



COMMENTARY

Disability Rights During COVID-19: Emergency Law and Guidelines in England

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ABSTRACT

Disabled people may be disproportionately impacted by the response to the COVID-19 outbreak because of the kinds of countermeasures needed to tackle it, and serious disruptions to the services on which they rely. There are reports from the disability community in England and elsewhere that measures taken to contain the spread of COVID-19 impact negatively on their human rights and experiences. This commentary focuses on the healthcare and social care systems in England and describes how laws and practices have changed under the COVID-19 pandemic, and how these changes affect the rights of disabled people.

KEYWORDS: Coronavirus Act 2020, COVID-19, disability rights, guidelines, healthcare, social care

I. INTRODUCTION

Early in the COVID-19¹ pandemic, both the World Health Organisation and United Nations called for governments to take action to prevent an increase of discrimination against disabled people.² Public health experts argued that the response to COVID-19

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1 According to the World Health Organisation, the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) causes the coronavirus disease (COVID-19).

2 UN News, 'Preventing Discrimination Against People with Disabilities in COVID-19 Response' (2020) <<https://news.un.org/en/story/2020/03/1059762>> accessed 2 August 2020.

must ensure, *inter alia*, that all public communication regarding COVID-19 is accessible to disabled people; that protective measures ensuring continuous access to healthcare and social care facilities must be prioritised; and that all healthcare staff should be provided with rapid training on the rights of disabled people to ensure equality in healthcare.³

Disabled people may be disproportionately impacted by the response to the COVID-19 outbreak because of the kinds of countermeasures needed to tackle it, and serious disruptions to the services on which they rely. For instance, there may be barriers for disabled people implementing basic hygiene measures, such as handwashing, since facilities may be physically inaccessible and a person may have physical difficulty rubbing their hands together thoroughly. Enacting social distancing in health and social care settings for disabled people may be difficult or impossible. Disabled people may also be negatively impacted by the closure of day centres along with most public buildings; the closure or limitations on transport services; and a shortage of care staff.⁴

There are reports from the disability community in the UK and elsewhere that measures taken to contain the spread of COVID-19 impact negatively on their human rights and experiences.⁵ The Chronic Illness Inclusion Project (CIIP), for example, has conducted a survey of people with chronic illnesses on their experiences during the pandemic and the results are harrowing: 86% of respondents reported that the pandemic has had a negative impact on their ability to access food and essential supplies; 66% reported disruption to care during the pandemic; and 56% of respondents reported that their health worsened since the pandemic began, with a significant number reporting the detrimental impact of increased stress and anxiety. Many respondents to the CIIP survey reported experiences of discrimination and ableism in shops, the NHS, the media, and public conversation.⁶ Calls for a disability-inclusive response to COVID-19, and emerging evidence of negative experiences of the response among disabled people, come against the background of a history and pre-COVID 19 reality of deep inequalities in accessing and using health and social care in respect of disability.⁷

3 R Armitage and L Nellums, 'The COVID-19 Response Must Be Disability Inclusive' (2020) 5(5) *Lancet Public Health* e257.

4 See further: World Health Organisation, 'Disability Considerations During the COVID-19 Crisis' (2020) <<https://www.who.int/publications/i/item/disability-considerations-during-the-covid-19-outbreak>> accessed 2 August 2020.

5 A Ruddock and A Gkiouleka, 'I Feel Forgotten: The Impact of COVID-19 on People with Chronic Illness' (2020) *The Chronic Illness Inclusion Project* <<https://www.centreforwelfarereform.org/library/i-feel-forgot-ten.html>> accessed 2 August 2020.

6 *ibid.*

7 See A Ali and others, 'Discrimination and Other Barriers to Accessing Healthcare: Perspectives of Patients with Mild and Moderate Intellectual Disabilities' (2013) 8(8) *PLoS One* e70855; H De Vries and others, 'Health Experiences and Perceptions among People with and Without Disabilities' (2016) 9(1) *Disability & Health Journal* 74; M Stilman and others, 'Healthcare Utilization and Associated Barriers Experienced by Wheelchair Users: A Pilot Study' (2017) 10(4) *Disability & Health Journal* 502; D Raymarker and others, 'Barriers to Healthcare: Instrument Development and Comparison Between Autistic Adults and Adults with or Without Other Disabilities' (2017) 21(8) *Autism* 972; RE Serrano, 'Working to Remove Barriers to Healthcare For People with Disabilities' (*World Health Organization*, 2012) <<https://www.who.int/westernpacific/news/detail/10-12-2012-working-to-remove-barriers-to-health-care-for-people-with-disabilities>>

