



# Ethical Considerations in Addressing the Exclusion of Individuals with Intellectual and Developmental Disabilities from Scarce Resource Allocation in the Context of COVID-19

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**Submission:** November 9, 2020; **Published:** December 03, 2020

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**Keywords:** Health systems; Patients; Intellectual and developmental disabilities; Communities; COVID-19

## Introduction

The creation of scarce resource allocation policies has had ripple effects throughout communities and health systems as the COVID-19 pandemic has led to increasing concern about access to essential medical services. These scarce resource allocation policies have been criticized for commenting on patients' age, comorbidities, and ability status as factors that should be taken into consideration by health professionals in deciding whether a particular patient should have access to potentially life-saving interventions when these interventions are in short supply. This is of particular significance to the disability community as hospitals and institutions are reviewing these policies in the context of increasing cases once again during the COVID-19 pandemic, where access to resources such as ventilators or therapeutics such as Remdesivir may again be limited. There has been a number of institutions that have already created policies excluding individuals with intellectual and developmental disabilities (IDD) from access to these interventions if they become limited in supply.

Because of this, the Arc of the United States filed a complaint with the U.S. Department of Health and Human Services Office for Civil Rights over the concern that the Alabama Department of Public Health's Emergency Operations Plan and the Washington State Department of Health were discriminatory against those with disabilities. In the State of Alabama, the exclusion of individuals with "severe or profound intellectual disability" from

the use of ventilators during the pandemic, as well as the State of Washington's consideration of "baseline functional status" including cognition in the triage allocation protocol has sparked outrage from the disability community.

COVID-19 magnifies the disparities at play in healthcare systems. Prior to COVID-19, the disability community had already experienced significant health inequities and unmet needs. Previous studies have demonstrated that communication challenges and adherence to medical recommendations are barriers to healthcare for those with intellectual and developmental disability [1]. Additionally, lack of availability of health services that meet the needs of individuals with IDD are compounded by an overall lack of health care professional who have the knowledge, understanding and experience to treat individuals with IDD [2]. During a pandemic crisis with scarce resource allocation, barriers to care such as communication and health services availability have increased dramatically, thus widening the gap. The use of resource allocation policies that discriminate individuals with IDD may serve to further decrease access to essential health care services.

Fundamental to public health philosophy is the utilitarian view of saving the most lives possible. However, when creating scarce resource policies for maximum benefit, several ethical principles must be considered to avoid discrimination. The ethical principle of justice is critical to uphold in these challenging situations.

When there is no clear evidence to exclude certain conditions and comorbidities from interventions, it is discriminatory to do so [3]. Categorical exclusions based upon “severe intellectual disability” violate the Americans with Disabilities Act and allows for a qualitative assessment of life that is worth living. Non-maleficence and promoting the wellbeing of patients is the goal of each health center and provider. Yet, when that obligation is impinged upon by a crisis, upholding the ethical principal of justice and fair distribution without discrimination must be written into policy.

Distribution of limited resources remains a dilemma, however the creation of policies that increase barriers and create new inequalities for disabled individuals and other marginalized groups is not the solution. Given that non-disabled individuals may underestimate the quality of life of a disabled individual [4], utilizing an medical ethics framework emphasizing justice may be important in ensuring that individuals with disabilities continue

to have equal access to life-saving interventions throughout the COVID-19 pandemic.

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DOI: [10.19080/GJIDD.2020.07.555707](https://doi.org/10.19080/GJIDD.2020.07.555707)

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