

# House of Commons House of Lords

Joint Committee on Human Rights

# Protecting human rights in care settings

# Fourth Report of Session 2022–23

Report, together with formal minutes relating to the report

Ordered by the House of Commons to be printed 13 July 2022

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### **Joint Committee on Human Rights**

The Joint Committee on Human Rights is appointed by the House of Lords and the House of Commons to consider matters relating to human rights in the United Kingdom (but excluding consideration of individual cases); proposals for remedial orders, draft remedial orders and remedial orders.

The Joint Committee has a maximum of six Members appointed by each House, of whom the quorum for any formal proceedings is two from each House.

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# Summary

This inquiry into protecting human rights in care settings follows a torrid few years for care users: the pandemic caused great suffering and isolated residents from their loved ones. We have sought to shed a light on the human rights most at risk in care settings, and what can be done to better protect them. We have focused on four main issues: the provision of medical and personal care; ongoing concerns about visiting arrangements; the complaints process for when things go wrong; and the coverage of the protections of the Human Rights Act 1998 (HRA) to all those in receipt of regulated care services. As health services are devolved, our inquiry focuses on care settings in England although we draw on experiences elsewhere where useful through this report.

The Government is under a number of domestic and international obligations relating to the provision of medical and personal care services. Together, these require that those in care settings should have access to the highest attainable standard of health, as protected by Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR). They should also have their personal needs met, in light of the protection against torture and inhuman or degrading treatment (Article 3 of the European Convention on Human Rights (ECHR)) and the principle of human dignity. However, too often these standards are not met, and individuals suffer. The regulator for health and care services, the Care Quality Commission (CQC), must fulfil its duty to monitor providers' compliance with the required standards, and hold providers accountable in a timely way. Where services are commissioned, the commissioning body must ensure that there is sufficient provision for monitoring and accountability by the contracting public authority, to allow it to identify whether human rights obligations are being discharged. Specific training on human rights and its effects on the provision of services must be given by all registered providers to staff with the CQC working with all stakeholders to ensure this is taking place.

Some care users have Do Not Attempt Cardio-Pulmonary Resuscitation Notices (DNACPR) in place. These make recommendations that CPR is not given in instances where a person stops breathing or their heart stops beating. During the pandemic we were hugely concerned to hear that these were being applied to care users without their knowledge, in a blanket fashion, contrary to the right to life under Article 2 ECHR. We were disappointed to hear that concerns remain about the use of such notices, with what is often poor consultation with care users and their families, insufficient record keeping, and inappropriate use. We call on the Government to work with stakeholders to raise awareness about the appropriate use of DNACPR notices.

We were also concerned to hear about ongoing issues with Deprivation of Liberty Safeguards (DoLS), the check that is put in place to ensure that detention in care settings is within the law and in line with the prohibition of torture and inhuman or degrading treatment under Article 3 ECHR, and the right to liberty and security, under Article 5 ECHR. There are often unacceptable delays in authorisation of DoLS and there is often no access to legal aid if care users wish to challenge their deprivation of liberty in court. Whilst the DoLS system is going to be replaced by a new Liberty Protection Safeguards System (LPS), there is no timetable for this to be rolled out. We ask that the Government must work with the regulator and all stakeholders to ensure that providers

fully understand the functioning DoLS and comply with statutory requirements, and that access to legal aid for those who wish to challenge is widened. The Government should also set a timetable for rollout of the LPS system and keep us updated on progress.

We have reported before on the visiting arrangements for those in care settings during the pandemic. Evidence submitted to this inquiry showed that through and beyond the pandemic problems persisted with providers following guidance. We also believe a lesson learnt from the pandemic was the harm caused by blanket bans on visiting. We have called in the past for the Government to legislate and do so again here. The Government must introduce legislation to secure to care users the right to nominate one or more individuals to visit and to provide support or care in all circumstances, subject to the same infection prevention and control rules as care staff. The Government must also legislate to give the CQC the power to require care settings to inform them of any changes to their visiting status, and to report live data on levels of visiting and restrictions. The CQC must make compliance with visiting restrictions a key consideration when undertaking its regulatory and monitoring roles.

Under the HRA, public authorities must act compatibly with ECHR rights. Those providing care services in care settings, however, are not all public authorities. Unless care legislation, such as the Care Act 2014, contract law, or consumer standards provide equivalent protections, there is no way for privately funded individuals in private care settings to enforce human rights on the same basis as for those in publicly funded care settings. This can mean that two residents in the same care home might have different legally enforceable rights. We recommend that the Government should consult on extending the protections of the HRA to those receiving care and support from all regulated providers, and suggest a way this could be done through an amendment of the Care Act 2014.

When something goes wrong, the users of a service should have access to an effective complaints mechanism that is capable of investigating those complaints, and putting things right, in a way that is transparent, fair, and proportionate. However, the complaints system for care users is confusing, time consuming and too often does not result in effective resolution. The system needs to become easier to navigate. Care users must not be frightened of retribution if they complain. We recommend changes to streamline the process, with the roles of the CQC, the Local Government and Social Care Ombudsman (LGSCO), and the Parliamentary and Health Service Ombudsman (PHSO) clarified and with all three organisations operating a "no wrong door policy".

### 1 Introduction

- 1. Care settings provide services to some of the most vulnerable groups in our society, including the elderly and people with learning disabilities and/or autism. These are places in which closed cultures can easily develop, potentially leading to harm and to serious human rights breaches.<sup>1</sup> This inquiry has sought to consider:
  - What human rights issues need to be addressed in care settings, beyond the immediate concerns arising from the Covid-19 pandemic?
  - How effective are providers at respecting the human rights of people under their care?
  - How effective are regulators in protecting residents from human rights breaches and in supporting patients and residents who make complaints about their care provider?
  - What lessons need to be learned from the pandemic to prevent breaches of human rights legislation in the future?<sup>2</sup>
- 2. Since we launched this inquiry, the Government has introduced the Bill of Rights Bill 2022–23 into Parliament.<sup>3</sup> Some of the provisions of that Bill will impact on the ability of vulnerable care users to have their human rights respected. For example, the restrictions on positive obligations flowing from ECHR rights risks having an impact on the right to life (Article 2 ECHR), the prohibition on torture and inhuman or degrading treatment or punishment (Article 3 ECHR) and the right to family life (Article 8 ECHR) in weakening these positive obligations on public bodies to protect those rights. Changes to duties on public bodies, for example removing the requirement for them to apply the law in a way that is compatible with human rights, so far as it is possible to do so, will risk increasing the occasions when care users' rights are not respected in practice. Whilst we focus on the existing framework in this inquiry, we are mindful of the potential impacts of the changes that the Bill of Rights would bring to care users. The Government should consider very carefully the impact of its Bill of Rights proposals on those in care settings and the Department of Health and Social Care should publish such analysis.

### Scope

- 3. This report concerns care settings in England, as relevant policy is devolved to Scotland, Wales, and Northern Ireland. We do, however, draw on policies from elsewhere in the UK in this report.
- 4. We define care settings as the environments in which assistance and/or healthcare support is provided to individuals, so that they can live a more comfortable and healthy life. This kind of assistance can be provided by specialised public or private organisations or by individuals. Care settings include care homes, assessment and treatment units (ATUs), hospitals, housing schemes, and other environments.

<sup>1</sup> Care Quality Commission, Identifying and responding to closed cultures, 2020

<sup>2</sup> Joint Committee on Human Rights, <u>Call for Evidence: Protecting human rights in care settings</u>, accessed 8 July 2022.

<sup>3</sup> Bill of Rights Bill [Bill 117 (2022–23)]

- 5. This report is not intended to cover all instances of potential violation of human rights in care settings. We have focused on concerns we heard about most frequently in oral and written evidence provided to our inquiry. We have separated our findings into four main areas: provision of care, visiting arrangements, human rights framework, and complaints mechanisms. Other areas that engage human rights and may also be matters of concern, such as the expression of sexuality, modern slavery, and specificities relating to children's social care,<sup>4</sup> whilst clearly important human rights concerns, are not covered in this report.
- 6. We published a call for written evidence in September 2021, and received a total of 69 submissions. We also sought the views of the public through a confidential online survey which received 356 responses. We also held five oral evidence sessions. We are grateful to everyone who gave evidence to the Committee, and to our Specialist Adviser, Alex Ruck Keene QC (Hon).

### **Human rights engaged**

- 7. Care settings provide vital services to some of the most vulnerable in our society and, as such, the provision of these services can potentially engage a large number of human rights. Some of these rights, namely those contained in the ECHR, are incorporated into UK law through the HRA. Others, such as the Convention on the Rights of Persons with Disabilities (CRPD) are given effect through sectoral laws and policies. But they are all binding on the UK. Key rights that are engaged by the issues in this inquiry include the following:
  - The right to life (Article 2 ECHR, Article 10 CRPD).
  - Freedom from torture and inhuman or degrading treatment or punishment (Article 3 ECHR; Article 15 CRPD).
  - The right to liberty and security (Article 5 ECHR; Article 14 CRPD).
  - The right to family and private life (Article 8 ECHR; Articles 22 and 23 CRPD).
  - Freedom from discrimination in the enjoyment of human rights (Article 14 ECHR; Article 5 CRPD).
  - The right to the highest attainable standard of health (Article 12 International Covenant on Economic, Social and Cultural Rights (ICESCR); Article 25 CRPD).

### **Regulatory framework**

8. The CQC regulates all health and care services in England. Such services have to register with the CQC, and demonstrate they meet fundamental standards. The CQC monitors, inspects, and rates services, and is able to take action to protect service users. The CQC is also the body responsible for dealing with complaints related to the Mental Health Act 1983 (MHA).

<sup>4</sup> Although matters that are specific to children's care are not covered, considerations made in this report are also relevant and applicable to children and young people in care settings.

9. When something goes wrong, and the issue does not have to do with the application of the MHA, it can be investigated by the LGSCO or by the PHSO. Both Ombudsman bodies offer free, independent, and impartial services. The LGSCO investigates complaints about all adult social care providers (including care homes and home care agencies) in England, while the PHSO makes final decisions on complaints that have not been resolved by the NHS in England.

### Our previous work on care settings

10. This Committee has taken an interest in the rights of those who use care settings for some time, with inquiries into visiting arrangements during the pandemic; the detention of children and young people with autism and/or learning difficulties; and matters relating to deprivation of liberty safeguards.