This commentary focuses on the healthcare and social care systems in one place—England⁸—and describes how laws and practices have changed under the COVID-19 pandemic, and how these changes affect the rights of disabled people. The focus on both healthcare and social care is appropriate since their integration is part of a key long-term government strategy,⁹ and health and social care form an important part of all people’s experiences during the pandemic, including disabled people.¹⁰ The interrelation of healthcare and social care, as well as the added strain on both systems that the COVID-19 pandemic creates, is also reflected in the Coronavirus Act 2020 (CA 2020), which contains changes to pre-pandemic legislation covering both health and social care.¹¹

In the next section ‘The CA 2020 and the easement of the Care Act 2014’, I summarise the current (July 2020) law on the provision of social care in light of the suspension of the Care Act 2014 (Care Act) in England by the CA 2020. In the third section ‘Healthcare during the COVID-19 pandemic: guidelines on hospital responses during the pandemic’ of the commentary, I discuss healthcare by examining two separate, yet co-existing, guidelines on responses during the pandemic: the National Institute for Health and Care Excellence (NICE) guidelines on critical care; and the British Medical Association (BMA) guidelines on ethical issues. Both guidelines are considered examples of ‘best practice’ and it is an established practice that local health authorities follow them in order to comply with their duties to provide equal and effective healthcare.¹² The NICE and BMA guidelines gain added significance in light of the COVID-19 pandemic and the added strain on health and social care systems, since they will help to shape practice in a scenario where available resources are insufficient and decisions about their distribution will have to be made.

Finally, in the fourth section ‘Disability rights during the COVID-19 pandemic: some key reflections on the potential for unequal treatment’, I offer some thoughts on

accessed 2 August 2020. United Nations, ‘Persons with Disabilities: Breaking Down Barriers’ (2018) Report on the World Situation 2018, ch V <<https://www.un.org/development/desa/dspd/wp-content/uploads/sites/22/2018/07/Chapter-VPersons-with-disabilities-breaking-down.pdf>> accessed 2 August 2020.

8 Note that healthcare and social care are subject to different rules in the rest of the UK: Northern Ireland, Scotland, and Wales.

9 NHS Long Term Plan, ‘Chapter 1: A new service model for the 21st century’, s 5: moving to Integrated Care systems everywhere <<https://www.longtermplan.nhs.uk/online-version/chapter-1-a-new-service-model-for-the-21st-century/nhs-organisations-focus-on-population-health/>> accessed 2 August 2020.

10 R Murray and others, ‘Delivering Core NHS and Care Services During the Covid-19 Pandemic and Beyond: Letter to the Commons Health and Social Care Select Committee’ (2020) The King’s Fund publication <<https://www.kingsfund.org.uk/publications/letter-to-health-and-social-care-select-committee-covid-19>> accessed 2 August 2020.

11 For example, CA 2020, pt 1, cls 2–5 deal with emergency registration of health workers in EN, WA, SC, and NI. CA 2020, pt 1, cls 6 and 7 deal with temporary registration of social workers in EN, SC, and WA.

12 The various duties regarding the provisions of healthcare are spelled out in a number of pieces of legislation, including, but not limited to, the National Health Service Act 2016; the Public Health Act (Northern Ireland) 1967; the Public Health etc (Scotland) Act 2008; the Public Health (Wales) Act 2017; the Human Rights Act 1998; and the Disability Discrimination Act 2010. In this commentary, we do not provide a detailed discussion on emergency law interacting with wider duties applicable in England under, for instance, the Equality Act 2010 or the Human Rights Act 1998, which remain in force alongside and unaltered by the CA 2020, despite the CA 2020 temporarily restricting rights and freedoms previously enjoyed. We are preparing a longer academic article on the topic.

how the changes to both healthcare and social care provisions for disabled people during the COVID-19 pandemic may impact negatively on disabled people's rights during the crisis period by leaving them potentially exposed to unequal treatment. I focus my comments on what the suspension of the Care Act might mean for disabled people's experiences during the pandemic and how the BMA and NICE guidelines can be understood as dominated by a medical understanding of disability that might facilitate unequal treatment in relation to critical healthcare.

