 2012</b> highlighting action to be taken as set out in the Department’s interim report on Winterbourne View.</p> <p>NHS South West publishes its report of a review of commissioning of care and treatment at Winterbourne View in <b>August 2012</b>. It criticises how contracts for Winterbourne View were drawn up.</p>

<sup>19</sup> <https://www.cqc.org.uk/news/releases/cqc-report-winterbourne-view-confirms-its-owners-failed-protect-people-abuse>

<sup>20</sup> <https://www.gov.uk/government/publications/winterbourne-view-hospital-interim-report-improving-care-of-vulnerable-people-with-learning-disabilities>

<sup>21</sup> [https://www.cqc.org.uk/sites/default/files/documents/cqc\\_ld\\_review\\_national\\_overview.pdf](https://www.cqc.org.uk/sites/default/files/documents/cqc_ld_review_national_overview.pdf)

	<p><a href="#">The CQC releases 'Our role in Winterbourne View' report</a><sup>22</sup> in <b>August 2012</b>. The report highlights failings in the way it responded to the concerns of whistleblowers and led to changes in the way the CQC works with local safeguarding teams; follows-up on action plans when services aren't meeting national standards and developing new ways to analyse safeguarding alerts to spot trends.</p> <p><a href="#">The Serious Case Review of Winterbourne Review</a><sup>23</sup> is published in <b>September 2012</b>, showing that the abuse at Winterbourne View Hospital resulted from serious and sustained failings in the management procedures of Castlebeck Limited, as well as shortcomings in other organisations' systems and procedures in terms of commissioning care and safeguarding the wellbeing of patients before and during their stay at Winterbourne View hospital. Recommendations include a call for greater investment in community-based care in order to reduce the need for in-patient admissions at assessment, treatment and rehabilitation units such as Winterbourne View Hospital.</p> <p><b>In October 2012</b>, six former employees of Winterbourne View are given jail sentences for ill-treatment, abuse and wilful neglect. A further five receive suspended sentences. In total, they admit to 38 charges of neglect or abuse. The Nursing and Midwifery Council later takes action against 14 individuals, resulting in six striking off orders and two suspensions.</p> <p>The first Mandate between the Department of Health and the NHS Commissioning Board (now NHS England) is published in <b>November 2012</b>. It says <i>"The NHS Commissioning Board's objective is to ensure that Clinical Commissioning Groups work with local authorities to ensure that vulnerable people, particularly those with learning disabilities and autism, receive safe, appropriate, high quality care. The presumption should always be that services are local and that people remain in their communities; we expect to see a substantial reduction in reliance on inpatient care for these groups of people"</i>.</p> <p><b>In December 2012</b>, the Department of Health publishes its final Winterbourne report, <a href="#">'Transforming care: a national response to Winterbourne View hospital'</a>, the Concordat agreement for the way forward, a summary of responses to the report's engagement, and good practice examples. The report sets out timetabled actions for health and local authority commissioners working together to transform care and support for people with learning disabilities or autism who also have mental health conditions or behaviours viewed as challenging, whilst the Concordat sets out the commitment to work with system partners, as well as individuals and families, and with the groups which represent them, to the improve quality of care and ensure better outcomes.</p>
<b>2013</b>	<p><b>In June 2013</b>, the Department of Health, NHS England, Local Government Association, Association of Directors of Adult Social Services, Care Quality Commission and the National Forum of People with Learning Disabilities issued a joint statement emphasising their commitment to making the lives of people with learning disabilities better and safer, and improving their health and care.</p>

<sup>22</sup> <https://www.cqc.org.uk/news/stories/our-role-winterbourne-view-changes-we-will-make-protect-people-abuse>

<sup>23</sup> <http://www.southglos.gov.uk/news/serious-case-review-winterbourne-view/>