### Visiting Arrangements

- 11. In February 2021 we wrote to the Secretary of State for Health and Social Care regarding visiting arrangements for those in care settings during the pandemic. We appended a draft Statutory Instrument, which would have required visiting rights for care users to be subject to individualised assessments.<sup>5</sup> In May 2021, we produced a report on the same subject, in which we called for better protections for residents' right to private and family life (Article 8 ECHR) and again called for our statutory instrument to be made law.<sup>6</sup> In our report, we highlighted how "the Government and providers should have done more to recognise the importance of quality of life for care home residents". We also noted that "it was wrong to deny essential care givers the right to see their relatives". \*\*
- 12. We have, on numerous occasions since the publication of the May 2021 report, called on the Government to put visiting guidance on a statutory footing. Most recently, on 9 March 2022 the Prime Minister was asked about care home visiting during Prime Minister's Questions. He noted that care home visiting guidance had been relaxed. We wrote to him to note that the guidance was not binding and asking him to put it on a statutory footing. He wrote in response:

[The CQC] follows up on all visiting concerns raised with it. (  $\dots$  ) DHSC ministers are also considering legislative options, and how their effect would differ from the current complaints process. <sup>10</sup>

### Use of restrictive practices

13. We have also reported on the use of restraints, solitary confinement, and the detention of young people with learning disabilities and/or autism. In 2020, we published a report on Human Rights and the Government's response to covid-19 focused on the

<sup>5</sup> Letter to the Secretary of State for Health and Social Care on visiting restrictions, 3 February 2021

Joint Committee on Human Rights, Fifteenth Report of Session 2019–21, Care homes: Visiting restrictions during the covid-19 pandemic, HC 1375/HL Paper 278

Joint Committee on Human Rights, Fifteenth Report of Session 2019–21, Care homes: Visiting restrictions during the covid-19 pandemic, HC 1375/HL Paper 278, para 42

Joint Committee on Human Rights, Fifteenth Report of Session 2019–21, <u>Care homes: Visiting restrictions during</u> the covid-19 pandemic, HC 1375/HL Paper 278, para 28

<sup>9</sup> Letter to the Prime Minister regarding restrictions in care homes, 11 March 2022

<sup>10</sup> Letter from the Prime Minister regarding visiting restrictions in care homes, 9 May 2022

detention of young people who are autistic and/or have learning disabilities.<sup>11</sup> Previously, in the 2017–19 Parliament, the Committee published a report into the detention of young people with learning disabilities and/or autism in November 2019,<sup>12</sup> and a report on youth detention: solitary confinement and restraint in April 2019.<sup>13</sup> Some of the Committee's main conclusions and recommendations from these reports were:

- Solitary confinement of children, and prolonged solitary confinement of adults, is contrary to the UN Mandela Rules on Prisoners and must be avoided.<sup>14</sup>
- The detention of individuals in the absence of individualised, therapeutic treatment risks violating an individual's Article 5 right to liberty and security. In some cases, detention may even reach the threshold of degrading treatment contrary to Article 3.<sup>15</sup>
- The Government must revise the financial eligibility criteria for legal aid with a view to widening access to those who would otherwise be unable to enforce their human rights.<sup>16</sup>

### Deprivation of Liberty Safeguards

- 14. The Committee also looked into the Deprivation of Liberty Safeguards (DoLS) system in the 2017–19 Parliament, in the context of proposed reforms and the implementation of the new system of Liberty Protection Safeguards which are to replace the DoLS framework. The Committee's previous work includes (i) The right to freedom and safety: reform of the Deprivation of Liberty Safeguards;<sup>17</sup> and (ii) Legislative Scrutiny: Mental Capacity (Amendment) Bill.<sup>18</sup> Some of the Committee's conclusions and recommendations were:
  - The current system has produced arbitrary limitations on individuals' right of
    access to a court. Legal aid must be available for all eligible persons challenging
    their deprivation of liberty, regardless of whether an authorisation is in place.<sup>19</sup>

Joint Committee on Human Rights, Second Report of Session 2019, Fifth Report of Session 2019–21, Human Rights and the Government's response to covid-19: the detention of young people who are autistic and/or have learning disabilities, HC 395/HL Paper 72

Joint Committee on Human Rights, Second Report of Session 2019, The detention of young people with learning disabilities and/or autism, HC 121/HL Paper 10

<sup>13</sup> Joint Committee on Human Rights, Nineteenth Report of Session 2017–2019, Youth detention: solitary confinement and restraint, HC 994/HL Paper 343

Joint Committee on Human Rights, Second Report of Session 2019, Fifth Report of Session 2019–21, Human Rights and the Government's response to covid-19: the detention of young people who are autistic and/or have learning disabilities, HC 395/HL Paper 72, para 20

Joint Committee on Human Rights, Second Report of Session 2019, The detention of young people with learning disabilities and/or autism, HC 121/HL Paper 10, para 87

Joint Committee on Human Rights, Second Report of Session 2019, The detention of young people with learning disabilities and/or autism, HC 121/HL Paper 10, para 53

Joint Committee on Human Rights, Seventh Report of Session 2017–19, The right to freedom and safety: reform of the Deprivation of Liberty Safeguards, HC 890/HL Paper 161

Joint Committee on Human Rights, Twelfth Report of Session 2017–19, <u>Legislative Scrutiny: Mental Capacity</u>
(Amendment) Bill, HC 1662/HL Paper 208

Joint Committee on Human Rights, Seventh Report of Session 2017–19, The right to freedom and safety: reform of the Deprivation of Liberty Safeguards, HC 890 HL/Paper 161, para 67

• Whilst some of the provisions in the Mental Capacity (Amendment) Bill (now the Mental Capacity (Amendment) Act 2019) may comply with Article 5 ECHR, there are serious reservations about whether the Bill does enough to protect those who are at risk of unlawful detention.<sup>20</sup>

### 2 Provision of care

### Medical and personal needs

- 15. Article 2 ECHR, which is incorporated into UK law through the HRA, places an obligation on the State to take appropriate steps to safeguard the lives of those within the State's jurisdiction. This means that the State and its agents have a responsibility to take appropriate steps to provide access to adequate treatment, diagnosis, and specialised care where necessary.<sup>21</sup>
- 16. The right to health can also form part of the right to life. The right to health appears in different forms in international conventions that the United Kingdom has ratified, including Article 12 of the International Convention on Economic, Social and Cultural Rights (ICESCR), Article 25 of the CRPD, Article 12 of the UN Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) (which stipulates the right to health care of women), Article 24 of the UN Convention on the Rights of the Child (CRC), and Article 5(e)(iv) of the Convention on the Elimination of All Forms of Racial Discrimination (CERD).
- 17. Article 12 ICESCR recognises "the right of everyone to the enjoyment of the highest attainable standard of physical and mental health". This right imposes three levels of obligations on State parties (to respect, to protect, and to fulfil), which leads to considerations about ensuring that care users have their medical and personal needs met.
- 18. Inadequate provision of medication, or lack of access to appropriate treatment, has the potential to amount to a breach of the right to life (Article 2 ECHR)<sup>22</sup> and of the protection against inhuman or degrading treatment (Article 3 ECHR).<sup>23</sup>
- 19. Those in care settings often require a greater or lesser degree of personal care, such as access to fluids and food, or to clean clothes and incontinence products. Inadequate provision of personal care could amount to a breach of the protection against torture and inhuman or degrading treatment (Article 3 ECHR), as well as a to a violation the central principle of human dignity, which underpins human rights protections.
- 20. We heard evidence from Sharon Clay, whose mother is in a care home, that issues with provision of medical and personal care are observed "time and time again".<sup>24</sup> One person shared with us a striking account of how their father's personal care was neglected:

Dad was allowed to get sore as his continence care was not maintained. ( ... ) They would try to feed him quickly with a table spoon instead of a teaspoon as stated on his care plan. He needed small amounts to help him cope with the food not large amounts shoved in his mouth. He would cough and they would give up. He was often left in the same shirt no trousers

<sup>21</sup> European Court of Human Rights, Thematic Report on health-related issues in the case-law of the European Court of Human Rights, June 2015.

<sup>22</sup> Aftanache v. Romania [2020] ECHR 339.

<sup>23</sup> Herczegfalvy v Austria [1992] ECHR 83.

<sup>24</sup> Q6 [Sharon Clay]

laying on top of the bed, with the room door open, no dignity afforded to him. ( ... ) His teeth were not cleaned making his mouth painful. ( ... ) My father died a long cruel death.<sup>25</sup>

21. The Relatives and Residents Association (R&RA) highlighted concerns about the adequate provision of both medical and personal care. They noted that in some cases there are problems relating to "lack of food or fluids leading to malnutrition/dehydration", and "neglect or lack of care leading to harm/suffering". They provided an example from an anonymous helpline client:

A son became concerned about his father's care after noticing he was not always getting his medication or appropriate diet, was becoming depressed and had a poor quality of life. R&RA supported the son to secure a review of his father's needs and he was moved to a more appropriate setting.<sup>26</sup>

- 22. The CQC has an important role in preventing abuse and neglect. As the regulator of all health and care services in England, the CQC has a duty to monitor care settings to ensure that they operate satisfactorily, and to take action when this is not being done. The CQC does not inspect providers' compliance with the HRA directly, but it applies human rights principles to inspections and other services carried out.<sup>27</sup> The CQC's fundamental standards, below which care must never fall, include assurances that people will always be treated with dignity and respect, and will be safe from abuse or improper treatment.<sup>28</sup> The CQC's enforcement policy outlines that it can work with providers to improve standards of service, and intervene where patients are at an unacceptable risk of harm or where providers repeatedly or seriously fail to comply with their legal obligations.<sup>29</sup> The regulator must fulfil its duties, ensuring that care users have access to adequate personal and medical care, and taking swift action where care falls below fundamental standards.
- 23. According to the CQC, in 2020–2021, 1% of registered locations were rated as inadequate and 13% were rated as requires improvement.<sup>30</sup> But we have heard serious criticisms about how the CQC is fulfilling its monitoring and regulatory role. Some individuals noted that even care settings rated as "good" may sometimes provide inadequate services. Kari Gerstheimer, from Access Social Care, told us about a case involving a care setting rated as "good" by the CQC, which was found to suffer from serious failings in the provision of care that were not picked up by the CQC at the time of inspection.<sup>31</sup> John's Campaign also shared with us an account from an individual who showed signs of distress when receiving services from a care setting rated as "good", which were only alleviated when he was moved to a different care home.<sup>32</sup>
- 24. Many have expressed they do not feel they can trust the CQC to adequately regulate and monitor care settings. One individual shared with John's Campaign their personal experience dealing with the CQC:

<sup>25</sup> Anonymous (HCS0005)

<sup>26</sup> Relatives and Residents Association (HCS0048)

<sup>27</sup> Care Quality Commission, Our human rights approach for how we regulate health and social care services: February 2019, February 2019

<sup>28</sup> Care Quality Commission, The Fundamental Standards, accessed 5 July 2022

<sup>29</sup> Care Quality Commission, Enforcement Policy, February 2015

<sup>30</sup> Care Quality Commission, Annual Report and accounts 2020/21, January 2022

<sup>31</sup> Q35 [Kari Gerstheimer]

<sup>32</sup> John's Campaign (HCS0007)

I explained to her [an assistant inspector at CQC] what had happened, how anxious and upset I was and how badly I felt the care home had behaved and continued to behave. ( ... ) I was left feeling that CQC did not care what the care home had done or how unprofessionally and callously they had acted. I totally lost faith in CQC at that point to be an effective regulator and to protect the most vulnerable people in our society.<sup>33</sup>

- 25. People in care settings have the right to the highest attainable standard of health, as protected by Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR). They also must have their personal needs met, in light of the protection against torture and inhuman or degrading treatment (Article 3 ECHR) and the principle of human dignity.
- 26. Even one instance of inadequate service that goes unnoticed is too many. The CQC must adequately monitor providers' compliance with expected standards and hold providers accountable in a timely way.

### Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) notices

- 27. Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) notices record recommendations made by healthcare teams following appropriate consultation with the individual or their representatives that if a particular person goes into cardiac arrest, cardiopulmonary resuscitation should not be attempted, as it would be futile or it would not be in the best interests of the person concerned. If cardiac arrest does occur, then medical professionals should take a DNACPR recommendation into account, but ultimately must use their own judgement as to whether CPR is appropriate in the circumstances. In evidence to us, we heard DNACPR notices referred to as "orders". This should not be done; they do not make mandatory requirements.
- 28. The use of DNACPR notices can engage the right to life (Article 2 ECHR), as well as the respect for personal autonomy as part of the right to private and family life (Article 8 ECHR). DNACPR notices can also engage the right to non-discrimination in the enjoyment of other ECHR rights (Article 14 ECHR), if they are used in a blanket fashion on the basis of, for example, disability or age.
- 29. Our 2020 report into Human Rights and the Government's response to covid-19 investigated the use of DNACPR notices in the context of the pandemic.<sup>35</sup> We called on the Government to implement a national DNACPR policy that made clear, amongst other things, that blanket DNACPR notices must never be imposed by care providers and that individuals should be adequately involved in the decision-making process.<sup>36</sup>
- 30. The Government noted in their response to our report that it had asked the CQC to review how DNACPR decisions were made during the pandemic. In March 2021, the CQC published its review, which found evidence of misuse of such notices, and recommended

<sup>33</sup> John's Campaign (HCS0007)

<sup>34</sup> Representatives from the NHS, for example, repeatedly used the term "DNACPR orders" when providing evidence to us on 23 March 2022.

