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RAPID ETHICS REVIEW

COVID-19 POLICIES AND THEIR UNEQUAL IMPACT ON THE RIGHTS AND DIGNITY OF DISABLED PEOPLE

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OVERVIEW

- During the pandemic disabled people's life has been endangered by ableist triage protocols, crisis mismanagement in care institutions, and negligent communication. They have also faced exclusion and loss of dignity due to lack of support services, shielding, stigma and abuse.
- Ableist triage protocols are discriminatory. Suspension of care services and shielding are also directly discriminatory as they went on longer than restrictions for the general public.
- Services suspension, inaccessible information and failure to tackle stigma and abuse are indirectly discriminatory as they disadvantaged disabled people compared to others in facing the pandemic.
- While adult safeguarding is often seen as a balance between autonomy and protection, the pandemic emphasised the importance of other values, such as trust.

Covid-19 has led to a lowering of standards in relation to disability rights. [1] During the pandemic, the UK government has failed to fulfil a number of its obligations under the UN Convention on the Rights of Persons with Disabilities (CRPD). Disabled people have suffered due to the suspension of fundamental services [2, 3] and the adoption of a medicalised approach to the pandemic, which has seen a focus on clinical considerations while ignoring the wider needs of disabled people. [4]

During the first wave, suspending some services and rights could have been seen as inevitable and, indeed, this occurred through, for example, the 'easements' to social care legislation, and changes to the implementation of mental health legislation. Such measures seem to have had a disproportionate impact on disabled people. [2, 3] After more than two years dealing with Covid-19, the government, local authorities and the NHS have had time to adjust and should be able to manage the pandemic while respecting the rights of disabled people. However, there are clear arguments that policy choices relating to the pandemic have put – and still appear to be putting - disabled people at significant disadvantage compared to others in society. [5, 6]

This review will therefore focus on the following question:

To what extent does the UK's approach to Covid-19 discriminate against disabled people and infringe their rights?

The aim of this review is to:

- Summarise human rights issues involving disabled people in relation to Covid-19;
- Discuss persistent ableist biases in our society unveiled by the Covid-19 crisis;
- Reflect on the pandemic impact on balancing disabled people's autonomy and protection;
- Clarify criteria for a disability-inclusive response to this - and future - public health crises.

Dealing with such questions is important even at this stage of the pandemic. While restrictions have been lifted, many disabled people still have to limit their social life, [7] because of concerns about the virus, particularly among those with compromised immune systems, and many are denied support due to persisting backlogs in health and social care services. [8] Such issues will be addressed in this review from the perspective of human rights law. [9] In particular, we will focus on the CRPD (ratified by the UK in 2009), the Equality Act 2010 (for England, Wales and Scotland) and the Disability Discrimination Act (DDA) 1995 (for Northern Ireland). While the Equality Act 2010 and the DDA 1995 are pieces of national legislation fully

enforceable within their relevant jurisdictions, the CRPD, though internationally binding for the UK government, is not directly enforceable in front of UK courts. Nonetheless, it is of great relevance at a policy level, as it is the most authoritative source on disability rights, being generally recognised as setting up the 'gold standard' for disability policies, being the main frame of reference for international and national governmental and non-governmental bodies in evaluating policies and interventions for disabled people. [2] Therefore, all these sources constitute heuristic tools to navigate ethical dilemmas and unfair behaviour involving disabled people independently of whether they end up in court.

1. METHODOLOGY

We commenced with a narrative thematic review of the main literature on disability rights during the pandemic in the UK, using key databases such as ProQuest and Google Scholar. The main search terms employed have been: Covid-19 AND Human rights AND disability AND UK; suspension of rights AND Covid-19 AND disability; Disability AND Covid-19; care assessment backlog AND Covid-19 AND disability. Literature included academic articles, reports and blogs written in English and published between February 2020 and May 2022. Despite the relatively short period of time, a surprisingly high amount of material has been published, much of which consists of reports of the opinions of disabled people themselves. We have complemented these findings with the inputs received in the context of the project 'COVID-19 and Adult Safeguarding and Social Care', funded by The Health Foundation, and from disabled people through public discussions, such as that which took place within the panel 'Disability Care and Covid Justice' at the Annual Conference of the Socio-Legal Studies Association Conference, in York on the 7th April 2022, convened by Dr Lucy Series.

