

Written evidence from the Equality and Human Rights Commission (HCS0050)

What human rights issues need to be addressed in care settings, beyond the immediate concerns arising from the Covid-19 pandemic?

1. Health and social care engages a range of human rights, including the right to life, freedom from inhuman and degrading treatment, to liberty and to enjoy a private and family life. The UK Government has also committed through its international human rights obligations to ensure everyone can enjoy the highest attainable standard of physical and mental health, and that disabled people can access the services and support they need to live independently as part of the community.¹
2. The Committee has previously supported the [Commission's advice](#) that the right to independent living should be incorporated in domestic law, which would help ensure disabled people's rights in and to care are protected and can be enforced. Social care – integrated with healthcare and broader community support including housing and transport – is key to enabling independent living and therefore to ensuring disabled people can enjoy their full range of rights.

Social care need

3. Significant pressures on adult social care in England have led to [sustained regression in the enjoyment of human rights](#) and a detrimental impact on the lives of disabled people, older adults and their carers.² Requests for care are increasing while the number of people receiving support has reduced.³ There are unprecedented numbers waiting for needs assessments or for agreed care and support arrangements to be put in place.⁴ In some areas people only have access to poor quality services.⁵

¹ The right to live independently is about ensuring disabled people are included in the community, live with dignity, and have the same choice and control as others. It does not mean that disabled people should always live alone or without support, but does mean they should be able to access support close to home and not in institutions.

² See EHRC (2020), [Access to healthcare – UK Government assessment](#) [accessed 12 October 2021].

³ See Kings Fund (2021), [Social care 360](#). Between 2015/16 and 2019/20, 120,000 more people requested social care support, but around 14,000 fewer people received support.

⁴ Association of Directors of Adult Social Services (2021), [Spring survey](#). More than 75,000 people were waiting for assessments.

⁵ CQC (2020), [The state of health care and adult social care in England 2019/20](#).

Home care

4. There is insufficient high-quality home care to support people to live in and receive care close to home and avoid unnecessary stays in hospitals or other residential settings.⁶ Our 2019 [housing inquiry](#) also identified a significant shortage of accessible housing and unacceptable delays and bureaucracy involved in installing home adaptations.
5. While home care can support greater independence and respect for people's rights, there are risks associated with care provided 'behind closed doors'. Our [2011 home care inquiry found](#) evidence of human rights breaches including people not being fed, neglect for personal care, and physical and financial abuse.

People who lack capacity

6. People who lack capacity are at increased risk of human rights breaches. We are ready to advise the Government on implementing new liberty protection safeguards to ensure care arrangements are appropriate and proportionate, in line with article 5 ECHR and other human rights standards. We recommend further detailed consideration of how the rights of people who lack capacity can be strengthened across the care system, including through supported decision-making and access to independent advocacy.

Mental health detention

7. The UK Government has committed to parity of esteem for mental and physical health.⁷ However, too many people continue to receive mental health care at a point of crisis through restrictive and coercive routes, particularly people from Black ethnic groups.⁸ Our [key priorities for reforming the Mental Health Act](#) include:
 - reduced overall and disproportionate levels of detention and restraint
 - sufficient high quality community-based services and therapeutic alternatives to detention
 - a revised capacity test to prevent inappropriate detention and involuntary treatment
 - improved access to advocacy
 - greater ability to challenge detention and treatment decisions

⁶ Ibid.

⁷ See eg DHSC (January 2021), [The NHS Constitution for England](#).

⁸ See EHRC (April 2021), [Response to the white paper on reforming the Mental Health Act](#).

Support for people with learning disabilities and/or autism

8. We remain concerned about the inappropriate detention of people with learning disabilities and/or autism, which may breach articles 3, 5 and 8 ECHR. Many people live in inpatient settings for long periods, often far from home, and are subject to restraint and restrictive interventions.⁹ Allegations of physical and psychological abuse [REDACTED] raise serious questions about whether lessons have been learnt since Winterbourne View in 2011. We welcome steps by the Department for Health and Social Care to reduce the number of people in inpatient settings,¹¹ though to have the desired impact, plans will need clear targets, timescales and accountability.

How effective are providers at respecting the human rights of people under their care?