Joint Committee on Human Rights, Seventh Report of Session 2019–21, The Government's response to COVID-19: human rights implications, HC 265/HL Paper 125

As per Tracey v Cambridge Uni Hospital NHS Foundation Trust & Ors [2014] EWCA Civ 822 and Elaine Winspear v City Hospitals Sunderland NHS Foundation Trusts [2015] EWHC 3250 (QB).

changes in information, training, and support, as well as improved oversight and the adoption of a consistent national approach to advance care planning.<sup>37</sup> The CQC noted that "there appeared to be a perception that if somebody had received training, they would be able to make decisions in line with best practice and legislation", but that they had heard "little about oversight and monitoring of practices". They said:

As a result of our findings, we were concerned that there aren't processes in place to monitor decision making around DNACPR decisions across local areas, and ensure that health and care workers have the relevant training ( ... ) Without proper oversight, systems could not be sure that clinicians, professionals and workers were being supported to keep their professional practice and knowledge up to date in line with best practice, and to work within this.<sup>38</sup>

- 31. Results of a survey conducted in 2021 by the Essex Autonomy Project, and shared with us as written evidence for this inquiry, showed that 55% of their respondents witnessed DNACPR notices being added without consultation, most often because of a blanket decision (28%) or a group decision (e.g. on basis of age or frailty, 25%). They also noted that a subset (17%) of survey participants reported that DNACPR notices, once recorded, were used to make other decisions as well. One respondent to their survey said that "some staff see DNR as 'do not care', or 'do not seek any medical treatment." Another respondent to the same survey noted that DNACPR notices are wrongly perceived by some as being also about access to antibiotics, access to fluids, and to hospital treatment. They are only in fact about CPR and there should be no read across to other forms of treatment or medical response.
- 32. Mencap and the Challenging Behaviour Foundation also expressed concerns about notices being inappropriately used based on disability, in violation of Article 14 ECHR, that protects individuals from discrimination in the enjoyment of their ECHR rights:

We have seen evidence of inappropriate DNACPRs, and people encouraged to consider these decisions, and to not seek admission to hospital should they become unwell, due to their support needs.<sup>41</sup>

- 33. The CQC told us that they had found what they described as a "worrying picture" of "poor involvement of people using services, poor record keeping, and a lack of oversight and scrutiny of the decisions being made".<sup>42</sup>
- 34. In March 2022 the Ministerial Oversight Group, established by the Department of Health and Social Care in 2021, oversaw the publication of guidance prepared by a coalition of partners including NHS England, bodies representing medical staff and third sector organisations on the Universal Principles for Advance Care Planning.<sup>43</sup> Whilst this

- 39 The Essex Autonomy Project, University of Essex (HCS0033)
- 40 Ibid
- 41 Mencap and the Challenging Behaviour Foundation (HCS0043)
- 42 Care Quality Commission (HCS0045)
- 43 Universal Principles for Advance Care Planning, March 2022

<sup>37</sup> Care Quality Commission, Protect, respect, connect – decisions about living and dying well during COVID-19 - CQC's review of 'do not attempt cardiopulmonary resuscitation' decisions during the COVID-19 pandemic, 18

<sup>38</sup> Care Quality Commission, Protect, respect, connect – decisions about living and dying well during COVID-19 - CQC's review of 'do not attempt cardiopulmonary resuscitation' decisions during the COVID-19 pandemic, 18 March 2021

is welcome, evidence to us suggests that more needs to be done to bring about changes in attitudes in care staff and providers. This will require not only adequate training, but also monitoring of compliance. The CQC has said that they "must continue to seek assurance that people are at the centre of personalised, high-quality and safe experiences of DNACPR decisions". <sup>44</sup> We agree.

- 35. It is also crucial that, where DNACPR notices are already in place, policies exist to allow reviews to occur periodically and appropriately, reflecting changes in CPR status, and adequately involving relevant individuals.<sup>45</sup>
- 36. Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) notices relate solely to cardiopulmonary resuscitation. Such notices must never be applied in a blanket fashion to groups of individuals, nor be conflated with decisions about other treatment escalation or admission to health and care settings. The Government must work with providers, the CQC, and other stakeholders to take steps to raise awareness and prevent inappropriate use of DNACPR notices.
- 37. There must be adequate involvement of care users and their relatives and representatives in DNACPR notices, so as to secure the care users' right to private life and their personal autonomy under Article 8 ECHR. Comprehensive records must be kept, monitored, and reviewed periodically. The Universal Principles for Advance Care Planning are welcomed, but it is crucial that the principles are observed in practice.
- 38. In its monitoring, assessing, and inspecting activities, the CQC must continue to seek assurances that care users are placed at the centre of DNACPR notices, in a way that protects their human rights.

### Restrictive practices and deprivation of liberty

### Restrictive practices

39. Restrictive practices, such as the use of chemical and physical restraints and seclusion, can violate the prohibition of torture and inhuman or degrading treatment under Article 3 ECHR, or engage the right to liberty and security, under Article 5 ECHR. In 2019, our predecessor Committee noted that the detention of young people with learning disabilities and/or autism often happens inappropriately, in unsuitable settings that do not adequately respond to individuals' particular needs, causing suffering and harm.<sup>46</sup> Mencap told us that such concerns remain:

Restrictive practices are often used because those settings are fundamentally unsuitable and those people should not be there. ( ... ) In many cases, the

<sup>44</sup> As per the CQC's recommendations in Care Quality Commission, Protect, respect, connect – decisions about living and dying well during COVID-19 - CQC's review of 'do not attempt cardiopulmonary resuscitation' decisions during the COVID-19 pandemic, 18 March 2021.

As noted by the CQC in GP mythbuster 105: Do not attempt cardiopulmonary resuscitation (DNACPR), accessed 5

Joint Committee on Human Rights, Second Report of Session 2019, The detention of young people with learning disabilities and/or autism, HC 121/HL Paper 10

environment there is totally unsuited for them and puts people in a position where they are trapped, where behaviours escalate and they cannot get the support they need.<sup>47</sup>

- 40. In October 2020, the CQC published a report reviewing the use of restraint, seclusion and segregation for autistic people and people with a learning disability and/or mental health condition. In written evidence to our inquiry, they noted that their "Out of Sight Who Cares" report found "too many examples of undignified and inhumane care, in hospital and care settings where people were seen not as individuals but as a condition or a collection of negative behaviours". They went on: "the response to this has often been to restrain, seclude or segregate them". A number of recommendations were made in the CQC's report, on areas such as monitoring, regulation, establishment of independent review procedures, and provision of adequate care. However, as highlighted in their Progress Report, out of the 17 recommendations made to the Government and other stakeholders, only four have been partly achieved and none have been fully achieved. The lack of progress in this area is very concerning.
- 41. Restrictive practices should only be used where strictly necessary, as they could amount to a breach of the prohibition of torture and inhuman or degrading treatment (Article 3 ECHR) and the right to liberty and safety (Article 5 ECHR). The Government must work with the CQC and the Ombudsman bodies to review existing guidelines to ensure that they comply with the requirements of human rights law, and to take appropriate steps to ensure that providers only have recourse to restrictive practices as a last resort. This is of particular importance for people with dementia and people with a learning disability and/or autism, who may be more likely to be subject to restrictive practices, due to their specific health and care needs.

### Deprivation of liberty safeguards (DoLS)

42. For the purposes of deprivation of liberty safeguards (DoLS), a person is considered to be deprived of their liberty when they are "under continuous supervision and control and not free to leave, and the person lacks capacity to consent to these arrangements." This means that a person might be considered to be deprived of their liberty if they were, for example, not allowed to leave a care home or a hospital at night, or not allowed to go outside, and they lacked capacity to agree to such arrangements. In 2004, in the case of HL v UK, the European Court of Human Rights decided that a patient with autism who lacked capacity to consent to his treatment had been deprived of his liberty after being informally admitted to a hospital without contact with his carers. The lack of procedural safeguards and access to court was held to be a violation of the right to liberty and security (Article 5 ECHR), and resulted in the introduction of Deprivation of Liberty Safeguards (DoLS) through the Mental Capacity Act 2005, which are safeguards that must be used for the protection of people who are deprived of their liberty but lack the capacity to consent to their treatment and care.

<sup>47</sup> Q19 [Dan Scorer]

<sup>48</sup> Care Quality Commission, Out of sight – who cares? A review of restraint, seclusion and segregation for autistic people, and people with a learning disability and/or mental health condition, October 2020

<sup>49</sup> Care Quality Commission (HCS0045)

<sup>50</sup> Care Quality Commission, Out of Sight Progress Report, March 2022

P (by his litigation friend the Official Solicitor) v Cheshire West and Chester Council & Anor [2014] UKSC 19.

<sup>52</sup> HL v UK 45508/99 [2004] ECHR 471.

- 43. There is a complex procedure to authorise a deprivation of liberty.<sup>53</sup> Initially, the hospital or care home will identify those at risk of deprivation of liberty, and will request an authorisation from the supervisory body, which in England will be a local authority. The supervisory body will arrange for six assessments to be undertaken and completed within 21 days, which will include ascertaining the relevant person's age, their mental capacity, and whether they have a mental disorder within the meaning of the MHA,<sup>54</sup> as well as establishing that the deprivation of liberty is in the best interests of the individual. If assessments support an authorisation, deprivation of liberty can be authorised up to a maximum period of one year, and a representative for the relevant individual will be appointed (or in some circumstances an advocate).
- 44. The managing authority, which is responsible for the care home or hospital, has the duty to monitor each case of deprivation of liberty to check whether circumstances have changed and if individuals might no longer need to be deprived of their liberty. DoLS authorisations cannot be renewed, but a fresh authorisation can be sought before the end of the relevant period. Urgent authorisations can be granted by hospitals or care homes for a period of seven days, renewable for a further seven days, while a standard authorisation is sought. DoLS applications cannot be made where the relevant individual is either below the age of 18, or not being cared for in a hospital or a care home (in such cases, an application would need to be made to the Court of Protection).
- 45. Where a DoLS authorisation has been granted, there is a route of challenge for the person and/or those interested on their behalf, including ultimately to the Court of Protection. An authorisation may be challenged, for instance, when an individual disagrees with their deprivation of liberty, or where there is disagreement about what the individual's best interests are. However, where there has been a delay in granting a DoLS authorisation, or the route of authorisation is to the Court of Protection, the person will not have access to non-means-tested legal aid. What this means is that, in such cases, if a person crosses the low threshold set by the relevant legal aid rules, they will have to fund their own participation in proceedings about whether their deprivation of liberty is lawful. Therefore, many will not readily be given the support needed to challenge authorisations.<sup>55</sup>
- 46. The DoLS framework has itself been found to be in need of reform. The Mental Capacity (Amendment) Act 2019 established a system for replacing DoLS with Liberty Protection Safeguards (LPS). The LPS are intended to streamline processes, by allowing, for example, the renewal of authorisations, and by introducing procedures for preauthorisation reviews, and for applications to be made for people aged 16 and over. The new framework was originally planned to be rolled out in April 2022, but it has been delayed. A new date for implementation has not yet been announced and, when asked by the Committee, the Government said they were unable to provide a timeframe for

As noted in Department of Health and the Association of Directors of Adult Social Services in England (ADASS),
 Deprivation of liberty safeguards: resources, updated in January 2018, and accessed 5 July 2022, as well as in Deprivation of Liberty Safeguards, Briefing Paper Number 8095, House of Commons Library, September 2018.
 The MHA defines mental disorder, in its s1(2), as "any disorder or disability of the mind".

