

# What is fair? Ethical analysis of triage criteria and disability rights during the COVID-19 pandemic and the German legislation

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## ABSTRACT

This essay discusses the ethical challenges and dilemmas in allocating scarce medical resources during the COVID-19 pandemic, using the German legislative process as a starting point. It is guided by the right to non-discrimination of people with disability and generally contrasts utilitarian and rights-based principles of allocation. Three approaches that were suggested in the German discussion, are presented, the lottery principle, the first come first served principle and the probability to survive principle. Arguments in favour and against each principle are discussed. The focus is on the utilitarian probability to survive principle, which was adopted in German legislation in 2022, and its discriminatory potential against people with disability. The essay suggests ways to mitigate the concerns of discrimination related to the probability to survive principle. It concludes that resolving the triage dilemma requires a balanced approach between utilitarian and rights-based concerns, which promotes both maximising the number of patients surviving and the right not to be discriminated against and be treated equally. It calls for a further debate on how many ethical values such as equity, fairness and non-discrimination we are willing to sacrifice for a higher number of survivors and when we are willing to sacrifice survivors to secure ethical values.

## INTRODUCTION

The healthcare resource scarcity during the COVID-19 pandemic and a lacking legal background raised questions about a fair resource allocation in Germany during pandemic triage. In Germany, the discussion focused on the potential discrimination of people with disability.<sup>iii</sup> Generally, allocation criteria for the COVID-19 pandemic were defined in triage protocols in the beginning of the pandemic. They were often utilitarian, stating

that resources should be allocated to do the greatest good to the greatest number of people.<sup>1</sup>

In Germany, a guideline for triage in COVID-19 was developed by the Deutsche Gesellschaft für Intensiv- und Notfallmedizin, the German Interdisciplinary Association for Intensive Care and Emergency (DIVI), a medical association of intensive care professionals. It was also generally motivated by utilitarian concerns, aiming to save as many patients as possible. To do so, the DIVI's principle was based on evidence regarding the initial assessment of the patient's probability to survive and their urgency to be treated.<sup>2</sup> People with disability worried that such existing guidelines from medical associations discriminate against them and filed a constitutional complaint at the German Federal Constitutional Court.<sup>3</sup> The following legislative process on pandemic triage in Germany serves as an example and is insightful for jurisdictions in other countries. Article 3, §3 of the German constitution prohibits discrimination based on disability and served as a basis for this complaint.<sup>4</sup> Two possible approaches to resource allocation hence seem to stand against each other: The utilitarian approach defended by the DIVI guideline, aiming to save as many patients as possible, and the rights-based approach defended by the community of people with disability, aiming to protect people with disability from discrimination.

Although a new law was enacted in December 2022, the issue remains controversial as the law may still discriminate against people with disability.<sup>5</sup>

This essay acknowledges this tension. It considers the tension as inherent to the topic of triage which cannot be sufficiently addressed without considering both theoretical perspectives. Being aware of both, the normative-ethical and the meta-ethical dilemma character of triage, the essay nevertheless aims at sounding out perspectives for ethically justifiable strategies of deciding in triage situations. I will first describe decision making during triage and then discuss three (out of many possible) criteria for triage (lottery approach, first come first serve and probability to survive principle) and lastly, propose a balanced approach to addressing the tension between consequentialist and rights-based approaches to triage allocation.

## HOW TO DECIDE ON THE IMPOSSIBLE

Triage decisions are complex and pose a genuine dilemma since all patients included in the triage decision require medical attention and desire to receive treatment (otherwise they are not included

<sup>i</sup>Language matters when speaking about people with disability. We chose the person first approach which is recommended by the United Nations Office at Geneva as part of the United Nations Disability Inclusion Strategy, <https://www.ungeneva.org/en/about/accessibility/disability-inclusive-language/annex-i>, accessed 13 September 2023.

