ABLEISM AND AGEISM: INSIGHTS FROM DISABILITY STUDIES FOR AGING STUDIES

By Joel Michael Reynolds & Anna Landre

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Eds. Marlene Goldman, Thomas Cole, and Kate de Medeiros

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Feel free to send any suggestions/corrections to joel [dot] reynolds [at] georgetown [dot] edu

Abstract:

The guiding question of humanistic age-studies—*What does it mean to grow old?*—cannot be answered without reflecting on disability. This is not simply because growing old invariably means becoming impaired in various ways, but also because the discriminations and stigmas involved in ageism are often rooted in ableism. We here draw on research in philosophy of disability as well as the interdisciplinary field of disability studies to explore the relationship between ageism and ableism.

Keywords:

Social Gerontology, Gerontology, Disability Studies, Philosophy of Disability, Ageism, Ableism, Aging

The medical-industrial complex is an overwhelming thicket. It has become the reigning authority over our body-minds from before birth with prenatal testing to after death with organ donation. It shapes our understandings of health and well-being, disability and disease. It establishes sex and gender. It sets standards for normal weight and height. It diagnoses, treats, and manages the human life cycle as a series of medical events: birth, puberty, pregnancy, menopause, aging, and death, each with its own medicine.

—Eli Clare¹

The extent of one's intelligence depends on a struggle between different ideas, different chains of information, a struggle mediated by the available concepts as well as the ego's clinging to its own standpoint.

—Terresa Brennan²

Everyone, if they live long enough, will experience disability. Despite the precipitous rise of disability rights movements across the globe as well as the large, interdisciplinary field of disability studies, this simple and obvious fact is strangely underappreciated. Strange indeed, since it is not only a question of biological fact—it is also a question of desire. If you desire a long life, you desire a life that will experience impairment and disability. This is the human condition. Disability is an integral and essential part of what it means to be human.

In what follows, we argue that the guiding question of humanistic age-studies—What does it mean to grow old?—cannot be answered without reflecting on disability. This is not only because growing old invariably means becoming impaired in various ways, but also because the discriminations and stigmas involved in ageism are often rooted in and intersect with ableism (cf. Overall 2006; Weiss 2017). Drawing on work in social epistemology concerning personally "transformative experiences," we argue that age-associated ability transitions can lead to profound epistemological and ethical transformations at the level of one's lived experience and understanding of the world. Problematically, these transitions can also be easily impacted by bias and prejudice, including that which results from ageist and ableist assumptions as well as from living in an ageist and ableist social context.

We begin by contrasting the lived experience of age-associated impairments through two case studies. We then use these case studies as a launching point to discuss three fundamental misconceptions of disability and the narratives and supposed truths they generate. We demonstrate how these ableist misconceptions overlap with and support ageist assumptions by analyzing the work of prominent bioethicists and health policy experts such as Ezekiel J. Emanuel and Daniel Callahan. Lastly, we argue that work concerning aging, whether in gerontology, public health, or other fields, should more carefully engage work in disability studies and philosophy of disability, just as the latter should engage the former.

¹ Eli Clare, *Brilliant Imperfection: Grappling With Cure* (Durham: Duke University Press, 2017), 69.

² Teresa Brennan, *The Transmission of Affect*, 2004, 138.

To Rascal or Not to Rascal?³

My (JMR) maternal grandfather, Papa Jack, was a unique combination of ferocious and tender. A WWII vet who fought in the South Pacific, he prided himself on strength and courage. At the same time, he prioritized loving others, especially his family. When my brother, Jason, was born with multiple, significant physical and cognitive disabilities, Papa Jack treated him no differently than any other loving grandfather would treat their grandson. My grandfather did not seem to anticipate, however, that his own life course would lead him to experience disability as well. He learned to smoke—and smoke a lot—during the war to cover the smell of the dead as he dug ditches to bury his fellow soldiers in the Bougainville and Cebu islands. A hack turned into a habit, and, thirty years later, a part of his left lung had to be excised to keep him breathing. He quit cold turkey after that surgery. But the damage was done. Emphysema, congestive pulmonary disease, and other complications would follow. These complications became manifest when my mother found him one day at home delirious with an oxygen saturation below eighty. From that point on, he had to always use assisted oxygen, among other things. But this story is not about his lungs. It is about his attitude.

A few years into needing oxygen to live day-to-day, it became clear that walking on his own was a serious risk. We suggested that he use a wheelchair. My brother had used one his entire life, and wheelchair-use was just as normal in my family as walking around. We thought nothing of it. But Papa Jack did. Despite his acceptance when it came to valuing my brother's life, the idea of using a wheelchair was hard for him to accept owing to ableist assumptions he had about independence. He fought the idea for quite a while. As the near-falls and inability to go where he wanted took their toll, we kept pushing him: using a Rascal would make things *easier*. He finally gave in. After a remarkably short time, he quite liked his electric wheelchair. The Rascal gave him a level of freedom he hadn't had for years. He could go a mile or more from the house to go wherever he needed thanks to this device. He wasn't "wheelchair-bound," as people today still ignorantly and offensively say; he was *wheelchair-free*. But he didn't understand or experience it that way until he gave up his *assumptions* about disability and about impairments that result in non-ambulation in particular. Once he got over those ableist assumptions, his life was decidedly better. So why the initial fight to use a Rascal?