	<p>In <b>July 2013</b>, Connor Sparrowhawk dies from drowning in July 2013 in a residential care unit (Slade House) run by Southern Health NHS foundation trust after having an epileptic seizure in the bath. Two months after his death, an unannounced Care Quality Commission inspection of Slade House found the unit to be inadequate in all 10 measures of assessment. Enforcement notices were issued and it subsequently closed. In <b>October, 2013</b>, A jury inquest finds that neglect contributed towards the death of Connor and in <b>February 2014</b>, an <a href="#">independent report by Verita, commissioned by Southern Health</a><sup>24</sup>, found his death was preventable and was the outcome of a combination of poor leadership and poor care in the unit. Following publication of this report, Oxfordshire Safeguarding Adults Board and NHS England (South) commissioned <a href="#">a second report</a><sup>25</sup> from Verita to find out whether there were wider commissioning, leadership or management issues that could have contributed to the inadequate care that Connor received. This was published in <b>October 2015</b> and identifies a number of problems in commissioning, leadership and management of learning disability services, both locally and nationally. In <b>March 2018</b>, Southern Health pleads guilty to two breaches of Section 3(1) of the Health and Safety at Work etc. Act 1974 and is fined a total of £2million.</p> <p>The Department of Health publishes its report, <a href="#">Winterbourne View: Transforming Care One Year</a><sup>26</sup> On in <b>December 2013</b>. It found that most of the 75 commitments in the Concordat have been delivered or were on track. However, the report's foreword acknowledged that the pace of progress would need to be accelerated to meet the pledge that, by June 2014, people with learning disabilities and / or autism inappropriately placed in hospital would be moved to community based support.</p>
<b>2014</b>	<p>In <b>April 2014</b>, the Department of Health launches Positive and Proactive Care, new guidance on reducing the use of restrictive interventions.</p> <p>In <b>November 2014</b>, Sir Stephen Bubb publishes his report <a href="#">Winterbourne View – Time for Change</a><sup>27</sup>, which was commissioned by NHS England to make recommendations for a national commissioning framework under which local commissioners would secure community-based support for people with learning disabilities and/or autism. The report was prompted by the failure to meet the June 2014 target to move people inappropriately placed in hospital into community based support.</p>
<b>2015</b>	<p>In <b>January 2015</b>, the Department of Health publishes '<i>Transforming care: 2 years on</i>'<a href="https://www.gov.uk/government/publications/winterbourne-view-2-years-on">https://www.gov.uk/government/publications/winterbourne-view-2-years-on</a><sup>28</sup> a collective account from partners across the health and care system providing an update against the actions in the original report. It showed that not as much progress had been made as was intended.</p> <p>NHS England also publishes '<a href="#">Next Steps in Transforming Care</a>'<sup>29</sup> in <b>January 2015</b>, setting out plans to accelerate progress on the Transforming Care programme..</p>

<sup>24</sup> <https://www.verita.net/library/reports/?pid=464>

<sup>25</sup> <https://www.gov.uk/government/publications/winterbourne-view-progress-report>  
<https://www.england.nhs.uk/wp-content/uploads/2015/10/indpdnt-rev-connor-sparrowhawk.pdf>

<sup>26</sup> <https://www.gov.uk/government/publications/winterbourne-view-progress-report>

<sup>27</sup> <https://www.england.nhs.uk/wp-content/uploads/2014/11/transforming-commissioning-services.pdf>

<sup>28</sup> <https://www.gov.uk/government/publications/winterbourne-view-2-years-on>

<sup>29</sup> <https://www.england.nhs.uk/wp-content/uploads/2015/01/transform-care-nxt-stps.pdf>



In **February 2015**, the National Audit Office publishes its report, '[Care services for people with learning disabilities and challenging behaviour](#)',<sup>30</sup> which looked at the progress that had been made in delivering the Transforming Care programme. The report acknowledged whilst the speed of progress had improved, NHS England faced significant challenges in establishing a new model of care in more appropriate settings. NHS England publicly commit to a programme of closing inappropriate inpatient facilities and establishing stronger support in the community.

In **June 2015**, the Learning Disabilities Mortality Review programme is established. The programme was commissioned by NHS England to support local areas in England to review the deaths of people with a learning disability to:

- Identify common themes and learning points
- Provide support to local areas in their development of action plans to take forward the lessons learned

In **July 2015**, Sir Stephen Bubb publishes a review of the progress being made by the [Transforming Care programme, 'Winterbourne View - Time is Running Out'](#)<sup>31</sup>, providing an update on January's Transforming Care Two Years On. Sir Stephen acknowledges that there was "a definite shift in the direction and commitment to change" that was not present when the review started. However, the pace of change remained slow.

Also in **July 2015**, NHS England, the Local Government Association (LGA) and the Association of Directors of Adult Social Services (ADASS) publish their draft national service model on supporting people with a learning disability and / or autism who have a mental health condition or display behaviour that challenges. The model sets out what good services look like to ensure some national consistency in health, social care and housing services, whilst giving commissioners the flexibility to design services that best meet the needs of their local population.

['Building the right support: A national implementation plan to develop community services and close inpatient facilities](#), is published by NHS England, the LGA and Government Association ADASS in **October 2015**.