Before I proceed, I note that within the UK health and social care are devolved matters.¹³ Parts of the CA 2020 apply to England, Scotland, Wales, and Northern Ireland (eg emergency registration for health workers),¹⁴ but all devolved nations have the right to pass specific legislation on health and social care reflecting their different health and social care settings. Social care practitioners have argued that the four nations will most likely 'seek an alignment'.¹⁵ In this commentary, I focus specifically on England, with the understanding that the experiences of disabled people in England will likely mirror the experiences of disabled people in the other devolved nations. Therefore, an interrogation of how the laws and practices around healthcare and social care in England have changed in light of the pandemic would be useful for scholars and practitioners examining the rest of the devolved nations.

II. THE CA 2020 AND THE EASEMENT OF THE CARE ACT 2014

The CA 2020 was introduced in March 2020.¹⁶ It is a comprehensive piece of legislation bringing in a number of emergency provisions covering various aspects of life during the pandemic. The CA 2020 has two main parts: Part 1 covers the Main Provisions of the Act and Part 2 covers the Final Provisions. The Act has twenty-nine schedules providing more details on the main provisions of the Act. Within Part 1 of the Act, there is a definition of 'coronavirus' and other terminology (section 1). Provisions on the emergency registrations of health professionals and social workers are found in sections 2–7. Section 10 modifies the existing mental health and mental capacity legislation. Sections 14–17 make changes to the NHS and Local Authority provision of care and support. Provisions of fingerprinting and DNA are found in section 24, followed by provisions on food supply (sections 25–29). Inquests during the pandemic are covered by sections 30–32. Section 36 covers vaccinations. Schools are the subject of sections 37 and 38. Statutory sick pay is addressed in sections 39–44. The final sections (48–52) address powers given to health officials to protect public health, to deal with people potentially infected, and to issue guidance on social gatherings, events, and premises.¹⁷

13 S Greer, 'Devolution and Health in the UK: Policy and Its Lessons Since 1998' (2016) 118(1) *British Medical Bulletin* 16.

14 *Coronavirus Act 2020*, pt 1: Emergency registration of health professionals, cls 1–5.

15 Carers UK, 'Coronavirus Act- What It Means for Carers. Detailed Briefing on the Health and Care Provisions on the Act' (2020) <https://www.carersuk.org/images/News_and_campaigns/Coronavirus/Coronavirus_Act_2020_detailed_provisions_affecting_carers_2.4.2020.pdf> accessed 2 August 2020.

16 *Coronavirus Act 2020*, full text available at <<http://www.legislation.gov.uk/ukpga/2020/7/schedule/12/enacted>> accessed 2 August 2020.

17 This is not an exhaustive list of all the CA 2020 provisions.

The emergency provisions within the CA 2020, for example, the extraordinary powers given to public health officials, including immigration officers and police officers, to detain, question, remove, and force into treatment individuals merely suspected of being infected with coronavirus, have prompted human rights experts to raise concerns about potential human rights breaches.¹⁸ As part of this commentary on both healthcare and social care during the pandemic from a disability perspective, the focus in this section is on the potential of unequal access to social care as spelled out in section 15 of the CA 2020 and the corresponding Schedule 12 Part 1, which deals with Local Authority care and support in England.¹⁹

Schedule 12 essentially suspends a number of duties imposed on Local Authorities under the Care Act 2014.²⁰ The latter imposes a duty, *inter alia*, on Local Authorities to promote the individual's well-being (section 1),²¹ a duty to assess adults' and carers' needs for care and support (sections 9 and 10),²² and a duty to involve the disabled person in the construction of their care and support plan (section 25).²³ A key feature of the Care Act is the strong focus on personalisation of care and independent living.²⁴

Under Schedule 12 of the CA 2020, a number of the pre-CA 2020 duties on Local Authorities regarding social care have been temporarily suspended during the pandemic. For example, Schedule 12 suspends the duty on Local Authorities to assess an adult's needs for care and support under section 9 of the Care Act 2014. Schedule 12 of the CA 2020 also suspends the duty under section 10 of the Care Act 2014 to assess a carer's needs for care and support. Schedule 12 further suspends the duties to assess children's needs for care and support, child's carers' needs for care and support, and young carers' needs for care and support.²⁵ In addition, the CA 2020 suspends the duty under section 12 of the Care Act 2014 to make further provisions regarding assessments of needs. It suspends the duty under section 13 of the Care Act 2014 to make a decision following an assessment on whether a person's needs are eligible needs.²⁶ There is an explicit exemption to the suspension of duties under the Care Act 2014 in England: Schedule 12 of the CA 2020 gives effect to section 18 of the Care Act 2014 (duty to meet needs for care and support) to avoid a breach of an