According to the NHS's <u>official statistics</u> on DoLS, 119,740 applications had not been completed by the end of the reporting year in 2021. It is likely that many of these involve cases where emergency applications have expired, and individuals are currently ineligible for non-means-tested legal aid. Further, all individuals who may be deprived of their liberty but are outside of the DoLS standard framework (such as those under 18) are also ineligible for non-means-tested legal aid.

implementation.<sup>56</sup> Whilst it is important that implementation is done properly and is not unduly rushed,<sup>57</sup> it is important that all arrangements connected to DoLS comply with current statutory requirements.

- 47. The CQC 2020/2021 report on the state of health care and social care in England noted that there are significant concerns about delays in DoLS authorisations, which mean that "individuals are deprived of their liberty longer than necessary, or without the appropriate legal authority and safeguards in place".<sup>58</sup> This is a long-standing problem, which has existed since the DoLS framework was established, but was significantly exacerbated after 2014 when the Supreme Court clarified that many more people are deprived of their liberty than had been understood at the time that the DoLS framework was introduced.<sup>59</sup>
- 48. The LGSCO shares concerns about delays in processing. In November 2020, it published the results of an investigation into DoLS applications considered by the Cheshire East Council, which found that more than 1,000 applications, considered low or medium priority, were waiting to be assessed, with the oldest application still unassessed dating from April 2014.<sup>60</sup> In September 2021, the LGSCO found evidence that the Kent County Council also had a significant backlog of DoLS cases, and it noted that such problems do not seem to be isolated to these two council areas.<sup>61</sup>
- 49. Official statistics released by the NHS about DoLS applications in 2020–21 confirm the issue is widespread.<sup>62</sup> NHS Digital explained that "the proportion of standard applications completed within the statutory timeframe of 21 days was 24% in 2020–21, the same as the previous year", and a small improvement in comparison with 2018–19, when only 22% of applications were completed within statutory timeframes.<sup>63</sup> The average length of time for all completed applications was 148 days.
- 50. All providers must notify the CQC about the outcomes of applications for deprivation of liberty. During the pandemic, the CQC observed a concerning fall in the number of notifications, and noted that "with providers increasingly looking towards the introduction of the Liberty Protection Safeguards (LPS), providers' focus on DoLS has waned and training in some areas has stagnated. Poor understanding of DoLS has remained a fundamental issue. This together with the delays and uncertainty over the progress of LPS may mean there is an increasing risk of people being deprived of their liberty without the proper authorisation".<sup>64</sup>

<sup>56</sup> Q75

<sup>57</sup> Q29

<sup>58</sup> Care Quality Commission, The state of health care and adult social care in England 2020/2021, 21 October 2021

In 2014, the Supreme Court clarified that an individual will be deprived of their liberty if they are "under continuous supervision and control and is not free to leave, and the person lacks capacity to consent to these arrangements". P (by his litigation friend the Official Solicitor) v Cheshire West and Chester Council & Anor [2014] UKSC 19. The expansion of the definition of deprivation of liberty resulted in a ten-fold increase in the number of deprivation of liberty applications following the decision, as per NHS Digital, Mental Capacity Act (2005) Deprivation of Liberty Safeguards (England) England 2015–16 National Statistics, 28 September 2015.

<sup>60</sup> Data available at: https://www.lgo.org.uk/decisions/adult-care-services/assessment-and-care-plan/19-010-786, accessed 5 July 2022

<sup>61</sup> Local Government and Social Care Ombudsman, Kent couple lost valuable time together because of council errors, September 2021. Accessed 5 July 2022

NHS Digital, Mental Capacity Act 2005, Deprivation of Liberty Safeguards - 2020–21. Official Statistics, 19 August 2021

<sup>63</sup> NHS Digital, Mental Capacity Act 2005, Deprivation of Liberty Safeguards England, 2018–19. Official Statistics, 21 November 2019

<sup>64</sup> Care Quality Commission, The impact of COVID-19 on the use of Deprivation of Liberty Safeguards, last updated on 12 May 2022, accessed 5 July 2022

51. Richard Charlton, a solicitor who specialises in mental health and deprivation of liberty cases, told us about delays in processing and assessing DoLS applications:

No case that we take on ( ... ) does not include periods of unlawful detention ( ... ) Sometimes we see the paperwork and a person has been unlawfully detained for years ( ... ) What is so tragic on a human level is you see in that time that the person concerned has been objecting but has not reached or engaged in the process at all and, in that time, they have become much more disabled.<sup>65</sup>

52. Our attention was also drawn to the lack of important data on the use and impact of DoLS. Dr Lucy Series, Fellow and Lecturer in Law at Cardiff University, highlighted how the NHS and the CQC could better take into account the experiences of care users:

I would like better data to be collected on ( ... ) understanding whether the safeguards actually change care outcomes for people. This is not data that is systematically gathered in the official statistics held by NHS Digital. It is also not something that the CQC routinely or reliably reports on. Sometimes we have to rely on anecdotal data, and what we really want is a systems-level picture of how often, when these safeguards are implemented, people's situations improve as a result. ( ... ) We know next to nothing about how the people who are directly subject to the safeguards( ... ) feel about this process. We know slightly more but still relatively little about how their families experience it. 66

We welcome the addition of Question 28 in the draft LPS National Minimum Data Set,<sup>67</sup> which asks about outcomes for the person in terms of wishes and feelings being taken account of during the LPS process. This is a step in the right direction. It is important to ensure that the new framework will in practice capture the impact of LPS on those deprived of their liberty in ways that the current DoLS framework does not, giving proper weight to the experiences of care users.

- 53. Every person who is deprived of their liberty without the completion of an application within statutory timeframes is unlawfully deprived of their liberty. Where this happens, it is clearly unacceptable and constitutes a breach of the right to liberty and security (Article 5 ECHR).
- 54. While Liberty Protection Safeguards (LPS) are not fully implemented, the Government must work with the regulator and all stakeholders to ensure that providers fully understand the functioning of the Deprivation of Liberty Safeguards (DoLS) and comply with statutory requirements.
- 55. Where unlawful detention has taken place, care users and their representatives must be able to challenge it. Non-means-tested legal aid must be available for all eligible persons subject to deprivation of liberty, regardless of whether an authorisation is in place.

<sup>65</sup> Q26 [Richard Charlton]

<sup>66</sup> Q28 [Dr Lucy Series]

Open Consultation, LPS implementation: draft LPS National Minimum Data Set (England), last updated 21 June 2022, accessed 5 July 2022

56. It is important that the new LPS framework does not repeat the failings of the DoLS framework, particularly regarding delays in processing, legal aid, and data gathering. We appreciate the Government wishes to ensure that it gets its implementation right, but we are concerned that there is no timetable for full implementation. The Government must not allow any unnecessary delays to the implementation of the LPS framework, should commit to a firm timetable for its implementation, and should update us every three months on progress.

# Human rights considerations in training and commissioning health and care services

### Training

57. Adequate human rights training in care settings is crucial to ensure that those who provide services are able to satisfactorily fulfil their duties in accordance with the law. As noted by the British Institute of Human Rights (BIHR), understanding the human rights framework applicable in care settings, which includes the HRA, can lead to "real shifts in knowledge, confidence, and changes to right respecting practice and policy".<sup>68</sup> Yet, we have heard evidence about a widespread lack of human rights training available for care staff. The R&RA told us:

There is a widespread lack of knowledge of human rights amongst care providers. This is due to a lack of training on human rights, the HRA and other laws which protect rights (including the Mental Capacity Act and Equality Act). This leads to care users' rights not being respected or protected. It also means one of the stated aims of the HRA, to create a culture of respect for rights, has not taken place in care settings. The Government seem unaware of this knowledge gap, making references to the HRA and Equality Act in guidance for providers during the pandemic with little recognition of the lack of knowledge of these laws amongst care workers.<sup>69</sup>

- 58. Wayne Martin, from the Essex Autonomy Project, agreed that there is "a training gap" in care settings on human rights,<sup>70</sup> a point that was also supported by Kari Gerstheimer, who highlighted the importance of working with people on real-life situations, and providing continuing professional development to staff.<sup>71</sup>
- 59. Dr Aidan Fowler, National Director for Patient Safety for the NHS, told us that the NHS had recently introduced their "first ever training" on patient safety but that it did not "specifically refer to human rights as such". He continued: "It is reasonable ( ... ) to suggest that we should be more explicit about how our safety training relates to the Human Rights Act". "We agree.

British Institute of Human Rights (HCS0067)

<sup>69</sup> Relatives and Residents Association (HCS0048)

<sup>70</sup> Q32 [Wayne Martin]

<sup>71</sup> Q32 [Kari Gerstheimer]

<sup>72</sup> Q51 [Dr Aidan Fowler]

60. As highlighted by the BIHR, "human rights cannot be reduced to 'good practice' or compassion or kindness. They are the law, with legal duties that staff must fulfil". <sup>73</sup> We agree with the BIHR that:

Learning programmes must provide staff with a safe space to reflect on their current practice and to apply human rights in realistic scenarios.<sup>74</sup>

61. Specific training on human rights and its effects on the provision of services must be given by all registered providers to staff. The CQC should work with all stakeholders to ensure this is happening in practice. It is crucial that training programmes go beyond simply stating rights or obligations, and effectively demonstrate the relevance of and use of human rights in making decisions regarding care and treatment.

### Commissioning health and care services

62. Commissioning refers "to the process by which arrangements are made with third parties to deliver services, facilities or resources, or to exercise certain functions, on the authority's or health provider's behalf". However, individuals in receipt of those public services must still have their human rights respected and protected, notwithstanding any contractual arrangements – indeed the contractual arrangements should explicitly ensure that human rights are protected and this should be a valued part of the commissioning process. We have heard evidence that practical human rights considerations are often not taken into account when commissioning health and care. Sanchita Hosali, CEO of the BIHR, told us:

In the commissioning agreements that we have seen, there is usually a long list of laws which you are required to comply with as part of your commissioning contract, and it is often just a list. It just says to comply with the Human Rights Act, the Equality Act, and a range of other Acts. That is not sufficient. That is not telling those providers that they have a specific legal duty to uphold human rights.<sup>76</sup>

- 63. She continued, saying that "If they [providers] know that the commissioner will ask them specific questions about their human rights compliance, that ( ... ) is a driver for change."
- 64. Kari Gerstheimer also expressed concerns about the lack of human rights considerations in commissioning decisions, noting that there is a worry that "too much care is currently being commissioned purely on price".<sup>78</sup>
- 65. A public authority cannot abdicate its duty to protect the human rights of the people it serves when it outsources services to third-party providers. Where public bodies outsource the provision of health and care through commissioning, they have

<sup>73</sup> British Institute of Human Rights (HCS0067)

<sup>74</sup> British Institute of Human Rights (HCS0067)

The Lexis Nexis Practice Note, in partnership with Ros Ashcroft of DAC Beachcroft, Commissioning of health and social care by local authorities, accessed 5 July 2022

<sup>76</sup> Q35 [Sanchita Hosali]

<sup>77</sup> Ibid

<sup>78</sup> Q35 [Kari Gerstheimer]

an ongoing duty to ensure that the human rights of care users are respected. There must be sufficient provision for monitoring and accountability by the contracting public authority, to allow it to identify whether human rights obligations are being discharged.

# **3** Visiting Arrangements

### The importance of visiting those in care settings

66. The ability of care users to maintain relationships with family members and other loved ones has been heavily affected by the imposition of visiting restrictions in care settings. Article 2 ECHR requires the State to protect lives, and, therefore, to take action to keep care users safe. Those in care settings are often at the greater risk of harm from diseases, such as covid-19,<sup>79</sup> so it is of course right that the State should seek to protect the lives of care users. However, care users and their families also have other rights that must be given proper weight, such as the right to private and family life, under Article 8 ECHR. Whilst we appreciate the Government has tried to balance these rights, too often the correct balance has not been struck and too much has been left to individual care settings to determine.

