
The Extended Body: *On Aging, Disability, and Well-being*

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The function of a social structure is to set up institutions to serve needs. A society that drives its members to desperate solutions is a non-viable society, a society to be replaced.

—Frantz Fanon¹

Insofar as many older adults fit some definition of disability, disability studies and gerontology would seem to have common interests and goals. However, there has been little discussion between these fields.² The aim of this paper is to open up the insights of disability studies as well as philosophy of disability to discussions in gerontology. In doing so, I hope to contribute to thinking about the good life in late life by more critically reflecting upon the meaning of the body, ability, and the variability of each. My central argument is that we should conceptualize age-associated bodily variations and abilities not in terms of individual capacity, but in terms of what I call “the extended body.” It is in light of the meaning of embodiment and ability in general that we must think differently and more capaciously about the meaning of late life in particular.

Frail or Failed—Framing Social Gerontology

If philosophy or religion is one’s guide, then the good life is hard to achieve. The good life in late life appears harder still. However one conceives of it, at no age is the good life merely a question of individual will or ability—it is possible only thanks to social contexts and environ-

ments that support it. In light of this insight, scholars in social gerontology have called concepts such as “successful aging” and “frailty” into question, noting their overly individualistic framing and stigmatizing effects.³ This *deficit model* of aging is especially potent in discourses surrounding Alzheimer’s and other forms of dementia and concerning the “fourth age,” in which substantial age-associated impairments begin to occur. Critics argue that the deficit model exacerbates already prevalent ageism in individualistic cultural milieus such as in the United States and that it mischaracterizes the variety and complexity of lived experiences pertaining to late life.

Such criticisms sound similar in multiple respects to those found in disability studies and philosophy of disability. Scholars have long argued that philosophers and political theorists mistake and misunderstand the nature of our bodies and the range of flourishing humans experience. This misunderstanding, critics argue, is rooted in ableism (that is, the privileging of the “normal” able body), a profound lack of knowledge about the lived experiences of disability, and the ableist conflation of disability with pain, suffering, and disadvantage.⁴ Are these misunderstandings at the root of deficit models of aging as well? With this question in mind, I turn to a brief history of disability studies and disability theory.

A Brief History of Disability Theory

Disability studies is a multidisciplinary and interdisciplinary field that examines human experience through the lens of disability. The field involves researchers using the tools of empirical, data-driven science as well as those of reflective, critical inquiry. Since its origins in the early 1980s, disability studies has extended into numerous fields spanning the humanities and social

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sciences. According to most accounts, disability studies began by following the insights of disability activists in the United Kingdom and United States and by arguing against the *medical model* of disability. On the medical model, “disability” indicates a personal misfortune or tragedy due to genetic abnormality or environmental accident: disability is something bad that happens to an individual. Contrast this with the *social model*, which relies on a core distinction between disability and impairment. “Impairment” refers to an atypicality or abnormality of one’s body or bodily state, whereas “disability” refers to the negative effects caused by social and political responses to impairment.

The textbook example of this distinction concerns wheelchair use: one might be impaired with respect to ambulation, but it is a world intentionally designed without curb cuts, ramps, or elevators and filled with gawkers and people continually asking, “What’s wrong with you?” that makes one disabled. The social model of disability profoundly affected local and global understandings of disability, informing arguments that led to the passage of the Americans with Disabilities Act of 1990 as well as those of the United Nation’s 2006 Convention on the Rights of Persons with Disabilities.

However, multiple scholars have come forth in the last two to three decades to criticize its limitations, offering what I’ll here group as *critical models* of disability. Philosopher Susan Wendell and sociologist Tom Shakespeare contend that the social model fails to take into consideration forms of disability concomitant with pain or significant illness, for disability is not solely a question of social conditions and responses to impairment. It is a “complex predicament.”⁵ For example, no amount of curb cuts will substantively benefit one with epilepsy or neuropathic pain; in cases such as those, the medical model is in many respects apt, necessary, and beneficial.

