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The art of medicine

Urgent care: disability, pandemic, and the value of a life

Ranked below average on nearly any development scale, my teenaged son with Down syndrome has unexpected talents for flourishing in a pandemic. Early on in the COVID-19 pandemic while the rest of our household languished in confinement, Henry thrived on life's narrowness. What we experienced as the enervating tedium of remote work and school closures, he embraced as welcome consistency. He loves eating the same meals, rarely worries about the future, and his best friends are toy figurines. He doesn't mind wearing a mask, especially if decorated with his favourite Star Wars characters. And he found pigeons landing on our window ledge as delightful as the trip to Disneyland that had to be cancelled along with so many other plans made before the COVID-19 pandemic.

My son was also our greatest source of terror, since people with Down syndrome can be at increased risk of complications from COVID-19. We live in New York City, NY, USA, which had one of the first and most devastating waves of COVID-19 in the country. Our apartment is around the corner from a major hospital, and the constant wail of ambulances reminded us of a medical system stretched to breaking point. In a time of crisis, we worried that Henry might not have access to the care he needed to survive.

This is not merely a hypothetical question. When resources are under pressure or health-care systems overwhelmed, people with disabilities generally go to the back of the line. Emergency plans designed by hospitals and local governments are usually premised on utilitarian principles that aim to maximise the number of lives, or predicted years of life, saved. Some

of these measures might discriminate against people with disabilities. For instance, early on in the pandemic the state of Alabama's Emergency Operations Plan restricted ventilator access to patients "with severe or profound mental retardation", "moderate to severe dementia", and "severe traumatic brain injury". After protests from disability rights organisations, it was revised in April, 2020 to ensure that the policy did not "discriminate against people with disabilities in accessing lifesaving care". But other US states, including Kansas, Utah, Tennessee, Pennsylvania, and Oklahoma, had similar policies. So did a number of other countries. According to a global report on the pandemic from the Disability Rights Monitor, "Several written testimonies from Canada, the United Kingdom, the United States of America, Austria, Luxembourg, the Netherlands, Georgia, France, and South Africa said that their governments indicated that hospital triage should discriminate against COVID-19 patients with disabilities in the event of a shortage of hospital places. Triage guidelines explicitly or implicitly instructed health workers to decide on a person's right to life based on their disability." The Disability Rights Monitor report also highlighted the need to "ensure that persons with disabilities have equal access to basic, general, specialist, and emergency health care and that triage policies never discriminate on the basis of disability or impairment".

Other emergency plans do not intend to discriminate, but nonetheless have the effect of putting people with disabilities at a disadvantage when it comes to accessing care. Apportioning care based on simple measures of survivability privileges those who are fit and healthy. Giving lower priority to patients with underlying conditions disproportionately impacts marginalised populations who are disabled by poverty, stress, and inadequate access to health care. And judgments based on quality of life often pit the opinions of health professionals against the self-reporting of people with disabilities and their supporters.

Additionally, people with disabilities who have COVID-19 could be at increased risk of receiving inferior care, even when medical resources are not an issue. In Oregon, more than one person with an intellectual disability hospitalised with COVID-19 was issued a do-not-resuscitate order on the assumption that they had low quality of life. Similar cases were reported in the UK, Belgium, and Australia. No-visitor policies in health-care settings also had a disproportionately negative impact on people with disabilities. Being gravely ill and isolated



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from friends and family is a terrifying situation for any patient, but especially those who need assistance with communication or understanding.

These problems are especially acute for people with intellectual disabilities, but they also extend to people with physical impairments. The debate and legal case after the death of 46-year-old father of five and quadriplegic Michael Hickson touches on some of these issues; Hickson had multiple disabilities and died with COVID-19 in 2020 in Texas, USA, after the withdrawal of life-sustaining treatment, including artificial nutrition and hydration. His complex case reveals an absence of public consensus about the meaning of a good life and, in times of scarcity, who should have the right to decide which lives are worth saving.

In non-pandemic times, the idea that people with disabilities are better off dead is not uncommon among the able-bodied. Disability advocate and lawyer Harriet McBryde Johnson, who had muscular dystrophy, wrote of strangers approaching her on the street to say “if I had to live like you I think I’d kill myself”. When anthropologist William Peace, a wheelchair user, was admitted to hospital with an infected pressure wound, he described how doctors offered to discontinue his antibiotics to save him from the suffering and expense of prolonged illness. Peace writes of the chilling realisation that the people charged with his care believed “disability is a fate worse than death”.

Thankfully, nobody has ever suggested my son is better off dead. But I do routinely confront assumptions that his life is unhappy or burdensome. I once told a colleague who is an expert in infectious disease that I have a son with Down syndrome. He responded by saying, “I’m sorry”. I think he meant well, perhaps intending to acknowledge the cost and difficulty of caring for a disabled child. But whether he meant to express sorrow for my burdens or for the fact that my son exists at all, his words have the same effect. They associate disability with tragedy and regret. In the non-crisis atmosphere of a professional seminar, I could correct his misimpressions by responding pertly, “I’m not sorry”. But as the pandemic raged I was scared to think that many health-care professionals, faced with a dire emergency, might make judgments about patients with disabilities on the basis of such misconceptions.

The history of medicine is filled with tremendous achievements that have prolonged and improved the lives of people with disabilities. But there is also a long history of withholding care to take life from those who have been deemed unwanted or burdensome. In the USA, the Baby Doe Law is named for a baby denied lifesaving care at birth in 1982. Born with Down syndrome, Baby Doe also had a lethal but treatable condition of the oesophagus that required immediate

surgery, but her parents refused the treatment and the infant subsequently died of dehydration and pneumonia. It is a sign of progress that it is now illegal to withhold lifesaving treatment for a baby who has any chance of survival. But determinations of survivability are still subject to competing views of health status and whether disability is compatible with living a worthwhile life.

At this point, it is important to acknowledge that, with a few memorable exceptions, my son has always been treated with kindness and respect by health-care providers. Henry did have a non-COVID-19 medical emergency during the pandemic, and he received stellar medical care. When he complained of unbearable pain in his hip area, the paediatrician took his symptoms seriously, diagnosed a testicular torsion, and sent us directly to the emergency room. The emergency room staff were compassionate and professional. Nobody suggested that his disability compromised his care in any way. That said, it was May, 2020, not February. We are white, with good health insurance provided by my employer. No-visitor policies in hospitals, which had been so damaging for people with disabilities, had been lifted. I was there to advocate for my son, support him, and show that he is a cherished member of a family.

In a crisis, there is no perfectly just way to distribute limited medical resources. But there is now widespread acknowledgment that there has been discriminatory treatment of people with disabilities in the COVID-19 pandemic. There must be better ways of deciding who merits our care. And when the crisis stage of this pandemic passes, we need to grapple with the larger questions it has exposed, about which lives matter, who is capable of living a good life, and who gets priority when disagreements among health-care providers and advocates or caregivers arise.

Recent novels about fictional pandemics can help us imagine what happens when the commitment to care for the vulnerable goes out the window in favour of naked survival. One of my favourites is Colson Whitehead’s zombie thriller, *Zone One*, where New York City is ground zero for the struggle for survival between the healthy and their infected counterparts. In the novel’s dystopian end, the protagonist recognises defeat and joins the hungry crowd of zombies moving through lower Manhattan. When humans are reduced to naked self-interest, they might as well be zombies. The current pandemic is not a zombie plague. But those monsters haunt our fiction to make us think about who counts as human and what it means to value a life.

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I am the author of *Raising Henry: A Memoir of Motherhood, Disability, and Discovery* (Yale University Press, 2013).

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