

**COMMENTARY**

# Ableism at the Bedside: People with Intellectual Disabilities and COVID-19

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**People with intellectual and developmental disabilities have a higher risk of mortality from COVID-19 than the general population. Providers may assume that this is due to the burden of comorbidities for this population; however, the disparity in mortality persists even when controlling for comorbidities. We review the current policies and practices that may be contributing to this higher level of mortality. We contend that pervasive ableism among medical providers leads to a variation in the medical care options that are provided to people with intellectual disabilities and their families. Due to this bias, poor outcomes for people with intellectual disabilities may become a self-fulfilling prophecy. We make recommendations to address the modifiable factors that are contributing to the higher level of mortality for people with intellectual disabilities who are infected with COVID-19, provide strategies to combat ableism within the medical field, and discuss the unique role of the primary care physician as an advocate. (J Am Board Fam Med 2022;35:390–393.)**

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*Janet\**, a 60-year-old woman with Down syndrome (DS) and early Alzheimer's disease, was admitted to the hospital in the fall of 2020 with COVID-19-associated pneumonia. On the general medical unit, she received supportive treatment with oxygen, steroids, and remdesivir. She was fortunate to have her primary care physician (PCP), a family physician who also serves as director of a specialized clinic for adults with DS, as her inpatient attending. He discussed goals of care with Janet and her family (including her sister who serves as her legal guardian), clarifying what they would want if Janet's condition were to worsen suddenly. Would they want any limits on her treatment, such as a do-not-

resuscitate (DNR) order? The PCP counseled that there was no definitive evidence that Janet would not benefit from intensive treatment, and they all agreed that Janet had a rich, full life. A full code status was maintained. Her condition worsened over the next 24 hours, and she was transferred to the intensive care unit (ICU). The ICU team, on assuming care, asked her PCP why she did not have a DNR order.

People with DS (and other intellectual/developmental disabilities, or IDD) are known to be one of the highest risk groups for COVID-19 infectivity and mortality. A large cross-sectional study found that "having an intellectual disability was the strongest independent risk factor other than age for Covid-19 mortality."<sup>1</sup> The reasons for this heightened risk are not clear but may include genetic factors (such as cardiac defects or immune dysregulation in DS), comorbid conditions (such as obesity and type 2 diabetes, which are more prevalent in individuals with IDD),<sup>2–5</sup> and structural vulnerabilities, such as socioeconomic disadvantage, congregate living, and poor preventive

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health care.<sup>6-8</sup> Even after controlling for comorbidities, however, the increased risk of COVID infection and mortality persists.<sup>1,9</sup> Indeed, one international survey described a hospitalized 40-year-old with DS as having the same risk of mortality from COVID-19 as a hospitalized 80-year-old without DS, again controlling for comorbidities.<sup>10</sup>

*Over the next 6 days, Janet's PCP was asked by the ICU team at least 4 times to confirm her code status, even as her overall condition began to improve. The PCP ultimately challenged the team on why he was repeatedly being asked this question. Did they feel her treatment was not of medical benefit? If so, what were the data to support this position? If they did not have data, it felt like disability bias was behind the repeated questioning. He told them that before hospitalization, although Janet needed some supervision and assistance with her activities of daily living, she enjoyed many things - coloring, music, dancing, movies, and attending her nieces' and nephews' sporting events. Her guardian had made an informed decision regarding her code status based on her best interest and likelihood of medical benefit. After this discussion, the ICU team did not repeat their question. A few days later, Janet was transferred out of the ICU. One week later, she was discharged, a bit deconditioned but otherwise functioning at her premorbid status.*

Unlike many patients in the era of hospital medicine, Janet was fortunate to have her long-standing PCP involved in her care decisions.<sup>11</sup> Their relationship served to mitigate what is known as disability bias, also known as ableism, or the belief that the quality of life or worth of a person with a disability (PWD) is inherently less than that of a nondisabled person.<sup>12</sup> Ableism presents on both an individual and a structural level. Structural disability bias and discrimination were evident in the early stages of the pandemic as states

scrambled to develop Crisis Standards of Care (CSC) or triage guidelines. Some CSC included categorical exclusion criteria for people with certain disabling conditions, which would effectively deprioritize them from intensive care services.<sup>13</sup> Disability discrimination complaints were lodged, and the U.S. Department of Health and Human Services Office of Civil Rights (OCR) warned that "Persons with disabilities... should not be put at the end of the line for health services during emergencies." In addition, "an individualized assessment... based on the best available objective medical evidence" is required.<sup>14</sup>

