

# If Not Now, Then When?

## *Taking Disability Seriously in Bioethics*

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Overall, bioethics has not progressed nearly enough in its understanding of and approach to disability. Especially through the practice of clinical ethics, the ableism that persists in bioethics can lead to health care decisions that are prone to bias, mistreatment, and a lack of consideration of viable options for thriving with disability. To promote human flourishing and social justice, solutions are needed at the individual, interpersonal, and structural levels.

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If I were listing the most dangerous people in the U.S. today,” Alice Mailhot declared in a 1994 piece in *Mouth Magazine*—the “voice of the disability nation”<sup>1</sup>—“bioethicists, AKA medical ethicists, would top my list—way above skinheads, whose beliefs they appear to share.” When Mailhot made this statement, in “Bioethics: Introduction to Theories from Hell,” debates about health care rationing and cost were at the forefront of bioethics. She asserted that bioethicists “teach medical professionals and community elites to decide who lives and who dies.”<sup>2</sup> This impression of bioethicists as dangerous is still a common theme in the disability

movement, and it has been resurgent during the Covid-19 pandemic. Yet when we present this quotation about bioethicists as dangerous to audiences of health care professionals, including clinical ethicists, there is a look of surprise. There are at least three responses: this is from the past, and we are different now; this is an angry and extremist position; and the Americans with Disabilities Act and other efforts in disability rights have solved historical inequities.

In this essay, we will take on each of these points and argue that unexamined assumptions about people with disabilities and ableism in bioethics have continued to flourish despite decades of counter-narratives, research, and divergent perspectives. In fact, bioethics and the practice of clinical ethics are inextricably linked with the unquestioned goal of medicine to prevent disability. We write this essay

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as nondisabled women trained in bioethics and, in Kristi Kirschner's case, medicine, in Debjani Mukherjee's, psychology, and, in Preya Tarsney's, law and as the founding, former, and current directors, respectively, of the Donnelley Ethics Program at the Shirley Ryan AbilityLab, formerly the Center for the Study of Disability Ethics at the Rehabilitation Institute of Chicago. The program was started twenty-seven years ago, in 1995. The program's twenty-fifth anniversary prompted us to reflect on the past and take notice of changes in clinical ethics—or the lack thereof. We draw on our collective experiences and the historical record to underscore that ableism in clinical ethics practice can lead to health care decisions that are prone to bias, mistreatment, and a lack of consideration of viable options. The shift in thinking and practice that we would expect given the proliferating scholarship on disability over the past several decades has not taken place—in bioethics or in clinical practice more generally.<sup>3</sup> As bioethics moves toward certification examinations and new generations join our ranks, this oversight needs to be rectified with solutions at the individual, interpersonal, and structural levels.

Woven throughout our discussion is the point that the lack of attention to ableism has also undermined the goals of social justice.<sup>4</sup> As clinical ethicists turn to justice and health equity concerns raised by the Covid-19 pandemic, there is a critical opportunity to shift understanding and include disability in considerations of diversity and inclusion.

### **First Objection: We Are Different Now**

**I**n the summer of 2020, as bioethicists around the country were reeling with the ramifications of Covid-19, Michael Hickson, a forty-six-year-old Black man with anoxic brain injury who was blind and had quadriplegia, died after his doctors and temporary guardian decided that

life-sustaining treatment would be withheld. A disturbing recording of the conversation between Hickson's wife and a physician surfaced and caused great alarm among many in the disability justice community. Joseph Shapiro's National Public Radio piece "One Man's COVID-19 Death Raises the Worst Fears of Many with Disabilities" describes competing narratives about what happened: "Melissa Hickson says her husband was denied potentially life-saving treatment because doctors at the hospital made a decision based on their biases that, because of his disabilities, Michael Hickson had a low quality of life. The hospital says it acted based on the man's dire medical prognosis and that it would have been pointless and cruel to give him invasive treatment."<sup>5</sup>

Reactions were similarly diverse on the bioethics listservs where this case was discussed. For some, the story was a familiar trope in a modern-day context. He was disabled. He was Black. He could not advocate for himself. Others saw questions of medical futility and focused on why Hickson had an interim guardian. Others noted the recording of the doctor's comments about Hickson's quality of life and how these comments seemed to loom large in the decision-making. The disability paradox,<sup>6</sup> a well-known phenomenon in which external observers—including doctors and ethicists—judge the quality of lives of people with disability as more negative than do people who live with the disability, was discussed.

