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# **BOFAXE**

# COVID-19 Triage and the Persistent Problem of Disability Discrimination in Healthcare (Part 1)

The COVID-19 pandemic continues to create major challenges for public healthcare. Numerous countries are faced with the difficult task of allocating scarce medical resources, e.g. ventilators, to COVID-19 patients (see, e.g., case studies concerning <a href="Italy and France">Italy and France</a>, <a href="Italy and Italy an

Persons with disabilities (PWD) are especially vulnerable in the wake of the pandemic (see <a href="here">here</a>, p. 4-7). Their right to equal access to healthcare under Article 25 of the International Convention on the Rights of Persons with Disabilities (ICRPD) is belied by the reality of discrimination in public health care systems. Biases towards PWD distort judgment in triage situations, possibly leading to discriminatory deprivation of medical treatment.

This blog post lays out the relevant framework under the ICRPD, contrasts it with the realities of exclusionary healthcare and triage practices around the world, and presents ways to bridge the gap in accordance with international human rights law. A recent case before the German Federal Constitutional Court illustrates how States are starting to recognize and address the problem.

## **Equal Access to Healthcare under the ICRPD**

Article 25 ICRPD obligates State parties to provide the "same range, quality and standard" of healthcare to persons with and without disabilities and to "prevent discriminatory denial of health care [...] on the basis of disability." In essence, the ICRPD forbids substandard levels of healthcare on the basis of disability (see <a href="here">here</a>, p. 263). Article 11 ICRPD clarifies that this framework also applies during public emergencies. In those times, PWD experience an increased risk of discrimination (see <a href="here">here</a>, para. 43).

Equal access to healthcare, on the one hand, requires measures against environmental barriers, e.g. wheelchair ramps on hospital premises (see <a href="here">here</a>, para. 7 and <a href="here">here</a>, para. 12 (b) (ii)). Even more significant, however, is the reduction of attitudinal barriers in healthcare (see <a href="here">here</a>, p. 285 and <a href="here">here</a>). In this context, the social model of disability underlying the ICRPD plays a central role. In contrast to the outdated medical model, this approach stresses that disabilities result from the "interaction between persons with impairments and attitudinal and environmental barriers" (see <a href="here">here</a>, Preamble (e) and, generally, <a href="here">here</a>, p. 41-59). Disability is no personal medical problem, but rather an issue of extrinsic barriers created by society (see <a href="here">here</a>, p. 5-7). Rejecting the medical model of disability means rejecting the notion that PWD are inherently and incurably less healthy (see <a href="here">here</a> and <a href="here">here</a> and <a href="here">here</a>, p. 246). This then opens the door to treatment based on actual medical evidence instead of preconceived notions about disability.

# Disability Discrimination in Healthcare

Unfortunately, the realities in healthcare are different. The UN Committee on the Rights of Persons with Disabilities (CRPD) has noted that State parties have not abandoned the medical model of disability (see <a href="here">here</a>, para. 2). This persistent convolution of disability and illness impairs the level of healthcare granted to PWD. Discrimination occurs, for example, in the form of "diagnostic overshadowing", i.e., the prejudicial attribution of ailments to a patient's disability without a medical basis. This issue has been shown to lead to underdiagnosis, mistreatment, and generally inferior levels of medical care (see <a href="here">here</a>, p. 118 and, generally, <a href="here">here</a>). Furthermore, doctors tend to be affected by biases regarding the resilience, quality of life, and prospects of recovery of PWD (see <a href="here">here</a>, p. 287-288, <a href="here">here</a>, p. 9, and <a href="here">here</a>, p. 246). The quality of life is often evaluated on a functional basis instead of focusing on the patient's actual enjoyment of life. Consequently, treatment is sometimes considered "futile" based solely on the fact that the patient is disabled (for an extensive study of medical futility and disability bias, see <a href="here">here</a>, for an inquiry into a particularly severe manifestation, see <a href="here">here</a>). Decision-making based on such preconceived notions about disability amounts to discrimination contrary to the ICRPD (see <a href="here">here</a>, p. 515).

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# **BOFAXE**

### COVID-19 Triage and the Persistent Problem of Disability Discrimination in Healthcare (Part 2)

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### **Disability Discrimination in COVID-19 Triage**

Triage aims at maximizing the amount of human life saved by healthcare by establishing a prioritization between patients when resources do not allow the treatment of everyone (see <a href="here">here</a>, p. 2051-2053). This approach relies on two major questions: how dire is the need for treatment and to what extent will the patient benefit from treatment? The second aspect is where the persistent medical conception of disability leads to discrimination (see <a href="here">here</a>, p. 246). Even though the chances of clinical success, expected quality of life, and prospective remaining years of life <a href="prima facie appear neutral">prima facie appear neutral</a> in relation to disability, they are vulnerable to an intrusion of biases (see <a href="here">here</a>, p. 516). Discrimination occurs when disability is used as a shorthand for lower chances of medical success or an "inferior value" of a survivor's life without medical evidence (see <a href="here">here</a>, p. 4).