18 Amnesty International UK, 'Coronavirus: The Effect on Human Rights Impact in the UK' (2020) <<https://www.amnesty.org.uk/human-rights-uk/coronavirus-effect-human-rights>> accessed 2 August 2020. See also Lord Sanhurst QC and Anthony Speaight QC, 'Pardonable in the Heat of the Crisis-But We Must Urgently Return to the Rule of Law' (2020) The Society of Conservative Lawyers publication <https://e1a359c7-7583-4e55-8088-a1c763d8c9d1.usfiles.com/ugd/e1a359_017552492cac41868ee7eed2a53fe99d.pdf> accessed 2 August 2020.

19 Coronavirus Act 2020, sch 12: Local authority care and support, pt 1: Powers and duties of Local Authorities in England, <<http://www.legislation.gov.uk/ukpga/2020/7/schedule/12/enacted>> accessed 2 August 2020.

20 Care Act 2014, full text available at <<http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>>.

21 Care Act 2014, s 1: Promoting individual well-being.

22 Care Act 2014, s 9: Assessment of an adult's needs for care and support. Care Act 2014, s 10: Assessment of a carer's needs for care and support.

23 Care Act 2014, s 25: Care and support plan, support plan.

24 D Barnes and others, 'Personalisation and Social Care Assessment- The Care Act 2014' (2017) 41(3) British Journal of Psychology Bulletin 176.

25 Respectively, ss 58, 60, and 63 of the Care Act 2014.

26 CA 2020, sch 12, pt 1, s 2.

individual's human rights under the European Convention on Human Rights as codified in the Human Rights Act 1998.²⁷

In summary, the various duties imposed on Local Authorities by the Care Act 2014 have been suspended and replaced with a duty to assess and meet needs under the CA 2020 only if failing to meet needs results in a human rights violation. In all other cases, the Explanatory Notes to the CA 2020 point out that Local Authorities have a power to meet needs.²⁸ Local Authorities are 'expected' to meet needs if they can do so, but if not able to meet all needs then they are expected to 'prioritise provisions as necessary'.²⁹ The Department for Health and Social Care in England is allowed to issue guidelines and in such cases, the Secretary of State for England is allowed to direct Local Authorities to follow such guidelines.³⁰ Local Authorities are allowed to meet needs for care and support without a full assessment under the Care Act 2014 provisions or a financial assessment.³¹

To help clarify further how the CA 2020 has changed the pre-pandemic duties to provide care and support under the Care Act 2014, I turn to the guidelines on the 'easement' of the Care Act provided for Local Authorities.³² Section 3(1) of the guidelines explains that Local Authorities do not have a duty to carry out detailed assessments of needs for care and support. But they are still 'expected' to respond to requests for care and support in a timely manner that avoids human rights violations. Local Authorities are also 'expected' to respond to the needs and wishes of individuals and their carers and family, as well as to assess what needs have to be met. Section 3(2) of the guidelines confirms that Local Authorities do not have to carry out financial assessments but can still charge people for the care and support they receive during the pandemic in a retrospective manner. Section 3(3) of the guidelines allows Local Authority to not prepare and review care and support plans, but Local Authorities are 'expected' to provide 'proportionate people-centred care planning' with 'sufficient' information provided to all parties concerned. Section 3(4) of the guidelines elaborates on duties under the Care Act 2014 to meet needs being replaced with a 'power' to meet needs, allowing Local Authority to prioritise available resources in case they are unable to meet everyone's care and support needs as usual. The legal semantic here is important: a *duty* imposes a concrete obligation based on a concrete provision of the Care Act 2014 that applies to *every* individual, such as the duty to meet an adult's needs for care and support under section 18 of the Care Act 2014. A *power* enables Local Authority to prioritise responding to those individuals considered to be *most in need*.

It becomes clear from this summary that the suspension of duties under the Care Act 2014 applies in a scenario where the social care system is overrun and unable to

27 *ibid*, sch 12, pt 1, s 4.

28 CA 2020 Explanatory Notes, para 232 <<https://publications.parliament.uk/pa/bills/lbill/58-01/110/5801110en.pdf>> accessed 2 August 2020.

29 *ibid*, para 234.

30 *ibid*, para 235.