In **December 2015**, the report of the '[Independent review of deaths of people with a learning disability or mental health problem in contact with Southern Health NHS Foundation Trust April 2011 to March 2015](#)'<sup>32</sup> (known as the Mazars review) was published. This sought to establish the extent of unexpected deaths in Mental Health and Learning Disability services provided by the Trust and to identify any themes, patterns or issues that may need further investigation. Whilst most of the 10,306 deaths during this period were expected, 1,454 of these were unexpected. The report concludes that failures by the trust's board and senior executives meant that no effective management of deaths or investigations took place and there was a lack of an effective focus or leadership from the board.

<sup>30</sup> <https://www.nao.org.uk/wp-content/uploads/2015/02/Care-services-for-people-with-learning-disabilities-and-challenging-behaviour.pdf>

<sup>31</sup> <https://www.challengingbehaviour.org.uk/cbf-articles/latest-news/time-is-running-out.html>

<sup>32</sup> <https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2015/12/mazars-rep.pdf>

<p><b>2016</b></p>	<p>Sir Stephen Bubb publishes his third and final report, '<a href="#">Time for Change – the Challenge Ahead</a>'<sup>33</sup> in <b>February 2016</b>. In it, he outlines the findings of his consultations with people with learning disabilities, their families and service providers.</p> <p>The Royal College of Nursing (RCN) also publishes <a href="#">Connect for Change – an update on learning disability services in England</a><sup>34</sup> in <b>February 2016</b> which finds that many children and adults with learning disabilities were not receiving the care and support they needed because of issues with staffing, strategy and services.</p> <p><b>In December 2016</b>, the CQC publishes '<a href="#">Learning, candour and accountability. A review of the way NHS trusts review and investigate the deaths of patients in England</a>'<sup>35</sup> It found that some providers were not giving learning from deaths sufficient priority and were missing valuable opportunities to identify and make improvements in quality of care.</p>
<p><b>2017</b></p>	<p><b>In January 2017</b>, Dame Christine Lenehan publishes '<a href="#">These are our children</a>'<sup>36</sup>, her review of the care, support and treatment provided to the group of children and young people with complex needs (and behaviour that challenges) involving mental health problems and learning disabilities and/ or autism. Her report makes 11 recommendations for government departments and partners at a national level on how to improve the system.</p> <p><b>In March 2017</b>, the National Quality Board (NQB) introduces <a href="#">new guidance</a><sup>37</sup> for NHS providers on how they should learn from the deaths of people in their care. The guidance states that all inpatient, outpatient and community patient deaths of people with learning disabilities should be reviewed so that learning can contribute to service improvements. The guidance also states that individual trusts should publish mortality data on a quarterly basis from 2017-18 including estimates of how many deaths are thought to be due to problems in care, including deaths of people who had a learning disability.</p> <p><b>In March 2017</b>, the National Audit Office also publishes its report '<a href="#">Local support for people with a learning disability</a>'<sup>38</sup>. The report acknowledged that good progress had been made by the Transforming Care programme, but the necessary conditions to make the programme a success, such as community-based accommodation were not in place.</p>
<p><b>2018</b></p>	<p>The University of Bristol publish their <a href="#">second annual report of the LeDeR programme</a><sup>39</sup> in <b>May 2018</b>. Covering the period July 2016 to November 2017, the report includes 1,311 deaths notified to the programme and it set out nine recommendations based on the 103 reviews completed in this period. Reviewers indicated that in 13 cases, the</p>

<sup>33</sup> <https://www.acevo.org.uk/news/winterbourne-view-time-change-report-launch>

<sup>34</sup> <https://www.rcn.org.uk/professional-development/publications/pub-005525>

<sup>35</sup> <https://www.cqc.org.uk/sites/default/files/20161213-learning-candour-accountability-full-report.pdf>

<sup>36</sup> [https://www.ncb.org.uk/sites/default/files/field/attachment/These%20are%20Our%20Children\\_Lenehan\\_Review\\_Report.pdf](https://www.ncb.org.uk/sites/default/files/field/attachment/These%20are%20Our%20Children_Lenehan_Review_Report.pdf)

<sup>37</sup> <https://www.england.nhs.uk/wp-content/uploads/2017/03/nqb-national-guidance-learning-from-deaths.pdf>

<sup>38</sup> <https://www.nao.org.uk/report/local-support-for-people-with-a-learning-disability/>

<sup>39</sup> <http://www.bristol.ac.uk/sps/leder/news/2018/leder-annual-report-2016-2017.html>

	person's health had been adversely affected by one or more of the following; gaps in service provision, organisation dysfunction; or neglect or abuse. The Government published its <a href="#">response</a> <sup>40</sup> on <b>12 September 2018</b> .
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<sup>40</sup> <https://www.gov.uk/government/publications/government-response-to-the-learning-disabilities-mortality-review-leder-programme-2nd-annual-report>