67. The availability of meaningful contact with loved ones plays a vital role in the support and care of individuals in care settings, and visiting restrictions have seriously affected this. Helen Wildbore, from the Relatives and Residents Association, told us:

We are talking about meaningful contact with people who are most important to you, and maintaining relationships and lifelong bonds. Restrictions have had a hugely detrimental impact, not just on residents' mental well-being but physically ( ... ) We know that people have stopped eating and drinking. They have lost weight, mobility and speech ( ... ) These restrictions are isolating for family members and friends on the outside too, locked out of the usual roles that they play as a loved one, as a carer and as an advocate ( ... ) They are feeling guilt, ( ... ) and pain, anxiety and frustration, but they feel powerless. People tell us that they are grieving for someone who is still alive. 80

68. Ruthie Henshall, who like many faced serious obstacles to be able to visit a loved one in a care home, echoed these comments. She told us:

There are some wonderful carers, but they do not have my mother's memories. They do not love my mother the way I loved her. I would read to her. I would paint her nails. I would hug her. I would stroke her face. I would be there for hours, rather than five minutes to feed and do what they needed to do. ( ... ) It was so distressing as a family to watch the decline from behind a window.<sup>81</sup>

69. We heard many other powerful accounts that we feel show that insufficient respect was given to ensuring meaningful contact between care users and their family members and loved ones during the pandemic, and in some cases, since general restrictions on the public ended.

<sup>79</sup> NHS, Who is at high risk from coronavirus (COVID-19), last reviewed in June 2022, accessed 5 July 2022; and Fiona Grimm and Sarah Deeny, Do all care home residents face an equal risk of dying from COVID-19?, Health Foundation, May 2020, accessed 5 July 2022.

<sup>80</sup> Q12 [Helen Wildbore]

<sup>81</sup> Q2 [Ruthie Henshall]

- 70. Concerns about the visiting guidance in relation to the adequate protection of the right to private and family life (Article 8 ECHR) are not new. In 2020, we noted in our report on the human rights implications of the Government's response to covid-19 that we were "very concerned about the impact of lack of visiting on those living in care [and] that blanket visiting bans for those deprived of their liberty are contrary to the rights of residents and their families under the [European Convention on Human Rights]".<sup>82</sup>
- 71. In February 2021, we wrote a letter to the Secretary of State, and appended a draft Statutory Instrument, which would have required individualised assessments for care users.<sup>83</sup> In May 2021, we reported on visiting arrangements in care settings, finding that the Government's guidance had "not adequately acknowledged the importance of families to residents' wellbeing", and that "it was wrong to deny essential care givers the right to see their relatives".<sup>84</sup> Since then, we have continued to make these points in our exchanges with Government officials and the CQC.<sup>85</sup>

### Issues with the Guidance on visiting

- 72. From July 2020 to March 2022, the Government released guidance to care homes on visiting arrangements. This was updated more than 30 times since its original publication. Specific guidance on visiting has now been withdrawn, but guidance still exists as part of the broader "COVID-19 supplement to the infection prevention and control resource for adult social care". The current guidance notes that "every care home resident should have one visitor who can visit in all circumstances (including during periods of isolation and outbreak)". Sa
- 73. The frequent updating of the guidance meant that providers were often not aware of changes or had very little time to prepare for changes to be implemented, intensifying the mismatch between care users' expectations and the reality of the service they receive. Nadra Ahmed, Chairman of the National Care Association, which represents small and medium sized providers and affiliated local associations, said:

Sometimes it [visiting guidance] came out on a Friday night at 8 pm, which caused us great distress, and would be implemented on the Monday. We were trying to make sure that the right was being met rather than not met.<sup>89</sup>

74. We note with concern that the CQC's own guidance at times has contradicted the Government's guidance. One such example could be found in CQC's guidance for providers about infection prevention and control in care homes, in the section "What

Joint Committee on Human Rights, Seventh Report of Session 2019–21, <u>The Government's response to COVID-19:</u> human rights implications, HC 265/HL Paper 125

<sup>83</sup> Letter to the Secretary of State for Health and Social Care on visiting restrictions, 3 February 2021

<sup>84</sup> Joint Committee on Human Rights, Fifteenth Report of Session 2019–21, <u>Care homes: Visiting restrictions during</u> the covid-19 pandemic, HC 1375/HL Paper 278

For more information, view: Letter to the Minister of State for Care and Mental Health on the urgent situation regarding visiting restrictions, 29 October 2021; Letter to the Chair of the Care Quality Commission on visiting restrictions, 29 October 2021; Letter to the Prime Minister regarding restrictions in care homes, 11 March 2022.

Publication update history can be viewed at https://www.gov.uk/government/publications/visiting-care-homes-during-coronavirus#full-publication-update-history, accessed 5 July 2022.

<sup>87</sup> Department of Health and Social Care, COVID-19 supplement to the infection prevention and control resource for adult social care, last updated 7 July 2022, accessed 12 July 2022

Department of Health and Social Care, <u>Summary of changes to COVID-19 guidance for adult social care</u> providers, last updated 7 July 2022, accessed 12 July 2022

<sup>89</sup> Q41 [Nadra Ahmed]

good looks like and guidance" as updated on 20 May 2022. The CQC said that "people are supported to isolate in their own rooms where this is recommended under the current admissions guidance, for example when returning to a home from hospital due to an admission for emergency care". However, Government guidance from 3 May 2022, clearly stated that "care home residents should not be required to self-isolate when discharged back to the care home following an admission into hospital, subject to a negative PCR or lateral flow test". O Although the CQC's guidance was updated to correct this discrepancy on 23 June 2022, contradictions such as this can cause significant confusion and further deteriorate protections available to care users and their loved ones.

### Adherence to the guidance

- 75. Not only has the guidance varied and often not struck the right balance, but providers have also never been bound by the available guidance, only by the law. Responsibility rests with individual providers for keeping residents safe and meeting their welfare needs, while ensuring that visits are facilitated. In our May 2021 report, we argued that "guidance should not be second guessed or selectively applied by care home providers, absent a cogent and clearly explained basis for doing so."
- 76. Although visiting guidance has been amended to allow more visits, we have continued to receive evidence showing that guidance has not been consistently applied across different settings.<sup>93</sup> A respondent to our online survey said:
  - I feel the government has failed people in care homes by only offering guidance and not mandating what needed to happen. This has provided a culture where care homes can argue that it's only ever guidance and not law.
- 77. Age UK told us that they had heard reports that visiting policy in some settings "continues to be more restrictive than current guidance recommends", and that:
  - ( ... ) this could be a result of a lack of individualised approach to managing challenging situations such as outbreaks. The pandemic has once again highlighted the lack of protection for residents and their right to private and family life.<sup>94</sup>
- 78. The Government told us in December 2021 that they were "satisfied that the CQC has sufficient regulatory powers to take action where providers do not appropriately or proportionately support people to have access to visits and their rights are compromised." However, it is unclear how the CQC is able to adequately gauge when it is appropriate to take regulatory and enforcement action against providers. Data on visiting is collected to some degree through the Capacity Tracker, a digital tool that was expanded to support
- 90 Department of Health and Social Care, <u>Summary of changes to COVID-19 guidance for adult social care</u> providers, as updated 3 May 2022, accessed 5 July 2022
- 91 Care Quality Commission, CQC's Guidance for providers: Infection prevention and control in care homes, last updated on 23 June 2022, accessed 5 July 2022.
- 92 Joint Committee on Human Rights, Fifteenth Report of Session 2019–21, Care homes: Visiting restrictions during the covid-19 pandemic, HC 1375/HL Paper 278, para 55
- As highlighted by Relatives and Residents Association (HCS0048), Alzheimer's Society (HCS0008), Anonymous (HCS0022), Anonymous (HCS0038). The vast majority of the 356 respondents to our online survey also told us that their human rights, and those of their close friends or relatives, have been undermined by the imposition of visiting restrictions.
- 94 AgeUK (HCS0046)
- 95 Letter from the Minister of State for Care and Mental Health, 20 December 2021

the covid-19 response. However, providers are only encouraged, and not obligated, to use this tool, and the CQC does not have the power to compel care homes to report levels of visiting.<sup>96</sup>

79. Disappointment with the CQC was expressed by many individuals who shared evidence with the Committee about the monitoring of compliance with visiting guidance. A respondent to our online survey said:

I have reported the care home to the CQC anonymously months ago because of lack of access and no communication but nothing changed. I wish mum was in prison then I am sure I would have better access and not pay for the privilege of her being locked away.

80. To ensure better compliance with visiting guidance, the Scottish Government has recently introduced the National Care Service (Scotland) Bill to the Scottish Parliament. Amongst other things, the Bill would place a duty on Ministers to require providers of care home services to comply with any direction Ministers make about either visits to residents of care home accommodation or visits by such residents. Ministers would be required to consult with Public Health Scotland and others as appropriate before issuing a "visiting direction". No similar provision currently exists in England.

### A way forward

- 81. We still do not believe that there are sufficient measures in place to ensure adequate respect for the right to private and family life (Article 8 ECHR) in relation to care users and visiting arrangements in care settings.
- 82. We remain concerned that in England, non-statutory guidance that intends to restrict visiting does not adequately meet the criteria of "in accordance with the law" that is required for any interferences with human rights. Moreover, given the variable application of the guidance, it also seems to be failing to ensure adequate positive protection for the right to family and private life. Even if every care setting now complied with the guidance seeking to facilitate visiting, stronger assurances would be needed to adequately protect the rights of care users and their loved ones against future improper interference.
- 83. The Government must introduce legislation to secure to care users the right to nominate one or more individuals to visit and to provide support or care in all circumstances, subject to the same infection prevention and control rules as care staff.
- 84. The Government must legislate to give the CQC the power to require care settings to inform them of any changes to their visiting status, and to report live data on levels of visiting and restrictions. The CQC must make compliance with visiting restrictions a key consideration when undertaking its regulatory and monitoring roles.

<sup>96</sup> Care Quality Commission, Statement on visiting in care homes following a change in guidance from the Department of Health and Social Care, 12 May 2022

<sup>97</sup> National Care Service (Scotland) Bill.

# 4 Application of the Human Rights Act

85. Under the HRA, public authorities must act compatibly with ECHR rights. Care providers in care settings, however, are not all considered to be public authorities for the purposes of the HRA. Therefore, these obligations apply to care providers when they are publicly-run or in respect of residents whose care is funded or arranged by a local authority. The Government have recently introduced the Bill of Rights Bill to repeal and replace the HRA. The Bill maintains the requirement for public authorities to act compatibly with ECHR rights in its clause 12(1) (currently section 6 HRA), although removes the requirement for them to read legislation in a manner compatible with ECHR rights (so far as it is possible to do so), which will likely impact on the practical application of human rights for care users. Other measures in the Bill of Rights may, additionally, make it more difficult for human rights to be enforced.

86. Self-funders in private care homes are not able to rely on the HRA to protect and enforce their rights directly. The Act also does not apply where the care is funded or arranged by the NHS under continuing healthcare arrangements. Unless care legislation (such as the Care Act 2014), contract law, or consumer standards provide equivalent protections, there is no way to enforce human rights on the same basis as for those in publicly-funded care settings. This can mean that two residents in the same care home might have different legally enforceable rights, depending on their funding arrangement or how and why they ended up as a recipient of the care. Moreover, if the language of contractual obligations, rather than the language of rights (such as personal autonomy, or right to see family) is used for certain groups of individuals, it will be even more difficult for them to get their rights taken seriously and protected even in informal discussions with care providers. It is not justifiable to treat particular individuals as less deserving of having their human rights, such as personal autonomy or right to see family, effectively protected.

