

VIEWPOINT

Autistic people must not be denied access to ventilators

BY SARA LUTERMAN

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As more people are hospitalized with COVID-19, the healthcare system is struggling to meet the need for ventilators and critical-care beds. How should we allocate these scarce resources? How do doctors decide who lives and who dies? Are some lives more valuable than others?

These questions may seem unthinkable or even ghoulish, but for those of us with disabilities, they are terrifyingly real. An **analysis of policies** in 30 U.S. states, conducted by the nonprofit Center for Public Integrity, found that all but 3 have adopted policies that could deny necessary care to disabled people during the pandemic, particularly people with cognitive disabilities such as autism.

Healthcare rationing and disability discrimination are not new. The coronavirus pandemic is merely exacerbating the **existing fault lines** in our society. Long-standing healthcare disparities involving race, class and disability status are coming to a head.

Some of my **friends** and **colleagues** in the self-advocacy and disability rights movements have already died, either from COVID-19 itself or as an indirect result of the strains on the healthcare system and cuts in disability services. It feels like watching a tsunami in slow motion — I can see it coming but cannot do anything to stop it.

Right now, the coronavirus is tearing through **group homes, nursing homes, residential schools** and **state institutions**. In Los Angeles County, California, for example, **40 percent of coronavirus deaths** have occurred in skilled nursing facilities. Direct-support professionals, who assist disabled people with some of their most intimate needs, often do not have enough or any personal protective equipment.

To make matters worse, many of the facilities facing the highest rates of infection have long-standing problems in managing infections. According to the *Los Angeles Times*, 89 percent of the skilled nursing facilities in the Los Angeles area with coronavirus outbreaks had **previously been cited** for violating federal safety rules on infection control.

Meanwhile, home- and community-based services, many of which have been underfunded and short-staffed for years, have become further strapped by the pandemic. And it doesn't appear that addressing these issues is a priority for policymakers.

Quality of life:

In fact, some state policies blatantly discriminate against those with disabilities. Washington state, for example, recommended that doctors consider referring people with "loss of reserves in energy, physical ability, cognition and general health" to palliative care instead of ventilator support. Alabama was **forced to rescind** a policy that would deny ventilators to people with "profound mental retardation" after disability organizations made a federal civil-rights complaint.

It is worth noting that the word 'retardation' and its derivatives are widely considered offensive by people with intellectual disability and their families.

The doctors and bioethicists making decisions about how to triage ventilator support are not monsters. Their goals are utilitarian: to maximize the number of lives saved and the quality of those lives. Laudable though this seems, there are hidden assumptions built into their notion of quality. This is likely to include the unspoken belief that disabled lives are, by definition, worse than non-disabled ones.

Quality of life is difficult to measure. There are no satisfaction antibodies to detect in the bloodstream. All we have is self-reporting, and people with autism have more **difficulty with self-reporting** than others. We have trouble **reading our own emotions**. And minimally verbal autistic people may find it difficult to communicate their thoughts and feelings.

Autistic people do appear, on average, to be **less happy** than their neurotypical peers. I recognize that I am less happy than many of my neurotypical peers, but it is unclear whether that is a result of autism itself or of the way the world interacts with me.

Autistic people tend to be lonelier, as well as more likely to be unemployed, than others. Who isn't unhappy when faced with isolation, boredom and financial trouble? Distress is a completely normal reaction. And why should we consider those problems inherent to disability?

I am fortunate compared with some of my peers with disabilities. I struggle with co-occurring mental illness, but I live independently, and I can advocate for myself. If I turned up in an emergency room struggling to breathe, I doubt I would be denied medical care.

But it is deeply abhorrent to think that people who have more significant disabilities — including some of my friends and colleagues in the disability community — might be denied care when their lives are just as worthy as mine. I wish more non-disabled people felt the same way.

Sara Luterman is a freelance writer whose work has appeared in The Washington Post, The Nation and Vox.