Firstly, triage guidelines themselves have been shown to discriminate against PWD. Some guidelines set out the existence of certain impairments or the need for daily support as exclusion criteria (see <a href="here">here</a>, p. 1-2). Others call for the application of the Clinical Frailty Scale (CFS) in triage even though it has been developed for elderly patients and may be misleading in the context of PWD (see <a href="here">here</a>, p. 4 and <a href="here">here</a>, p. 6-7). Similarly, using disability adjusted life-years (DALYs) as a criterion for prospective benefits puts a lower value on the lives of PWD (see <a href="here">here</a>, p. 246-247).

Secondly, the preconceived notions of practitioners lead to discrimination. Limited time and prognostic uncertainty render triage decisions particularly vulnerable to implicit biases (see <a href="here">here</a>, p. 8-9). The issue of "diagnostic overshadowing" here causes the assumption that PWD are less likely to benefit from treatment (see <a href="here">here</a>, p. 4). Evaluations of the quality of life are particularly subjective, as has been laid out above (see <a href="here">here</a>, p. 363-364). Further problems arise when stereotypical assumptions about life-expectancy are made (see <a href="here">here</a>, p. 1-2).

States are violating the prohibition of discrimination when they uphold discriminatory guidelines and fail to counteract implicit biases (see <a href="here">here</a>, p. 1061). Recent evidence shows that such discrimination against PWD in COVID-19 triage takes place around the world (see <a href="here">here</a>, p. 42).

### The Triage Decision of the German Federal Constitutional Court

A recent decision by the German Federal Constitutional Court illustrates how these problems are addressed by State parties to the ICRPD. On 16 December 2021, the Court held that Germany's regulation of triage is insufficient. The State was thus declared to be in breach of the prohibition of discrimination under Article 3 (3) second sentence of the German Basic Law as well as Article 25 ICRPD.

Relying on expert evidence, the Court saw a significant risk of disadvantages for PWD in triage due to subconscious stereotyping. The existing guidelines by professional associations were held to be insufficient in counteracting this risk. According to the judgment, the guidelines may even exacerbate risks of discrimination because they set out comorbidities and frailty as significant factors. It cannot be ruled out, according to the Court, that disability will be equated with comorbidities. This risk must be counteracted with binding legislation. Furthermore, relevant legislation must stipulate that the likelihood of survival as a factor in determining the prospects of success only refers to the survival of the "acute medical episode in question".

According to unofficial reports (see <a href="here">here</a> and <a href="here">here</a>), the German government is preparing pertinent draft legislation. The draft allegedly sets out the will of the patient, medical urgency, and the current and short-term chances of survival as permissible criteria. Comorbidities and frailty are included as relevant factors only insofar as they considerably reduce the current or short-term chances of survival. Particularly the inclusion of clinical success, frailty and comorbidities has already elicited criticism by disability rights advocates (see <a href="here">here</a> and <a href="here">here</a> and <a href="here">here</a>). It remains to be seen which form the official draft will take.

## A Way Forward in Line with the ICRPD

Article 4 (1) (b) ICRPD obligates State parties to take all appropriate measures to abolish discriminatory laws, regulations, customs, and practices. First and foremost, this entails repealing discriminatory triage rules. Several States already reacted by adapting their guidelines in the wake of the pandemic. Pertinent COVID-19 regulations in South Africa and the UK now clarify that the CFS is not applicable for young patients with "stable long-term disabilities" (see <a href="here.p.4">here.p.4</a>).

But States must also actively counteract biases of healthcare professionals. This requires the development of frameworks for triage decisions which consider the implicit biases in healthcare. The framework must encourage practitioners to avoid broad categorizations and instead focus on factors which are grounded in scientifically sound medical evaluations (see <a href="here">here</a>, p. 1). A promising practice in this regard is the Guidance of the Bioethics Committee of the San Marino Republic for triage decisions concerning persons with disabilities (see <a href="here">here</a>, p. 2, for the Committee's statement, see here).

The precise substantive criteria of triage protocols are subject to – primarily ethical – debate and admittedly difficult to nail down from an international law perspective. However, the ICRPD gives some guidance as to how those discussions should take place. Article 4 (3) ICRPD obligates State parties to "closely consult with and actively involve" PWD when developing legislation relevant to them (see also <a href="here">here</a>, p. 9). In line with the aphorism "nothing about us without us", the ICRPD demands meaningful participation of PWD (see <a href="here">here</a>, para. 4). This will help to prevent to consolidation of implicit biases. A practical example is the COVID-19 Disability Advisory Group to the Canadian government, which enables PWD and their representative organizations to advise the government on "the real-time lived experiences of persons with disabilities during this crisis", helping to solve "disability-specific issues" in the pandemic (see <a href="here">here</a>).

Legislation alone will not be sufficient in uprooting stereotypes about the health of PWD. The ICRPD further requires State parties to undertake "adequate awareness-raising measures and measures to change or abolish compounded pejorative disability stereotypes and negative attitudes" (see <a href="here">here</a>, para. 39). More specifically, Article 25 (d) ICRPD demands training medical professionals regarding the specific needs and unique experiences of PWD. Higher medical education is famously lacking in this respect, particularly with a view to abandoning the medical model of disability (see <a href="here">here</a>, p. 2 and <a href="here">here</a>, p. 2 and <a href="here">here</a>, p. 1815). The inclusion of PWD in medical education can help to raise awareness of disability as a lived reality instead of a cluster of medical diagnoses (see <a href="here">here</a>, p. 1797).

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