Our work is informed by a human rights approach to disability, which focuses on societal responses to include disabled people in society and promote their rights. [10] In line with such an approach we adopt a definition of disability based on the so-called 'social model', [11, 12] which sees disability mainly as a social dynamic created by the barriers which disabled people face in everyday life, and focuses on removing such social barriers, rather than on medical and clinical aspects. In this regard we distinguish disabled people from clinically extremely vulnerable (CEV) individuals, who are those clinically more exposed to severe Covid symptoms. Indeed the review will point out how, on the one hand, disabled people who were not generally classifiable as CEV (e.g. many people with mental health conditions) might have been unnecessarily subjected to some restrictions. On the other hand, some CEV individuals, who prior to the pandemic would have not been perceived as having a disability, during the pandemic have been disabled by restrictions and lack of services which have impacted their freedom and wellbeing.

2. THE SUSPENSION OF DISABILITY RIGHTS

2.1 Main disability rights violations during Covid-19

During the pandemic, the UK has contravened many commitments under the CRPD, despite the UK National Disability Strategy (NDS) (2021), [13] developed in the midst of the pandemic, when the challenges posed by Covid-19 were known, promised new actions to further those commitments. The NDS has been recently declared unlawful by the High Court, [14] so its formal validity is questionable. Nonetheless, it still provides an insight on the (unmet) commitments the government took with regards to disability policies.

While impacts vary, depending on the particular individual in question (below, we indicate the different categories of disabled people worse hit by specific issues), evidence shows that being part of the disabled people category puts an individual at a notable disadvantage compared to others [2, 6] both in relation to Covid-19, but also generally when it comes to health and wellbeing outcomes.

Some of the most salient violations happened in the following areas:

Right to life (Article 10 CRPD).

- On 20th March 2020, the National Institute for Health and Care Excellence (NICE) issued a rapid guideline on critical care for adults during the Covid-19 pandemic, [15] recommending, in case of pressure on intensive care units (ICUs), to triage patients on the basis of the Clinical Frailty Scale (CFS) which leads to exclusion from life-saving treatment those more care-dependent due to physical or cognitive impairments. [16] Around the same period, the UK Moral and Ethical Advisory Group (MEAG) developed the NHS COVID-19 Decision Support Tool, operating through a points-based system (the higher the score, the lower the position on the care priority list). [17] Points were attributed on the basis of the CFS combined with other criteria relating to the age and comorbidities of the individual. The use of such instruments put some wheelchair users or people with intellectual disabilities at risk. In addition, the British Medical Association (BMA) issued a guidance note on ethical issues in Covid-19, controversially stating that 'although doctors would find these decisions difficult, if there is radically reduced capacity to meet all serious health needs, it is both lawful and ethical for a doctor, following appropriate prioritisation policies, to refuse someone potentially life-saving treatment where someone else is expected to benefit more from the available treatment'. [18] Due to an uproar by activists and a threat of a legal judicial review action against the NICE guidance, [19] the NHS decided not to adopt and formally recognise these guidelines [17] and NICE released an updated version of their guidance clarifying that the CFS should not be used in younger people, people with stable long-term disabilities, learning disabilities, autism or cerebral palsy. [20] Similarly, the BMA had to clarify that under their guidance a certain age or disability were not valid criteria to exclude someone from treatment. [21] Such clarifications did not entirely convince disabled people [19] and, anyway, the initial proposal of ableist guidelines sent a bad initial signal as to how disabled people were considered.
- In this regard, a rise has been seen in 'blanket policies', such as do-not-attempt-resuscitation decisions (DNAR) in which disabled people were allowed to die without consulting them or their families, citing as a rationale their disability or frailty. [22]
- The Learning Disability Mortality Review found that, in the first wave of the pandemic, on average, people with intellectual disabilities died of Covid far younger than the rest of the population. [23] Several of the people with learning disabilities included in the review who died of Covid never received a letter instructing them to shield. Around 44% of those who died received care that fell short of good practice. In almost 21% of cases