When we were fellowship trained in clinical ethics (Kirschner in 1994, Mukherjee in 2000, and Tarsney in 2010), we were confronted both with the ubiquity of disability<sup>7</sup> and with clinical ethics' misunderstandings about the range of possible outcomes and limited curiosity. While our experiences are anecdotal, they speak to the persistence and multidisciplinary nature of the issues. We each recall discussions during our respective ethics fellowships in which assumptions

about quality of life with a disability were core to the ethical analysis. One of us (Kirschner) clearly remembers a startling moment during an ethics case discussion about whether to continue life-sustaining treatment for an infant who was going to lose all four limbs due to a disseminated bacterial infection. After a discussion about likelihood of survival with treatment, the conversation moved to a discussion of the child's likely quality of life and whether it would be more compassionate to take advantage of the "window of opportunity" to withdraw treatment. She heard one bioethicist ask, "What would you want if this was you or was your child?" which led her to question the validity of using the Golden Rule as a heuristic device in medical decision-making.<sup>8</sup> Another made a crude joke that the child would never do more than "play second base." A second one of us (Mukherjee) heard a similar joke years later about a different pediatric ethics case: the child would be more likely to "be second base than play second base."

For clinicians and others, gallows humor, which "treats serious, frightening, or painful subject matter in a light or satirical way," can be a way of responding to emotion-laden subjects,<sup>9</sup> but jokes about disability are often ill informed. As rehabilitation professionals, we know that people who have quadruple limb deficiencies or amputations may not have an easy path, but many thrive. Where is the evidence, or the curiosity, about the lived experience of people with such disabilities? Take, for example, John Kemp, a man born with congenital quadruple limb deficiency in 1949—well before the technological interventions available today such as power wheelchairs and robotic assistive devices. By the 1980s, John was one of the most prominent disability rights lawyers in the country, and he is still a leader today, actively working in the field.<sup>10</sup> He is not alone. There is a growing body of published research about the outcomes of people living with disabilities, including amputa-

tions. In 2019, researchers published a report showing health-related quality of life (HRQOL) and life satisfaction in thirty-two French patients who had required amputations due to sepsis.<sup>11</sup> All the patients had had at least two amputations, and 84 percent had had quadruple amputations. At the time of the HRQOL assessment, “they considered themselves in good health and preferred to be treated again despite disability.”<sup>12</sup> As the authors note, “before withdrawing life-sustaining therapies in such situations that one could no longer consider worth living, intensivists should remember that the appraisal of bad or good outcome based on forthcoming disability may not reflect the patient’s future satisfaction and HRQOL.”<sup>13</sup> Such data should be systematically collected and used to inform medical decisions. In the absence of data, however, disability specialists and disability peer advisors can offer first-hand experience of treatment and possible outcomes. If the same rigor of evidence were applied to disability factors and outcomes as to other medical questions, the ethics discussion about disability would be very different.

Disability stigma and discrimination are global problems, and notions of what is normal and abnormal, functional and dysfunctional, good and bad abound in many spaces, including health care.<sup>14</sup> Many in the disability movement have focused on the work of academic bioethicists such as Peter Singer<sup>15</sup> or on legislation on assisted suicide, or aid in dying;<sup>16</sup> the ideas found in these sources about lives worth saving or lives worth living likely affect clinical ethics consultation in daily practice. The lack of humility coupled with misinformation and prevailing ableism can be a lethal combination. We see these conversations continue in health care settings to this day—with rushes to judgment about futility and a lack of imagination about possibilities.

## The Past into the Present

The histories of bioethics and disability are intertwined with the history of medicine and marked by eugenic-based notions of normalcy, dehumanization, quality of life, burden to society, the need to segregate, and moral obligations to prevent disability.<sup>17</sup> Health professionals are still largely taught that one of the goals of medicine is to normalize the individual body to “species typical” functioning and appearance whenever possible.<sup>18</sup>

A history of disability is intertwined with the birth and genesis of bioethics. Many classic bioethics cas-

engage with and consider in their modern-day form. We continue to see echoes of each of these themes in bioethics discussions in classrooms, on listservs, and in clinical ethics consultations at the bedside.

*Hide away or display.* For most of history, doctors did not have much to offer when faced with some disabilities. They could make recommendations—perhaps that the child or adult with disability be institutionalized, put away in the back rooms of houses, or otherwise hidden from view.<sup>20</sup> Society offered little and expected less. Disability was the family’s “shame” and the family’s problem. The freak show in the late 1800s

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es are about disability and judgments about personhood, quality of life, and lives “worth living,” including the use of life-sustaining treatment. For example, people with brain injury (Karen Ann Quinlan, Nancy Cruzan, Robert Wendland, Michael Martin, Terry Schiavo, and Jahi McMath, to name a few prominent cases), burn injury (Dax Cowart), spinal cord injury (David Rivlin, Larry McAfee, Kenneth Bergstedt, and Tim Bowers), and developmental or genetic disability (Elizabeth Bouvia, Baby Doe, and Jerika Bolen) and those who have received growth-attenuation treatments (Ashley X) all represent cases in which notions of disability are central. Without critically understanding the complexities of disability in these cases and the counternarratives offered by disability activists,<sup>19</sup> bioethicists have an incomplete history of our field.