31 *ibid*, para 236.

32 Department of Health and Social Care, 'Care Act Easements: Guidance for Local Authorities' (2020) <<https://www.gov.uk/government/publications/coronavirus-covid-19-changes-to-the-care-act-2014/care-act-easements-guidance-for-local-authorities#what-the-powers-actually-change>> accessed 2 August 2020.

cope. The same concerns about insufficient resources and inability to cope are shared in relation to the health system. Having summarised the changes to the law on social care provision in England during the pandemic, I move now to discuss how the provision of healthcare during the pandemic in England would change in a similar scenario where the health system cannot meet everyone's needs. To do so, I look at the NICE guidelines on the provision of critical care and the BMA guidelines on ethical issues that might arise when health professionals are expected to prioritise access to scarce resources during a pandemic.

III. HEALTHCARE DURING THE COVID-19 PANDEMIC: GUIDELINES ON HOSPITAL RESPONSES DURING THE PANDEMIC

A. NICE COVID-19 Rapid Guidelines: Critical Care in Adults

The NICE COVID-19 Rapid Guidelines (NICE guidelines) were originally released in March 2020, bringing together other national guidelines and policies, as well as advice from NHS health practitioners on best practices during the COVID-19 pandemic in a situation where the available health resources are insufficient.³³ The original guidelines were amended in April 2020 following a proposed judicial review on the basis of disability discrimination inherent in the guidelines.³⁴ NICE fully accepted the arguments set out in the proposed review, in particular the concerns raised that the use of a Critical Frailty Scheme (CFS) would label disabled patients who depend on a carer or a personal assistant as inherently frail. NICE thus amended the guidelines accordingly, removing certain patients from the CFS approach.³⁵

The (amended) NICE guidelines aim to maximise the safety of patients and NHS staff and enable the best use of available NHS resources. The guidelines provide clarity on admission to hospital, admission to critical care, starting, reviewing and stopping critical care systems, clinical decision-making, and service organisation.³⁶

According to the NICE guidelines, some patients (not those with disabilities) should be assessed upon admission to hospital according to the CFS.³⁷ The CFS has nine degrees of frailty, ranging from very fit (one point on the scale) to terminally ill (nine points on the scale). For anyone scoring five points or higher on the CFS (mildly frail, moderately frail, severely frail, very severely frail, and terminally ill), the guidelines suggested that hospital admission might not be appropriate. By contrast, for people scoring fewer than five points on the CFS, hospital admission was seen as appropriate. In addition, the original guidelines contained a reference to discussing sensitively 'do not attempt cardiopulmonary resuscitation' with people scoring five or more points on the CFS scheme.³⁸

33 NICE COVID-19 Rapid Guidelines: critical care in adults <<https://www.nice.org.uk/guidance/ng159>> accessed 2 August 2020.

34 The proposed judicial review was brought forward by Hodge, Jones, and Allen Solicitors <<https://www.hja.net/press-releases/nice-amends-covid-19-critical-care-guideline-after-judicial-review-challenge/>> accessed 2 August 2020.

35 NICE COVID-19 rapid guidelines Equality Impact Assessment <<https://www.nice.org.uk/guidance/ng165/evidence/equality-impact-assessment-pdf-8722432477>> accessed 2 August 2020.

36 See n 34, Overview.

37 The CFS is provided by the NHS Specialised Clinical Frailty Network, full text available at <<https://www.nice.org.uk/guidance/ng159/resources/clinical-frailty-scale-pdf-8712262765>> accessed 2 August 2020.

After the amendment brought by the proposed judicial review on the basis of disability discrimination, the CFS is not to be used for younger people, people with stable long-term physical disabilities, people with learning disabilities, and people with autism. Instead of the CFS, health practitioners are expected to use an individual assessment. The CFS is to be used for all other patients. Comorbidities and underlying conditions are always to be considered with all patients, including disabled patients.³⁹

In starting, reviewing and stopping critical care treatment, the NICE guidelines further refer health practitioners to the BMA guidelines on ethical issues arising from the pandemic (see below for a detailed discussion),⁴⁰ to the Royal College of Physicians Ethical dimensions of COVID-19 for frontline staff guidelines,⁴¹ and to the General Medical Council Ethical Guidance for Doctors.⁴² All of these guidelines have provisions specific to disability and are meant to be referred to by health practitioners in need of further advice.⁴³