no reasonable adjustments to service provision were put in place, and access to healthcare, Covid-19 testing, specialist learning disabilities services and nurses, and specifically tailored care and support were problematic. An empirical study commissioned by Learning Disability England, with data from 12 universities, found that during the course of the pandemic around half of the participants (who all have learning disabilities) did not manage to have an annual check with their doctor either at a distance or in person. [24] Also, access to community nurses, psychologists and other health and care professionals has not come back to pre-pandemic levels. [24]

Right to independent living.

Article 19 CRPD states that disabled people have the right to choose 'where and with whom they live on an equal basis with others' and have access to 'personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation'. The NDS contains pledges for access to services enabling disabled people to have control over their lives (e.g., accessibility, home abuse protection services, better public transport, etc.).

- However, during Covid-19, disabled people faced strong barriers to meeting with their personal assistants and carers, due to containment measures, and delivery services websites/phonelines were at times inaccessible for people with sensory impairments. [2] Those who cannot drive have also been disadvantaged by reduced train and bus timetables. [27] Face masks posed a serious communication barrier for people with hearing loss. [28] Wearing a face mask was also challenging for some autistic people. [29] Because of such issues, even disabled people who were not technically CEV might have ended up suffering unnecessary restrictions to their everyday life.
- Abuse against disabled people has increased. [1] People with hidden disabilities have been subject to violence for (legitimately) not wearing masks. [30] People living in institutions have been further cut off from the rest of the world and prevented from meeting visitors and routinely still are when care homes have to go into 'lockdown' following an outbreak of Covid-19. [1]
- Due to such problems, also some CEV individuals who before the pandemic were not perceived as having a disability (because they could manage their vulnerability without restricting their life, for example through pharmacological therapies) might have found themselves dis-abled by barriers and restrictions arising after the appearance of SARS-CoV-2.

- Even now, while it is not advised to shield anymore, disabled people and CEV still do not feel they can safely go back to their usual activities, feeling threatened by the fact that the general public is not even required to wear facemasks. [31]

Participation in social life.

According to Article 30 CRPD, disabled people must ‘enjoy access to places for cultural performances or services, such as theatres, museums, cinemas, libraries and tourism services’ and ‘in recreational, leisure and sporting activities’ on ‘an equal basis with others’. However, the shielding programme, though designed to protect disabled people, has disproportionately impacted these rights.

- Shielding programmes create a tension with the values of equality and solidarity as they put the responsibility for their own Covid-19 outcomes onto disabled people, instead of recognising it as a problem which comes from the virus circulating through society and, therefore, requiring solidarity and more containment measures for the general public. [32]
- In the UK, the debate on this issue caught up especially after the so called ‘freedom day’ of 19th July 2021 on which the government lifted most Covid-19 restrictions for the general public in England (including the duty to wear face masks in public indoor spaces), despite Covid-19 infection rates still being high, shifting the focus of their Covid-19 strategy on focused protection of CEV individuals. A letter to *The Lancet* medical journal, signed by 31 scientists (the so-called John Snow Memorandum), pointed out that such a policy decision would have caused a wider circulation of the virus, which would have forced CEV individuals to further reduce their freedom and social activities to avoid the now greatly enhanced risk to be infected. [33] As Rosie Duffin, a CEV individual interviewed by the BBC at that time, put it: ‘For us it’s not freedom day, is it? It’s “Becoming a hermit day” once again. [...] I’ve got a theatre trip booked but there’s no way I’m going to be sitting in a theatre next to people who are not wearing masks.’ [34] As noted by Hughes, by limiting the spread of SARS-CoV-2, general containment measures allow more freedom space for vulnerable individuals. [35] Therefore, if, for example, even after the first two Covid-19 waves, we would have retained the duty to wear masks in indoor public places or nationwide indications to theatres and cinemas to keep at least some socially-distanced performances/screenings (a policy adopted voluntarily by some institutions such as the Royal Shakespeare Company or the Theatre Royal Stratford East) we could have better guaranteed the right to a social life to some CEV disabled people. [34]