For people like Janet, this OCR directive is necessary but insufficient to protect them against the bias that presents on an individual level. Most crisis-oriented medical decisions take place at the bedside by medical professionals who have little knowledge or training about disability and within a health care system where ableist attitudes are pervasive.<sup>1,15</sup> In a recent nationwide survey, 82.4% of 714 U.S. physicians agreed that "people with significant disability have worse quality of life than non-disabled people" despite prior studies indicating that many PWD self-report a good or excellent quality of life.<sup>15</sup>

If physicians do not think the lives of individuals with IDD are worth living, how will that guide their decision on whether or not to intubate someone with DS suffering from COVID? What likelihood of success will they predict for the intervention? Studies have shown that physicians are quite poor at predicting whether a patient will survive an ICU stay, tending to overpredict death before discharge.<sup>16</sup> We submit that these dual forces - overpredicting poor outcomes and undervaluing the lives of PWD, including those with IDD - lead to disparities in the

**Table 1. Recommendations to Improve Healthcare Services for Individuals with Intellectual and Developmental Disabilities**

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| Involve primary care physicians, other disability professionals, and advocates who can communicate a patient's baseline cognitive, functional, and medical status and the patient's and family's values and perception of quality of life with an inpatient team. |
| Consider implementing other communication strategies, such as health passports, to provide critical medical and disability-specific information to any new care provider.   |
| Increase health professional and staff awareness and education about the lived experience of individuals with disabilities. Integrate core competencies related to disability into medical school curricula.  |
| Encourage dialogue about ableism in the healthcare system. Providers should ask themselves if the presence of the disability influences their decisions and, if so, why? What is the medical evidence to justify differential treatment?                          |
| Create, if not already in place, and engage the disability access (or resource) coordinator or other professional responsible for hospital compliance with Section 504 and the ADA to promote an inclusive, patient-centered care culture.                        |
| Ensure that persons with disabilities have a seat at the table, including involvement in hospital policy discussions, ethics committees, and the healthcare workforce.  |

care provided. In fact, despite increased rates of COVID-19 hospital admission and mortality, people with intellectual disability were no more likely to be admitted to the ICU than people without disabilities.<sup>1</sup> This suggests that they either were not offered or chose not to pursue a higher level of care, decisions that are usually highly influenced by physicians' recommendations. Until we address ableism in health care, the outcomes for people with IDD will remain a self-fulfilling prophecy.

Janet is currently alive and well due to the care she received in the hospital. However, her outcome might have been much different without the presence of her PCP, who understood her baseline status and advocated for her. We contend that medical decisions for people with IDD are best made with a PCP and/or a specialist with knowledge of the disability who can help teams understand how the acute illness fits into the person's life trajectory. We need to embrace better communication strategies within and across health care systems so that inpatient teams know how to, and more frequently choose to, contact these providers. Tools, such as health passports, can identify these contacts and also communicate succinct, valuable medical and disability-specific information to provide context for an inpatient team.<sup>17</sup> In addition, health care systems may consider a model in which some physicians focus their care on a particular complex population and follow their patients from the outpatient to the inpatient setting.<sup>18</sup>

Even in the absence of these experts and tools, however, it is imperative that providers who are less familiar with these conditions be mindful of their own potential biases and listen to the patients with IDD and their families. We must take an approach of narrative humility, because "[a]ssuming that our reading of any patient's story is the definitive interpretation of that story is to risk closing ourselves off to its most valuable nuances and particularities."<sup>19</sup> We must ask ourselves: would we make this same recommendation for a comparable person without IDD? If not, what difference does the IDD make? What are the data that the patient is less likely to benefit from treatment? Educational resources aimed specifically at individuals with IDD are one easily available tool that might enhance the delivery of equitable care.<sup>20</sup>

The COVID-19 pandemic has underscored the need for systems-level changes to combat the influence of ableism at the bedside. The Affordable Care Act requires hospitals to "designate a responsible

employee to coordinate their efforts to comply with Section 504 and the Americans with Disabilities Act (ADA)".<sup>21</sup> We must actively engage these individuals in creating an inclusive, patient-centered care culture and in increasing staff awareness of disability biases and disparities. We must include PWD and their families as stakeholders at all levels of a health system, such as in policy discussions, on our ethics committees, and within the health care workforce itself. In medical schools, we must integrate core competencies related to disability into the curricula and highlight the effects of ableism and its intersection with other forms of bias and discrimination. Our recommendations are compiled in Table 1.