Susan Wendell explains that "something more powerful than being in a different body is at work" in the failure of able-bodied people to identify with those who are disabled and to recognize their own, inevitable and personal relationship with various states of impairment. "Suffering caused by the body, and the inability to control the body, are despised, pitied, and above all feared. This fear, experienced individually, is also deeply embedded in our culture" (248; cf. Dohmen 2016; cf. Scuro 2017). She continues, "not only the architecture, but the entire physical and social organization of life, assumes that we are either strong and healthy and able to do what the average able-bodied person can do, or that we are completely disabled, unable to participate in life." Whether physical or psychological in nature, bodily variabilities we today categorize as "disabilities" have sometimes been excluded entirely from the purview of ethics and political philosophy—

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³ "Rascal" is the brand name of a popular mobility scooter sold primarily in the USA. There are, of course, questions surrounding class and other social factors that play a role in who can get access to this type of scooter. If memory serves me correctly, Medicare (a federally funded program for those sixty-five and older) did at the time cover most of the costs for my grandfather to get this scooter.

they have even been excluded, strikingly, from the realms of inquiry that most directly deal with social and political life as such (Reynolds 2022). Part of the reason for this is that people with disabilities have historically been taken as paradigmatic examples of a lack of flourishing, as in John Stuart Mill's writing, or as only questionably possessing dignity and thus moral standing, as in Immanuel Kant's.⁴

For those not exposed to disability studies, even the mere mention of the term "disability" can draw a blank—both in the sense of nothing happening and in the sense of a misfire. For example, someone might say, "Oh, you study disability? . . . So, you help the handicapped?" The idea that thinking about disability necessarily involves "helping" and, further, involves those bureaucratically categorized as "handicapped" (which hasn't been an appropriate word for decades) is an example of drawing blanks because it evidences a failure to understand even the most basic concepts pertaining to disability (impairment, difference, stigma, debility, accessibility, medical vs. social models, etc.). But herein lies the rub. What this conceptual vacuum concerning disability does for aging people is *rob them* of some of the most essential conceptual tools necessary to understand and communicate about their experiences of aging.

But Some Things Are Just Bad

To better appreciate this point, contrast my [JMR] Papa Jack with my Papa Dave. Papa Dave was a proud man. A blue-collar construction worker, he was wiry, unemotional, and, above all else, fiercely independent. His ability to build, to do and create what he wanted when he wanted—this perceived power defined his life. As I palmed the tissue to wipe the stool from his behind after an ischemic stroke, I saw a profound look in his eyes—one that glimmered with shame, anger, and resignation. This event, six months old as we sat in the bathroom that night, rendered half of his body without conscious control. Due to a deep-seated combination of patriarchalism and ableism, he viewed this state of what we often call "disability" and "dependency" as devastation. He wanted, in many respects, to die after that stroke, especially in the initial weeks. But his family wanted to care for him.

Tellingly, years earlier, Papa Dave had a hard time accepting my brother as *my brother*, as the *son* of his youngest child, my father, Alan. For reasons I do not fully understand, the idea of disability actually seemed to scare him in a way that it did not for Papa Jack. Still, after the stroke completely paralyzed half of Papa Dave's body, it was difficult to judge where the ableism stopped and the genuine difficulties began...or where they intersected. To be sure, it wasn't simply ableist attitudes that made life after his stroke problematic—that would be a difficult ability transition for anyone. At the same time, a more capacious approach to the variety of embodied states in which people flourish would surely have improved his attitude towards his condition. Nevertheless, the differences between the experiences of Papa Dave and Papa Jack are crucial. To repeat,

⁴ John Stuart Mill and Jeremy Bentham, *Utilitarianism And Other Essays*, ed. Alan Ryan, Penguin Classics (New York: Penguin Books, 1987); Immanuel Kant, *Practical Philosophy*, trans. Mary J. Gregor, The Cambridge Edition Of The Works Of Immanuel Kant (Cambridge; New York: Cambridge University Press, 1996).

⁵ The paragraph that follows borrows from the language of Joel Michael Reynolds, "Infinite Responsibility in the Bedpan: Response Ethics, Care Ethics, and the Phenomenology of Dependency Work," *Hypatia: A Journal of Feminist Philosophy*, 31(4): 779-774, 2016, DOI:10.1111/hypa.12292.

an ischemic stroke is *profoundly difficult* to contend with regardless of one's attitudes toward and knowledge of disability. Having to use a Rascal to get around is simply not difficult in the same way. The difference between my grandfathers is, then, not simply questions of implicit or explicit ableism. It's also about the lived experience and particular quality of the impairments in question. Some impairments are difficult to deal with regardless of who or how one is. Others are less so. Papa Jack found freedom in his in his Rascal. Papa Dave simply could not use one.