Clear and accessible information (Article 9 and 21 CRPD).

- Covid-19 information has not always been distributed in plain language, or easy-to-read formats, and has often failed to reach people in institutions and with mental health conditions. [2, 5] At the SLSA Conference panel on Covid-19 and disability, Professor Anna Lawson pointed out that shielding letters and other informative material on Covid were not accessible for blind people. Some government press conferences lacked sign-language interpretation. [2].
- Empirical studies reporting the experiences of disabled people show that letters/texts on shielding have not been received by a large number of stakeholders. [5] Guidance on shielding has often appeared arbitrary. In this regard, the way in which advice to shield was withdrawn in June 2020 appeared particularly disconcerting. For example, in the House of Commons inquiry, the mother of two disabled children declared that ‘when you talk to your own healthcare professionals, they are specifically telling you to shield until June 30 [...] yet we are now being told it’s safe to go outside.’ [2, p. 35] Many disabled people have declared themselves confused as to who should be in the CEV group. [2] Disabled people and activists participating in the SLSA Conference panel on Covid-19 and disability pointed out that, after the start of the Covid-19 vaccination programme, many were not formally advised to shield any more, but still advised by their doctors to do so. This put them in front of a dilemma, also because they were now without a legal basis to justify, for example, requests to work from home.

2.2 To what extent is the suspension of disability rights discriminatory during a pandemic?

In England, Wales and Scotland, the main rules governing discrimination are contained in the Equality Act 2010, while in Northern Ireland disability discrimination is regulated by DDA 1995, as amended by The Disability Discrimination Act 1995 (Amendment) Regulations (Northern Ireland) 2004. The principle of prohibition of discrimination is also affirmed in Article 14 and Article 1 of Protocol No. 12 ECHR. This legislation prohibits:

- **Direct discrimination**, which happens when ‘because of a protected characteristic [e.g. disability], [a person] A treats B less favourably than A treats or would treat others’ (Equality Act 2010 section 13 and DDA 1995 sections 3A(1) and (5) and, among others, European Court of Human Rights (ECtHR) cases *D.H. and Others v. the Czech Republic*

2007, [36] *Burden v. the United Kingdom* 2008, [37] and *Biao v. Denmark* 2016 [38]);

- **Indirect discrimination** (not recognised in Northern Irish legislation), when A applies to B a policy which applies to others as well, but it puts, or would put, B or people with the same protected characteristic as B at a particular disadvantage and cannot be justified as a proportionate means of achieving a legitimate aim (section 19 Equality Act 2010, and among others, ECtHR cases *D.H. and Others v. Czech Republic* 2007, [36] and *Biao v. Denmark* 2016 [38]);
- **Insufficient reasonable adjustments for disabled people.** Section 20 of the Equality Act requires that relevant public and private actors actively intervene to remove barriers such as:
 - Provisions, criteria or practices putting disabled people at substantial disadvantage compared to non-disabled people (e.g. disabled people struggle more than others to fulfil a certain criterion for being hired in a certain job) (Section 21(3));
 - Physical barriers (e.g. steps, lack of lifts) (Section 21(4));
 - Cases in which a disabled person needs an auxiliary aid to participate in society on an equal footing (e.g. personal assistants for the person's special needs) (Section 21(5))
 - Inaccessible information (Section 21(6)).