Briefly, there are four key historical themes that bioethicists should

was a notable exception, as disabled people’s bodily differences were commodified and subject to objectifying gazes.<sup>21</sup> Institutions for people with disabilities were bare-bones, understaffed facilities at best, and sometimes they were places of abuse and neglect. In 1965, Senator Robert Kennedy, whose sister Rosemary had mild intellectual disability and underwent a lobotomy in 1941 at the age of twenty-three, made an unannounced visit to Willowbrook State School in New York<sup>22</sup> and in a press conference likened Willowbrook to a “snake pit.”<sup>23</sup> Seven years later, Geraldo Rivera snuck into Willowbrook and took footage, exposing many of the same conditions.

Since the 1960s, there have been efforts to close large-scale institutions and build smaller, more personalized home-care settings.<sup>24</sup> With the passage of the Individual with Disabilities Education Act in 1975, children began to have the right to a

free public education appropriate for their needs. With the major relevant civil rights laws—the Rehabilitation Act’s section 504 and the Americans with Disabilities Act—and the Olmstead Supreme Court decision that supported the right to live in the least-restrictive environment (if cost neutral), the social levers were in place to support change.<sup>25</sup>

Unfortunately, the medical system has been largely stuck in the medical model,<sup>26</sup> in which disability is seen as negative, a problem of the individual and body to be prevented—cured when possible and “normalized” when not. The health professional is the agent of change, and once the issues of the body have been addressed, the health professional’s job is done. Knowledge of an expanded model with psychological, social, and environmental components that also can profoundly affect health lags in clinical practice. For example, health care professionals often accept nursing-home placement as the inevitable or only possible option for many upon discharge from acute care, unaware of the range of options in the postacute continuum of care or of the differences between acute inpatient rehabilitation programs, skilled nursing, home health, and intermediate care.<sup>27</sup>

Health disparities, poor access, segregation, and discrimination continue into the present. It will take structural change, with alignment of financial incentives between the various levels of care, to counter the bias in favor of institutionalization. Yet a wise and thoughtful choice at the point of discharge may change the patient’s options and trajectory.<sup>28</sup> There are home- and community-based service programs available, and the United States has a network of national independent living centers run by and for people with disabilities.<sup>29</sup> Accessing these programs takes knowledge, perseverance, time, and support. Even though these services are often more cost effective and many, if not most, people prefer to live in the community, institutionalization is frequently a one-way street.

Clinical ethicists who are consulted for discharge dilemmas can and should know about the range of options and advocate for the home- and community-based services that align with the patient’s preferences and values. Clinical ethicists can and should allow people with disabilities to participate in this planning and should make room for disabled voices, ensuring that they do not get drowned out by expediency or by surrogates without lived experience of disability.<sup>30</sup>

**Better breeding to extermination.** The late 1800s brought the rise of eugenics, or the pseudoscience of good breeding, to the fore. Doctors such as Harry Haiselden championed the euthanasia of disabled newborns,<sup>31</sup> and state fairs perpetuated Aryan myths of beauty and health with fittest-family contests, much as they celebrated the best cow or largest pumpkin. The United States instituted marriage prohibitions and sanctioned state sterilization laws that targeted people with particular disabilities,<sup>32</sup> drafting a eugenics roadmap that the Nazis later adopted. Doctors were willing and active participants in the Nazi’s T4 program, which led to the killing of 275,000 to 300,000 people with disabilities and the development of the gas chambers later used for mass killings in concentration camps.<sup>33</sup> Physician Josef Mengele saw people with disabilities as objects of fascination and often subjected them to brutal studies. The subsequent Nuremberg Trials resulted in worldwide condemnation of the Nazi physicians’ roles, leading to the Nuremberg Code for international human rights research standards and the United Nations Declaration of Human Rights.

