



# Disability Discrimination, Medical Rationing and COVID-19

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## Abstract

The current public health crisis has exposed deep cracks in social equality and justice for marginalised and vulnerable communities around the world. The reported rise in the number of ‘do not resuscitate’ orders being imposed on people with disabilities has caused particular concerns from a human rights perspective. While the evidence of this is contested, this article will consider the human rights implications at stake and the dangers associated with using ‘quality of life’ measures as determinant of care in medical decision-making and triage assessments.

**Keywords** Disability rights · Medical necessity · Right to dignity · Medical treatment

## Introduction

At the height of the COVID-19 pandemic, there were concerns about how health services would cope with the rising numbers of patients in a critical condition, thereby leading to the question of how patients with disabilities might be ‘triaged’ under insufficient ventilators or staff (Bagenstos 2020). Vulnerable members of society, including older persons and people with disabilities, were seen as being most at risk, and healthcare professionals were advised to prioritise those who had the best chance of recovery in the event of a mass outbreak. These attitudes and approaches raise complex ethical and legal questions which challenge our commitment to human rights and equality. There are further concerns about the appropriateness of resorting to a

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utilitarian model of distributive justice in medical rationing during crisis and whether this can be permitted under human rights law, specifically the UN Convention on the Rights of Persons with Disabilities (CRPD).

This article will critically discuss the human rights tensions regarding medical rationing on the basis of disability in this context. In the article, we use ‘medical rationing’ as an umbrella concept referring to the reported ‘do not resuscitate’ (DNRs) orders and other forms of triage protocols which seek to exclude people with disabilities from accessing lifesaving treatment. We acknowledge a possible utilitarian defence for imposing such measures on the basis that, particularly in cases of a public health crises, decisions may need to be made out of ‘necessity’ about resources distribution and rationing (Emanuel et al. 2020). This article argues that while rationing is somewhat unavoidable during a pandemic, therefore, decisions as to the allocation of resources may come down to a decision as to which patients have the highest chance of survival. However, we contend that the defence of medical necessity cannot amount to a blanket discretion to exclude persons with disabilities from accessing healthcare and disability should not serve as a disqualifying factor in triage protocols.

As the ‘quality of life’ indicators are relevant to people with all types of disabilities, the article does not differentiate them further, although we acknowledge persons with disabilities is a diverse community.

## Access to Healthcare for Persons with Disabilities during COVID-19

Distributive justice refers to the fair allocation of resources and services in healthcare. This is rooted in the principle of maximising benefits for the largest number of people (Persad et al. 2009). It requires that patients are to be treated equally, without discrimination, and ‘for there to be overarching equality of access to finite health resources’ (Fisher et al. 2020). With the uncertainty at the beginning of the COVID-19 outbreak, many began to question how resources could be allocated to ensure the greatest chance of survival for as many people as possible. Triage protocols were revised to ensure that if a hospital became overburdened, doctors could rely on ‘wartime’ triage to assess patient’s suitability for treatment (Mounk 2020). While triage frameworks differ around the world, they typically assess the patients’ chances of survival. In Italy, those who had the greatest chance of survival and therapeutic success were to be prioritised in access to intensive care (Mounk 2020).

Questions about about the application of triage protocols and whether safeguards are in place to ensure fairness, accountability and respect for a patient’s rights and preferences. Examples include requiring all staff undergo unconscious bias training and ensuring that all allocation decisions should be made by a team of practitioners rather than any one individual. Such precautions are essential, particularly given the intersectionality of patients, and the risk of heightened vulnerability for those who present in a number of the ‘at-risk’ categories, including older people with disabilities. While decisions as to resource allocation in times of a pandemic are fraught with difficulties, we argue that the focus should be on identifying those who are most unlikely to survive, even with medical intervention. This must not give rise to possible exclusions of persons based on age, disability or other disabling indicators such as their quality of life. Further regard must also be paid to ensure that health inequalities are not exacerbated for certain communities, for example, in Australia where Aboriginal and

Torres Strait Islander communities already face systemic barriers in accessing healthcare. The question of equity in access to healthcare is therefore critically important, and all triage protocols should be designed to ensure an equitable and fair approach that does not discriminate against specific groups.

In the USA, the Washington State Department of Health suggested that patients should be triaged for ‘loss of reserves in energy, physical ability, cognition and general health’ regarding scarce resources allocation (Washington State Department of Health and Northwest Healthcare Response Network 2020). Disability Rights Washington (2020) argued that this approach would prioritise people who are younger and healthier and would leave those who are old and sicker, including people with disabilities, to die. Further guidelines issued to medical professionals in Kansas and New York also included ventilator allocation protocols which seemingly endorsed the removal of ‘ventilators from people using them for a chronic condition who are judged lower priority, in order to give them to other individuals’ (Disability Rights Center of Kansas 2020). This policy may pose a particular challenge to persons with disabilities who rely on a ventilator due to a chronic condition and may further prevent them from accessing appropriate healthcare even in non-COVID-related cases.