- 87. Human rights must be at the centre of Government's approach to the provision of adult social care, and as such, we were surprised that the Director-General for Adult Social Care at the Department of Health and Social Care, appeared to not fully understand the limits on the applicability of the HRA to care homes in her oral evidence. The Minister wrote to us after the evidence session setting out the law as it stands, the ware concerned this reveals the extent of confusion about the enforceability of human rights in care settings, as well as a lack of focus on the importance of respect for human rights. This can only impede effective enforcement of human rights.
- 88. The system of rights enforcement for those in care settings can be close to if not incoherent when viewed from a user perspective. For instance, any confinement to which a care provider might subject an individual, regardless of how the individual's care was

<sup>98 &</sup>lt;u>Bill of Rights Bill</u>, Clause 12(1) [Bill 117 (2022–23)]: It is unlawful for a public authority to act in a way which is incompatible with a Convention right.

<sup>99</sup> Section 73 of the Care Act 2014 amended the HRA so that the Act applies against providers where the care is local authority-funded or arranged.

<sup>100</sup> Q78

<sup>101</sup> Letter from the Minister of State for Care and Mental Health, 1 June 2022.

funded or arranged, is already seen to be a State responsibility. However, in many other areas, where the State might take a more hands-off approach, it may be difficult to enforce rights directly against care providers.

- 89. This inquiry has shown just some of the extent of human rights issues that arise in the care settings context. Some can be predictable, others harder to foresee and adequately protected against through bespoke legislation.
- 90. It is vitally important that care users (or their loved ones or representatives on their behalf) are able to access real and enforceable human rights protections in care settings irrespective of the particular structural system, or funding system, providing that care. We have heard how efforts to enforce human rights in many care settings do not get off the ground.
- 91. We do not find it justifiable to offer lesser human rights protections in private care settings for privately funded individuals and those whose care is funded or arranged by the NHS under continuing healthcare arrangements, as compared to other care users whose care is paid for or arranged by a local authority.
- 92. The HRA does not apply equally to all those in care settings. It only applies when care is local authority funded or arranged. The discrepancy between levels of legal protection for those in care settings can seem unfair the human rights of all those receiving care should be protected equally. That the Government appeared to be unclear as to the applicability of the HRA is of great concern.
- 93. The Government should consult on whether the protections of the HRA should be extended to those receiving care and support from all regulated providers. This could be done, for example, by repealing s. 73 (3) Care Act 2014, and amending s. 73 (2) Care Act 2014 to read:
- (2) The provider is to be taken for the purposes of [section 6(3)(b) of the Human Rights Act 1998 (acts of public authorities) (and the equivalent clause of the Bill of Rights Bill 2022–23, c 34(1)(b) (meaning of "public authority")) to be exercising a function of a public nature in providing care or support.

# 5 Complaints mechanisms

- 94. When something goes wrong, the users of a service should have access to an effective complaints mechanism that is capable of investigating those complaints, and putting things right, in a way that is transparent, fair, and proportionate. The evidence we have received shows that care users can be reluctant to pursue complaints due to fears of retaliation, and that those who wish to pursue complaints often find the available framework complex, confusing, and ineffective.
- 95. A complaint in care settings should in the first instance be made to the care provider. <sup>104</sup> If a complaint is not resolved and it is related to the application of the Mental Health Act (MHA) 1983, then the complaint can be made to the CQC. <sup>105</sup> If the unresolved complaint is unrelated to the MHA, it should be made to the LGSCO, or with the PHSO (in case of NHS services). Where complaints involve elements of health and social care services, the LGSCO can carry out a single joint investigation in tandem with the PHSO, investigating across all areas of the complaint. Decisions made by the LGSCO and the PHSO are non-binding recommendations, but are usually complied with. <sup>106</sup>
- 96. Caroline Abrahams, Charity Director at Age UK, told us that complaints against care homes or local authorities is a "heavy duty" and time-consuming thing to do, which can be particularly problematic in the case of older or unwell care home residents:
  - [it] takes a long time, as well as a lot of effort and energy. Ultimately, you can go to the ombudsman, but that takes ages. Let us remember that the average stay in a care home is 18 months to two years. People need quick answers to problems. There is no point being embroiled in some lengthy process that does not conclude until after your loved one has died.<sup>107</sup>
- 97. In the same vein, Margaret Flynn, a safeguarding expert and Chair of the National Mental Capacity Forum, told us:

[The CQC] does not investigate complaints and ( ... ) people are bounced from one organisation to another. I know that some complaints have gone unresolved for many, many years, and families are left feeling extraordinarily frustrated and with a sense of strong grievance. The CQC has not assisted families on this front. <sup>108</sup>

<sup>103</sup> As noted by the LGSCO in its Guidance on Effective Complaint Handling for local authorities, accessed 5 July 2022.

<sup>104</sup> If care is publicly funded, complaints can also be made with the local council if it is felt that the care provider did not effectively investigate and resolve the complaint.

<sup>105</sup> Mental Health Act 1983, s. 120(4) provides that "the regulatory authority must also make arrangements for persons authorised by it to investigate any complaint as to the exercise of the powers or the discharge of the duties conferred or imposed by this Act in respect of a patient who is or has been detained under this Act or who is or has been a relevant patient".

The LGSCO reported that 99.8% of its recommendations were followed in 2020–21 (Review of Adult Social Care Complaints 2020/21, September 2021). The PHSO reported that, out of 745 recommendations made in 2020–21, 543 recommendations closed were complied with and 2 were not (The Ombudsman's Annual Report and Accounts 2020–2021, July 2021).

<sup>107</sup> Q9 [Caroline Abrahams]

<sup>108</sup> Q9 [Margaret Flynn]

98. The CQC does not consider it to be within its remit to investigate individual complaints unrelated to the MHA. However, information gained from a complaint can still be used by the CQC, for example to carry out a focused inspection or to raise concerns with providers and to seek a response. Further, Regulation 16 of the Health and Social Care Act 2008 (Regulated Activities) makes it clear that looking into how well health and social care providers identify, receive, record, handle, and respond to complaints is within the CQC's remit.

99. There is significant confusion about the roles of the CQC, the LGSCO, and the PHSO in the handling of complaints. Nadra Ahmed, for example, who has been Chairman of the National Care Association since 2001, and who has worked in social care for over 35 years, said to the Committee:

The CQC does look into individual cases. If it receives a complaint about a breach, it looks into the service where it is required to. That is what it is supposed to do.<sup>110</sup>

100. The CQC does not investigate individual complaints unless they are made under the MHA.<sup>111</sup> However, given that the CQC does, in fact, take *action* based upon information raised by individuals, it is perhaps unsurprising that Ms Ahmed had this understanding.<sup>112</sup> More fundamentally, the fact that an experienced professional, who has worked with providers for decades, does not have a clear understanding about which organisations can look into individual complaints, shows the urgency in clearing up the confusion about complaints mechanisms in care settings.

101. We have also heard concerns that care users are put off making formal complaints because they face retaliation after making complaints. Rachel Barber, founder and Managing Director of Living 4 Moments, told us that "some people have risked evictions or even more abusive treatment of their loved ones when they have raised their concerns". She continued to say that some care settings claim they are no longer able to meet the needs of some individuals as "an excuse to move someone on whose family has criticised the management". This is unacceptable.

102. The LGSCO has told us that "many people in receipt of care lack the ability to complain. They may not have mental capacity, they may be isolated and alone, they may have no living relatives or friends to speak on their behalf, or they might be frightened to exercise their right to complain because they fear offending those who care for them". 115 Despite this, the LGSCO and the PHSO do not have the ability to investigate proactively on behalf of care users, even where there is evidence of problems. The LGSCO said:

Giving LGSCO the power to investigate bodies within our jurisdiction based on evidence gained through our casework, without the need for a specific individual complaint, would mean we were able to use our evidence to its full potential to give a voice to the voiceless.<sup>116</sup>

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109 Q56 [Kate Terroni]
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<sup>110</sup> Q44 [Nadra Ahmed]

<sup>111</sup> Q59 [Kate Terroni]

<sup>112</sup> Q63 [Kate Terroni]

<sup>113</sup> As noted in our letter to Peter Wyman CBE DL, 29 October 2021.

<sup>114</sup> Mrs Rachel Barber (Managing director at Living 4 Moments ltd) (HCS0004)

<sup>115</sup> Michael King (Chair at Local Government and Social Care Ombudsman (LGSCO)) (HCS0069)

<sup>116</sup> Michael King (Chair at Local Government and Social Care Ombudsman (LGSCO)) (HCS0069)

We agree. More needs to be done to address circumstances where care users might be unable or unwilling to lodge complaints, and giving the LGSCO the power to proactively investigate issues would be a step in the right direction. Given the existing framework for complaints mechanisms, we believe the same powers should also be granted to the PHSO.

# Investigation of complaints related to the Mental Health Act 1983 (MHA)

103. There is a question mark over the effectiveness of the CQC's complaint handling procedures in relation to its duties under the MHA. The CQC told us that in 2020/2021 they received "2,280 complaints and concerns about the MHA", 117 mostly from people who use services and from carers, and the majority by telephone. They only opened seven of these to be investigated as complaints. 118 It is not entirely clear if 2,280 refers to the number of MHA complaints arising by virtue of s. 120(4) MHA, 119 as the CQC has, at different times, called such cases "enquiries", 120 and "complaints and concerns" 121. We asked both the CQC and the DHSC to provide us with data to explain why so few MHA investigations (0.3%) have taken place. The CQC told us they "do not hold the granular data about the individual steps taken in the 2,280 cases". They went on to say that they employed a "robust, staged process to hold providers fully to account in how they respond to every single complaint we pass to them". 122 However, without any data to show what has happened to the majority of complaints and concerns received, we cannot be assured that the CQC is adequately investigating such complaints.

104. We note the draft Mental Health Bill published on 27 June 2022 contains proposals to improve information as to complaints mechanisms for different categories of people subject to the Mental Health Act 1983. These proposals respond to recommendations made by the independent Review of the Mental Health Act 1983. In its White Paper preceding the draft Bill, the Government agreed in principle with the recommendation of the Review that the government and CQC should take steps to improve the systems that handle complaints from patients and their carers across providers, commissioners, police and local authorities to improve transparency and effectiveness across the system. But the draft Bill does not contain proposals for making substantive improvements to complaints-handling mechanisms.

105. Complaints mechanisms that involve care settings must be clarified and streamlined. All complaints relating to care settings should be investigated either by the LGSCO or by the PHSO, and not by the CQC. Section 120(4) MHA 1983 should be amended accordingly to transfer the duty to investigate complaints related to the Mental Health Act 1983 in England, along with the CQC's enforcement powers for such investigations

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117 Care Quality Commission (CQC) (HCS0065)
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<sup>118</sup> Care Quality Commission (HCS0045)

<sup>119</sup> Mental Health Act 1983, s. 120(4)

<sup>120</sup> Care Quality Commission (HCS0045)

<sup>121</sup> Care Quality Commission (CQC) (HCS0065)

<sup>122</sup> Care Quality Commission (CQC) (HCS0065)

<sup>123</sup> Draft Mental Health Bill, clauses 35–37, June 2022

<sup>124</sup> Department of Health and Social Care, Modernising the Mental Health Act: Final Report of the Independent Review of the Mental Health Act 1983, December 2018

<sup>125</sup> Department of Health and Social Care, Consultation outcome. Reforming the Mental Health Act, updated August 2021

and decisions, from the regulator to the LGSCO or the PHSO. This change would help minimise some of the confusion as to which body one should direct complaints, and could better enable the CQC to focus on its monitoring and regulatory role.

- 106. The Government should consult on giving Ombudsman bodies the power to look proactively at areas of care in which problems are perceived, but people might not be able or willing to lodge formal complaints.
- 107. The LGSCO, the PHSO, and the CQC must have a "no wrong door" policy for complaints. If a complaint is out of scope of one body, they must direct it to the appropriate organisations in an adequate timeframe.
- 108. In its regulatory and monitoring role, the CQC must take proper account of how complaints are being handled by providers, and how decisions made by the Ombudsman bodies are being implemented. The CQC must also routinely look at how health and care contracts between individuals and providers are being terminated and work alongside the Ombudsman bodies and providers to ensure that individuals are not suffering retaliation after lodging complaints.
- 109. The confusion over the complaints system in care settings has an impact on the ability of care users to enforce their rights. Along with the recommendations above, complaint handling bodies together with the Government must consider options for raising awareness of the existing complaints processes.