At the root of these strategies is empathic curiosity - the willingness to listen and learn from those who live with disabilities and their families. Changing the ableist culture of medicine is a long road, but respect, humility, and openness are required to take the first step.

*\*Name changed to protect patient privacy. Patient's guardian provided permission to share case.*

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We thank the patient and her family for the opportunity to learn and grow from their lived experience.

To see this article online, please go to: <http://jabfm.org/content/35/2/390.full>.

## References

1. Gleason J, Ross W, Fossi A, Blonsky H, Tobias J, Stephens M. The devastating impact of Covid-19 on individuals with intellectual disabilities in the United States. *N Engl J Med Catalyst Innovations in Care Delivery*; 2021.
2. Melville CA, Hamilton S, Hankey CR, Miller S, Boyle S. The prevalence and determinants of obesity in adults with intellectual disabilities. *Obes Rev* 2007;8:223-30.
3. Capone GT, Chicoine B, Bulova P, Down Syndrome Medical Interest Group DSMIG-USA Adult Health Care Workgroup, et al. Co-occurring medical conditions in adults with Down syndrome: a systematic review toward the development of health care guidelines. *Am J Med Genet A* 2018;176:116-33.
4. Reichard A, Stolze H. Diabetes among adults with cognitive limitations compared to individuals with no cognitive disabilities. *Intellect Dev Disabil* 2011; 49:141-54.
5. Turk MA, Landes SD, Formica MK, Goss KD. Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis. *Disabil Health J* 2020;13:100942.
6. Landes SD, Turk MA, Wong AWWA. COVID-19 outcomes among people with intellectual and developmental disability in California: the importance of

- type of residence and skilled nursing care needs. *Disabil Health J* 2021;14:101051.
7. Anderson LL, Humphries K, McDermott S, et al. The state of the science of health and wellness for adults with intellectual and developmental disabilities. *Intellect Dev Disabil* 2013;51:385–98.
  8. Patel JA, Nielsen FBH, Badiani AA, et al. Poverty, inequality and COVID-19: the forgotten vulnerable. *Public Health* 2020;183:110–1.
  9. Clift AK, Coupland CAC, Keogh RH, Hemingway H, Hippisley-Cox J. COVID-19 mortality risk in Down Syndrome: results from a cohort study of 8 million adults. *Ann Intern Med* 2021;174:572–6.
  10. Hüls A, Costa ACS, Dierssen M, et al. Medical vulnerability of individuals with Down syndrome to severe COVID-19-data from the Trisomy 21 Research Society and the UK ISARIC4C survey. *EClinical Med* 2021;33:100769.
  11. Bell CM, Schnipper JL, Auerbach AD, et al. Association of communication between hospital-based physicians and primary care providers with patient outcomes. *J Gen Intern Med* 2009;24:381–6.
  12. Janz HL. Ableism: the undiagnosed malady afflicting medicine. *CMAJ* 2019;191:E478–E479.
  13. Center for Public Representation. COVID-19 medical rationing & facility visitation policies: complaints filed with HHS Office of Civil Rights and Resolutions. Accessed September 1, 2021. <https://www.centerforpublicrep.org/covid-19-medical-rationing/>.
  14. HHS Office for Civil Rights. Bulletin: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19). Mar 2020. Available at: <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>.
  15. Iezzoni LI, Rao SR, Ressler J, et al. Physicians' perceptions of people with disability and their health care. *Health Aff (Millwood)* 2021;40:297–306.
  16. Meadow W, Pohlman A, Frain L, et al. Power and limitations of daily prognostications of death in the medical intensive care unit. *Crit Care Med* 2011;39:474–9.
  17. Alexander R, Ravi A, Barclay H, et al. Guidance for the treatment and management of covid-19 among people with intellectual disabilities. *J Policy Pract Intellect Disabil* 2020.
  18. Meltzer DO, Ruhnke GW. Redesigning care for patients at increased hospitalization risk: the Comprehensive Care Physician model. *Health Aff (Millwood)* 2014;33:770–7.
  19. DasGupta S. Narrative humility. *Lancet* 2008;371:980–1.
  20. Centers for Disease Control and Prevention. COVID-19 Materials for people with intellectual and developmental disabilities. Accessed September 8, 2021. <https://www.cdc.gov/ncbddd/humandevelopment/COVID-19-Materials-for-People-with-IDD.html>.
  21. U.S. Department of Health and Human Services. Discrimination on the basis of disability. Accessed September 1, 2021. <https://www.hhs.gov/civil-rights/for-individuals/disability/index.html>.