



Commentary on 'All Bodies': US perspective

Kristi L. Kirschner, MD

Clinical Professor, Departments of Medical Education, and Neurology and Rehabilitation, and Adjunct, Department of Disability and Human Development, College of Allied Health Sciences, University of Illinois, Chicago

Corresponding Author:

Dr. Kristi L Kirschner
Department of Medical Education
University of Illinois, Chicago 60607, USA
Email: kkirschn@uic.edu

Received: 19-MAY-2020

Accepted: 19-MAY-2020

Published Online: 21-MAY-2020

The commentary is in response to the graphic titled "All Bodies" which is accessible at <http://rhime.in/ojs>



Artist

Michaela Oteri @Ogrefairry
"All Bodies"

Source: Oteri M. All Bodies.
RHIME. 2020;7:106-7.

"Disabled people know what it means to be vulnerable and interdependent. We are modern-day oracles. It's time people listened to us. Even before the coronavirus pandemic, systems have always tried to kill and oppress marginalized people. Attempts to repeal the Affordable Care Act. Human gene editing. Wildfires in California. Voluntary power shutoffs by PG&E. Medicaid work requirements. Public charge rule. These crises and assaults reconfirm who is considered disposable and unworthy of assistance, resources, attention, and treatment. This time feels different for me with the very real threats of health care rationing and shortage of ventilators for critically ill patients in the United States."[1]

- Alice Wong, Disability activist, Founder of the Disability Visibility Project

Cite this article as: Kirschner KL. Commentary on 'All Bodies': US perspective. RHIME. 2020;7:108-11.

The image titled "All Bodies" forces us to acknowledge that every person counts. COVID-19 has laid bare the fracture-lines in the US between people with disabilities and those without. Not that we didn't know these ruptures were there beforehand, as Ms. Wong notes. We did. As recently as the fall of 2019, a series of five bioethics and disability reports, commissioned by the National Council on Disability, were released on the following topics: organ transplantation, physician-assisted suicide, genetic testing, quality-adjusted life years, and medical futility.[2]

The National Council on Disability (NCD), "an independent federal agency charged with advising the President, Congress, and other federal agencies regarding policies, programs, practices, and procedures that affect people with disabilities" commissioned the reports to document disparate treatment, inaccurate knowledge about disability, bias (implicit and explicit), lack of access and accommodations which can affect decisions in all these contexts and result in devaluation of the lives of people with disabilities. The series of reports made robust recommendations for policy makers, including Health and Human Services and Office of Civil Rights. In other words, these agencies and disability activists were primed for what happened next: which was COVID-19.

Wuhan announced the first clustering of cases on December 31, 2019 and by January 21 we had the first case in continental US (a citizen who had traveled to China).[3] Ten days later the World Health Organization declared a public health emergency, and by March 11 they felt compelled to use the "P"-word (pandemic) which they had resisted for fear of triggering panic and economic fallout. In the space of six weeks we had gone from one to over 1,000 cases in the US, and the world had over 10-times that number of cases confirmed worldwide (undoubtedly an underestimate given the marked testing shortages.)

By 29 February, 2020, a deadly outbreak of COVID-19 was announced in Life Care Center in Kirkland, Washington; by April 2, 37 residents had died and over 2/3's of the residents and staff had tested positive. [4] More alarming reports began to appear with COVID moving through long-term care (LTC) facilities like wildfires. Fragile older adults with disabilities and chronic illnesses, inadequate infection control practices and personal protective equipment (PPE), and inability to socially distance made for a deadly combination. LTC facilities account for over 50% of overall deaths now in six states.[5] Death rates in New York for people with Intellectual and Developmental Disability (IDD) are also high - almost 2.5 times higher than the average death rate.[6]