In Northern Ireland, section 3A(2) of the DDA 1995 establishes a similar rule, and the ECtHR has recognised the right to reasonable accommodation of disabled people in, for instance, *Çam v. Turkey* (2016) [39].

The CRPD goes one step further. Indeed, as stressed by the Committee on the Rights of Persons with Disabilities (CRPD Committee), the Convention's official monitoring body, it proposes an 'inclusive equality' approach which includes anti-discrimination measures (Article 5 CRPD), but also requires deeper systemic change based on:

- Equal recognition of disabled individuals as persons;
- Positive accommodation of difference;
- A participative dimension emphasising disabled people's equal right to belong;
- (Re)distributive policies to concretely realise such goals [40].

Discrimination in relation to the right to life (Article 10 CRPD).

In light of such provisions, blanket DNAR policies targeting disabled people appear directly discriminatory. [41]

Moreover, the first version of the NICE guidance on critical care of adults during the pandemic and the NHS Covid-19 Decision Support Tool appear also directly discriminatory as they allow exclusion from life-saving care on the basis of a protected characteristic (disability) or a proxy which is the direct expression of that characteristic (frailty). Indeed, being based on the CFS, they attribute points (which are inversely proportional to the probability of being cured) on the basis of how much the individual is dependent on others, which is an inherent feature of disability. [17, 41] This is especially evident in the NHS Covid-19 Support Tool which looks at both the person's frailty/dependence according to the CFS and the comorbidities/impairments at the basis of such frailty, substantially counting the same factor twice and putting disabled people at particular disadvantage. [17] However, the revised version of the NICE guidance also appears problematic as it leaves the door open to ableist decisions and might lead to indirect discrimination. [41] Indeed, though requiring that the CFS is not applied to disabled people, it states that in such cases doctors should 'make an individualised assessment of frailty' (NICE Guide 2.5), defined by NICE as 'a loss of resilience that means people don't bounce back after a physical or mental illness'. [42] So, if the person is predicted to 'bounce back' less quickly than another 'competitor' (as is very often the case with disabled people), then they still risk being excluded from life-saving treatment. In this sense the NICE guide appears also in contrast with the indications of the WHO which requires that decisions to allocate scarce care resources are not based on pre-existing impairments or higher support needs. [43]

Similar considerations apply to the BMA guidance. Indeed, in their clarification on the use of age and/or disability, the BMA do not explicitly correct their previous declaration in the part in which it states that 'decisions about how to meet individual needs will give way to decisions about how to maximise overall benefit' and that choices must be 'based on maximising the overall reduction of mortality and morbidity'. [18, p. 3] As noted by Antova, this shows how under the BMA guide doctors are authorised and even encouraged to set aside individual needs and rights in favour of utilitarian considerations and to sacrifice disabled people to decrease morbidity. [41] In addition the BMA clarification still admits that doctors can exclude from ICU treatment disabled people not only in case of seriously low chances of survival (futility), but also when the person's disability might impact the 'speed of recovery' or lead to 'worse outcomes'. [21, 41] This is a very problematic implementation of utilitarian thinking, moving the threshold for treatment from avoiding futile treatment interventions to one of making judgements about quality-of-life post-treatment - a quality of life assessment that might have nothing to do with the impact of Covid-19 on that person. Utilitarian considerations could still be broadly applied to triage decisions, just as long as they do not constitute discrimination. [44]

The lack of appropriate health care services and reasonable accommodations for individuals such as people with intellectual disabilities seems like an infringement of the duty to implement reasonable adjustments. [24] With regard to deaths in care homes, the government could have promoted a shift towards placing disabled people and individuals in need of care in the community (a setting relatively less prone to uncontrollable contagion), introduced adjustments to the use of spaces (even resorting to outsourcing or requisition of private spaces), and adjusting the rotas (and salaries) of care workers in order to help avoid contagion as care structures started doing later on in the pandemic (and arguably too late). [2, 26, 45]

Discrimination in relation to the rights to independent living (Article 19 CRPD), participation in social life (Article 30 CRPD) and clear and accessible information (Articles 9 and 21 CRPD).