<sup>iii</sup>Different legal and social definitions of disability exist, and it goes beyond the scope of the paper to analyse the diversity of disability. We refer to medical disabilities, including but not limited to physical, sensory and psychosocial disabilities. Some disabilities play a larger role in this discussion because they are influenced by comorbidities. That is what we focus on in this paper while being aware that also disabilities not correlated to comorbidities can lead discrimination during triage due to stereotypes and biases of physicians.



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in the triage decision), but due to limited resources, treatment must be denied to some, resulting in harm and potentially leading to death. To provide quick guidance, the DIVI issued a (multiply revised) guideline at the beginning of the COVID-19 pandemic in 2020. The DIVI recommended a utilitarian approach, using the clinical prospect of success, supported by the Clinical Frailty Score, the Sequential Organ Failure Assessment Score (SOFA score) and comorbidities impacting COVID-19 infections to decide who receives intensive care treatment.<sup>2</sup> The approach is utilitarian because by selecting patients for treatment in light of the clinical prospect of success, one maximises the number of people benefiting from treatment. The lack of inclusion of people with disability representatives in the definition of these triage criteria and the absence of a broader societal debate about them have raised criticism, particularly from the people with disability community.<sup>6</sup> Many quickly released triage protocols prioritised saving the most lives and maximising post-treatment life expectancy, which may entail discriminatory outcomes for people with disability.<sup>7</sup>

Concerns regarding potential injustices motivated nine people with disability and their legal representatives to file a constitutional complaint at the German Constitutional Court in 2020. They argued that the German state is obliged to protect people with disability better from discrimination in the COVID-19-induced triage of intensive care resources as stated in Article 3, §3 of the German constitution, which states that ‘no person shall be disfavoured because of disability’.<sup>4</sup> The complainants indicated that the current legislation fails to safeguard this fundamental right when it comes to the allocation of scarce healthcare resources during the pandemic. They further claimed that withholding scarce medical treatment based only on the criteria established by medical associations (such as the DIVI) is illegal and demanded a broader societal discussion and a legal regulation.<sup>3</sup>

In December 2021, the German Federal Constitutional Court decided that the government must ensure the effective prevention of any discrimination related to disability in the distribution of scarce intensive care treatment resources during a pandemic. The Court recommended the short-term probability of survival as the main allocation criterion.<sup>8</sup> In response, the German government released a draft law in October 2022, adopting the current, short-term probability of survival as the allocation criterion.<sup>9</sup> Then, more than 50 associations, including patient representatives, disability associations and medical professional associations, were invited to comment on the draft law. For this essay, the different suggestions made in these position papers were summarised into three schools of thought: some commentators advocated for randomisation, such as a lottery principle, while others supported the first come first served procedure. Still others emphasised the current short-term probability of survival as the primary principle for allocation. The next paragraph provides an overview of the arguments in favour and against each of the three principles.

## WHAT IS FAIR? THREE PRINCIPLES FOR THE ALLOCATION OF SCARCE RESOURCES

### The survival lottery

In the context of the German legislative process, the principle of randomisation has been supported especially by institutions advocating for the rights of people with disability, including church-driven institutions, such as Caritas Behindertenhilfe, and public organisations, such as the Forum behindertener Juristinnen

und Juristen. Three arguments supporting a randomisation will be explained and criticised in the following:

The main argument is based on the idea that physicians should use a lottery to allocate scarce resources to grant everyone an equal chance of receiving treatment. Individuals should be given an equal chance of receiving scarce treatment when arriving at the intensive care unit (ICU) simultaneously because they are equally worthy, regardless of their characteristics, including disability.<sup>10</sup> The idea of giving everyone equal chances makes this approach non-utilitarian. Rather than looking at the desired consequence of maximising the number of patients benefiting from treatment, equal chances to receive such treatment become important. However, it can be questioned whether equality of chance outweighs potential differences in claims to the scarce resources. It may simply not be seen as fair to give a person treatment because they won it by lottery if there is another patient that would benefit more from treatment or that would need treatment more urgently.<sup>11</sup> Hence, a lottery approach may provide equality of chances but not an equitable distribution of scarce resources. Equity refers to treating people fairly and without discrimination. Denying treatment to someone in need just because they did not win the lottery seems unfair. It can also be claimed that more patients could die using the lottery principle than the adopted current, short-term probability of survival principle. If treatment is started for a patient chosen by lottery, this patient could have a very bad a priori chance of survival and die during treatment, which goes against the societal interest of maximising the number of patients who survive. Therefore, it can be argued that sacrificing equality of chance is necessary to satisfy the claims of more patients to survive.<sup>12</sup>

The argument from tie-breaking states that randomisation should be used when the claims of the individuals are equal, that is, when they have an equal chance to benefit from scarce treatment.<sup>11 12</sup> Nonetheless, it may be difficult to examine whether two patient’s claims to treatment are equally strong and, in most of cases, they are different, and a tie-breaking situation does not occur. Maybe, when physicians are unsure what would be the morally right thing to do, using a lottery to allocate scarce resources can relieve them of the responsibility of choosing one patient over another, making it easier for them to accept the allocation scheme.<sup>10</sup> But just because making that decision is difficult, is not enough to justify using a lottery principle. Acquiring more information about the allocation problem can help to resolve uncertainty.<sup>12</sup> Moreover, using the lottery principle may also be a burden for doctors as they may have to reject treatment for a patient who is likely to survive, while under other circumstances, they would focus on the well-being of all their patients.

Lastly, the argument from unjust discrimination states that using a lottery principle prevents unjust discrimination. When judgements of individual probabilities to survive are difficult to make and subconscious bias may shape decisions, a lottery approach can be desirable to avoid discriminatory decisions. However, a lottery does not effectively correct structural or social discrimination, in contrast to other allocation schemes which may be able to do so. Not everyone needing treatment arrives at the hospital at the same time and not everyone can be included in the lottery. Usually those who arrive first are socially better off patients with better access to healthcare than those arriving later. Those that arrive late may arrive too late to participate in the lottery.<sup>11</sup>

In conclusion, the lottery approach is not utilitarian since it does not promote overall survival, and leans towards a rights-based approach. It does acknowledge the right to be treated equally and to non-discrimination, but as described, these rights

are not granted due to access inequality and people with disability are still subject to discrimination when enacting a lottery.

### First come, first served

Another allocation principle that has been debated in the international ethical discourse and in the context of the German legislation is to randomise by time. In the German debate, for instance, the Forum behinderteter Juristinnen und Juristen, an organisation representing lawyers with disabilities, suggests using chronological order (also known as first come, first served) for all patients that are not too sick to benefit from intensive care, not too healthy to survive without intensive care and that actually want intensive care.<sup>13</sup> Given that condition, allocation by first come first served maximises distribution equality as it gives all patients equal chances and expresses their equal status. The first come first served principle does not take morally irrelevant characteristics, such as social status or disability into account.<sup>14</sup> There are similar arguments in favour of a first come first served principle to the lottery principle, as well as similar concerns. Patients allegedly have equal chances to arrive first at the hospital but in reality, similar to a lottery principle, this is shaped by social circumstances. Patients who are socially better off may have better and faster access to healthcare, leading to the selection of well-off patients and potentially discriminating against poorer patients who arrive later at hospitals. This can also affect people with disability, who may have equal chances for treatment but not necessarily equal access to healthcare.<sup>14</sup> They often suffer from social disadvantage and inequalities.<sup>15</sup> Hence, health inequities for people with disability can be deepened by following a first come first served approach.<sup>12</sup>

Therefore, additional measures would be needed to reduce health inequities and ensure equal access to healthcare for people with disability before enacting a lottery or first come first served principle.<sup>14</sup> The moral issues regarding the argument from tiebreaking cannot be resolved with such measures. From a patient-centred point of view, all patient's claims to be treated are valid and they have a right to be treated. This should not be undermined using a lottery or first come first served principle just to relieve society or the doctor from the moral responsibility to come up with a more equitable allocation scheme.