Rights breaches

9. There is widespread use of restraint and restrictive interventions in mental health settings, disproportionately affecting people from ethnic minority groups, women, girls and those with learning disabilities and autism. This may result in breaches of the right to a private and family life, and in extreme cases the right to life and to be free from inhuman and degrading treatment. We note that the Care Quality Commission has recently rated several settings for people with learning disabilities and autism as inadequate, including examples where people were not kept safe from avoidable harm, abuse and poor care.¹²
10. The pandemic has exposed significant issues in social care. Our [briefing on care homes during Covid-19](#) identifies evidence that human rights and equality standards have not been upheld, including in decisions about admissions, visits and access to critical care. Improved performance of equality duties could support greater respect for human rights in decision-making, policy and practice.

⁹ See EHRC (June 2021), [Briefing for the debate on the 10th anniversary of the Winterbourne View hospital scandal and progress on moving people with a learning disability and/or autism out of inpatient units](#).

¹⁰ [REDACTED]

¹¹ See DHSC (2021), [National strategy for autistic children, young people and adults: 2021 to 2026](#), and DHSC (2021), [Autism strategy implementation plan: 2021 to 2022](#).

¹² [REDACTED]

Knowledge of human rights

11. There is a lack of knowledge about equality and human rights among staff across the sector, and people in care services are not empowered to understand and claim their rights. We have developed [guidance on rights for people detained under the Mental Health Act](#), given the particular risks for this group. Evidence from our pilots showed it was a valuable tool for patients, families, advocates and staff to better understand and realise rights.¹³ We have recommended a duty to provide a similar standard ‘notification of rights’ under the proposed new Mental Health Bill.

Commissioning and integrating services

12. Commissioning and join-up between services is also an issue. Proposals in the Health and Care Bill provide an opportunity to improve integration between health and social care - and across wider services such as housing and transport - to help tackle inequalities facing groups sharing protected characteristics and deliver a person-centred approach.

Valuing the workforce

13. We recognise the workforce, in which women and people from ethnic minorities are overrepresented, is under significant pressure. Using our inquiry powers we are continuing to [explore the treatment of people from ethnic minorities](#) in low-paid roles on the frontline of health and social care. We expect to report our findings and recommendations shortly. A workforce that is appropriately valued, trained and qualified is key to improving care quality and strengthening protections for people’s rights.

How effective are regulators in protecting residents from human rights breaches and in supporting patients and residents who make complaints about their care provider?

Identifying poor standards and abuse

14. We welcome the incorporation of human rights in the Care Quality Commission (CQC) inspection standards and thematic work - for example the review of ‘do not attempt resuscitation’ decisions during the pandemic and ongoing work on restraint, segregation and seclusion. Our [memorandum of understanding](#) with CQC sets out a framework for collaborative working to help safeguard and strengthen people’s rights.

¹³ We piloted the guidance over the course of 5 weeks in 2019 with people detained under the Mental Health Act in a range of settings. It was also used with advocates, mental health professionals and carers.

15. We recognise there have been occasions when inspections have failed to identify poor care, including deliberate abuse.¹⁴ Our strategic partnership with CQC prioritises work to address ‘closed cultures’ that can lead to human rights breaches. Our advice on the Health and Care Bill also supports the proposed new duty for the CQC to assess how effectively local authorities discharge key aspects of their social care duties.

Social care complaints

16. We are concerned that routes to challenge local government decisions about whether and how care needs will be met may be inadequate. These decisions affect whether people have choice, control and dignity in their day-to-day lives, and can maintain relationships and participate in the community. We are carrying out an inquiry to help understand and address these issues.
17. Barriers to raising complaints about the quality of care may include fear of repercussions or retaliation by providers (including eviction), lack of advocacy, complex complaints processes and low expectations that complaints will lead to change.¹⁵ The Local Government and Social Care Ombudsman is upholding a higher rate of complaints, and while compliance with its recommendations is high, it is not consistently achieved to agreed timescales.¹⁶

Patient safety

18. We support the introduction of a new statutory Health Services Safety Investigations body through the Health and Care Bill to improve patient safety. Our advice to Government on setting up this body focuses on ensuring its investigations are properly independent, embed the voices of patients and families, generate meaningful and lasting improvements, and have regard to the different risks and experiences of people sharing protected characteristics.

What lessons need to be learned from the pandemic to prevent breaches of human rights legislation in the future?

Covid-19 recovery

19. It is important that people with care needs are not left behind in the recovery from the pandemic. Care home residents still face limits on visits and are advised to keep physical contact with loved ones to a minimum.¹⁷ This has a significant impact on wellbeing and is in sharp contrast to the situation for the rest of the population, who are free to be with friends and relatives.