Failure to consider the needs of disabled people when accessing support during the pandemic measures, including services such as transport, constitutes indirect discrimination and failure to implement reasonable adjustments. [2, 27] This failure puts disabled people at a particular disadvantage compared to the general population, because, rather than simply being inconvenient, it prohibits access to the rights that these services bring to life, such as healthcare and education. Therefore, in light of the human rights and equality principles explained above, the government and public authorities are not ethically or legally entitled to suspend such services even during a crisis. In fact, such services guarantee that minimal level of support and dignity for disabled people to face the challenges of the pandemic on an equal basis with others.

With regard to visits in care homes, they could have been still permitted while putting in place precautions. Possible precautions could have been having visits outdoors and at a safety distance, or requiring that visitors submit a negative PCR Covid test before visiting. [46] The government could have provided more timely instructions in this sense to ensure that such precautions were observed throughout the country and at an earlier stage. Anyway, the government could have been more attentive in monitoring what was happening in institutions. [25, 47] With regard to face masks, exemptions were in place for disabled people, though the rules could have been clearer. [48] The failure to provide accessible information and sensible communication highlighted above is a failure to provide reasonable adjustments, which would have not required additional resources, but just a bit of attention in developing materials and organising press conferences. [2] [5] The High Court has declared it directly discriminatory under the Equality Act 2010 to have failed to provide sign-language interpretation on the Prime Minister's Covid-19 press conferences. [49]

If we look at other countries, these policy failures appear avoidable. In their comparison of English and Australian Covid-19 responses, Kavanagh et al. point out that while, after lobbying by advocacy groups, the Australian government put in place a leadership group composed of people with lived experience of disability, and a National Management and Operational Plan for disabled people, England never had a coordinated response in this area. [50] This situation leads us even further from the ideal of equality that underpins the CRPD. In this regard, the UK's approach appeared like a 'disability exclusive' approach to the pandemic. [51]

2.3 Disability, Covid, rights hypocrisy

The UK's approach to Covid-19 also shows the hypocrisy which is visible in media representations. For example, in the 'Hold Still' exhibition, organised by the National Portrait Gallery, images of struggling disabled people tend to be presented as positive examples of resilience, while forgetting that these people are struggling largely because of the suspension of support services. [52] Such media images clash with Article 8 of the CRPD (on raising awareness on disability), requiring the media to promote the recognition of the skills, abilities, merits and rights of disabled people. This can be seen particularly clearly comparing images from this exhibition with those from the UN exhibition 'Images of Ability' (2015), [53] which had a more progressive and empowering ethos.



Figure 1 'Shielding Mila' (from 'Hold Still', 2020)
© National Portrait Gallery, London



Figure 2 'Dancing Pair' (From 'Images of Ability, 2015)
© United Nations

The image of Mila, though presenting a positive example of resilience, is still about disabled people not doing things and reverts back to the stereotypical, limiting image of the disabled poster child centred on pity. This acts as social anaesthetic to the removal of rights, making us forget that the child in question is in that situation due to containment measures not taking into account her social and relational needs or due to the lack of adaptations allowing, for example, her dad to stay home from work to care for and support his daughter. By contrast, the UN's photographic images, particularly the 'Dancing Pair', demonstrates the totality of life with a disability and that disabled people of all ages can, should and do hold the same rights to social inclusion and participation as all other members of their community. This image underscores the importance of championing and facilitating access to these rights as a community,

rather than disabled people having to fight for themselves through extraordinary actions.

The issues analysed so far show how the response to the pandemic has been characterised by a medicalised approach, whose soundness has been questioned, even in public health terms. [54] Such a model has not taken into account the added challenges for disabled people and the importance of social adaptations. [4] This contrasts with the social models of disability, [11] which underpins human rights approaches in the CRPD and sees disability as a social dynamic determined by contextual barriers which have to be removed in order to include disabled people in society.