### Current, short-term probability to survive

The allocation of healthcare resources in a pandemic can shift from patient-centred care to public healthcare, seeking to efficiently maximise benefits for the maximum number of people using limited resources.<sup>12</sup> This can be done using the probability to survive as allocation criterion. In November 2022, the German federal government amended the Infection Protection Act ('Infektionsschutzgesetz'), postulating that only the current, short-term probability of survival may be used to decide which individuals to provide with scarce treatment during pandemic triage. Discrimination based on disability, age, ethnic origin, religion, gender or sexual orientation is prohibited. Comorbidities can be taken into account only if they significantly reduce the probability of survival of the current illness. The new regulation also includes framework conditions, such as documentation requirements and the multieye principle. In addition, *ex post* triage, which refers to the practice of withdrawing care already allocated from a patient in favour of another, based on their higher expectations of survival, is now prohibited.<sup>4</sup> The Deutsche Gesellschaft für Anaesthesiologie und Intensivmedizin and other organisations support the principle adopted, arguing that the complex assessment of the prospects of success should be done by experienced intensive care physicians within this legal

framework.<sup>16</sup> Although this principle avoids the critique of the lottery and first come first served principle of not saving the maximum amount of people, there are several concerns.

First, saving as many lives as possible is a utilitarian goal and can be a desirable goal of public healthcare regulations, but as sketched out above, this may happen at the cost of people's equal right to treatment and lead to the discrimination of people with disability.<sup>1</sup> Two ethical theories are in conflict: utilitarianism (the goal of maximising population health outcomes), and a rights-based theory (promoting an equitable allocation of scarce resources). Society may choose to sacrifice equity to save more lives or try to find a more equitable way, a balanced approach, to solve the dilemma.<sup>17</sup> The latter approach will be discussed later in this article.

Second, discrimination still occurs, even if one does not exclude patients from scarce treatment because they are disabled but for other reasons such as a considerably reduced probability of survival, which can be linked to disability. Hence, people with disability are more likely to be denied treatment.<sup>18</sup> In the end, maximising the number of survivals based on probabilities to survive results in selecting only the healthiest members of society. Desiring a diverse society, one would in contrast be trying to give all members equal chances to succeed and to promote welfare for all groups. A current, short-term probability of survival principle promotes unequal treatment of groups already disadvantaged.<sup>17</sup> Furthermore, the maximisation principle creates a homogeneous pool of relatively healthy patients, not giving physicians the opportunity to improve the care of people with disability, because they are more likely not to receive scarce treatment.<sup>12</sup>

Third, it is feared that the negative criteria now provided in German law do not offer enough guidance for objective decisions by medical staff in situations where comorbidities significantly reduce the current probability of survival. Doctors make decisions based on prior beliefs about the patient's condition, age, gender, socioeconomic status, race or ethnicity.<sup>12</sup> Intuition remains a significant influence on decision-making in healthcare and is often informed by subjective beliefs. Disability is often viewed as a personal tragedy or a deficiency rather than a status shaped by socioenvironmental factors.<sup>19</sup> This negative perception of disability can affect how healthcare providers quantify the survival chances of people with disability, leading to the denial or termination of treatment during triage. As such, I argue that relying solely on the negative criteria provided in the new infection control law does not necessarily eliminate these subjective factors.<sup>1</sup> In order to overcome this challenge, it is essential to explore possible solutions that promote more objective decision-making during triage.

### ASSESSING SURVIVAL PROBABILITIES IN CLINICAL PRACTICE

To summarise, the current probabilities to survive principle is a good criterion to efficiently allocate scarce healthcare resources. However, measures to promote a more rights-based approach should be taken to reduce discrimination of people with disability and provide a more equitable distribution of scarce resources.

