An Exploration of Ableism in Healthcare Resource Allocation

INTRODUCTION

When healthcare resources become scarce and providers must choose who receives treatment, the Hippocratic principle of Justice is often the most difficult to honor. Clinicians may turn to decision-making algorithms in hopes of minimizing personal bias, but these tools inevitably introduce the biases of their creators. Algorithms do not transcend prejudice; they reproduce it. If bias exists in an algorithm's parameters, it will shape its outputs. A common tool among rationing algorithms is the use of Quality of Life Years (QLY), a metric that appears objective but in practice embodies ableist bias. This paper explores the discriminatory nature of QLYs, examining their origins, definitions, and conflicts with core principles of medical ethics.

ALGORITHMS BORN OF BIAS

With the rise of "black box" algorithms and deep learning systems, researchers have recognized that algorithmic outputs are only as good as the data and structures upon which they are built.

Belief in algorithmic objectivity is widespread but unfounded: algorithms, whether advanced neural networks or simple clinical guidelines, reflect the values of the societies that create them[1, 2]. Thus, when society undervalues certain populations, algorithms inevitably do the same.

One clear example is the treatment of disabled individuals. Research repeatedly demonstrates that society undervalues their quality of life, a dynamic captured in the "Disability Paradox"[3].

Although disabled people themselves often report meaningful and fulfilling lives, broader societal perception continues to assume diminished well-being. Historical injustices, culminating in the 1990 Anti-Disability Act[4], illustrate recognition of these biases at a cultural and political level, but healthcare rationing guidelines remain slow to adjust. Asch argues that stigma runs even deeper, rooted in psychological discomfort: disability serves as a reminder of human vulnerability, fueling subconscious desires to marginalize disabled people, as evidenced by permissive attitudes toward physician-assisted suicide in cases of severe disability.[5]

Another factor complicating equality is the structural difference between disability and other forms of marginalization. While stigma against most other demographic groups can be addressed by shifting attitudes, disabled people require both destigmatization and material investment. A wheelchair user, for instance, cannot fully integrate into society until physical accommodations like ramps are provided. This dual burden (needing both acceptance and resource allocation) makes destigmatization even harder to achieve. Shakespeare suggests

that such obstacles can make bias feel insurmountable, and current rationing protocols inevitably reflect these systemic inequities.[6]

QLYS IN CONTEXT

QLYs aim to quantify the benefit of medical interventions by multiplying survival years by a score for perceived quality of life. Despite their fragile theoretical foundations, they remain central in rationing decisions. The UK's National Institute for Health and Care Excellence (NICE) explicitly incorporates them in its guidelines.[7] In the United States, the Organ Procurement and Transplantation Network (OPTN) does not directly admit to the use of QLYs, stating reliance on principles of Utility, Justice, and Respect for Persons. However, "Utility" is defined to consider survival and quality of life as decisive factors.[8] Because disabled patients are often defined as having both reduced survival and lower quality of life, they are systematically disadvantaged. The dynamic known as "double jeopardy" is exemplified by the OPTN's transplant protocols, which state that the health state of these individuals is further harmed by deprioritization due to an existing health condition. The OPTN's lung transplant system explicitly cites conditions commonly associated with disability such as rheumatoid arthritis and cystic fibrosis as lowering quality of life and reducing priority for organ allocation.

Other organizations cloak QLY use through Cost-Effectiveness Analysis (CEA), a framework borrowed from economics that evaluates value per dollar spent. While useful for budget allocation, CEAs reflect utilitarian ethics rather than the deontological traditions of medicine. During COVID-19 ventilator shortages, hospitals often avoided explicit CEAs[9], but researchers and policymakers used them in modeling and simulations to optimize distribution.[10, 11] This approach risks shifting care away from patient benefit toward economic efficiency, penalizing those with disabling conditions that might lower perceived post-treatment productivity. Although CEAs are not explicitly utilized in most cases, their reliance may expand as cost pressures increasingly shape healthcare systems.

DEFINITIONAL PROBLEMS WITH QLYS

At its core, a QLY multiplies life-years by a quality score. This seems straightforward, but in practice the numbers are arbitrary. They depend on one group's assessment of another's lived experience, a process fraught with inaccuracy. The Disability Paradox highlights the gulf between societal perception and disabled people's self-reports. Broader psychology confirms this mismatch goes beyond quality of life and is fundamental to the human experience: people's self-judgments differ dramatically from how others rate them across traits such as attractiveness, intelligence, and psychological well-being.[12]

Experts have shown that quality-of-life numbers are not only biased but also inconsistently generated. Some are assigned by physicians with limited perspective on the conditions in question, while others are set by policymakers or insurers with no clinical expertise.[13] Attempts to improve accuracy by polling disabled individuals also face limitations. Research shows that newly disabled people often rate their quality of life poorly at first, but

over time, adaptation leads to improved self-assessments.[14] This phenomenon of adaptation complicates any effort to distill lived experience into a single decimal. Ultimately, QLYs reduce the richness of human life to an oversimplified metric ill-suited for ethical decision-making.

THE PROBLEM OF QLYS IN MEDICINE

Although QLYs are convenient, they are incompatible with medical ethics. Economists champion them because they align with utilitarian ideals[iv], and societies often revert to utilitarianism in times of crisis, such as an acute shortage of a healthcare resource.[15] Yet medicine has worked to move beyond this "default" ethical mode. Justice in medicine emphasizes equity rather than maximizing majority outcomes.[2, 16] By prioritizing those with the greatest utilitarian return, QLYs and CEAs deny disabled individuals equitable access and reinforce systemic disparities.

Disability scholarship further undermines QLY assumptions. The Medical Model defines disability as a deficit managed by physicians, while the Social Model reframes it as a mismatch between ability and environment.[17] Most scholars recognize reality lies between these models, but QLYs remain entrenched in the Medical Model, ignoring environmental adaptations that can dramatically alter functionality. For example, a wheelchair user facing stairs and one facing a ramp may experience vastly different abilities, yet QLYs assign both the same reduced score.

Such rigidity reinforces outdated views and undermines fair allocation of resources.

PROPOSALS FOR REFORM

Deprioritizing disabled people not only worsens disparities but also deprives society of the contributions they could make if given equitable care. Continuing to use biased algorithms is unjust; once bias is identified, the only ethical path is reform. Survival criteria already disadvantage disabled people due to shorter life expectancies, while resource commitment criteria compound discrimination by undervaluing their quality of life.

Bioethicist Stramondo proposed combining survival with an inverse form of current resource commitment standards, essentially adjusting for bias by weighing algorithms in favor of those who need the most care, during ventilator distribution debates in the COVID-19 pandemic.[18] This approach seeks to maximize lives saved while ensuring that disabled patients are not excluded. While no algorithm can ever be fully unbiased, revising endpoints to prioritize fairness is a step toward equity.

Even so, theoretical fixes have limits. Algorithms require expert oversight, and as artificial intelligence grows more complex, fewer users fully understand their mechanics. This raises the risk of blind reliance on flawed tools. The most effective path forward may be less about perfecting algorithms and more about recommitting to patient-centered care. Clinicians must strive to understand not only the technical tools and medical processes that guide decisions but also the lived experiences of their patients.

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ENDNOTES

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