Key messages

- During the pandemic, disabled people have suffered infringements of their rights to life, independent living, participation in social life and accessibility.
- Such infringements are discriminatory in at least one of the three forms contemplated by equality law (direct discrimination, indirect discrimination and lack of reasonable adjustments).
- Pitying and patronising media representations of disabled people during the pandemic reveal our society's hypocrisy toward disability rights and the resurgence of disempowering, ableist, medicalised approaches and biases, seeing disabled lives as abnormal and less worth living.

3. THE ASSESSMENT BACKLOG

According to the Care Act 2014, the Social Services and Well-being (Wales) Act 2014, the Social Work (Scotland) Act 1968, and the Social Care (Self-directed Support) (Scotland) Act 2013, when an adult appears in need of care and support, the local authority in which they live has a duty to carry out a needs assessment evaluating:

- Whether the person has needs for care and support, and if so, what these are.
- Whether – and if so, what – care and support they should receive.

However, legislation introduced early in the pandemic (e.g. the Coronavirus Act 2020) allowed local authorities to suspend needs assessments should demand overwhelm them; these were known as 'easements'. Prior to the Covid-19 pandemic, disabled people were already facing barriers to accessing health and social care services due to lack of funding and inefficiencies by local authorities. The Coronavirus Act, for example, only worsened this situation. [2] Although only a relatively small number of local authorities formally implemented them, Coronavirus easements, together with the practical barriers faced by all local authorities and social workers during the pandemic, still created a backlog of around 55,000 needs assessments, and around 19,000 people waiting for

care and support following an assessment, which is still increasing. [55] However, the very essence of social care law is to ensure disabled people have the care and support they require. Baginsky et al. stress how such laws should not be suspended during a public health crisis, when they are arguably most needed. [56] Article 11 of the UNCRPD seems to permit for the suspension of some services or regulations in case of emergency, stating that 'States Parties shall take [...] all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.' Yet as a participant in Shakespeare's et al.'s study put it, 'every single public announcement has been around keeping the vulnerable safe [...] yet what they actually do is to cut services to vulnerable people.' [5] In addition, and perhaps even more importantly, even when easements were not formally implemented and assessments were not suspended, due to logistical challenges and resource constraints exacerbated by the pandemic, disabled people have very often had to face significant disruptions in essential care and support services preventing them from properly managing everyday tasks in their homes, having access to food, being protected from abuse. [24, 57]

Bottery highlights how the level of unmet need for social care during the pandemic has increased due to changes in services and social care professionals' sickness/absence. [58] Trying to quantify the number of people affected is difficult, as estimates vary, and data is slow in coming through. Several surveys estimate that the unmet need for social care varies between one in five to two-thirds of people. This is mirrored in the Covid-19 Disability Rights Monitor study, which highlights that 45% of participants state the Government took no action to support them living in the community, with 38% reporting reductions in care support services during the pandemic. [1] Participants shared their experiences and voiced concerns such as, 'persons with disabilities will suffer the most because most of their support interventions have been stopped' and 'the government has supported virtually everyone else, and left people with disabilities to fend for themselves' [1]. Unfortunately, due to such a large backlog, these inequalities currently continue.

This breakdown of community services is directly discriminatory and unethical when one considers the essential nature of equality. While restrictions for the majority of citizens have been lifted, even prematurely at times, measures such as the 'easements' remained in place unchanged until July 2021. [13] This approach to care services during the pandemic, and provisions like advising some disabled people to shield while the rest of the population goes out and about, have been defended by some scholars. [59] They maintain there would be no point in promoting 'levelling-down equality' by restricting access to services and the social life of all in order to protect a few vulnerable people. Other scholars have demonstrated how this argument seems in reality fallacious. [35] Anyway, even arguments against levelling-down approaches do not undermine some basic principles central to any conception of equality, in this case, offering more to a majority whilst a minority lacks access to even essential goods and services. The unfairness of such an unequal distribution is perpetuated even further by the approach to care because it is the fact that able-bodied people are allowed to go on with their lives unrestricted that ends up putting even more pressure on hospitals and care services and putting disabled people even more at risk.