In order to reduce the potential of the current, short-term probability of survival principle for discrimination against people with disability, it can help to define positive criteria for measuring probabilities to survive based on empirical evidence for the specific pandemic. In the beginning of the pandemic, scoring systems such as the SOFA Score and the Clinical Frailty score were frequently recommended for evaluating the probability of survival for COVID-19 patients.<sup>2</sup> However, studies have shown that these scoring systems can lead to discrimination

against people with disability since the latter more often suffer from comorbidities.<sup>1</sup> The SOFA score assesses organ dysfunction and mortality risk based on specific parameters for breathing, circulation, nervous system function, liver function, haematological situation and kidney function. It was developed using collective data and not individual parameters. Therefore, it can be useful as a starting point, but doctors should mainly consider individual parameters for decision-making. The Clinical Frailty score assesses a patient's frailty using nine categories, and has been used during the COVID-19 pandemic to identify patients who are unlikely to benefit from intensive care.<sup>2</sup> It is effective for patients older than 65, but is not appropriate for all COVID-19 patients because it discriminates against younger patients who may need a wheelchair but otherwise have a good chance of survival.<sup>20</sup> The score is based on a subjective definition of the 'normal population', which introduces biases.<sup>21</sup>

Individual parameters, such as the C reactive protein, D-Dimer, creatinine, blood pressure and vital signs, also correlate to the probability of survival.<sup>22</sup> However, these parameters are influenced by comorbidities and disabilities, potentially discriminating against people with disability. Comorbidities such as chronic obstructive pulmonary disease, kidney disease, liver disease, cancer, immune deficiency and diabetes significantly affect ICU patients' survival probability and can be linked to disability.<sup>20, 23</sup> Although the new infection control law prohibits the use of disabilities to evaluate survival, they still indirectly impact decision-making when a comorbidity significantly impacts the probability to survive. Conclusively, the positive criteria for assessing the probability to survive presented in this article can provide some guidance to physicians but they have discriminatory potential, and physicians should not rely solely on these criteria. In order to meet the German Federal Constitutional Court's requirement of preventing discrimination against people with disability, decision-makers must adopt further measures to promote a more rights-based approach and protect people with disability from discrimination when applying a current, short-term probability of survival principle.

## WAYS TO REDUCE THE DISCRIMINATION OF SCORING CRITERIA

Various strategies to promote the rights of people with disability while using scoring criteria will be explored in the following.

One solution could be replacing scoring systems, such as the SOFA score, with broad categorisations that assign patients high, medium or low priority for treatment. This approach simplifies the categories and reduces the significance of small differences in survival probabilities.<sup>21</sup> The numeric scale of the SOFA score leaves little room to adapt to the individual patient and their situation. Broader categories leave more room for individual decision making. They give more responsibility for doctors to view each patient as an individual. Socioeconomic and institutional factors can be taken into account. Nonetheless, it has to be acknowledged that this solution requires the reduction of potential stereotypes doctors may have towards people with disability.

Another approach is to address socioeconomic disparities that affect the health and healthcare of people with disability.<sup>15</sup> Doctors could prioritise disadvantaged patients within the group that meets the chosen threshold of likelihood to survive.<sup>12</sup> They can use an index such as the Area Deprivation Index (ADI) in the USA. Public health specialists could develop a similar index for Germany to correct triage scores, such as the SOFA score, for patients affected by structural disadvantage. This also prioritises people with disability indirectly. The ADI is a tool used to