Philosopher Eva Kittay argues that, especially with respect to forms of disability that require intensive care, the social model poorly conceptualizes nested conditions of interdependence and the labor surrounding caregiving.⁶ Upon giving experiences of disability their philosophic due, Kittay suggests that they should lead us to reconfigure the very foundation of dominant social and political theories, placing care alongside traditional core values such as liberty, equality, and justice. Cultural critic Lennard J. Davis asserts that disability as an identity is fundamentally unstable in ways that upset understandings of both impairment and disability on the social model. Whether one looks to technological advances or shifts in medical knowledge and practice, everything from polio to moderate visual impairment to attention deficit hyperactivity disorder have either nearly disappeared or grown as forms of disability. Recognition of this fact, Davis holds, demands a “new ethics of the body,” one far more attuned to its profound

variability and critical of the social and political power wielded by the concept of normality.⁷ Bioethicist and literary scholar Rosemarie Garland-Thomson argues that it is not the figure of the human primate, but that of the “normate” against which we judge bodily difference and by which we ascribe worth to a life.⁸ Across her body of work, she demonstrates how it is more the presence or absence of supportive environments and less the intrinsic value of certain abilities or “normal” ways of being that makes people fit or instead *misfits*.⁹

Philosophers Fiona Kumari Campbell and Shelly Tremain maintain that once one takes into account the history of modern medicine, jurisprudence, and the rise of public health governance, the meaning of impairment is as shot through with social and political history as is the meaning of disability.¹⁰ Uncritically conceptualizing impairment as a fact about bodies misses the historical forest for the political trees. Finally, bioethicist Erik Parens, building on years of work at the intersection of bioethics and disability studies, suggests that a sagacious engagement with disability studies requires one to don a “binocular” view of human well-being, one that critically fuses medical and social models together in context.¹¹ Echoing concerns animating scholars such as Wendell and Shakespeare, a binocular approach to the meaning of disability attempts to take into greater account the multiplicity of disability experiences across a given lifetime and across social, cultural, and historical contexts.

Although the thinkers I have discussed use the term “ableism” with varying frequency, each demonstrates the ways in which ableism is foundational to understanding what it means to be disabled. Whether one employs medical, social, or critical models of disability, the fact that the world is, on the whole, structured for the “normal” able body is an undeniable fact. And the able body, according to the curious logic of common-sense ableism, is a body that does not experience substantive ability transitions. Being able-bodied is further taken to mean that one is able to do something of one’s own accord. This logic ignores the fact that no one can do anything without an environment that supports one’s purposive action as well as the general conditions of purposivity itself, namely, one’s body. Actions and abilities require affording environments, both social and natural.

Ageism and Ableism

For those who have not reflected on the pervasive role that ableism plays in human life, the experience of becoming disabled through aging is especially revelatory. Every institution, every community, and every practice operate by virtue of assumptions and expectations concerning the abilities of their participants. When one becomes com-

Aging “successfully” is not a question of one’s individual will or effort. It is a question of such will or effort in intricate concert with a vast range of social, political, economic, legal, and other factors.

paratively less abled due to aging, one’s world transforms. For many, this might mean an acquired inability to work, to engage in certain types of valued activities, or to think and be in the same manner. Ableism, the privileging of the “normal” able body, is at work with respect to any and every stage of human life because anything and everything can be cast under the light of normality, the light of ever-twined assumptions about how bodies are and should be. Just as one cannot conceptualize aging without ability, one cannot conceptualize ageism without ableism.

Despite the fact that ableism is at the core of ageism, it has not been a central concern for many gerontologists, a problem exacerbated by individualistic theories of aging. In their 1998 book *Successful Aging*, John Rowe and Robert Kahn laid out arguments that would heavily influence gerontology for years to come. On their account, successful aging involves three components: overall well-being, low probability of disease and disability, and high cognitive and physical capacity and active engagement with life.¹² Note, first of all, that the ableist conflation is at work here: disability is conflated with pain, suffering, disease, and illness, despite the fact that they are fundamentally different phenomena.¹³ This is further aggravated by the fact that Rowe and Kahn appear ignorant of the social model’s crucial distinction between disability and impairment. Secondly, and unsurprisingly from a disability studies perspective, critics argue that the successful aging paradigm renders those who don’t or can’t meet its requirements as failed: “frailty and decline” are in many ways a euphemism for “failure and divide.”¹⁴ This issue is leveraged by what I take to be the paradigm’s primary, if not fatal, error: its overly individualistic understanding of the body and well-being. As I will argue below, such an understanding of the body and of ability fundamentally misunderstands the nature of each as well as the role that ableism plays in shaping human experience.

At this point, one might retort, how else than with “frailty” and “decline” should one describe and conceptualize a period of life that does, in point of fact, involve comparative impairment, loss, illness, and often various forms of pain? And especially if one is referring specifically to Alzheimer’s or similarly degenerative conditions? In light of the vast body of work in disability studies surveyed above, there are many ways to describe, conceptualize, and

experience such ability transitions and their resulting ability states. Let me offer one such way.