To think more carefully about these differences requires engaging with disability studies and disability activism; it requires drawing upon the (thankfully ever-growing) body of research that takes these experiences seriously. But there is no amount of knowledge that will make an ischemic stroke enjoyable or the embodied experience that results from it. And, in a walkers-world, to use or not to use a Rascal will involve dealing with stigma, pride, and personal attitudes no matter who you are. This is one reason why disability studies is so essential for aging studies, for each of these issues have been explored in great detail for over fifty years by scholars working in fields spanning the humanities and social sciences.⁶

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Part of the negative press that disability gets is a product of the fact that able-bodied people—or, those who have insufficient knowledge concerning critical disability studies—assume that *becoming* impaired and resultingly disabled will be negative on the whole. Call this the problem of ability transitions. There is some truth to this assumption. If I am hit by a car tomorrow and move from being ambulatory to paraplegic, that transition will be certainly be difficult. But that doesn't mean that *being paraplegic* is in and of itself bad. If "bad" simply means that one will, *relative* to one's current state, lose autonomy, efficiency, and engagement in certain previously desirable activities, then of course it will be bad. But that is to mistake an otherwise habitable forest for particularly intimidating trees. A significant body of research shows that even with significant and difficult ability transitions—such as that from being ambulatory to paraplegic—people develop new normals. Judgements we make concerning the challenges associating with transitioning from one embodied state to another do not automatically transfer to judgments about ways of being in the world.

As L.A. Paul argues in *Transformative Experience*, there are certain experiences that we simply cannot imagine or understand (2014). This is not merely because they are far from our own lived experience; it is because they are the sort of experiences that personally *transform* a person as a knower. And, insofar as they transform one as a knower, they transform one as a subject, as a person: they transform who one is. Becoming impaired through aging—and thereby experiencing disability in the social model's sense of *societal responses to impairment*—is a transformative experience. The sort of person one will become through these experiences will be changed. In this light, the person who judges them abstractly, who judges them from their not-yet-aged-in-the-sense-of-becoming-impaired-in-various-ways position, isn't making an "informed" judgment.

⁶ To be clear, we are not claiming that the issues we have discussed so far—including othering, dealing with illness or lack of health, dealing with uncertainty or unexpected bodily transitions—are not dealt with in aging studies. Far from it. Our point is that work in disability studies is a boon to better appreciating the distinctive links between ageism and ableism as well as between aging and certain sorts of disability experiences more generally.

They may be well-intentioned, but they have no idea what the other person thinks or feels. Among other things, this means that when we talk about disability in late life, we need much more than intuition, common sense, imagination, empathy, or the like. What we need, perhaps above all else, is evidence that tracks those experiences as they are lived and a critical framework that allows us to place those experiences in the context of how a given socio-cultural context shapes people's lived experience. With the concepts of ability transition, transformative experience, and the problem of assumptions concerning aging now in hand, we have the tools to discuss and analyze three large, general misconceptions concerning disability that impact how people think about aging.

THREE MISCONCEPTIONS ABOUT DISABILITY

Disability as (Ab)Normal

Able-bodied people typically perceive disabled people as *other* (Nario-Redmond 2019). The phenomenon of othering is well-studied in the social sciences, and it is a common response that people have to those whom they perceive to be different. Of course, recognizing difference is not bad in and of itself; the problem is that othering can easily place someone else outside the realm not only of one's concerns, but of one's lived experience. Here are some familiar tropes of disabled othering: "I feel sorry they have to use the handicapped parking space—that must suck." "It's so cute to watch Deaf people sign—it must be so strange to 'talk' like that." Note that both of these examples refer to experiences that are part of the human condition (mobility limitations and variable levels of hearing are facts of human life, not science fiction scenarios), and yet that are taken in the ableist imaginary to place another *outside* the realm of one's "normal" life and way of being.

Disability as (Un)Healthy

There is an (in)famous social scientific study that has come to be known under the moniker, "the disability paradox." Widely discussed and debated in disability studies and beyond, this paradox is framed as follows: "Why do many people with serious and persistent disabilities report that they experience a good or excellent quality of life when, to most external observers, these individuals seem to live an undesirable daily existence?" (Albrecht & Devlieger 1999). The set-up of this paradox begs the question on many fronts. Why should the assumption of able-bodied people be the standard against which people with disabilities' views about their own quality of life are assessed? Why would the assumptions of able-bodied people about the quality of forms of lived experience they have not experienced count as anything more than speculation? If you've ever watched late-night TV, you know that asking people about things of which they have no knowledge can be quite entertaining, but it seems indefensible to seriously rely on their answers rather than the insights of people who have experience living with disabilities.

⁷ One might worry that my account doesn't get at first-person lived experience because I am describing the experience of others, namely, my grandfathers. It is true that I am speaking about another's experience as opposed to my own, but I don't think that automatically renders such an account useless, especially insofar as the aim is not to fully capture the qualitative specificity of the lived experiences in question but instead the general structures that appear from there. For more on this point, see (Reynolds 2016).