Although the United States distanced itself from social Darwinism and eugenics at the end of World War II, threads of eugenics remain. The introduction of amniocentesis allowed for fetal testing for Down syndrome, and by 1976, amniocentesis was routine: you turn thirty-five; you have amnio.<sup>34</sup> When less-invasive and -risky testing became available (such

as the triple and then quadruple screen and now noninvasive prenatal screening), the recommendation for testing was made available to every pregnant person.<sup>35</sup>

Around the same time, a different kind of change—a social, not medical, change—began to occur with respect to Down syndrome. Many parents of children with Down syndrome begin to buck the recommendations of health professionals in the 1960s to place their children in institutions and instead kept them at home and advocated for better care, educational supports, and services. With this trend, a natural experiment was under way; the importance of the environment and nurturance in outcomes in determining phenotypic expression came into sharp view.<sup>36</sup> The outcomes were dramatically better than anyone had previously imagined possible. Life expectancy alone has more than doubled from twenty-five in 1983 to sixty today.<sup>37</sup> Yet despite the significant improvements in Down syndrome prognosis with better care and treatment, rates of termination following prenatal diagnoses remain high, with 67 percent of pregnancies in which fetuses are diagnosed with Down syndrome terminated.<sup>38</sup> One could wonder whether this gives credence to the expressivist argument that simply offering the test signals that Down syndrome is a condition that might be worse than death.<sup>39</sup>

Genetic, bioethics, and medical professional societies continue to grapple with how to think about genetic technologies, even as they get ever-more powerful. The last decade has brought widespread recommendations to use noninvasive prenatal testing to offer earlier and more sensitive testing for trisomies 13, 18, and 21. The gene editing technique of CRISPR has been mentioned as a method that might make it possible to cure genetic diseases such as sickle cell disease.<sup>40</sup> Preimplantation genetic diagnosis could be used to select embryos with or without particular characteristics. Each situation is complex

and requires individualized consideration. What constitutes a “severe” condition? What “goals of medicine” are being served when these technologies are employed? Who decides? Does society have an interest in regulating these technologies, and if so, when? Are such medical treatments privileged over environmental or public health approaches to disability?<sup>41</sup> Bioethicists, with and without disabilities, are involved in many of these discussions into the present,<sup>42</sup> and ethics curricula should consider divergent perspectives on these issues.

**Normalization to enhancement.** In the early twentieth century, normalization and prevention were exemplified in the polio epidemic. Polio could strike anyone—rich or poor—at any time but had a predilection for children. With the advent of anesthetics and safer surgical methods, doctors began to take an interest in experimental surgeries to see if they could normalize the body and restore walking ability. A child could spend many years in a hospital, encased in hot plaster casts, subjected to hours of physical therapy to achieve at best a few steps with braces and a cane. The “splendid deception”<sup>43</sup> of President Franklin Delano Roosevelt was a hopeful beacon for many children with polio.

Over time, concurrent with and influenced by the civil rights movements of the 1960s, many survivors of polio became social activists who threw away crutches and canes, adopted wheelchairs, refused to hide in back rooms, and demanded access to society. A focus of medicine during this time was the development of a vaccine to prevent polio, a major breakthrough. But the medical goals of focusing on function and integration were always possible in the absence of such treatment. Today, there are normalization debates about the benefits and risks of limb-lengthening procedures for short stature and surgeries for ambiguous genitalia—surgeries often performed on otherwise healthy children. And there is growth-attenuation treatment for

limiting the size of children with severe developmental disabilities.

Growth attenuation was brought to light by Daniel Gunther and Doug Diekema in 2006,<sup>44</sup> and bioethicists still vigorously argue for and against it. Is growth attenuation a medical treatment for a social problem and therefore a violation of the human right to bodily integrity, or is it a medical treatment that will improve quality of life and is thus worth the risk? Such debates about how to use the tools of medicine, for what goals or purposes, who decides, who pays for interventions, and who has access will likely become only more pressing as enhancement therapies are developed.<sup>45</sup> Bioethicists have an important role to play in considering questions involving medical research

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into and treatment of disability. The National Institutes of Health has recognized this role by continued funding to address the ethical, legal, and social implications of genetic research.

**Pride and inspiration.** Disabling war injuries acquired during World Wars I and II provoked a different response from other kinds of disabilities. Although pity was still common, shame was less so when the disability was acquired in the service of one’s country. Rehabilitation treatment, often through the veterans’ hospitals, became a greater focus in medicine, even though many people would still spend their lives in nursing homes or institutions. The field of physical medicine and rehabilitation was galvanized by the major wars of the twentieth century and the need to treat the large populations of injured soldiers. The narrative of the “super cripp”—of someone with a disability

who is defying the odds and doing extraordinary things—arose.

But disability advocates pushed back against labels like “special,” “differently abled,” and “heroic or inspiring.” People with disabilities denounced the “inspiration porn”<sup>46</sup> that puts the nondisabled gaze on the disabled and can be as objectifying as pity or shame. Others reclaimed “disabled” as an adjective, central and inseparable from their identity and a source of pride. There is no one-size-fits-all way of talking about people with disabilities; as with people in any identity group, understanding how each individual self-identifies is critical.