In addition, there are also reports of DNRs and advanced care directives being imposed on persons with disabilities as a pre-emptive measure to avoid later questions of resource allocation in hospitals. While there is no official data available to prove such a correlation between COVID-19 and the rise of DNR orders, there are some reports of blanket DNR orders being imposed on people in care homes (Lintern 2020; Clarke 2020). In Wales, a general practitioner reportedly sent letters to high-risk patients advising them to sign a DNR form as they would be ‘unlikely to receive hospital admission’ should they contract the virus and ‘certainly’ would not be offered a ventilator (ITV News 2020). Similar reports from Belgium and Australia also suggest that nursing home residents have been refused access to hospitals to avoid a run on resources (Stevis-Gridneff et al. 2020; Malone 2020).

These examples suggest a worrying trend in the international response to COVID-19. While some countries are now beginning to lift their lockdown restrictions and return to ‘normal’, further research is needed to consider the accuracy of reports relating to the exclusion of people with disabilities from accessing healthcare as a response to COVID-19. Key concerns relate to the possible rise in the number of DNR orders, what advice or supports were offered to people before signing such an order, whether triage protocols specifically excluded certain categories of persons from receiving care and, finally, the accuracy of reports which suggest that residents of care homes should not be transferred to hospitals.

## Medical Necessity: a Possible Defence?

There is perhaps no right course of action when it comes to resource allocation and triage decision-making in times of a pandemic on the current scale. It is true that medical practitioners should be provided with a certain amount of discretion to make decisions which they believe to be correct in an emergency, without fear of potential liability. Decisions regarding the withdrawal and refusal of life-sustaining treatment are usually made by doctors on the basis that continued treatment is not medically justified

or futile (Levine 1994) or where there is no prospect of a significant recovery (Winter and Cohen 1999; Asch et al. 1995). In times of crisis or where there are not enough supplies or staff members to attend to each individual patient, there is rational that hospitals resort to a utilitarian approach to prioritise those with the greatest chance of survival. In that vein, it may be conceivable that decisions are justified on the basis that they were necessary at the time.

For example, decisions to ventilate (or not to ventilate), a critical measure of last resort during COVID-19, are never straightforward due to the invasive nature. While death rates continue to fluctuate around the world, there are some indications that up to half of COVID-19 patients who were on ventilation have died (Winfield Cunningham 2020). Given the nature and seriousness of a decision to ventilate, coupled with factors such as prognosis and the recovery period, it is clear that medical professionals are best placed to make these decisions on a case-by-case basis, ideally guided by clear triage protocols. The limited supplies will need to be distributed based on principles of exclusion or priority, and because of this, some people may be excluded from access to healthcare (de Castro-Hamoy and de Castro 2020). However, we argue that the grounds for exclusion must be set out clearly and should ensure compliance with human rights laws including the CRPD.

The full scale of the crisis is still unknown. As discussed, further research is needed to assess the accuracy of reports relating to the rise in DNR orders and the extent to which people in care homes have been excluded from hospital care. Further questions abound in relation to people who have been treated in hospitals, including the breakdown of those who received ICU or ventilation and how often patients were deemed unsuited to critical care based on their disability (or other quality of life marker), the seriousness of condition or likelihood of survival. Transparency is key and will enable health systems to better prepare for future public health crises in a non-discriminatory and just manner. It is essential that this information is made publicly available to assess the true impact of the virus around the world.

It is true that saving lives is the core goal in the response to COVID-19; ultimately this may require a utilitarian approach to rationing and triaging those who are most likely to survive (Persad 2020). According to Persad (2020), disability can be used as an exclusionary ground to differentiate between patients who are most deserving of care in what is referred to as ‘evidence-based triage’, and this would be permissible under disability laws. We fundamentally disagree with this position and argue that viewing disability in this way is harmful and reflective of eugenics ideology as it indicates that the lives of persons with disabilities are less valuable (see Shakespeare 1998). Moreover, it is fundamentally at odds with the CRPD, which Persad does not engage with at any point. Where triage is necessary, we contend that doctors should be required to evaluate the likely benefits of receiving intensive care, rather than discriminating against disability or other discriminatory markers such as ‘quality of life’ (Wong 2020). This ensures that access to medical care and treatment is available to all patients in a legal, just and ethical manner; and the next section will discuss the legal implications in the context of the CRPD and the moral evolution reflected on it. An example of triage protocols that respect disability rights will also be raised.

## Social Model of Disability and International Human Rights Law

While the pandemic created a sense of panic around the world, it is likely that persons with disabilities experienced heightened levels of anxiety owing to the narrative that they would be prevented from accessing treatment due to scarce medical resources. This is reflective of a now-outdated understanding of disability, known as the medical model, which viewed people with disabilities as objects of pity rather than as rights-holders (Kanter 2003). By associating the experience of disability as a medicalised experience, people with disabilities were ‘othered’ and differentiated from those able-bodied members of society on the basis that they were different or abnormal (Shakespeare 1994), subsequently legitimising the marginalisation and oppression of persons with disabilities around the world (Dorfman 2017; Stein and Waterstone 2006). This conception of disability as a negative trait was further perpetuated by the widespread institutionalisation of people with disabilities which saw them removed from general society and subjected to forced medical treatment or even sterilisation of women and girls.