Key messages

- The Coronavirus Act 2020 has allowed local authorities to suspend care assessments and services.
- Such provisions have deprived disabled people of essential support and created backlogs.
- Coronavirus Act easements appeared discriminatory, as they have carried on longer than restrictions for the rest of the population and have impacted on the dignity of disabled people even when others were allowed a relatively normal life.

4. THE CHANGING RELATIONSHIP BETWEEN AUTONOMY AND PROTECTION

Adult safeguarding, and the delivery of adult social care more broadly, often involves a consideration of some acute ethical questions. The tension between promoting a person's autonomy while also ensuring they are sufficiently protected against abuse and neglect is, for example, a common one, and is envisaged by the CRPD which not only puts emphasis participation and enhancing autonomy, but also recognises – in Article 16 – the need to protect people with disabilities from abuse. [60]

It is therefore unsurprising that early in the pandemic, the Department of Health and Social Care acknowledged the impact that Covid might have on navigating some of these questions, and issued guidance on the ethical framework for adult social care in light of Covid-19. [61]

It is also clear that the pandemic, and responses to it, have also curtailed the autonomy of many disabled people excessively. One such example is the routine suspension of any visitors for those living in institutional settings, and a lack of provision for ensuring people living in these settings were still able to go out and about, which impacted also on those disabled people who were not necessarily identifiable as CEV. [62] There have also been widespread concerns that care in such settings has become overly restrictive and not rights-focussed. Such a situation could have constituted a violation of disabled people's right to liberty (Article 14 CRPD). Several scholars have shown that, also in light of case law, lockdowns and other Covid measures imposing social restrictions do not constitute a deprivation of liberty, as they did not entail constant supervision within the place of residence and people were still free to leave (these are the prerequisites to declare a liberty deprivation established in the so called 'acid test' by the Supreme Court), and anyway people are allowed to (remotely) maintain social contacts and to go out to work or perform other essential activities. [9, 63] However, the Care Quality Commission, has expressed concerns that, in many care homes, restrictions were de facto far more oppressive than this, with residents being constantly monitored, forbidden to leave, and unable to even remotely maintain social contacts. [64] Such forms of liberty deprivation seem to have been often imposed without following the procedures required by the Mental Capacity Act and the Deprivation of Liberty Safeguards to protect the individual's rights, and hence appear unlawful. [62] In this regard, during the course of the pandemic the charity John's Campaign, set several pre-action protocol letters threatening legal actions against the blanket ban on care home visits imposed by the government. [65] Such initiatives led to the blanket ban being removed in favour of case-by-case assessments.

Yet the pandemic has also emphasised the importance of other ethical values in adult safeguarding. In our project exploring the impact of the pandemic on adult safeguarding, a key finding was the way in which Covid-19 had compromised the possibility of building trust in relationships between disabled people and practitioners, largely through day-to-day changes such as increasing reliance on technology. As one participant reflected, "I can only support people and we can only support people, as an authority, if we've got a good relationship with them, if we know what's going on...I can't just expect somebody to trust me, and particularly, during Covid when I couldn't even meet them". [66]

Key messages

- Adult safeguarding – preventing abuse and neglect among disabled adults – has often been seen to involve a tension between respecting a person's autonomy while also protecting them.
- The pandemic, however, has also revealed the prominence that other ethical principles play in adult safeguarding; notably, the role of trust.

About this submission

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About the UK Pandemic Ethics Accelerator

The UK Ethics Accelerator is a UKRI/AHRC-funded initiative that aims to bring UK ethics research expertise to bear on the multiple, ongoing ethical challenges arising during a pandemic emergency. We provide rapid evidence, guidance, and critical analysis to decision-makers across science, medicine, government, and public health. We also facilitate public stakeholder deliberation around key ethical challenges.

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