For nondisabled clinical ethicists, interrogating their own reactions to and relationship with disability, from

pity to inspiration and every reaction in between, is an important part of continuing professional development. Cultural images are undoubtedly at the root of ableism and many of the ableist stereotypes and implicit biases.<sup>47</sup> To combat them, we need to be self-aware, to critique them, and then to challenge and replace them with more accurate counternarratives.

### Second Objection: This Is Angry and Extremist

The second reaction to the quotation characterizing bioethicists as dangerous is that the response from disability advocates is angry and extremist. For all of us working in health care, experiencing the anger and distrust of patients has become common. For clinical ethicists, this collective anger aimed at a field that we believe is part of the solution can

be hard to hear. The three of us recall various encounters throughout the years in which we felt the tensions in the room and watched well-meaning bioethicists disengage from the tough conversations. We understand that inclination. For example, one of us (Mukherjee) distinctly remembers being called a “colonizer” on an American Society for Bioethics and Humanities panel when describing her own experiences working in a rehabilitation hospital. The confrontation made her pause; her parents were born under colonial rule in India, and she had done research in a school of women’s studies in Calcutta (now Kolkata) and was familiar with post-colonial theory. That the comment came from a White U.S. male who seemed unaware of his own privilege was particularly unsettling. The power differentials are not always clear and familiar. Such encounters did not stop us from learning and engaging, but they certainly could have.

Another one of us (Kirschner) noted early in her career as a physician how edgy and angry<sup>48</sup> some patients with disabilities initially seemed, particularly if they had congenital or long-standing chronic conditions. It put her off, but when she got beyond that immediate reaction to listen and probe, she learned that they often described feelings of being misunderstood, mistreated, ignored, and disrespected by prior doctors and the health care system at large. Some people with disabilities experience great anxiety and sometimes a reaction akin to symptoms of post-traumatic stress disorder when they must engage with the health care system. She learned that many people with disabilities distrust that they will receive competent, equitable, and unbiased care. The ableist chapters described above have undoubtedly left their residue, as has the egregious medical history of anti-Blackness and racism. She realized as a young physician many years ago that, as a member of the health profession that had perpetrated these harms, she needed to listen to these stories, engage with

this history, and earn trust by working to dismantle ableism and other isms. Part of being a member of a profession is about collective accountability.

The voices of disability advocates are not extremist. And some within and contiguous to bioethics have been in dialogue and pushing for changes for many decades. Scholars and activists such as Paul Longmore and Carol Gill have written op-eds and commentaries about prominent ethics cases and identified the frames offered by the courts, doctors, and bioethicists as ableist.<sup>49</sup> They have brought the lens of the social model, offering an alternative narrative, that disability is not just a problem of the individual or the “body” but is interactional. Adrienne Asch repeatedly and emphatically translated these views in the early bioethics community,<sup>50</sup> and she was joined by Eva Kittay, who challenged Peter Singer’s view on the permissibility of neonatal infanticide in the face of severe disability and wrote about her daughter with intellectual and developmental disabilities, Sessa.<sup>51</sup> Anita Silver has written extensively about the Americans with Disabilities Act, disability, and nondiscrimination.<sup>52</sup> And these are just some prominent examples, including the voices of bioethicists with disabilities, who are part of the mainstream.

Notably, some leaders in the field have also publicly shifted their perspectives over time. In 2004, in an essay titled “A Bioethicist Offers an Apology,” Howard Brody expressed his regrets about missing the role of social oppression and the lack of viable options to live outside the nursing home in David Rivlin’s request to be removed from the ventilator.<sup>53</sup> Rebecca Dresser has written about her resistance to accepting her oncology team’s recommendation of a feeding tube, reflecting on how prior bioethics work had cultivated her negative views about feeding tubes.<sup>54</sup> Margaret Battin wrote a reflection about her husband’s high-level spinal cord injury and resulting ventilator dependence—a condition that chal-

lenged her thoughts about her prior views on the right to die.<sup>55</sup> These colleagues offer powerful testimony to the fact that you cannot presume to know about disability without the voices of lived experience and substantive engagement with people with disabilities. We need to share more stories like these.