Questions concerning quality of life are often proxies for questions of health. Because of pervasive ableism, disability is often linked with disease and unhealthiness. Even a cursory engagement with empirical research concerning disability illustrates that this link is little more than the result of prejudice and stigma. Of course, many disabilities involve various states, conditions, or acute occurrences that can be characterized in terms of "health." But that is by no means true of all disabilities. Ignorance of this fact gets the so-called "disability paradox" off the ground. Humanistic and social scientific research even suggests that there can be "health within illness" (Carel 2007). In short, one can experience forms of homeostasis normally associated with "health" even when one is undergoing a medically specified form of "illness." Furthermore, a growing body of phenomenological research concerning the experience of illness suggests that in many ways it is distinct from any number of experiences of disability (Toombs 2004; Svenaeus 2009; Leder 2016). In short, there is no automatic link between disability and health.

Disability as (Un)Expected

Consider the practice of reporting that one's baby has been born "healthy." This idea draws not merely upon the conflation of disability with a state of unhealth, but also with the idea that impairments are *unexpected*. Yet, that idea is absurd. Whether dyslexia, short stature, anxiety, diabetes, or any number of other things, most children, if not most teenagers, will experience various impairments—some fleeting, some chronic, and some in between. The idea that one would be happy that one's child is "healthy" is understandable, but ultimately misguided. Able-bodiedness and health are *ideals* that presume their opposites are negative and refer to a lack in one's being (Campbell 2009). But that flies in the face of the reality of embodiment—on any given day, one will move through any number of states of attention and lack of focus, energy and lethargy, and the like. And over the course of even very short spans—days, months, years, or what have you—one will almost invariably experience various sorts of impairments.

While "fixed" states of impairment, like being paraplegic as opposed to ambulatory, function differently in important respects than day-to-day fluctuations, the larger point here concerns how we conceptualize the relationship between being human and disabled. One of the biggest takeaways from disability activism and disability studies is that disability, impairment, and the many more fine-grained ways of categorizing various states in the flux between the experience of the "I can" and the "I cannot" are more accurately described by the phrases: "I can access this" vs. "I cannot access this." The idea of "personal ability" that operates at the level of common sense for most people is little more than ruse—it is a wide range of accessibility and affordances that in fact make our comings and goings, doings and havings, in the world possible.

⁸ Albrecht and Devliger are ultimately *critical* of the disability paradox despite their use of it as a framing device. They write, "the sociological evidence suggests, then, that low quality of life for persons with disabilities is based on difficult-to-manage impairments, lack of knowledge and resources and disabiling environments. Theoretical efforts to understand quality of life among persons with disabilities and intervention efforts designed to enable and empower these individuals will build on both the organic base of impairments and the social model of disability" (986).

⁹ Which is not to say that there is no intrinsic link between certain forms of disability and health. Our claim is about the link between disability *simpliciter* and health.

When Should Ezekiel Emmanuel Die?

Operating with the three misconceptions we just criticized—seeing disability as abnormal, unhealthy, and unexpected—can have grave consequences not just for individuals, but also for society and how we set policy. One particularly egregious example of this fact is the October 2014 article published in *The Atlantic* by bioethicist and health-policy expert Ezekiel Emanuel, wherein he outlines multiple reasons why he hopes to die at the age of 75. His arguments will likely appear ridiculous to any gerontologist or bioethicist. But we find it worthwhile to highlight and refute such a perspective on the way to critiquing a more serious argument. This piece was, after all, deemed legitimate enough to be published in one of the world's most widely-read and prestigious cultural magazines, and it does in fact reflect entrenched ableist and ageist views held by far too many.

Emanuel's main assertion throughout the piece is that growing old is a worse fate than dying, specifically because it means developing disabilities. He argues that although death is "a loss," old age "renders many of us, if not disabled, then faltering and declining" and that we would thus "be better off if nature takes its course swiftly and promptly."¹⁰ The assertion that disability is a fate worse than death—and that older individuals should therefore be allowed to die before being allowed to become disabled is far from new, but has been refuted at length by disability bioethicists and disabled activists (Barnes 2020; Estreich 2019; Stramondo 2020). Emanuel's specific arguments concerning the ways in which aging and disability affect one's quality of life are little more than generalizations that do not accurately represent the disability experience. He indiscriminately claims that aging, due to its inevitable experience of disability, "robs us of our creativity and ability to contribute to work, society, the world" and that "we are no longer remembered as vibrant and engaged but as feeble, ineffectual, even pathetic ... stooped and sluggish, forgetful and repetitive." He also claims that "by 75, creativity, originality, and productivity are pretty much gone" and "our older years are not of high quality." These assertions are put forward despite clear evidence to the contrary for many disabled and older folks who thrive when provided the resources necessary to have their needs met (de Medeiros and Rubinstein 2014).