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¹⁵ Competition & Markets Authority (2017), Care homes market study, final report.

¹⁶ Local Government and Social Care Ombudsman (2021), Annual review of adult social care complaints 2020-21.

¹⁷ Department for Health and Social Care (2021), Guidance on care home visiting, updated 23 August 2021.

20. We are aware of concerns that visiting guidance is not being followed consistently, including on supporting essential caregivers and end of life visits. While our direct enforcement powers are generally limited to breaches of the Equality Act, we continue to monitor intelligence to identify potential legal cases where our support could help achieve a successful outcome.

The future of social care

21. We are pleased the UK Government has committed to wide-ranging and sustainable reforms to adult social care. Reforms should be guided by the following principles, which are based on the requirements of the Equality Act 2010, the Human Rights Act, the UN Convention on the Rights of Persons with Disabilities, and the International Covenant on Economic, Social and Cultural Rights.
- **Available.** Everyone with care needs should be able to access the support they need. The system should be sufficiently and sustainably funded to achieve that.
 - **Accessible.** Social care should be easy to navigate and empower people to make informed choices. Services must anticipate the needs of disabled people and the adjustments they might need, including independent advocacy.
 - **Person-centred.** Care should be personalised and tailored to individuals' needs, including needs arising from their protected characteristics. Health, care and wider community services should be joined up around people.
 - **Choice and control.** Individuals should have maximum choice and control over what care they receive and how it is provided. The voices of those with care needs should be at the centre of decisions that affect them, in line with the principles of participation and co-production.
 - **Community and connection.** People should be supported to live in and access care close to their own homes, communities and support networks.
 - **Robust regulation and effective redress.** Regulators should work to promote equality and human rights and ensure accountability and continuous improvement. Routes to challenge decisions and raise complaints should be effective and accessible.
 - **Support for unpaid carers.** Services should recognise the vital role of unpaid carers and work in partnership with them. Carers should be able to access the support they need, including financial help.
 - **Valuing the workforce.** Caring should be a valued profession with fair recruitment, pay and treatment, and opportunities for training, development and progression. This should be recognised as key to driving higher standards of care and upholding people's rights.
22. We recognise that the Human Rights Act does not necessarily apply in situations where care is arranged and funded privately, creating a potential gap in protections. We welcome further consideration of how this could be addressed.

- 1) The right to independent living should be incorporated in domestic law, in line with our proposed legal model, to ensure disabled people's rights in and to care are protected and can be enforced.¹⁸
- 2) Disabled and older adults should be meaningfully consulted and engaged in establishing and directing the public inquiry into the Covid-19 pandemic. The inquiry findings should be used on an ongoing basis to identify and implement changes in policy and practice to ensure the rights of people with care needs are protected.
- 3) The Department for Health and Social Care should bring forward detailed proposals for reforming social care as a priority and before the end of 2021. Reforms should focus on enhancing the rights of and promoting equality for people with care needs and carers, guided by the principles we set out above.
- 4) The Department for Health and Social Care should bring forward a Mental Health Bill at the earliest opportunity and ensure proposals seek to prevent unnecessary detention and disproportionate treatment.
- 5) The Department for Health and Social Care should publish and oversee a new action plan without further delay to improve the treatment of people with learning disabilities and autism, and significantly reduce the number detained in hospitals.
- 6) The Department for Health and Social Care should ensure the health and care workforce at all levels, including those with commissioning responsibilities, receives effective support, guidance and training on upholding human rights and promoting equality.
- 7) The Department for Health and Social Care should continue to build on progress to integrate health, social care and wider community services to ensure a person-centred approach to care.
- 8) The Department for Health and Social Care, NHS England and the Care Quality Commission should continue to focus efforts on preventing inappropriate use of restraint and restrictive interventions, and addressing disproportionate treatment for groups sharing protected characteristics.
- 9) The Care Quality Commission should continue to prioritise preventing and identifying closed cultures to ensure disabled and older adults are not subject to poor standards of care, neglect or abuse.
- 10) The proposed new duty for the Care Quality Commission to assess local authorities' performance of their social care duties should consider their full range of duties at both the strategic commissioning and individual levels, and include an assessment of how effectively they promote equality and uphold people's rights.
- 11) The proposed new Health Services Safety Investigations Body should be established in line with human rights standards, including ensuring its investigations are effective and fully independent.

¹⁸ See EHRC (May 2021), [Strengthening the right to independent living](#), at the appendix.

15/11/2021