### **Third Objection: ADA Legislation Has Solved the Problem**

The third response to the quotation about the dangerousness of bioethicists is that the Americans with Disabilities Act has addressed access and protections. Passed in July 1990, the ADA was targeted at providing people with disabilities greater access to public services and accommodations, as well as certain protections against discrimination. At the time, the ADA was hailed as an “emancipation proclamation” for people with disabilities and a “landmark moment” of a new order due to its hard-won protections.<sup>56</sup> Indeed, as depicted in the movie *Crip Camp*,<sup>57</sup> it took an organized and tireless disability rights movement, coupled with advocacy, to outline how the previous laws were insufficient in providing people with disabilities access to public spaces and employment opportunities. One of the primary legislative missions of the ADA was to put teeth into employment protections previously outlined in the 1973 Rehabilitation Act, which were not being enforced and had not been extended to private employers. By addressing the employment issue explicitly alongside previous wrongs, the ADA, it was thought, could “assure equality of opportunity, full participation, independent living and economic self-sufficiency for such individuals.”<sup>58</sup> Although these goals were intended and lauded by those championing for rights for people with disabilities, there is much evidence to suggest that the law itself, while focused on discrimination, can-

not by its design create or mandate inclusion.

In fact, the ADA does not yield the “in” behind “inclusion” for many people living with disabilities. For starters, the law is limited, in that the focus of real redress is on the individual. To hold others accountable, individuals must bring private actions alleging discrimination or a failure to provide reasonable accommodations to evoke change. It is obviously a burden for people who may be acutely ill or in need of assistance to raise a claim. It is a burden even for those who have reasonable access to advocates, given that litigation is usually a multiyear, costly process with redress years in the making. Moreover, the ADA has been indicted for failing to provide robust remedies because, in some instances, it does not allow for monetary damages unless there is “intentional discrimination” (see title II of the ADA) or limits remedies to only “injunctive relief” (see title III).<sup>59</sup>

Although individual actions filed in court under the ADA have resulted in changes for others, these changes are still limited in scope. And though an expansion of the definition of “disability” through amendments to the ADA in 2008 sought “to shift the focus from whether the individual had a ‘qualifying disability’ to whether accommodations are reasonable,”<sup>60</sup> the amendments did not broaden the reach of the law or fortify enforcement; they merely kept legal precedent from further limiting the applicability of the ADA. Put another way, the amendments did not eradicate barriers to access or promote substantive inclusion of people with disabilities in the arenas of public life that are critical to social well-being, like housing, transportation, and education. Indeed, some scholars argue that the ADA in effect pushed some problems, such as abuse and mistreatment of people with disabilities, back into private spaces, for example, guardianship proceedings, where individuals are less able to collect and where discrimination by

others is less visible.<sup>61</sup> In fact, issues with guardianship proceedings and guardianship’s cousin, conservatorship, have recently been reborn in the public consciousness through high-profile cases like Brittany Spears’s. Although Spears’s journey may be unique, her situation raises a multitude of concerns for people with disabilities under conservatorships: the loss of the dignity of risk (which concerns honoring an individual’s choices even when they pose potential harms),<sup>62</sup> the loss of basic human rights (including the rights to counsel and to parent), and the conservator’s ability to retain control without real appeal or reexamination.<sup>63</sup> Add to this picture that many guardianship

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proceedings “proceed uncontested, with the majority of guardians appointed without the respondent present.”<sup>64</sup>

Some legislative changes in these realms are starting to emerge. For example, Illinois recently enacted legislation known as the Supported Decision-Making Agreement Act,<sup>65</sup> which enables people with intellectual and developmental disabilities to designate a supporter to assist them with everyday activities, such as those related to health care and living arrangements, while explicitly retaining decision-making authority. Such new legislation and compounding issues with guardianships and conservatorships highlight the fact that policy barriers to greater participation or agency in areas of public life still exist and loom large for people with disabilities many years after the passage of the ADA and its amendments.

Although there is no conflict between the privacy protections in the Health Insurance Portability and

Accountability Act and the ADA, the perception that HIPAA may be violated can limit generative discussions regarding reasonable accommodations. Privacy protections may be used as a shield to insulate employers or institutions from engaging in needed discussions and limit communications on how to design and then implement accommodations. The misunderstanding of this presumed conflict can reinforce the stigma that the ADA is meant to counter, rendering even uncontroversial interventions and accommodations invisible and, therefore, less well understood. It is also a lost opportunity to “re-design existing norms to allow for and encourage broader disclosure”<sup>66</sup> and

to lay groundwork for the “health, economic and social benefits” that could follow.<sup>67</sup> The stigma still faced by people with disabilities<sup>68</sup> has no boundaries, public or private, and no easy redress. Such stigma also contributes to “unabashed neglect or failure to consider people with disabilities in the design of public institutions.”<sup>69</sup> Hence, if stigma and unconscious bias are not addressed, it seems hard to advance the goals of “inclusion” and “agency” touted by the ADA. At best, there is work to be done in this realm so that people with disabilities may gain real access to life opportunities in the realms of “employment, relationships, health care and treatment,” among others.<sup>70</sup>

It is not lost on the three of us that the civil rights changes won by people with disabilities resulted not from efforts of the health professions or bioethics communities but from the hard work and tenacity of disability activists. As a field, bioethicists have not yet earned the right to

call ourselves allies in the disability civil rights movement. Indeed, the critique that bioethicists have often championed thin notions of autonomy that have overlooked the social justice movement of disability rights seems accurate. Without reasonable choices and access, how can we focus on autonomy?