Throughout the article, Emanuel uses the concepts of aging and disability as if they were synonymous with the loss of intrinsic goods and a significant decrease in quality of life — but he fails to provide any evidence concerning these assertions. Such conceptual slippage is common among bioethicists who lack basic literacy in disability issues, a common problem because "disability" is a blanket term for a complex community with widely varying life experiences. But as Elizabeth Barnes (2016) and others have made clear, a significant portion of those in various disability communities (including those who are disabled through aging) have "mere-difference" disabilities, which do not result in an automatic decrease in one's overall quality of life. It is true that the actual wellbeing of some disabled people might be lower than nondisabled people, but that is largely because we live in a world designed for the able-bodied and that is in too many cases

¹⁰ All citations to this piece will refer to Ezekiel Emanual, "Why I Hope to Die at 75," The Atlantic, 2014. https://www.theatlantic.com/magazine/archive/2014/10/why-i-hope-to-die-at-75/379329/

¹¹ An example of variations of these arguments appearing in scholarly literature is found in the much-maligned Allen E. Buchanan et al., *From Chance To Choice: Genetics And Justice* (Cambridge, U.K. New York: Cambridge University Press, 2000).

actively hostile and stigmatizing towards disabled people.

Other disabled scholars and activists concur with this sentiment by asserting that their disability is in fact a positive experience that they would not give up even if they had the opportunity. Emmanuel, though, does not include any of this nuanced context. He also dangerously equates "abnormalities" (cf. Estreich 2019) in function with conditions of intense suffering. In repeatedly doing so, he opts for oversimplification in lieu of engaging in an important conversation about how to address bad-difference disabilities that are constitutively detrimental to one's quality of life, like Tay-Sachs or living in chronic pain, etc. Having now briefly criticized Ezekiel Emanuel's twinned deployment of ableism and ageism, an admittedly easy target in many respects, we will now turn to a landmark text that, despite espousing some of the same views, does so in a far more careful and sophisticated manner.

Callahan, A Just Society, and Aging

Daniel Callahan, a founder and leader in the field of bioethics until his death in 2019, suggested in his book *Setting Limits: Medical Goals in an Aging Society* that the United States set an arbitrary age standard, likely one's late 70s or early 80s, beyond which medical care would be denied (Callahan 1995, 53). Callahan's suggestion is presented in a far more nuanced, fact-based, and decidedly less ableist manner than Emanuel's otherwise similar argument. Callahan seeks to set an age limit not because he believes those living past it lack inherent value or have no quality of life, but instead because he sees an unsustainable and unequitable problem with rising U.S. healthcare costs which, he believes, must be solved in *some* way. The best option, he regretfully concludes, is to make cuts to the healthcare of older Americans, for he argues that they have already had a chance to live a full life (Callahan 1995, 53). Regardless of whether or not one agrees with this argument on the whole, it is important to point out that Callahan constructs and defends it by employing common, ableist tropes about aging.

For example, Callahan paints older people as burdensome financially, socially, and otherwise—and specifically because of their age-associated disabilities. He warns of an "economic avalanche" (Callahan 1995, 20) if older Americans continue to have their medical needs met, arguing that "government cannot be expected to bear, without restraint, the growing social and economic costs of health care for the older" (Callahan 1995, 116). But given that, for example, the U.S. government regularly spends colossal amounts of money on questionable purchases (Bloch 2019)—including, for example, a projected lifetime cost of \$1.7 trillion for the recent F-35 fighter pilot—the problem here is not an overall *lack* of resources; it is a refusal to spend more of those resources on disabled and otherwise marginalized people, a significant portion of which are also older. Asserting that spending money on the medical needs of a specific group of

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¹² See also Thomas R. Cole, *Old Man Country: My Search for Meaning Among the Elders* (Oxford: Oxford University Press, 2019), chp. 12.

¹³ Sean McFate, "The F-35 tells everything that's broken in the Pentagon," The Hill, March 11, 2021, https://thehill.com/opinion/national-security/542412-the-f-35-tells-everything-thats-broken-in-the-pentagon. Add to this the fact that "fifteen years after the F-35's first flight, the Air Force has just 250 of the jets." David Axe, "The U.S. Air Force Just Admitted The F-35 Stealth Fighter Has Failed," Forbes, Feb. 23, 2021, https://www.forbes.com/sites/davidaxe/2021/02/23/the-us-air-force-just-admitted-the-f-35-stealth-fighter-has-failed/?sh=3e2fb6941b16. One might say this argument is unfair because we are using spending statics from years far after Callahan's book.

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Americans is unreasonable specifically because they have *a lot* of medical needs reflects a distinctly ableist value judgement about the worth of disabled people of any age.

Callahan also mentions the potential for "increasing the burden of social and familial dependency" (Callahan 1995, 20). In explicitly framing the needs of disabled older people as *socially* burdensome, he implies that needing to be cared for is unreasonable and beyond the scope of acceptable dependency on others. Ideas like this, which promote a certain level of ability as the norm and anything else as outside of the realm of acceptability, are worrisome. They can also be deadly; at one point Callahan points out that in caring relationships,

"The caregiver may become—by the sacrifice demanded and extracted—as much a victim of the illness or disability as the person who is cared for....That such a combination of feelings should on occasion produce fantasies about the death of the aged person is hardly surprising. It is the perfect imaginative solution to the moral burden of caring for another, at once decisively final in the liberation it promises and utterly acceptable as a social solution" (Callahan 1995, 99-100).