The Extended Body

Recall that debates over the meaning of disability ultimately turn on disagreements over the nature of the relationship between bodies and their social and natural environments. Each model emphasizes different nodes of this relationship, whether it be individual biology, social institutions, historical conditions, or political power. I will here suggest that a helpful way to understand this relationship is in terms of the extended body.

“The extended body” refers to the ways in which one’s body always extends into its environment, just as its environment extends into it. For example, my ability to run a five-kilometer race depends on a host of natural and social conditions, from proper running gear to navigable paths to a nontoxic environment. It also depends on the conditions of my upbringing and labor: what I was or was not exposed to as a child and the types of demands my economic situation places on my lungs and immune system. It of course also involves my particular body: circulation; central nervous system functioning; joint, ligament, and muscular strength and flexibility; the presence, absence, or particular formation of lower limbs; and so forth. But the point is that my body is just one component, and my ability to run extends far beyond it.

Even if I lacked lower limbs, I might run a 5k using prosthetics. Given current technologies, I might even be faster than someone with “organic” legs. But whether I have access to such technologies—a social, political, and historical question—becomes a condition of my body, just as my body is a condition of the need or relevance of such access. And whether there is air pollution in my immediate environment also becomes a condition of my body, just as my body is a condition of my comparative ability to manage poor air quality, allergies, and the like. To drive this point home, note that my environment and my body are also conditioned by what we could call my *social body*—my class, race, place, gender, sexuality, ethnic history, and so on, and the power and networks they afford. My social body will shape my ability to mobilize larger social and political forces to meaningfully alter things like air quality

or technological innovation, things that individual actors cannot change all on their own. My social body will also determine whether I get harassed while running, whether I get the police called on me or can call on them for help, and whether I am taken as a threat or spectator's object. In short, abilities neither end nor begin at the skin, but instead supervene on and extend to the world in which one lives and on which one ever depends. On the extended body view, abilities emerge through context-dependent relationships between an organism and its environment.

The Extended Mind and Body

To better understand the concept of the extended body, let us compare it to the famous philosophical argument for the "extended mind" introduced by Andy Clark and David Chalmers in 1995, an argument that uses an example of age-related disability to make its central point.¹⁵ They contend that we should consider the many tools humans use to expand our memory and problem-solving, from writing in notebooks to the innumerable abilities of computers, as extensions of our individual minds. Take their central thought experiment, which centers on just two characters: Inga and Otto. Inga wants to go to the Museum of Modern Art to see an exhibit. She recalls where MoMA is located and heads there. Otto, by contrast, has poor memory due to Alzheimer's disease and uses a notebook to remember things. Otto also wants to go to MoMA, so he refers to his notebook to determine where to go.¹⁶ Is there a philosophically important difference between these two cases? Clark and Chalmers argue no: "There is nothing sacred about skull and skin. What makes some information count as a belief [in one's memory] is the role it plays, and there is no reason why the relevant role can be played only from inside the body." But what if one takes their arguments about belief and the mind and extends them to the body? If memory is in neither the skull nor skin, what about human abilities more generally?

In modern industrial societies, we live in highly modified and constructed environments. Water and sewer sanitation. Roads and public transportation. Investment vehicles and trust funds, including Old-Age, Survivors, and Disability Insurance, also known as Social Security. Such structures exist to facilitate and, ideally, enrich life. Just as I argued above that the ability to run includes everything from the regulation of air pollution to one's social position and body, so we should consider these structures, systems, and modified environments as part of our ability to exist. Without these extensions of the body, many, if not most, bodies end up *dis*-abled, in the sense of having an impairment, and in multiple ways. Take Inga and Otto again, but let us expand the extended-mind thought experiment to

incorporate this argument. Call this "the extended body thought experiment."

It is not just the neurotypicality of Inga's brain that allows her to remember MoMA's location. It is also because Inga, as a white, cisgender, heterosexual, able-bodied, thirty-something, upper-middle-class individual, has benefited from her social position in multiple ways. For example, her stress levels have not affected her memory. To be clear, numerous factors affect cognitive functioning. While there are many types of life events that could have rebalanced the effects of her social privilege on her cognitive functioning (trauma, domestic violence and other abuse, death of a loved one, and so on), Inga has, so far, been lucky enough to avoid these.¹⁷ Her specific social positioning currently affords her access to healthy food, regular exercise, and multiple social supports; some mitigation of sexism; and buffering from the profoundly damaging effects of systemic racism, colonialism, cissexism, heterosexism, ableism, and classism.