The NICE guidelines do not explain in detail what an individual assessment (the assessment that should be used for disabled patients) is and on what basis it has been constructed as practice in assessing who should be prioritised for critical care. Section 4(2) of the guidelines provides some information on how health practitioners should carry out such an assessment:

Base decisions on admission of individual adults to critical care on the likelihood of their recovery, taking into account the likelihood that a person will recover from their critical care admission to an outcome that is acceptable to them.⁴⁴

In fact, as pointed out above, the NICE guidelines make a specific reference to the BMA guidelines on ethical issues that arise from the COVID-19 pandemic. The BMA guidelines are especially relevant to assessing the needs of disabled people and how best to prioritise the available resources when making difficult decisions on who should be prioritised. In the following, I discuss the BMA guidelines in more detail.

B. BMA Guidelines

The BMA guidelines on ethical issues arising from the COVID-19 pandemic were published in April 2020.⁴⁵ The main purpose of the guidelines is to address some of the main ethical challenges likely to arise during the pandemic and provide clarity for health practitioners concerned about their ability to provide safe and ethical care to the best of their abilities, and worried that their actions may attract criminal, civil, or

38 See n 34, Overview.

39 *ibid*, s 1: Admission to hospital.

40 BMA Guidance COVID-19: ethical issues <<https://www.bma.org.uk/advice-and-support/covid-19/ethics/covid-19-ethical-issues>> accessed 2 August 2020.

41 RCP Ethical dimensions of COVID-19 for frontline staff <<https://www.rcplondon.ac.uk/news/ethical-guidance-published-frontline-staff-dealing-pandemic>> accessed 2 August 2020.

42 GMC Ethical Guidance for Doctors, <<https://www.gmc-uk.org/ethical-guidance/ethical-hub/covid-19-questions-and-answers>> accessed 2 August 2020.

43 See n 34, s 3: Starting, reviewing and stopping critical care treatment.

44 *ibid*, s 4: Clinical Decision Making.

45 BMA Guidance COVID-19: ethical issues <<https://www.bma.org.uk/advice-and-support/covid-19/ethics/covid-19-ethical-issues>> accessed 2 August 2020.

professional liability. To this end, the BMA guidelines regard as legal those decisions that are based on the principles set out in the 2009 pandemic Government guidelines: decisions must be reasonable, based on best evidence available, made in accordance with other relevant guidelines, as collaborative as possible and promoting safe and effective care as far as possible.⁴⁶

The BMA guidelines address the notion that ethical issues would arise from the NHS facilities operating at capacity in a scenario where the NHS is overrun and unable to cope and where ‘providing care to existing standards is likely to be difficult’.⁴⁷ In such a scenario, individual needs may be trumped by considerations on the overall benefit of distributing resources. This position, of course, is on one level merely an extreme version of the need to allocate resources in the NHS during non-pandemic times. But on another level, the pandemic could force many more difficult resource-allocation decisions than in normal times, thus highlighting the inherent invidious choices in the system in a way that is not usually the case. The BMA guidelines recognise that there are ethical contradictions between providing the best healthcare for individuals and respective individual needs on the one hand and a utilitarian commitment to an equal concern for everyone on the other hand: ‘In dangerous pandemics the ethical balance of all doctors and healthcare workers must shift towards the utilitarian objective of equitable concern for all’—while maintaining respect for all as ‘ends in themselves’.⁴⁸ In short, according to the BMA guidelines, it would be both legal and ethical ‘to refuse someone potentially life-saving treatment where someone else is expected to benefit more from the available treatment’.⁴⁹

When health practitioners make decisions about who to prioritise in terms of limited resources, they should make ‘quantitative decisions based on maximising the overall reduction of mortality and morbidity, and the need to maintain vital social functions’.⁵⁰ The guidelines have a section specifically on direct and indirect discrimination, including on the grounds of age and disability. As doctors are required to assess a person’s eligibility for treatment on a ‘capacity to benefit quickly’ basis, the guidelines acknowledge that this would inevitably have a disproportionate impact on ‘older people and those with long-term health conditions that have a direct bearing on their ability to recover quickly’.⁵¹

An additional guidance note on the use of age and/or disability in decision-making further stipulates:

someone with a disability should not have that disability used by itself as a reason to withhold treatments, unless it is associated with worse outcomes and a

46 *ibid* 1.

47 *ibid* 1.