This statement paints older disabled people as "victims" of their disabilities, even though as discussed above, disability is not automatically a value-negative experience. Second, it centers the hardship of the caregiver at the expense of the humanity of the cared-for, and the similarly difficult feelings that disabled people face in care relationships. Finally, and most importantly, rather than interrogating the obvious structural problems inherent in the burden trope—that both parties lack access to proper financial resources to pay for personal care services—Callahan uses this dynamic as fuel for his argument that older people should be refused medical care to accelerate their deaths (Callahan 1995, 99-100). The ableist "burden" trope is again used to devalue the existence of older individuals.

Callahan also believes in limiting medical treatment for older individuals because medical interventions at more advanced ages may save the individual's life, but at the supposed "cost" of creating a life that involves disability. He laments that "the success of acute-care medicine ... has generated a sharp increase in chronic illness. Lives are saved, but lives that will be sick until death finally wins out" (Callahan 1995, 20). He sees an older and disabled existence as lesser in quality, and therefore not worth the same financial value as performing the same medical intervention on a younger person who is likelier to fully recover and also to live longer.

In step with some of Ezekiel Emanuel's statements criticized earlier, Callahan falls into the trap of equating disability with inherent or necessary sickness, suffering, and low quality of life. Callahan also falls into ableist trappings when he argues that setting an age limit for medical care is acceptable; he argues that the goal of medicine should not be "the prolongation of life" (1995, 61), but sustaining "health" (1995, 62), and then defines health as being "a natural standard or norm," by which he means *being nondisabled* (Callahan 1995, 62, 65). Anything beyond this is, he asserts, is "a threat to human wholeness" (Callahan 1995, 77). Implicit in his writing here is the derogatory idea that disabled individuals, older or otherwise, are not "whole" individuals, but are instead subhuman in some way.

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Yet, one can find similarly troubling sorts of statistics and examples when his book was written—US defense spending has not substantively changed in character between the time of Callahan's claims and ours.

Finally, Callahan employs ableism in his creation of a tentative hierarchy of what types of people should receive certain levels of care when they arrive at his to-be-determined age limit. Essentially, he argues that it is morally acceptable to offer less care to those who are more disabled so that they die more quickly and avoid using up financial resources (Callahan 1995, 181-184). In this discussion, he seems to use the concept of disability as interchangeable with "low quality of life" (Callahan 1996, 193) and thereby low "potentiality for personhood" (Callahan 1995, 193), a conceptual sleight-of-hand. Callahan frames withholding medical care from this group as alleviating their suffering, but as this chapter has repeatedly mentioned, more disability does not necessarily equal more suffering (Reynolds 2022). And judging what level of suffering is or is not preferable to death is, in many respects, a subjective and deeply personal decision. It is also worrisome that, at this point, financial cost of care does not seem to be what Callahan is ultimately objecting to; he even says that in the case of pneumonia, "the fact that the antibiotics are inexpensive and simple to provide is irrelevant" (Callahan 1995, 193). Tellingly, he judges that it would be immoral to deny individuals with a higher "physical and mental status" (Callahan 1995, 181)—read: less or nondisabled—access to the same interventions (Callahan 1995, 181-183).

In painting disability and aging as inherently and profoundly limiting to one's autonomy and possibility, in treating disability as abnormal, unhealthy, and unexpected, Emanuel and Callahan reinforce harmful societal stereotypes about both what it means to be older and also what it means to be disabled, not to mention their conjunction. Like other bioethical/public health policy arguments in favor of prematurely ending the lives of people with disabilities, this feeds into a self-fulfilling prophecy that contributes to discrimination and oppression and creates a world profoundly hostile to disabled people (Garland-Thomson 2015). As disability bioethicists have repeatedly established (Wieseler 2015; Scuro 2017; Estreich 2019; Barnes 2020; Stramondo 2020), neither being older, nor being disabled is in and of itself evidence of suffering; nor should either, we contend, warrant death at some set age or age range.

Tellingly, both Callahan and Emanuel begin their pieces by writing that they cannot say for sure if they will follow their own policy advice and refuse all medical treatment as they age. It is as if they both are aware that lived experience might prove their theoretical arguments fallow. Callahan, at the age of 79, accepted \$80,000 of medical interventions for a heart complication (Baker 2009). Emanuel is currently 63, so we'll see what he says and how he acts as he approaches 75. Callahan could do this in part because of his social position. But for scores of disabled and older people who lack the power and resources of a highly influential bioethicist like Emanuel or Callahan, ideas like those espoused in these texts can be deadly. Given the dangers of medical rationing (Guidry-Grimes, et al. 2020) and the growing availability of physician-assisted suicide (National Council on Disability 2019) for older individuals, these proposals can come to harm, not help those who do not fit within mainstream ideals of normalcy, productivity, or functioning. That is to say, despite Emanuel and Callahan both giving personal caveats in their pieces—e.g., "I retain the right to change my mind and offer a vigorous and reasoned defense of living as long as possible" (Emanuel 2014)—their writings have already done damage in reinforcing the devaluation of older individuals. Emanuel and Callahan's reliance on ableist and ageist stereotypes, as well as their curious confidence in their own personal preferences, reinforce harmful misconceptions and set the stage for dangerous arguments denying care and resources to those who are older and/or disabled in various ways. As our analysis has shown, these arguments should be taken as an example of how the