measure the socio-economic disadvantage in specific geographical areas. It is based on a combination of factors including income, education, employment, housing quality and household composition.<sup>17</sup> A set of variables related to socioeconomic status is initially identified to calculate the ADI. These variables are then combined using a statistical algorithm to create a single score for each geographical area, representing the level of socio-economic disadvantage in that area. The ADI score can range from 0 to 100, with higher scores indicating greater levels of deprivation. In the context of pandemic triage, the ADI could be used as a correction factor to adjust the priority assigned to patients based on their predicted probability of survival. Patients with similarly predicted probabilities of survival, for example, could be assigned a higher priority if they come from areas with higher levels of deprivation, reflecting the fact that they face additional barriers to accessing healthcare and other resources. Criteria such as quality of life, long-term life expectancy, broad social worth, gender and sexual orientation remain excluded.<sup>17</sup> Nonetheless, this approach can still fail to promote social justice, since healthy disadvantaged people could be selected, helping those not affected by the health effects of their disadvantage. Moreover, one can claim that access to healthcare should not be based on social but only medical criteria. Additionally, the accuracy of such indices can be questioned since they were not designed to guide life-or-death decisions but those in public health and social politics.<sup>12</sup>

In conclusion, indices such as the ADI may not be used directly to alter triage scores, but the idea of balancing discrimination against patients with disability and socially disadvantaged patients with some kind of procedure remains under discussion. Additionally, long-term solutions to address health inequalities require public health policies, and systemic changes to promote social and economic equality are necessary.<sup>21</sup> Approaches such as care ethics can provide insights into the dynamic of triage as being shaped by interpersonal and institutional relationships. They can add another perspective to the rights-based and utilitarian approaches and should be further included into the debate in future work.<sup>24</sup>

Another way to mitigate discrimination in triage criteria should be including disabilities advocacy groups and social workers in the decision-making process.<sup>21</sup> They can help to uncover unconscious bias, serve as patient advocates and develop discrimination-free scores.<sup>25</sup>

Lastly, medical education should include mandatory seminars on the structural discrimination of people with disability in healthcare, and students and doctors should be encouraged to learn more about the experiences of people with disability in order to reduce discrimination. That way doctors learn to reduce biases in their own decision-making.

## CONCLUSIONS

People with disability are subject to discrimination during pandemic triage. Decisions about the allocation of scarce resources are difficult and include balancing several moral values, such as equality, efficiency, equity and social justice, and the idea of conserving diversity in society. In Germany, a lawsuit regarding triage in a pandemic was filed at the constitutional court and this was followed by a legislative process, where different approaches and theories were discussed. This can be insightful for other jurisdictions. The three allocation systems discussed in Germany are a lottery principle, first come first served and current, short-term probability of survival principle. They are all subject to criticism. The current, short-term probability of survival, as

the adopted principle in new German legislation, does not fully avoid the discrimination of people with disability. To achieve a balance between utilitarian and rights-based claims, it is essential to develop clear and transparent guidelines for allocating scarce medical resources based on objective criteria to evaluate the probability to survive. At the same time, it is important to ensure that these guidelines do not discriminate against vulnerable and marginalised groups, including people with disability and that they adapt to each patient's individual situation. This may be achieved by incorporating correcting indices (such as the ADI) for social disadvantage into the scoring systems used to assess a patient's likelihood of survival, prioritising disadvantaged patients within the group of patients that meet the chosen threshold of likelihood to survive, and involving disability advocacy groups and social workers in the decision-making process. Furthermore, efforts should be made to address the underlying social determinants of health, such as poverty and systemic discrimination, which contribute to health inequalities and increase the vulnerability of certain groups during a pandemic. This may be achieved through long-term public health policies and systemic changes aimed at promoting social and economic equality. Overall, striking a balance between equity and efficiency during pandemic triage requires a combined approach that considers both the short-term need to save lives and the long-term goal of promoting equality, equity and social justice. Approaching the triage dilemma includes a further debate on these concerns, agreeing to which point we as society are willing to sacrifice people's right not to be discriminated against for a higher number of survivors and when we are willing to sacrifice survivors to secure people's rights. The dilemma remains unsolved, nonetheless this essay provided strong arguments for a further discussion on the topic.

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