### If Not Now, Then When?

About twenty-one years ago, Mark Kuczewski wrote an article for the *American Journal of Bioethics* titled “Disability: An Agenda for Bioethics”<sup>71</sup> that generated fifteen commentaries. *Theoretical Medicine and Bioethics* published a special issue on disability and bioethics in 2003,<sup>72</sup> and the *Journal of Clinical Ethics* produced a special section on disability ethics in 2004<sup>73</sup> (both of which were coedited by Kirschner). In a commentary in response to the *AJOB* target article, Dominic Sisti and Arthur Caplan argued that “[b]ioethics must take disability seriously not by developing a disability bioethics, which will merely create a subfield that remains unattached to the mainstream of bioethical thinking, but by making disability a core part of the mainstream.”<sup>74</sup> This response aspired to the integration of disability bioethics—its theoretical work, knowledge base, and practical application—into mainstream bioethics, but that has not yet happened. It is not clear why—perhaps owing to a lack of consensus, competing priorities, a lack of knowledge about how to proceed, or other reasons. But the downstream effect is that ableism, implicit biases, and harmful stereotypes have persisted in mainstream bioethics and likely in bedside clinical ethics consultation.

As the United States grapples with histories of discrimination and inequity, the time is ripe for bioethics to engage with the field’s complex relationship with disability. One of the strengths of bioethics and the health humanities is their breadth of disciplinary perspectives. But this

also means that the knowledge base is varied and clinical ethics training programs have their own emphases.

The term “ableism,” which emerged in the mid-1980s, has direct implications for the work of clinical ethicists, yet, in our experience at conferences and on listservs, the implicit ideas about health, illness, disability, and ability are simply subtexts and are not appreciated in depth. In our experience as clinical ethicists in rehabilitation settings, our consultations inevitably occur toward the end of a patient’s care continuum, and we know that the patient perspective and narrative have sometimes been missed or sidelined during the patient’s care. In some cases, the way ethics issues are framed or options are presented can reinforce discriminatory practices, creating anger and distrust. The issues related to disability are not at the fringe of bioethics; they are deeply connected to respect for persons and respect for autonomy. Missteps in these cases can have dire consequences. Add to this the fact that ethicists are often in the position of correcting power imbalances and misunderstandings. Ethicists must be open to learning from and engaging with people with disabilities.

Of course, disability is not an isolated variable, and ableism is not uniform. Every human has multiple identities and communities that become more relevant in certain contexts. Race, ethnicity, socioeconomic status, gender, sexuality, and urban or rural association (to name a few) are all interrelated aspects of how we see ourselves and others see us. Even though the Covid pandemic has shed light on health inequities among people with different characteristics, disability continues to be an afterthought. And in the spaces where clinical ethics consultations and meetings occur, ableism may have greater consequences, as people with disabilities are higher users of health care services. And the onset of disability may occur in clinical settings by the act of diagnosing.

The idea that bioethicists discriminate against people with disabilities is uncomfortable; it is easy to assume that there are merely a few discriminatory forces in bioethics but that most people in the field are unbiased. The same may be said about racism, ageism, or sexism. We do not want to argue whether the entire field is biased. The underlying truth is that every American bioethicist lives in a country that is reckoning with deep social injustices while also having great potential to change. Individual attitudes and exposure are one locus of change, but there also need to be changes at the institutional and cultural levels. Lack of attention to social justice is emerging as a dominant theme in bioethics. We believe that the time is now—that bioethics should embrace Sisti and Caplan’s call for disability to be a “core part of the mainstream.” But this will not be an easy task. It will require engagement with the many excellent disability studies scholars who have provided the counternarratives and critiques of bioethics. It will require moving from a stance of nondiscrimination to inclusion. And if bioethicists take seriously the idea “nothing about us without us,” then it will require a commitment to grapple with what community-based participatory ethics could look like.<sup>75</sup>

### Recommendations

We end with some recommendations at multiple intersecting levels that are directly related to bioethics and the training of health care ethics consultants. In our experience, with complex phenomena such as ableism, making changes at one level is not as impactful as addressing problems at various levels.