In the extended-body thought experiment, it is clear that Inga's body extends to all of the things that afford her extended memory in the first place. And it extends to the many more things afforded her given the type of body she has in her specific historical and sociopolitical context. In a phrase, abilities are relational.¹⁸ Inga's memory is not simply a matter of whether certain structures exist in her environment, but of *how* her identity, individual history, ancestral history, and the social capital leveraged by each interact with her environment. Just as her memory is not limited to her biological brain, neither are her abilities limited to her biological body. The human body, brain, and mind are extended. And this is a constitutive, not incidental fact: extension makes them what they are.

With respect to Otto, it is not just the neurodiversity of his brain that allows him to remember MoMA's location. It also because Otto adapted to memory impairment through medical resources provided by Medicaid as well as practical and emotional assistance from family members. Otto, as a Latino, bisexual, disabled, eighty-something, low-income individual, already had to learn many coping mechanisms to deal with the multiple structural oppressions presented by his social position before acquiring Alzheimer's.¹⁹ It is also the case that while Otto did not need a caregiver to go to MOMA today, he soon will. Otto's body extends to all of the paid caregiving labor from public funds and unpaid familial labor that, in part, afford him the ability to reliably use his notebook for memory, sometimes travel alone, and manage his life activities.

As this recasting of Inga and Otto makes clear, the extensions of the mind cannot be understood without the extensions of the body, and vice versa. Theorizing the good life in late life is a practice in thinking about the variability of the body, including the thoroughgoing extension of the

body into one's environment. On the extended body view, the ability to age "successfully" is not a question of one's individual will or effort—to think so would be to misunderstand the nature of ability. It is a question of such will or effort in intricate concert with a vast range of social, political, economic, legal, and other such factors. On the extended body view, losing one's memory, being unable to care for oneself, or having troubles with emotional regulation are not simply and solely negative for an individual—to think so would be to misunderstand the nature of ability and the transitions in ability that all organic life undergoes. Such events mark transitions in the foci, expression, supports, and projections of one's extended body. If one lives in a just, caring society and in the presence of caring providers, family members, and friends, the meaning and lived experience of these transitions will more reliably tend toward the positive.

Ability Transitions and the Good Life

If the thesis of the extended body is right, then the good life in late life is one conditioned by personal, social, and environmental flexibility to ongoing ability transitions. Instead of ableist paradigms of success or harrowing narratives of decline, the best way to conceptualize age-associated ability transitions in particular is in terms of a shift in one's extended body more generally. As the example of Inga and Otto makes clear, this includes the flexibility of everything around one: from caregiving to medical care to accessible housing and transportation to a supportive cultural milieu.²⁰ There are indeed a host of obstacles to overcome: fear of the body, interdependency, and ability transitions in general; inflexibility of the built environment (massive shortages of homes built for care, accessible public spaces, meaningful public representation, and so on); and inflexibility or sheer absence of structural social supports (health care systems, living wages, retirement plans). If for no other reason than the increased need for care and support that fall outside of ableist assumptions, aging can bring one into closer contact with the many psychosocial inaccessibilities and oppressions that structure our society today, from ageism to ableism, racism to classism, to sexism, cissexism, and heterosexism.

Consider a study in the United Kingdom that followed thirty-four people over seventy years of age, each of whom had health issues that required varying levels of support and care. The aim of the project was "to identify factors perceived to promote or undermine a sense of dignity in older people in need of support and care," and the analysis found that "[t]he prospect of being helped with personal care and of strangers seeing their naked bodies was unimaginable for some . . . [while] others described how they would accept

help in particular circumstances for 'a proper reason[.]' . . . highlighting the moral nature of such decisions."²¹

Note that the expressed concerns about aging here are tied not simply to engagement in valued activities but also to fear about interdependency. Yet it is not a fact of human nature that people are afraid to be touched by others or to be seen naked by strangers. For people such as myself, who have lived in families with people who require care, that fear appears as a pernicious effect of ableism and ageism. Our body is always and forever in contact with and supported by an infinity of things—our bodies are extended. It is our failure to better facilitate this contact and care in late life that is a primary hindrance to experiencing the potential goodness of this part of life. If ableism is indeed at the core of ageism, then critical reflection on each is necessary to more justly conceptualize and respond to the experiences of late life and to forge a communal future supportive of the good life in it for all.

1. F. Fanon, *Toward the African Revolution* (Harmondsworth, England: Penguin, 1970), 53. Many thanks to Andrea Pitts for pointing me to this passage.