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intertwining of ageism and ableism can result in problematic, if not dangerous, ways of thinking. By instead appreciating disability as expected, normal, and as having a complex relationship with health, such ageism and ableism can be better combatted.

This discussion is especially urgent given the fact that Ezekiel Emanuel has just been named to President Joe Biden's COVID-19 Advisory Board. During the pandemic, ableism and ageism have reared their ugly heads in multiple ways. In the U.S., the start of the pandemic was marked by politicians, celebrities, and laypeople alike explicitly calling for "sacrificing" older and disabled people for the sake of "the economy" (Hennessy-Fiske 2020; Jones 2020; Kukla 2020; Ne'eman 2020). Disabled Americans faced medical rationing policies that would have denied us treatment in favor of our nondisabled peers, and even once these discriminatory rules were struck down in many states, ableist rationing still happened (Landre and Parodi 2020). Countries like Brazil included "the ability to perform self-care activities," a thinly veiled proxy for disability, and age as standards to be considered in situations of medical rationing (Madeiro 2020). And once vaccines became available, while older people were generally prioritized, younger people with disabilities were often left behind, despite significant activism from the disability community (Johns Hopkins University 2021; Pulrang 2021; Vargas 2021). It should be clearer than ever today that the effects of ageism and ableism, especially in combination, continue to be widespread and deadly.

It is telling that, historically, descriptions of the human condition more commonly turn to concepts like freedom, purposivity, and possibility than interdependency, vulnerability, and the existential and practical transitions that in fact make up human life. Moreover, as illness in particular makes abundantly clear, what we perceive to be our "abilities" on any given day are not and can never be our "possessions." Abilities are at all times and in all places a product and function of relations with our environment. This is not merely to say that the meaning of ability and disability is complex conceptually. It is also complex at the level of practice and lived experience. The human condition is a *journey* that requires each of us to examine the meaning of ability and disability. As the differences between the stories of Papa Jack and Papa Dave evidence, the meaning of ability/disability is not fixed. It is, in the end, a project that one must take up. The sooner one takes it up and the sooner one does so with a careful appreciation of the significant labor—theoretical, practical, and otherwise—carried out by disability activists and disability studies scholars, the better equipped one will be to combat ableism and ageism, and, thereby, the better equipped one will be to live and live well, whatever one's age.

Works Cited

- Baker, Beth. 10 December 2009. "Renowned Ethicist Says To 'Set Limits' On Health Care." NPR. https://www.npr.org/templates/story/story.php?storyId=121283688
- Barnes, Elizabeth. 2014. "Valuing Disability, Causing Disability." Ethics, 125(1), 88-113. doi:10.1086/677021
- Barnes, Elizabeth. 2020. "Disability, Health, and Normal Function." In I. Cohen, C. Shachar, A. Silvers, & M. Stein (Eds.), Disability, Health, Law, and Bioethics (pp. 5-19). Cambridge: Cambridge University Press. doi:10.1017/9781108622851.004
- Bloch, Emily. 6 June 2019. "5 of the Most Ridiculous Things the United States Military Has Spent Money On." *Teen Vogue*. https://www.teenvogue.com/story/most-ridiculous-things-united-states-military-spent-money-on
- Callahan, Daniel. 1995. *Setting Limits: Medical Goals in an Aging Society*. Georgetown University Press. ISBN: 0878405720
- Clare, Eli. Brilliant Imperfection: Grappling With Cure. Durham: Duke University Press, 2017.
- Cole, Thomas R. Old Man Country: My Search for Meaning Among the Elders. Oxford: Oxford University Press, 2019.
- de Medeiros, Kate and Robert L. Rubinstein. 2014. ""Successful Aging," Gerontological Theory and Neoliberalism: A Qualitative Critique." *The Gerontologist*, 2015, Vol. 55, No. 1, 34–42. doi:10.1093/geront/gnu080
 - Emanuel, Ezekiel. 2014. "Why I Hope to Die at 75." *The Atlantic*. https://www.theatlantic.com/magazine/archive/2014/10/why-i-hope-to-die-at-75/379329/
- Dohmen, Josh. "Disability as Abject: Kristeva, Disability, and Resistance." *Hypatia* 31, no. 4 (2016): 762–78. doi:10.1111/hypa.12266.
- Estreich, George. 2019. "The Germline." In Fables and Futures: Biotechnology, Disability, snd the Stories We Tell Ourselves." *The MIT Press*. https://doi.org/10.7551/mitpress/11469.001.0001
- Guidry-Grimes, Laura, Savin, Katie, Stramondo, Joseph A., Reynolds, Joel Michael, Tsaplina, Marina, Burke, Teresa Blankmeyer, Ballantyne, Angela, Kittay, Eva Feder, Stahl, Devan, Scully, Jackie Leach, Garland-Thomson, Rosemarie, Tarzian, Anita, Dorfman, Doron, and Fins, Joseph J., "Disability Rights as a Necessary Framework for Crisis Standards of Care and the Future of Health Care," Hastings Center Report 50, no. 3 (2020): 28–32. DOI: 10.1002/hast.1128
- Hennessy-Fiske, Molly. "Sacrifice the old to help the economy? Texas official's remark prompts backlash." *Los Angeles Times*. https://www.latimes.com/world-nation/story/2020-03-24/coronavirus-texas-dan-patrick
- Johns Hopkins University. 2021. "COVID-19 Vaccine Prioritization Dashboard."