*Consultation at the bedside.* Individual health care ethics consultants (HECs) have the ability to help guide the process of resolving issues and concerns when values are in tension. HECs can identify ableism when it appears and open up space to address and combat it. This will



take awareness of ableism (a point we take up again below in our recommendations about education). HECs facilitate communication and can raise disability perspectives and cultivate disability ethics consciousness. They can also actively solicit and gather information from people with lived experiences of disability, examine and illuminate quality-of-life concepts and assumptions, and ensure that a full range of options is fairly presented and that important information is not missed. In addition, there are opportunities for ethicists to shift from being bystanders to “upstanders”<sup>76</sup> when faced with ableist frames. While “upstanding” has typically been discussed as a response to bullying, noticing, speaking up, and acting can be impactful in clinical settings. Slowing things down to add more process checks can also be beneficial.

Given that many discussions connected to consultations are confidential and involve smaller groups, they are a great opportunity to encourage providers to join in identifying and addressing ableism. Consultants need to be prepared to ask “the well-placed question” in consults—perhaps about the certainty of impairment, disease, and disability prognosis; about the role of potential bias and discrimination (“How might we think about this case differently if the person did not have a disability?”); about the medical evidence; or about the range of perspectives and the potential gaps, options, and assumptions. Understanding of disability civil rights laws, principles of universal design, and structural ableism is important.

**Education and dialogue.** Explicit and implicit bias in medical decision-making is a domain of study for the clinical ethicist. In addition to training about race, ethnicity, sexual and gender identity, and spiritual perspectives on health, HECs need training about disability. They need to have knowledge of the history of ableism in medicine, the debate about the medical versus social models of dis-

ability, and disability studies critiques of medicine and bioethics. They also need to have a holistic and conceptual understanding of disability. This can be gained through being exposed to narrative voices of lived experiences (including from the peer-visitor and independent-living-community perspectives), exploring the literature on adjustment to acquired disability, and familiarizing themselves with rehabilitation and disability services and resources. Concepts embraced in disability justice work, such as the dignity of risk, can also be explored.<sup>77</sup> Disability perspectives can be explored when teaching about clinical ethics topics such as decisional capacity<sup>78</sup> and disorders of consciousness.<sup>79</sup>

There has been significant work

## Ideally, professional representation in ASBH and in other bioethics communities, including clinical ethics training programs, would mirror society’s diversity in regard to disability.

to create competencies in relation to disability curriculum for health professions education.<sup>80</sup> We believe that many of these competencies could be adapted and augmented for the training of clinical ethicists.

The assumptions about disability could be more explicitly taught and questioned in addition to discussion about classical framings such as the right to die, futility, or respect for autonomy. This can be accomplished by devoting time in fellowship programs to these disability topics. Although disability is addressed in some measure in the Healthcare Ethics Consultant-Certified exam, administered by the American Society for Bioethics and Humanities, whether the topic receives appropriate attention in clinical ethics fellowship and training programs is not clear. This asymmetry could be remedied to make time and space for dialogue and discussions. There is also an opportunity for real-time continuing education on particular issues of central

importance to people with disabilities so that ethicists can stay abreast of information and trends.

A series of public events titled “The Art of Flourishing: Conversations on Disability,” hosted by The Hastings Center and available in online recordings,<sup>81</sup> and new journals such as the *Philosophy of Disability*<sup>82</sup> are recent examples of deep engagement with ableism and bioethics that clinical ethicists can and should be learning about. At the local level, clinical ethicists can engage in a variety of activities, such as connecting to (and inviting in) representatives from community groups or disability studies experts and including perspectives of people with disabilities on institutional ethics committees.

In turn, people with disabilities may learn about the breadth of issues and perspectives within clinical ethics. In other words, providing real space for and attention to the disability perspectives through substantive involvement would benefit both trainees and more seasoned bioethicists, as well as disabled stakeholders.

**Structural change.** While there are numerous policy and structural changes that would benefit people with disabilities and increase awareness about ableism, we have a very specific recommendation for our colleagues and the organization that now accredits HECs. We recommend thinking about intentional ways to make ASBH a more welcoming space for people who have not been part of the mainstream in bioethics. Of course, this includes many minoritized perspectives. What does diversity, equity, and inclusion work look like in bioethics? For disabled bioethicists, it requires taking the onus off of the individual to always have

to advocate for their needs and normalize universal design in the planning and implementing structures and communications. Ideally, professional representation in ASBH and in other bioethics communities, including clinical ethics training programs, would mirror society's diversity in regard to disability. Equal-status relationships are one of the most powerful ways we learn about different cultures and communities.

Bioethicists and particularly clinical ethicists can and should address the ableism that impacts our field; doing so requires a focused effort to move from being "dangerous" to being thoughtful and open. We can work toward this by understanding the history, the foundational disagreements, the counternarratives, and varying perspectives on clinical ethics as it relates to people with disabilities. In turn, people with disabilities may learn about the range of perspectives within bioethics. It is past time to take disability seriously.

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