48 *ibid* 2. There is no explanation within the guidelines of what the phrase ‘ends in themselves’ means. The phrase ‘treating persons as ends in themselves’ is part of the Kantian tradition in ethics and philosophy signifying that all people have equal dignity and worth as human beings and should be treated equally in such capacity. See G Wright, ‘Treating Persons as Ends in Themselves: The Legal Implications of a Kantian Principle’ (2002) 36 *University of Richmond Law Review* 271.

49 *ibid* 3.

50 *ibid* 3.

51 *ibid* 7.

lower chance of survival. A decision to exclude from treatment everyone above a particular age, or with a disability, would be both unacceptable and illegal. We also state clearly in our guidance that these decisions must not be based upon discriminatory judgments about the value or worth of individual lives.⁵²

The BMA guidelines explicitly confirm that legal duties under the Equality Act 2010, such as equal treatment and reasonable adjustment, are still in effect, despite the pressure from the pandemic. However, ‘the duty is to make “reasonable” adjustments and what is reasonable will inevitably be affected by the exigencies of a pandemic and the pressures on NHS services as a result of the pandemic’.⁵³

Both the BMA guidelines and the NICE guidelines acknowledge that difficult decisions will have to be made and that despite best efforts some disabled people may be subjected to potentially unequal treatment. In light of the historic barriers to health-care and social care disabled people have experienced, and the increased risk of contracting the virus, the difficult legal and policy landscape during the pandemic highlighted above requires further investigation of how the COVID-19 legal and policy response has impacted on disability rights. It is with this in mind that I turn now to comment on the problematic aspects of the CA 2020 and the NICE and BMA guidelines. In doing so, I discuss them in turn in the section below as legal and ethical responses that may not directly aim to curtail disability rights, but as responses to the pandemic that may not be compatible with the WHO, UN, and disability movement calls, noted at the outset, to protect and even bolster disability rights during the public health crisis.

IV. DISABILITY RIGHTS DURING THE COVID-19 PANDEMIC: SOME KEY REFLECTIONS ON THE POTENTIAL FOR UNEQUAL TREATMENT

The potential for unequal treatment of disabled people during the pandemic in relation to social care stems from the realisation that the CA 2020 diminishes the quality of the obligations on Local Authorities in England to assess and meet their needs. The duty to provide effective and person-centred care for everyone has been replaced with a power to do so, but only to avoid a human rights violation under the Human Rights Act 1998. From a narrow legal perspective, considering that there is no explicit right to social care in the European Convention of Human Rights (the Convention rights are codified in the Human Rights Act), it may be increasingly difficult for disabled people and for carers to prove that their rights have been violated during the pandemic.

Some in the disability community have argued that the CA 2020 ‘strips disabled people of our rights to this support and removes from Local Authorities the duties to provide it’.⁵⁴ It should be noted that any limitations to the existing duties on Local Authorities to assess and meet disabled people’s needs must be done in a

52 BMA, ‘Statement/Briefing about the Use of Age and/or Disability in Our Guidance’ <<https://www.bma.org.uk/media/2358/bma-statement-about-ethics-guidance-and-disability-april-2020.pdf>> accessed 2 August 2020.

53 See n 46, 7.

proportionate and legal manner. Due to the multiple duties under the Care Act 2014 being suspended, there is a concern that the easement of the Care Act 2014 may not be a proportionate, and therefore legally sound, response to the increased needs disabled people have for effective social care during the pandemic, despite the obvious and real strain on the social care system during the pandemic. The fact remains that under the CA 2020 many of the important duties on Local Authorities have been suspended, thus there is a definite potential for many disabled people in England to not have their needs met during the period in a situation where failing to meet their needs is not considered a human rights violation.

From a broader disability perspective, the nature of the CA 2020 suggests that the government has deviated from the person-centred approach evident in the Care Act 2014. Overall, the approach of the CA 2020 is to conceptualise disabled people's entitlements as 'collateral damage', meaning the approach allows for disabled people's rights to be rolled back to alleviate the social care system of the burden posed by COVID-19. The consequence of this legislative framing is to diminish the quality of rights enjoyed by disabled people before the CA 2020 entered into force. It is concerning that the strain of the pandemic on the social care system can be used to justify a roll-back of years of campaigning and activism of the disability movement to ensure that the social care system is person-centric and promotes the highest possible standard of care.