- https://disabilityhealth.jhu.edu/vaccine/
- Jones, Sarah. 8 July 2020. "No One Should Be Surprised That America Abandoned the Older to Die." *New York Magazine*. https://nymag.com/intelligencer/2020/07/america-is-sacrificing-the-older-to-coronavirus.html
- Kant, Immanuel. Practical Philosophy. Translated by Mary J. Gregor. The Cambridge Edition Of The Works Of Immanuel Kant. Cambridge; New York: Cambridge University Press, 1996.
- Kukla, Elliot. 19 March 2020. "My Life is More 'Disposable' During this Pandemic." *The New York Times*. https://www.nytimes.com/2020/03/19/opinion/coronavirus-disabled-health-care.html
- Landre, Anna and Germán Parodi. "ICU Beds At Capacity Cannot Equal More Discrimination Against People With Disabilities Plus Advocacy Resources to Help." *The Partnership for Inclusive Disaster Strategies*. https://disasterstrategies.org/icu-beds-at-capacity/?fbclid=IwAR3kSMTTJpbb3VutXZqNZRYmPkFCznfrCtwwf1Y7OM8b95GD7jLCA8WoRgI
- Madeiro, Carlos. 5 May 2020. "Chances, sobrevida e capacidade: como se escolhem pacientes na fila de UTI." *Universo Online (UOL)*. https://noticias.uol.com.br/saude/ultimas-noticias/redacao/2020/05/05/chances-sobrevida-e-idade-como-e-a-escolha-de-pacientes-na-fila-de-uti.htm?cmpid=copiaecola
- Mill, John Stuart, and Jeremy Bentham. Utilitarianism and Other Essays. Edited by Alan Ryan. Penguin Classics. New York: Penguin Books, 1987.
- National Council on Disability. 2019. "The Danger of Assisted Suicide Laws: Part of the Bioethics and Disability Series."

 https://ncd.gov/sites/default/files/NCD Assisted Suicide Report 508.pdf
- Ne'eman, Ari. 23 March 2021. "I Will Not Apologize for My Needs." *The New York Times*. https://www.nytimes.com/2020/03/23/opinion/coronavirus-ventilators-triage-disability.html
- Overall, Christine. "Old Age and Ageism, Impairment and Ableism: Exploring the Conceptual and Material Connections." NWSA Journal 18, no. 1 (2006): 126-137. muse.jhu.edu/article/195224.
- Pulrang, Andrew. 31 January 2021. "Disabled People Are Waiting, Anxiously, For Lifesaving Covid-19 Vaccinations." *Forbes*. https://www.forbes.com/sites/andrewpulrang/2021/01/31/disabled-people-are-waiting-anxiously-for-lifesaving-covid-19-vaccinations/?sh=1d63c13949b7
- Reynolds, Joel Michael. The Life Worth Living: Disability, Pain, and Morality. Minneapolis: The University of Minnesota Press, 2020.

- Scuro, Jennifer. Addressing Ableism: Philosophical Questions via Disability Studies. Washington, DC: Lexington, 2017.
- Stramondo, Joseph A. 2020. "Disability and the Damaging Master Narrative of an Open Future," in "For *All of Us*? On the Weight of Genomic Knowledge," ed. J. M. Reynolds and E. Parens, special report, Hastings Center Report 50, no. 3: S30-S36. DOI: 10.1002/hast.1153
- Vargas, Theresa. 13 February 2021. "They thought they'd be near the front of the line for the vaccine. Now, they don't know where they stand." *The Washington Post*.

 https://www.washingtonpost.com/local/they-thought-theyd-be-near-the-front-of-the-line-for-the-vaccine-now-they-dont-know-where-they-stand/2021/02/12/31f33b46-6d9f-11eb-9f80-3d7646ce1bc0 story.html
- Weiss, Gail. "The 'Normal Abnormalities' of Disability and Aging: Merleau-Ponty and Beauvoir" Feminist Phenomenology Futures. Eds. Helen Fielding and Dorothea Olkowski (Indiana University Press, 2017, 203-217).