# Annex: Survey responses summary

On 21 September 2021, we published a call for written evidence on protecting human rights in care settings. We also published an online survey, promoted on our website and social media. Our survey closed on 2 November 2021 and we received 356 responses. Although our self-selecting survey is unlikely to be fully representative, we were keen to hear varied points of view and provide a way for people with different opinions to engage with our work.

### **Overview**

We asked whether individuals have had their human rights, or those of a close friend or relative, undermined within a care setting in England in the last five years. 313 people (88%) answered 'yes'.

### **Visiting arrangements**

The vast majority of respondents said their human rights, and those of their close friends or relatives, have been undermined by the imposition of visiting restrictions in care settings during the covid-19 pandemic. Responses included:

Covid and the involvement of Government essentially keeping my mother a prisoner. Even as the country opens up she is left behind. ( ... ) We are not visitors we are family.

Loneliness kills. It is active neglect to deny someone access to the people they love and need when they are unwell and dying. There needs to be a better way.

### **Inadequate care**

Some respondents also expressed concerns about mistreatment and neglect of patients and residents, involving issues with personal and medical care. Responses included:

When he [respondent's father] became incontinent, they left him in dirty incontinence pants for 48 hours [ ... ] as he became bed bound, they left food and drink out of reach, no help with eating.

He [respondent's brother] told me about the conditions at the care home including that it was dirty and that call buttons were not responded to. He fell out of bed one night and fractured a bone. Staff did not respond to calls and he had to phone an ambulance himself.

### Do not Attempt Cardiopulmonary Resuscitation (DNACPR) notices

Some respondents reported a lack of involvement of relatives, patients, and residents in Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) notices. Responses included:

The GP put our Mum under a DNA notice during COVID even though she does not have capacity and went against her, and our wishes which were on file at the care home. Family were not involved in the assessment.

### Inadequate complaints mechanisms and fears of retaliation

Some respondents also noted that complaints mechanisms are not always effective and do not always afford sufficient protections to those who raise issues, which results in individuals fearing or suffering retaliation from care providers. Responses included:

We contacted every agency we could – CQC, safeguarding and government bodies, but to no avail, and we believe we were a nuisance to the care home provider.

I was banned from seeing my mother at the care home she was residing in with dementia only because I raised concerns with the home manager about poor care and [ ... ] safeguarding issues.

Residents [ ... ] are afraid to speak out and they are fearful of anything they may say against the home or careers and owners where they live.

We are grateful to everyone who took the time to send us their views.

## Conclusions and recommendations

### Provision of care

- 1. People in care settings have the right to the highest attainable standard of health, as protected by Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR). They also must have their personal needs met, in light of the protection against torture and inhuman or degrading treatment (Article 3 ECHR) and the principle of human dignity. (Paragraph 25)
- 2. Even one instance of inadequate service that goes unnoticed is too many. (Paragraph 26)
- 3. The CQC must adequately monitor providers' compliance with expected standards and hold providers accountable in a timely way. (Paragraph 26)
- 4. Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) notices relate solely to cardiopulmonary resuscitation. Such notices must never be applied in a blanket fashion to groups of individuals, nor be conflated with decisions about other treatment escalation or admission to health and care settings (Paragraph 36)
- 5. The Government must work with providers, the CQC, and other stakeholders to take steps to raise awareness and prevent inappropriate use of DNACPR notices. (Paragraph 36)
- 6. There must be adequate involvement of care users and their relatives and representatives in DNACPR notices, so as to secure the care users' right to private life and their personal autonomy under Article 8 ECHR. Comprehensive records must be kept, monitored, and reviewed periodically. The Universal Principles for Advance Care Planning are welcomed, but it is crucial that the principles are observed in practice. (Paragraph 37)
- 7. In its monitoring, assessing, and inspecting activities, the CQC must continue to seek assurances that care users are placed at the centre of DNACPR notices, in a way that protects their human rights. (Paragraph 38)
- 8. Restrictive practices should only be used where strictly necessary, as they could amount to a breach of the prohibition of torture and inhuman or degrading treatment (Article 3 ECHR) and the right to liberty and safety (Article 5 ECHR). The Government must work with the CQC and the Ombudsman bodies to review existing guidelines to ensure that they comply with the requirements of human rights law, and to take appropriate steps to ensure that providers only have recourse to restrictive practices as a last resort. This is of particular importance for people with dementia and people with a learning disability and/or autism, who may be more likely to be subject to restrictive practices, due to their specific health and care needs. (Paragraph 41)
- 9. Every person who is deprived of their liberty without the completion of an application within statutory timeframes is unlawfully deprived of their liberty. Where this happens, it is clearly unacceptable and constitutes a breach of the right to liberty and security (Article 5 ECHR). (Paragraph 53)

- 10. While Liberty Protection Safeguards (LPS) are not fully implemented, the Government must work with the regulator and all stakeholders to ensure that providers fully understand the functioning of the Deprivation of Liberty Safeguards (DoLS) and comply with statutory requirements. (Paragraph 54)
- 11. Where unlawful detention has taken place, care users and their representatives must be able to challenge it. (Paragraph 55)
- 12. Non-means-tested legal aid must be available for all eligible persons subject to deprivation of liberty, regardless of whether an authorisation is in place. (Paragraph 55)
- 13. It is important that the new LPS framework does not repeat the failings of the DoLS framework, particularly regarding delays in processing, legal aid, and data gathering. We appreciate the Government wishes to ensure that it gets its implementation right, but we are concerned that there is no timetable for full implementation. (Paragraph 56)
- 14. The Government must not allow any unnecessary delays to the implementation of the LPS framework, should commit to a firm timetable for its implementation, and should update us every three months on progress. (Paragraph 56)
- 15. Specific training on human rights and its effects on the provision of services must be given by all registered providers to staff. The CQC should work with all stakeholders to ensure this is happening in practice. It is crucial that training programmes go beyond simply stating rights or obligations, and effectively demonstrate the relevance of and use of human rights in making decisions regarding care and treatment. (Paragraph 61)
- 16. A public authority cannot abdicate its duty to protect the human rights of the people it serves when it outsources services to third-party providers. (Paragraph 65)
- 17. Where public bodies outsource the provision of health and care through commissioning, they have an ongoing duty to ensure that the human rights of care users are respected. There must be sufficient provision for monitoring and accountability by the contracting public authority, to allow it to identify whether human rights obligations are being discharged. (Paragraph 65)

### **Visiting Arrangements**

- 18. We still do not believe that there are sufficient measures in place to ensure adequate respect for the right to private and family life (Article 8 ECHR) in relation to care users and visiting arrangements in care settings. (Paragraph 81)
- 19. The Government must introduce legislation to secure to care users the right to nominate one or more individuals to visit and to provide support or care in all circumstances, subject to the same infection prevention and control rules as care staff. (Paragraph 83)
- 20. The Government must legislate to give the CQC the power to require care settings to inform them of any changes to their visiting status, and to report live data on levels of visiting and restrictions. The CQC must make compliance with visiting restrictions a key consideration when undertaking its regulatory and monitoring roles. (Paragraph 84)

### Application of the Human Rights Act

- 21. The HRA does not apply equally to all those in care settings. It only applies when care is local authority funded or arranged. The discrepancy between levels of legal protection for those in care settings can seem unfair the human rights of all those receiving care should be protected equally. That the Government appeared to be unclear as to the applicability of the HRA is of great concern. (Paragraph 92)
- 22. The Government should consult on whether the protections of the HRA should be extended to those receiving care and support from all regulated providers. This could be done, for example, by repealing s. 73 (3) Care Act 2014, and amending s. 73 (2) Care Act 2014 to read:
  - (2) The provider is to be taken for the purposes of [section 6(3)(b) of the Human Rights Act 1998 (acts of public authorities) (and the equivalent clause of the Bill of Rights Bill 2022–23, c 34(1)(b) (meaning of "public authority")) to be exercising a function of a public nature in providing care or support. (Paragraph 93)

### Complaints mechanisms

- 23. Complaints mechanisms that involve care settings must be clarified and streamlined. All complaints relating to care settings should be investigated either by the LGSCO or by the PHSO, and not by the CQC. Section 120(4) MHA 1983 should be amended accordingly to transfer the duty to investigate complaints related to the Mental Health Act 1983 in England, along with the CQC's enforcement powers for such investigations and decisions, from the regulator to the LGSCO or the PHSO. This change would help minimise some of the confusion as to which body one should direct complaints, and could better enable the CQC to focus on its monitoring and regulatory role. (Paragraph 105)
- 24. The Government should consult on giving Ombudsman bodies the power to look proactively at areas of care in which problems are perceived, but people might not be able or willing to lodge formal complaints. (Paragraph 106)
- 25. The LGSCO, the PHSO, and the CQC must have a "no wrong door" policy for complaints. If a complaint is out of scope of one body, they must direct it to the appropriate organisations in an adequate timeframe. (Paragraph 107)
- 26. In its regulatory and monitoring role, the CQC must take proper account of how complaints are being handled by providers, and how decisions made by the Ombudsman bodies are being implemented. The CQC must also routinely look at how health and care contracts between individuals and providers are being terminated and work alongside the Ombudsman bodies and providers to ensure that individuals are not suffering retaliation after lodging complaints. (Paragraph 108)
- 27. The confusion over the complaints system in care settings has an impact on the ability of care users to enforce their rights. (Paragraph 109)
- 28. Along with the recommendations above, complaint handling bodies together with the Government must consider options for raising awareness of the existing complaints processes. (Paragraph 109)

## Formal minutes

### Wednesday 13 July 2022

### **Hybrid Meeting**

Members present:

Joanna Cherry, in the Chair

Baroness Chisholm of Owlpen

Lord Dubs

Florence Eshalomi MP

Lord Henley

Baroness Ludford

Baroness Massey of Darwen

David Simmonds MP

Lord Singh of Wimbledon

### Protecting human rights in care settings

Draft Report (*Protecting human rights in care settings*), proposed by the Chair, brought up and read.

*Ordered*, That the Chair's draft Report be read a second time, paragraph by paragraph.

Paragraphs 1 to 109 read and agreed to.

Summary agreed to.

Annex agreed to

*Resolved*, That the Report be the Fourth Report of the Committee to both Houses.

*Ordered*, That the Chair make the Report to the House of Commons and that the Report be made to the House of Lords.

*Ordered*, That embargoed copies of the Report be made available, in accordance with the provisions of Standing Order No. 134.

### **Adjournment**

Adjourned till 20 July 2022 at 2.45pm.

# **Declaration of interests**

### **Baroness Chisholm of Owlpen**

• No relevant interests to declare

### **Lord Dubs**

• No relevant interests to declare

### **Lord Henley**

• No relevant interests to declare

### **Baroness Ludford**

• No relevant interests to declare

### **Baroness Massey of Darwen**

• No relevant interests to declare

### **Lord Singh of Wimbledon**

• No relevant interests to declare

Q68-80

# Witnesses

The following witnesses gave evidence. Transcripts can be viewed on the inquiry publications page of the Committee's website.