In response to these human rights abuses, a disability rights movement began in the 1960s (Degener 2014), which located the experience of disability as a product of the built environment and societal oppression. Social model theorists (advocates of this new model) challenged the belief that people with disabilities were ‘impaired’ by their ‘personal condition’ (Hacking 1999) but were instead disabled by the attitudes of others as well as institutional structures (Zola 2005). It is this understanding of disability which later informed the CRPD, which acknowledges disability as a part of human diversity and recognises that disability results from ‘the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others’ (art 3(d); Preamble 5; see also de Paor and O’Mahony 2016).

There are a number of core rights as outlined in the CRPD which are relevant to COVID-19. Of note, dying with dignity intact is embedded in the overall spirit of the Convention, as recognised by its core values and the respect for inherent dignity and autonomy rights of persons with disabilities (CRPD art 3(a)). These principles are breached in cases where a DNR order has been imposed on an individual without their free and (advanced) informed consent or where an individual is prevented from receiving treatment on the basis of their disability, falling into the scope of the principle of non-discrimination (art 3(b) & 5), the right to life (art 10), the right to protection in situations of risk and humanitarian emergencies (art 11) and the right to health (art 25). At the very heart of these rights and principles, the pandemic questions our societies’ commitment to equality and whether we truly value persons with disabilities ‘as part of human diversity and humanity’ (art 3(d)).

The CRPD prohibits all discrimination on the basis of disability (art 5), defined as ‘any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field’ (art 2). Depriving individuals from the equipment or health treatment they need, or deprioritising them in resources allocation, on the basis of their disability clearly violates their right to non-discrimination. Echoing this principle, the United Nations has promoted a promising example of

resources allocation provided by the Bioethics Committee of the San Marino Republic during COVID-19:

The only parameter of choice, therefore, is the correct application of triage, respecting every human life, based on the criteria of clinical appropriateness and proportionality of the treatments. Any other selection criteria, such as age, gender, social or ethnic affiliation, disability, is ethically unacceptable, as it would implement a ranking of lives only apparently more or less worthy of being lived, constituting an unacceptable violation of human rights. (UN Office of the High Commissioner for Human Rights 2020)

The implementation of this good practice requires further investigation, a critical aspect of which is whether the triaging criteria without referring to a disability would be disproportionately applied to persons with disabilities and, if positive, whether there exist justifications for such indirect discrimination. Before this assessment is possible, which requires full disclosure of factual evidence, another recommendation by the UN is worth noting to prevent discrimination, which is involving persons with disability in the process and development of medical guidelines (UN Office of the High Commissioner for Human Rights 2020).

Finally, the CRPD also protects the right to life and the right to health, obliging State Parties to ensure that persons with disabilities can enjoy and exercise their rights ‘on an equal basis with others’ (art 10 & 25). More specifically, States shall ‘provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons’ and ‘require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent’ (art 25(a)(d)). As discussed, whether some facially neutral criteria—not explicitly referring to disability—constitute indirect discrimination requires further investigation when more data becomes available. At very least, however, States Parties of the CRPD are required to take ‘all necessary measures to ensure the protection and safety of persons with disabilities’ in situations of risk and humanitarian emergencies (art 11) and, in doing so, the specific measure that are necessary to ‘accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination’ (art 5(4)).

To conclude, the CRPD provides a new moral and ethical guide that its States Parties are required to comply with to ensure that people with disabilities are treated as equal rights-holders, even during times of crisis. Therefore, if some resource allocating criteria includes a consideration of disability, they must be about the provision of reasonable accommodation or specific measures that are necessary to accelerate or achieve de facto equality, rather than allowing medical professionals to withhold or withdraw care on the basis of disability alone.

## Conclusion

The global response to COVID-19 has raised complex legal and ethical questions about the treatment of people with disabilities in times of crisis. These questions go to the very heart of how we as a society perceive disability and challenge the fundamental rights protections as set out under the CRPD. The reported problematic triage protocols

and the rise of DNR orders, as well as the language that has been used to describe those who are deserving and undeserving of care, are especially concerning as it reignites the harmful and antiquated perceptions of disability as a vulnerability or weakness. While medical rationing is perhaps unavoidable, we argue that this should be based on medical necessity alone and must not negatively take into account individual identities or experiences such as disability or age. It is clear that further research is needed to assess the true impact of COVID-19 across all sectors and communities, but it is also clear that further work is needed to address the systemic discrimination and pervasive attitudes that are still held about people with disabilities across the medical profession.

## Compliance with ethical standards

**Competing interests** The authors declare that they have no competing interest.

**Ethical approval** Not required.

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