These numbers are undoubtedly underestimates. Without a positive COVID test, the death is often not counted as due to COVID, even when it is strongly suspected. Prior to COVID it was known that 48% of death certificates of people with IDD were inaccurately coded, often noting the individual's disability as the cause of death and not the proximate cause.[7] Without universal COVID testing, this will be even a bigger problem. Unfortunately, disability statistics are not routinely gathered in health care and have to be extrapolated from diagnoses codes. Efforts are ongoing to require the collection of disability status, along with the required race and ethnicity data that has allowed us to document the disproportionate deadly impact of COVID on Black, Hispanic/Latino, and Native American communities.[8]

People with disabilities who are living in the community are also particularly at risk, particularly if they rely on personal care aides and can't socially distance due to the need for intimate personal care. Over 4 million people qualify for such services through Medicaid.[9] These are older adults, people of color, with chronic illnesses, and at high risk for serious illness and death if they contract COVID-

19.[10-12] Direct service workers (which include personal care aides) are essentially invisible in the current COVID workforce, without easy access to PPE and infection control training. Many make minimum wage, do not have health insurance or sick leave, and have to go from home to home to provide such care. [12] This is a recipe for COVID spread for both the client and the direct service worker, yet people in LTC facilities and people with disabilities and their personal care aides have been left out of pandemic planning. The consequences can be dire. If their in-home care system falls apart, they could easily end up with worsening health, and hospitalized or in nursing homes - the very facilities where spread is much more difficult to contain.

Which takes us to the issue of State and hospital guidelines for crisis standards of care and resource allocation. Resource allocation is a sanitized word for rationing - a hot-button word in the US, where we like to pretend we really don't ration, though we do so all the time, but mostly implicitly through income inequalities, insurance and immigration status, implicit bias, poor access, etc. A major strategy during COVID needs to be to prevent spread, but if an individual does become sick and needs to be hospitalized, will they have access to a ventilator under resource constrained conditions if needed? Crisis Standards of Care are written when needs exceed capacities to clarify the rules for designating priority status. As the details of the State guidelines emerged, it was clear that some had exclusion criteria that would eliminate people with intellectual disabilities and traumatic brain injuries from triage consideration. The criteria for triage also considered medical conditions and basal functional impairments that could disadvantage people with disabilities.

Disability activists moved into high gear very quickly and filed complaints and lawsuits with the states, the Office of Civil Rights alleging discrimination in the guidelines for Washington State, Alabama, and Kansas.[13] Disability rights activist Ari Ne'eman articulated the issue succinctly when he said, "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." [14] The Office of Civil Rights agreed and published a non-discrimination bulletin on 28 March, 2020. [15]

Sadly, for me as a physician, the activism and leadership efforts around COVID and discrimination have come largely from *outside* the medical and bioethics communities. Not unlike the HIV/AIDS pandemic, grassroots efforts are needed to force the government and health care sector to listen, to change and to respond to those who feel invisible and disenfranchised. The hashtag - #NoBodyIsDisposable - is one such grassroots group from Oakland, California - a collaborative of disability and weight discrimination activists who have taken charge, producing tips and guidelines to help prepare people with disabilities for possible hospitalizations and for the need to fight for their care.[16] I wonder though, what will it take for those in health care, public policy, and ethics to get on board, to really listen, and to lead?