2. In philosophical research more generally, there has been relatively little work on aging and even less on disability and aging. With respect to the latter, see G. Weiss, "The 'Normal Abnormalities' of Disability and Aging: Merleau-Ponty and Behavior," in *Feminist Phenomenology Futures*, ed. H. Fielding and D. Olkowski (Bloomington, IN: Indiana University Press, 2017). In both cases, such scholarship rarely, if ever, seriously engages gerontology.

3. R. L. Rubinstein and K. de Medeiros, "Successful Aging,' Gerontological Theory and Neoliberalism: A Qualitative Critique," *Gerontologist* 55, no. 1 (2015): 34-42; A. Grenier, L. Lloyd, and C. Phillipson, "Precarity in Late Life: Rethinking Dementia as a 'Fraild' Old Age," *Sociology of Health & Illness* 39, no. 2 (2017): 318-30.

4. J. M. Reynolds, "'I'd Rather Be Dead Than Disabled'—the Ableist Conflation and the Meanings of Disability," *Review of Communication* 17, no. 3 (2017): 149-63.

5. T. Shakespeare, "Nasty, Brutish, and Short? On the Predicament of Disability and Embodiment," in *Disability and the Good Human Life*, ed. J. E. Bickenbach, F. Felder, and B. Schmitz (New York: Cambridge University Press, 2011); S. Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disability* (New York: Routledge, 1996).

6. E. Kittay, *Love's Labor: Essays on Women, Equality, and Dependency* (New York: Routledge, 1999).

7. L. J. Davis, "The End of Identity Politics and the Beginning of Dismodernism: On Disability as an Unstable Category," in *The Disability Studies Reader*, ed. L. J. Davis, 4th ed. (New York: Routledge, 2013), 231-42.

8. R. Garland-Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (New York: Columbia University Press, 1997).

9. R. Garland-Thomson, "Misfits: A Feminist Materialist Disability Concept," *Hypatia* 26, no. 3 (2011): 591-609.

10. F. K. Campbell, "Inciting Legal Fictions: 'Disability's' Date with Ontology and the Ableist Body of Law," *Griffith Law Review* 42 (2001): 42-62; S. Tremain, ed., *Foucault and the Government of Disability*, 2nd ed. (Ann Arbor, MI: University of Michigan Press, 2015).

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11. E. Parens, *Shaping Our Selves: On Technology, Flourishing, and a Habit of Thinking* (New York: Oxford University Press, 2015).
12. J. W. Rowe and R. L. Kahn, *Successful Aging: The MacArthur Foundation Study* (New York: Pantheon Books, 1998). See Rubinstein and de Medeiros, "'Successful Aging,' Gerontological Theory and Neoliberalism," 34.
13. Reynolds, "The Ableist Conflation."
14. C. Gilleard and P. Higgs, "Aging without Agency: Theorizing the Fourth Age," *Aging & Mental Health* 14, no. 2 (2010): 121-28; Grenier, Lloyd, and Phillipson, "Precarity in Late Life"; A. J. Pifer and L. Bronte, *Our Aging Society: Paradox and Promise* (New York: W. W. Norton, 1986).
15. A. Clark and D. Chalmers, "The Extended Mind," *Analysis* 58, no. 1 (1998): 10-23. Given the aims of this paper, I focus more on memory than on beliefs embedded in memory, as do Clark and Chalmers.
16. To be clear, Clark and Chalmers do not describe Otto as going to MoMA as part of the well-known Meet Me at MoMA program for people with dementia and their caregivers.
17. I am thankful to two anonymous referees for pressing me to make this point.
18. J. J. Gibson, "The Theory of Affordances," in *Perceiving, Acting, and Knowing: Toward an Ecological Psychology*, ed. R. Shaw and J. Bransford (Hillsdale, NJ: Routledge, 1977).
19. In this thought experiment and in keeping with the obviously heuristic aim of making a strong contrast, Otto is decidedly not trans because the likelihood of survival to age sixty for trans folk and trans people of color in particular is so comparatively and appallingly low. This tragic fact itself attests to the truth and also import of the extended body. See "A Time to Act: Fatal Violence against Transgender People in America 2017," *Human Rights Campaign Foundation, Trans People of Color Coalition*, http://assets2.hrc.org/files/assets/resources/A_Time_To_Act_2017_REV3.pdf.
20. Matsudo, Japan, is an example of a community more open to and engaging of people with dementia.
21. L. Lloyd et al., "Identity in the Fourth Age: Perseverance, Adaptation and Maintaining Dignity," *Ageing and Society* 34, no. 1 (2014): 1-19, at 14.