

DISABILITY

I Will Not Apologize for My Needs'

Even in a crisis, doctors should not abandon the principle of nondiscrimination.

By Ari Ne'eman

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Times of crisis ask us who we are as a country. As hospitals prepare for shortages in ventilators and other scarce medical resources, many people with disabilities are worried about the answer to that question.

In Italy, doctors are already rationing access to care on the basis of age and disability. The Washington Post reports that many states are considering how to implement similar rationing measures here. Though almost everyone would agree doctors may deny care that is unlikely to benefit a patient, there may soon be too many patients in urgent need of lifesaving treatment and too few resources to treat them all.

When that happens, some are proposing to send the disabled to the back of the line. States across the country are looking to their Crisis Standards of Care plans — documents that explain how medical care changes amid the shortages of an unprecedented catastrophe. While each is different, many have a concerning common attribute: When there isn't enough lifesaving care to go around, those who need more than others may be in trouble.

Some plans single out particularly severe conditions, like Alabama's decision that people with severe or profound intellectual disability "are unlikely candidates for ventilator support" or Tennessee's listing people with spinal muscular atrophy who need assistance with activities of daily living among those excluded from critical care.

Others just lay out a broad goal, counting on clinical judgment to do the rest. Newly issued allocation guidelines from the University of Washington Medical Center argue for "weighting the survival of young otherwise-healthy patients more heavily than that of older, chronically debilitated patients." The existence of the nonelderly disabled, a group increasingly in fear for their lives, goes unacknowledged.

People with disabilities have a long and complicated history with the medical profession. While many disabled people need ongoing medical care, many doctors view life with certain disabilities as unworthy of living. Disabled people who require ongoing ventilator care and other forms of expensive lifelong assistance are used to being asked by medical professionals if they would rather abandon life-sustaining treatment — often with the clear implication that "yes" is the right answer.

When my friends with some of these needs go into the hospital, even under normal circumstances, those of us who love them try to organize lots of calls and visits. These aren't just to keep the patient's spirits up. They are designed to send a message to treating professionals: "Someone cares if this person lives or dies. You are being watched."

With visiting restrictions in place and many prominent authorities explicitly allowing the denial of care to disabled people, will that message now get through? I worry it will not.

Even when discrimination is not based on perceptions of quality of life, but instead on seemingly "rational" considerations of resource intensity, we should object to abandoning the disabled to second-class medical status.

Italian clinical guidelines have called for "the presence of comorbidity and functional status" to be evaluated as considerations in the allocation of resources, as "a relatively brief progression in healthy patients could become longer and thus more resource-consuming on the health care system in the case of elderly patients, fragile patients or patients with severe comorbidity."

This idea is both straightforward and concerning: Patients with disabilities may require more resources than the nondisabled. In a crisis, the nondisabled can be saved more efficiently. As a result, when doctors must choose between a disabled and a nondisabled patient with similarly urgent levels of need, the nondisabled patients should get priority, since they will recover more quickly, freeing up scarce resources.

Adopting such an approach would be a mistake. Even in a crisis, authorities should not abandon nondiscrimination. By permitting clinicians to discriminate against those who require more resources, perhaps more lives would be saved. But the ranks of the survivors would look very different, biased toward those who lacked disabilities before the pandemic. Equity would have been sacrificed in the name of efficiency.

Not only is such an approach poor ethics — it can also interfere with efforts to combat the pandemic.

In 2015, the New York State Department of Health developed guidelines on how to allocate ventilators in a crisis. Among other things, they permit hospitals to take away ventilators from those who use them on an ongoing basis in the community or at a long-term care facility if they seek hospital care. Not only is this a concerning precedent, it also interferes with the trust in the medical system that we need to combat the virus: Chronic ventilator users may have reason to avoid seeking needed hospital care if they become infected, based on a well-founded fear of being sacrificed “for the greater good.”

I spoke to a colleague of mine, Alice Wong of the Disability Visibility Project, on these issues. As a 46-year-old who uses a ventilator on a regular basis, she has a lot at stake.

“My vent is part of my body — I cannot be without it for more than an hour at the most due to my neuromuscular disability. For clinicians to take my vent away from me would be an assault on my personhood and lead to my death,” Alice writes. “I deserve the same treatments as any patient. As a disabled person, I’ve been clawing my way into existence ever since I was born. I will not apologize for my needs.”

She is correct. To allow discrimination against the disabled, even when there isn’t enough to go around, is simply wrong. Disability advocates are mobilizing to defend this position — on Thursday, the American Association of People with Disabilities sent a letter to Congress urging “a statutory prohibition on the rationing of scarce medical resources on the basis of anticipated or demonstrated resource-intensity needs.”

Though some insist otherwise, we should maintain a broad approach of “first come first served” when it comes to lifesaving care, even scarce medical resources like ventilators. We certainly should not remove ventilators from those who are already using them in the name of allocating more “efficiently.”

This is a sacrifice — but not so great as some might imagine. Maintaining nondiscrimination does not require hospitals to treat those who would die anyway. Even under nondisaster situations, clinicians can withhold care that is deemed futile — medically ineffective. But those who can be helped should not be given lower priority because of pre-existing disabilities, even those that will require more scarce resources.

I recognize that this approach imposes a cost. By maintaining “first come first served” for the provision of nonfutile lifesaving care, we may save fewer lives than through ruthlessly efficient optimization. If someone needs twice the average amount of time on a ventilator, maintaining that we shouldn’t turn them away — or deprive them of a ventilator they are already using — means that we are potentially costing the lives of two people who come into the I.C.U. after them.

But even in a crisis, can we not ascribe some value to maintaining our principles? I argue yes — though it may cost lives. This is an unorthodox position, and one that may earn me the ire of the esteemed bioethicists who crafted the rationing protocols now on the verge of deployment.

But I fight for it, because I believe that nondiscrimination is not just a tool to accomplish an end — it also is an end in and of itself. Federal authorities, like the Health and Human Services Office of Civil Rights, must defend the equality of disabled Americans, even now.

At its core, these debates are about value — the value we place on disabled life and the value we place on disability nondiscrimination. When Congress passed the Americans With Disabilities Act 30 years ago, did it do so as a form of charity limited to times of plenty? Or was our country serious about disability as a civil rights issue? Charity can end when resources are scarce — civil rights must continue, even if doing so imposes a cost in time, money and even lives. People with disabilities have an equal right to society’s scarce resources, even in a time of crisis.

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