References

1. Wong A. Disabled oracles and the Coronavirus. Disability Visibility Project. 2020 Mar 18 [cited 2020 May 18]. Available from <https://disabilityvisibilityproject.com/2020/03/18/coronavirus/>
2. Bioethics and Disability Report Series. National Council on Disability. 2019 Sep [cited 2020 May 18]. Available from <https://ncd.gov/publications/2019/bioethics-report-series>
3. Hauck G, Gelles K, Bravo V, Thorson M. Three months in: a timeline of how COVID-19 has unfolded in the US. USA Today. 2020 Apr [cited 2020 May 18]. Available from <https://www.usatoday.com/in-depth/news/nation/2020/04/21/coronavirus-updates-how-covid-19-unfolded-u-s-timeline/2990956001/>
4. Baker M. Nursing home linked to 37 Coronavirus deaths faces fine of \$600,000. The New York Times. 2020 Apr [cited 2020 May 18]. Available from <https://www.nytimes.com/2020/04/02/us/virus-kirkland-life-care-nursing-home.html>
5. Chidambaram P. State reporting of cases and deaths due to COVID-19 in long-term care facilities. Kaiser Family Foundation. 2020 Apr 23 [cited 2020 May 18]. Available from <https://www.kff.org/coronavirus-covid-19/issue-brief/state-reporting-of-cases-and-deaths-due-to-covid-19-in-long-term-care-facilities/>
6. Landes SD, Stevens D, Turk MA. COVID-19 and pneumonia: increased risk for individuals with intellectual and developmental disabilities during the pandemic. Lerner Center for Public Health promotion. 2020 Apr 27 [cited 2020 May 18]. Available from <https://lernercenter.syr.edu/2020/04/27/covid-19-and-pneumonia-increased-risk-for-individuals-with-intellectual-and-developmental-disabilities-during-the-pandemic/>
7. Stevens D, Landes S. Potential impacts of COVID-19 on individuals with intellectual and developmental disability: a call for accurate cause of death reporting. Lerner Center for Public Health promotion. 2020 Apr 14 [cited 2020 May 18]. Available from <https://lernercenter.syr.edu/2020/04/14/potential-impacts-of-covid-19-on-individuals-with-intellectual-and-developmental-disability-a-call-for-accurate-cause-of-death-reporting/>
8. Centers for Disease Control and Prevention. Coronavirus Disease 2019: COVID-19 in racial and ethnic minority groups. 2020 May 17 [cited 2020 May 18]. Available from <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/racial-ethnic-minorities.html>
9. O'Malley Watts M, Musumeci M, Chidambaram P. Medicaid home and community-based services enrollment and spending. Kaiser Family Foundation. 2020 Feb 4 [cited 2020 May 18]. Available from <https://www.kff.org/report-section/medicaid-home-and-community-based-services-enrollment-and-spending-issue-brief/>
10. Kwiatkowski M, Nadolny TL. 'We want to live': At-risk adults, home health care workers fear coronavirus. USA Today. 2020 Mar 26 [cited 2020 May 18]. Available from <https://www.usatoday.com/story/news/investigations/2020/03/26/coronavirus-strains-home-health-care-putting-vulnerable-risk/5083219002/>
11. Centers for Disease Control and Prevention. Coronavirus Disease 2019: Groups at higher risk for severe illness. 2020 [cited 2020 May 18]. Available from <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/groups-at-higher-risk.html>
12. It's time to care: A detailed profile of America's direct care workforce. PHI. 2020 [cited 2020 May 18]. Available from <https://phinational.org/wp-content/uploads/2020/01/lts-Time-to-Care-2020-PHI.pdf>
13. Whyte LE. State policies may send people with disabilities to the back of the line for ventilators. The Center for Public Integrity. 2020 Apr 8 [cited 2020 May 18]. Available from <https://publicintegrity.org/health/coronavirus-and-inequality/state-policies-may-send-people-with-disabilities-to-the-back-of-the-line-for-ventilators/>
14. Ne'eman A. 'I Will Not Apologize for My Needs.' The New York Times Editorial. 2020 Mar 23 [cited 2020 May 18]. Available from <https://www.nytimes.com/2020/03/23/opinion/coronavirus-ventilators-triage-disability.html?smid=tw-nytopinion&smtyp=cur>
15. OCR Bulletin. Civil Rights, HIPAA, and the Coronavirus Disease 2019. U.S. Department of Health and Human Services. 2020 Mar 28 [cited 2020 May 18]. Available from <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>
16. No Body Is Disabled. Fight Discrimination in COVID-19 Triage. 2020 [cited 2020 May 18]. Available from <https://nobodyisdisposable.org/>