### Wednesday 12 January 2022

Ruthie Henshall, Ambassador, Rights for Residents; Sharon Clay	Q1-7
<b>Helen Wildbore</b> , Director, Relatives and Residents Association; <b>Caroline Abrahams</b> , Charity Director, Age UK; <b>Margaret Flynn</b> , <b>Safeguarding expert</b>	<u>Q8–17</u>
Wednesday 23 February 2022	
<b>Dan Scorer</b> , Head of Policy and Public Affairs, Mencap; <b>Sam Cox</b> , Knowledge Officer (Legal and Welfare Rights), Alzheimer's Society	Q17-24
<b>Dr Lucy Series</b> , Senior Research Fellow and Lecturer in Law, Cardiff University; <b>Richard Charlton</b> , Director, Richard Charlton Solicitors; <b>Judy Laing</b> , Professor of Mental Health Law & Policy, University of Bristol's Human Rights Implementation Centre	Q25-29
Wednesday 9 March 2022	
<b>Professor Wayne Martin</b> , Principal Investigator, The Essex Autonomy Project, University of Essex; <b>Sanchita Hosali</b> , CEO, British Institute of Human Rights; <b>Kari Gerstheimer</b> , Founder and CEO, Access Social Care	Q30-36
<b>Professor Vic Rayner OBE</b> , CEO, National Care Forum; <b>Nadra Ahmed OBE</b> , Chairman, National Care Association	Q37-44
Wednesday 23 March 2022	
Roger Banks, National Clinical Director for Learning Disability and Autism, National Health Service; Tom Cahill, National Director for Learning Disability and Autism, National Health Service; Aidan Fowler, National Director for Patient Safety, National Health Service	Q45-55
Michael King, Local Government and Social Care Ombudsman and Chair of the Commission, Local Government and Social Care Ombudsman (LGSCO); Kate Terroni, Chief Inspector of Adult Social Care, Care Quality Commission (CQC); Jemima Burnage, Deputy Chief Inspector of Hospitals - Mental Health, Care Quality Commission (CQC)	Q56-67
Wednesday 18 May 2022	
<b>Gillian Keegan MP</b> , Minister of State for Care, Department of Health and Social Care; <b>Michelle Dyson</b> , Director General for Adult Social Care, Department of Health and Social Care; <b>Lyn Romeo</b> , Chief Social Worker for Adults, Department of Health and Social Care	Q68-80

### Published written evidence

The following written evidence was received and can be viewed on the <u>inquiry publications</u> page of the Committee's website.

HCS numbers are generated by the evidence processing system and so may not be complete.

- 1 Anonymous (HCS0001)
- 2 Anonymous (HCS0002)
- 3 Anonymous (HCS0003)
- 4 Anonymous (HCS0005)
- 5 Anonymous (HCS0006)
- 6 Anonymous (HCS0010)
- 7 Anonymous (HCS0012)
- 8 Anonymous (HCS0016)
- 9 Anonymous (HCS0022)
- 10 Anonymous (HCS0023)
- 11 Anonymous (HCS0024)
- 12 Anonymous (HCS0038)
- 13 Anonymous (HCS0051)
- 14 Anonymous (HCS0052)
- 15 Anonymous (HCS0058)
- 16 Anonymous (HCS0059)
- 17 Anonymous (HCS0060)
- 18 Access Social Care (HCS0062)
- 19 Access Social Care (ASC) (HCS0035)
- 20 Age UK (HCS0046)
- 21 Alzheimer's Society (HCS0008)
- 22 Barber, Mrs Rachel (HCS0004)
- 23 British Association of Social Workers (HCS0019)
- 24 British Institute of Human Rights (BIHR) (HCS0067)
- 25 Care England (HCS0017)
- 26 Care Quality Commission (CQC) (HCS0045)
- 27 Care Quality Commission (CQC) (HCS0065)
- 28 Charlie Gard Foundation (HCS0026)
- 29 Charlton, Richard (HCS0054)
- 30 Compassion in Dying (HCS0030)
- 31 Department of Health and Social Care (DHSC) (HCS0064)
- 32 Ealing Reclaim Social Care Action Group (ERSCAG) (HCS0028)
- 33 Essex Autonomy Project, University of Essex (HCS0033)

- 34 Flynn, Margaret, Chair of the National Mental Capacity Forum (HSC0053)
- 35 Hogarth, David (HCS0027)
- 36 Human Rights Implementation Centre (HRIC) (HCS0029)
- 37 Independent Age (HCS0032)
- 38 Isle of Wight Council Ethical task force (HCS0020)
- 39 John's Campaign (HCS0007)
- 40 LGB Alliance (HCS0036)
- 41 Laing, Professor Judy, HRIC, University of Bristol and Series, Dr Lucy, Cardiff Law School (HCS0061)
- 42 Learning Disability England (HCS0044)
- 43 Leonard Cheshire (HCS0021)
- 44 Local Government and Social Care Ombudsman (HCS0056)
- 45 Local Government and Social Care Ombudsman (HCS0069)
- 46 Martin, Wayne (HCS0063)
- 47 Mencap and the Challenging Behaviour Foundation (HCS0043)
- 48 National AIDS Trust (HCS0039)
- 49 National Care Forum (HCS0037)
- 50 National Survivor User Network (HCS0047)
- 51 NHS England and NHS Improvement (HCS0068)
- 52 Parliamentary and Health Service Ombudsman (HCS0066)
- 53 Quality and Human Rights Commission (HCS0050)
- 54 The Relatives and Residents Association (HCS0048)
- 55 Rights for Residents (HCS0034)
- 56 Rights Lab, University of Nottingham (HCS0009)
- 57 Series, Dr Lucy (HCS0055)
- 58 Serenity Welfare (HCS0049)
- 59 Social Care Innovators' Power and Rights Group (HCS0025)
- Society for Children and Adults with Learning Disabilities and their Families (HCS0015)
- The Policy Institute at King's King's College London; Nightingale Hammerson care home residents (HCS0057)
- 62 Todd, Mr Andrew (HCS0040)
- 63 Willis, Dr Paul; Powell, Dr Jillian and Vickery, Dr Alex (HCS0031)

# List of Reports from the Committee during the current Parliament

All publications from the Committee are available on the publications page of the Committee's website.

### **Session 2022–23**

Number	Title	Reference
1st	Legislative Scrutiny: Public Order Bill	HC 351 HL 16
2nd	Proposal for a draft State Immunity Act 1978 (Remedial) Order	HC 280 HL 42
3rd	The Violation of Family Life: Adoption of Children of Unmarried Women 1949–1976	HC 270 HL 43

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1st	Children of mothers in prison and the right to family life: The Police, Crime, Sentencing and Courts Bill	HC 90 HL 5
2nd	Legislative Scrutiny: Police, Crime, Sentencing and Courts Bill, Part 3 (Public Order)	HC 331 HL 23
3rd	The Government's Independent Review of the Human Rights Act	HC 89 HL 31
4th	Legislative Scrutiny: Police, Crime, Sentencing and Courts Bill (Part 4): The criminalisation of unauthorised encampments	HC 478 HL 37
5th	Legislative Scrutiny: Elections Bill	HC 233 HL 58
6th	Legislative Scrutiny: Police, Crime, Sentencing and Courts Bill (Parts 7 and 8): Sentencing and Remand of Children and Young People	
7th	Legislative Scrutiny: Nationality and Borders Bill (Part 1) – Nationality	HC 764 HL 90
8th	Proposal for a draft Bereavement Benefits (Remedial) Order 2021: discrimination against cohabiting partners	HC 594 HL 91
9th	Legislative Scrutiny: Nationality and Borders Bill (Part 3) – Immigration offences and enforcement	HC 885 HL 112
10th	Legislative Scrutiny: Judicial Review and Courts Bill	HC 884 HL 120
11th	Legislative Scrutiny: Nationality and Borders Bill (Part 5)— Modern slavery	HC 964 HL 135

Number	Title	Reference
12th	Legislative Scrutiny: Nationality and Borders Bill (Parts 1, 2 and 4) – Asylum, Home Office DecisionMaking, Age Assessments, and Deprivation of Citizenship Orders	
13th	Human Rights Act Reform	HC 1033 HL 191
1st Special Report	The Government response to covid-19: fixed penalty notices: Government Response to the Committee's Fourteenth Report of Session 2019–21	HC 545
2nd Special Report	Care homes: Visiting restrictions during the covid-19 pandemic: Government Response to the Committee's Fifteenth Report of Session 2019–21	HC 553
3rd Special Report	Children of mothers in prison and the right to family life: The Police, Crime, Sentencing and Courts Bill: Government Response to the Committee's First Report	HC 585
4th Special Report	The Government response to covid-19: freedom of assembly and the right to protest: Government Response to the Committee's Thirteenth Report of Session 2019–21	HC 586
5th Special Report	Legislative Scrutiny: Police, Crime, Sentencing and Courts Bill, Part 3 (Public Order): Government Response to the Committee's Second Report	HC 724
6th Special Report	Legislative Scrutiny: Police, Crime, Sentencing and Courts Bill, Part 4 (Unauthorised Encampments): Government Response to the Committee's Fourth Report	HC 765
7th Special Report	Legislative Scrutiny: Elections Bill: Government Response to the Committee's Fifth Report	HC 911
8th Special Report	Legislative Scrutiny: Police, Crime, Sentencing and Courts Bill (Parts 7 and 8): Sentencing and Remand of Children and Young People: Government Response to the Committee's Sixth Report	HC 983
9th Special Report	Human Rights and the Government's Response to Covid-19: Digital Contact Tracing: Government Response to the Committee's Third Report of Session 2019–21	HC 1198
10th Special Report	Legislative Scrutiny: Nationality and Borders Bill: Government Responses to the Committee's Seventh, Ninth, Eleventh and Twelfth Reports	HC 1208

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Number	Title	Reference
1st	Draft Jobseekers (Back to Work Schemes) Act 2013 (Remedial) Order 2019: Second Report	HC 146 HL 37
2nd	Draft Human Rights Act 1998 (Remedial) Order: Judicial Immunity: Second Report	HC 148 HL 41
3rd	Human Rights and the Government's Response to Covid-19: Digital Contact Tracing	HC 343 HL 59

Number	Title	Reference
4th	Draft Fatal Accidents Act 1976 (Remedial) Order 2020: Second Report	HC 256 HL 62
5th	Human Rights and the Government's response to COVID-19: the detention of young people who are autistic and/or have learning disabilities	HC 395 (CP 309) HL 72
6th	Human Rights and the Government's response to COVID-19: children whose mothers are in prison	HC 518 HL 90
7th	The Government's response to COVID-19: human rights implications	HC 265 (CP 335) HL 125
8th	Legislative Scrutiny: The United Kingdom Internal Market Bill	HC 901 HL 154
9th	Legislative Scrutiny: Overseas Operations (Service Personnel and Veterans) Bill	HC 665 (HC 1120) HL 155
10th	Legislative Scrutiny: Covert Human Intelligence Sources (Criminal Conduct) Bill	HC 847 (HC 1127) HL 164
11th	Black people, racism and human rights	HC 559 (HC 1210) HL 165
12th	Appointment of the Chair of the Equality and Human Rights Commission	HC 1022 HL 180
13th	The Government response to covid-19: freedom of assembly and the right to protest	HC 1328 HL 252
14th	The Government response to covid-19: fixed penalty notices	HC 1364 HL 272
15th	Care homes: Visiting restrictions during the covid-19 pandemic	HC 1375 HL 278
1st Special Report	The Right to Privacy (Article 8) and the Digital Revolution: Government Response to the Committee's Third Report of Session 2019	HC 313
2nd Special Report	Legislative Scrutiny: Covert Human Intelligence Sources (Criminal Conduct) Bill: Government Response to the Committee's Tenth Report of Session 2019–21	HC 1127
3rd Special Report	Legislative Scrutiny: Overseas Operations (Service Personnel and Veterans) Bill: Government Response to the Committee's Ninth Report of Session 2019–21	HC 1120
4th Special Report	Black people, racism and human rights: Government Response to the Committee's Eleventh Report of Session 2019–21	HC 1210
5th Special Report	Democracy, freedom of expression and freedom of association: Threats to MPs: Government Response to the Committee's Third Report of Session 2019	HC 1317
6th Special Report	Legislative Scrutiny: Police, Crime, Sentencing and Courts Bill, Part 4 (Unauthorised Encampments): Government Response to the Committee's Fourth Report	HC 765

Number	Title	Reference
7th Special Report	Legislative Scrutiny: Elections Bill: Government Response to the Committee's Fifth Report	HC 911