In a very similar fashion to the CA 2020, the NICE and BMA guidelines on healthcare during the pandemic acknowledge and attempt to justify the potential for unequal treatment of disabled people arising from the obvious and serious strain on the health system during the pandemic. In particular, both sets of guidelines make specific references to the legality and ethical soundness of a decision-making process that does not openly discriminate against disabled people but takes into consideration a variety of clinical factors and ethical factors that may result in a justifiable unequal treatment of disabled people. Therefore, on the one hand, the guidelines understand disability as a protected category and prohibit direct discrimination. On the other hand, the guidelines lack a consideration of how clinical and ethical factors, such as critical care survivability, interact with the lived experience of being a disabled person. The insight of Savin and Guidry-Grimes is key here:

Public health ethics holds that equity requires trying to maximize the total number of lives saved throughout the course of the pandemic. For many in the disability community, however, equity means that people with disabilities and chronic illnesses have the *same chance of receiving maximum healthcare as their nondisabled peers*. In a public health context, medical criteria related to critical care survivability is scientifically pertinent evidence and not considered discriminatory. Many people with disabilities, long having lived the harsh sociopolitical realities of inhabiting bodies with physiological differences, perceive the same medical criteria as the usual grounds for discrimination.⁵⁵

54 J Pring, 'Coronavirus: Disabled People Say "Shocking" New Laws Will Strip Away Rights' (2020) Disability News Service publication <<https://www.disabilitynewsservice.com/coronavirus-disabled-people-say-shocking-new-laws-will-strip-away-rights/>> accessed 2 August 2020.

Without questioning the commitment individual health practitioners have to upholding disability rights during the pandemic, there are instances in the NICE and BMA guidelines that allow for unequal treatment to potentially take place disguised as an attempt to prioritise insufficient resources, or as a utilitarian concern for maximising health outcomes for that part of the population considered healthier (having a higher chance to survive or benefit from treatment). In the absence of any detailed description of what an individual assessment that avoids direct discrimination might be in either of the guidelines, but with multiple reaffirmations of the importance of clinical factors (which may not be reflective of the complexity of disability experience), a great deal of potential for unequal treatment remains. As the possibility or even likelihood of a 'second wave' of the COVID-19 pandemic looms as we go towards autumn and winter, the concerns raised by disabled people remain pertinent.

V. CONCLUSION

What we have seen so far in terms of the legal and policy response in the UK to COVID-19 from a disability rights perspective is a complex and contradictory landscape, open to problems. Medical ethics and understanding (or lack of) disability underpin all the examples discussed in this commentary. This commentary does not offer an exhaustive list of problematic policy and legal responses. However, I conclude by offering some thoughts on disability rights and the lives of disabled people after the easing of the COVID-19 lockdown. In short, disabled people may struggle to fare well in the 'new normal'.

The long-term impact of the COVID-19 response being non-disability inclusive will be felt after the easing of the lockdown and in the 'new normal'. The impact of care needs denied during the pandemic, as well as health deterioration, will be a factor in disabled people struggling to 'bounce back' from the pandemic. Even though the emergency laws and policies are meant to be time-bound and interpreted narrowly, we do not know when the threat of the pandemic will be lifted, especially in relation to a possible (or even likely) 'second wave' of the virus, in which case the same measures might have to be applied again. The use of vague, discriminatory, outdated, and medicalised language and models of disability would impact negatively on the long-term ability of disabled people to argue for rights to independent living, personalised care, and actions to address the historic inequalities in healthcare and social care. The very idea of 'established' disability rights and principles, such as the right to independent living, equality, and dignity, is being challenged by the COVID-19 response. The CA Act 2020 and associated guidelines raise questions about how established these so-called fundamental principles are and to what extent legal and social mechanisms established to uphold these dignity-based principles are a fixed and certain part of the legal and policy landscape.

Most importantly, the COVID-19 is neither the first nor the last global pandemic we will experience as a society. The response so far has been problematic from a

55 K Savin and L Guidry-Grimes, 'Confronting Disability Discrimination During the Pandemic' (2020) The Hastings Centre publication <https://www.thehastingscenter.org/confronting-disability-discrimination-during-the-pandemic/?fbclid=IwAR2ssY8aVhxj5284pr19S2WqZUM3VZvtSzJGQ6DeX4cB_FhqmZ7vOv90msk> accessed 2 August 2020 (emphasis in original).

disability perspective. Now is the time to try and learn how not to make the same mistakes. Involving disabled people and their organisations in all levels of decision-making, policy creation, and health governance, during a pandemic and during 'normal' times, is a key element to disability inclusivity.