Valuing Old Age Without Leveraging Ableism

By Clara W. Berridge and Marty Martinson Our medical model of "successful aging" without disability sets up the majority of the population, especially women, for failure.

everal years ago, while working in a senior housing co-op development, one of us (Berridge) witnessed a troubling conversation between several residents in a high-end Midwest cooperative. The older adults discussed their desire to keep people who used wheelchairs from playing cards near the sunny lobby windows, where they would be visible to passersby. On another occasion, having heard from residentmembers that they had downsized and moved into the co-op because they wanted to age in place there, Berridge asked the architect why there were no universal design features-or at least grab bars-in any of the newly built bathrooms. The architect explained that the units would sell better this way. Some of the residents and architect apparently shared a concern that outsiders would see the co-op as a place for old and disabled people-an image they wanted to avoid.

Anthropologists Lamb, Robbins-Ruszkowski, and Corwin (2017) shared a similar story from

Lamb's research involving a Boston retirement home where residents considered banning wheelchairs in the main dining hall. One resident who supported the ban explained that seeing the wheelchairs disturbed her because, "I don't like the intermingling of the well and the sick."

Such examples of elders distancing themselves from and judging other elders who are disabled or ill are not surprising in the United States, where we often define and uplift the healthy older adult as one who is not disabled and is active, productive, and "not looking her age." Phrases such as "70 is the new 50" reflect a "positive aging" discourse, which suggests that the preferred way of being old is to not be old at all, but rather to maintain some image of middle-age functionality and appearance.

We can celebrate the fact that baby boomers will "do old age" in many different ways than those who came before them. It is not unusual for each new aging cohort to redefine old age from that of previous generations to fit with con-

→ABSTRACT Models of successful aging based primarily on the avoidance of disease, disability, and functional loss set up the majority of the older adult population for failure—a majority of whom are women, in particular, women of color. This article explores the ableism embedded in successful aging, as enacted through a medical model approach to disability. The authors propose understandings of aging that integrate a social model of disability, to de-pathologize disability, acknowledge the complex experiences of disability and disease, strengthen gerontology's interdisciplinary work, and avoid leveraging ableism to combat ageism. | **key words**: *disability, ableism, successful aging, social model*

temporary times. Like generative notions of gender performance (Butler, 1990), age is and can be performed in ways that hold liberating potential for older women to counter monolithic images of this life stage and break out of expected ways of being. These diverse, norm-defying ways of being old may challenge aging models put forth by gerontologists; or, as we describe here, they may fall in line with these models of aging in less liberating ways.

Successful aging has become the most prominent of several popular "positive aging" models (e.g., active aging, productive aging) developed by gerontologists in rejection of previous characterizations of aging that forecasted imminent decline and loss. In 1987, Rowe and Kahn first introduced a new distinction between "usual" aging and "successful" aging; a decade later, their refined model defined successful aging through three hierarchical components: first, avoidance of disease and disability, followed by maintenance of cognitive and physical function, which should enable social engagement (Rowe and Kahn, 1997).

Social gerontologists and other scholars have long noted the limitations of these binary models of positive aging, which imply that "negative" aging exists outside these parameters. In this article, we build upon two and a half decades of compelling critiques of successful aging by diving into one particular aspect: successful aging's ableism, as enacted in its privileging of the avoidance of disease, disability, and functional decline through the label of success. We define ableism as discrimination and prejudice against people with disabilities, based on assumptions of inferiority, abnormality, or diminished humanity, rather than understanding disability as a dimension of difference or another way for a body and mind to be.

We highlight the perspectives of several feminist and disability scholars and activists whose work on social models of disability has challenged our thinking and offered us a generative lens on aging. And, we explain how a social model's critique of the medical model of disability can stimulate an embracing and more relevant understanding of aging, particularly as it pertains to women, who are more likely to experience disability and live longer with disability (Gorman and Read, 2006). We put forth the challenge offered by disability and transformative justice organizer Mia Mingus (2011), who asks, "How do we build across our communities and movements so that we are able to fight for each other without leveraging ableism?"

Limitations of a Normative Model for Successful Aging

In previous work, we reviewed twenty-five years of published critiques of successful aging models and found several recurring themes: overly narrow criteria; the missing perspectives of older adults; perpetuation of individualistic views of aging consistent with neoliberal ideologies; and ageist and ableist impulses (Martinson and Berridge, 2015). We do not detail the many critiques, but will highlight some key points to provide context.

One major critique has been the narrow criteria for successful aging, as evidenced by McLaughlin and colleagues' (2010) finding that only 12 percent of people ages 65 and older meet Rowe and Kahn's three hierarchical criteria. Two key criteria-the avoidance of disease and disability, and the maintenance of physical and cognitive function-prove to be particularly rare occurrences among American older adults. While people may be living longer and healthier than previous generations as a whole, those who live without some kind of impairment or chronic illness are in the minority. Among the more than 43 million Americans older than age 64, approximately 80 percent have at least one chronic condition and 68 percent have at least two (National Council on Aging, 2017). About half are expected to experience severe cognitive impairment or require long-term care for support with two activities of daily living (Favreault and Dey, 2015).

Women are particularly impacted by disability. Women are more likely than men to have non-fatal chronic conditions and disabilities and to live more years disabled (Gorman and Read, 2006), and almost 80 percent of women turning age 65 will need long-term care in their lifetime, compared with 58 percent of men (Kemper, Komisar, and Alecxih, 2005-2006). Black and Mexican American women experience more functional limitations than do white women or men of any race (Erickson, Lee, and von Schrader, 2016), and American Indians and Alaska Natives experience far greater prevalence of disability than do their age counterparts of any race (Smith-Kaprosy, Martin, and Whitman, 2012).

Suffice it to say, setting criteria for "success" in aging based primarily on the avoidance of disease, disability, and functional loss sets up the vast majority of the older adult population for failure—a majority of whom are women, and in particular, women of color.

Critics have also argued that successful aging narratives can reflect and play into retrenchment politics that decrease the state's responsibility for social services, which in turn undermines equal opportunity for "successful aging." Recently, a colleague at a large aging services organization described her struggle in the face of significant funding cuts from a major donor. The funder had de-prioritized aging services, with the understanding that older adults are now aging successfully. This came at a time when the organization's wait lists were growing for service coordination and meal services for older adults with disabilities.

The staff was shocked by the funder's misconception about the needs of the aging population, and the executive director attributed this misconception to the influence of the successful aging narrative that represents older adults as healthy, disability-free, financially self-sufficient, and well-integrated into social life. Many other nonprofits that rely on foundation support have felt this pain as funders have de-prioritized older adults in favor of other age groups that are deemed needier.

The positive aging narrative risks obscuring the very real needs of many older adults, which has particular impact on women. In general, women accumulate less income over the life course and are likely to outlive spouses and partners, leaving fewer human and financial resources for them in later life. This means that older women are more likely to be harmed by cuts to health and social services.

About a third of the critiques we reviewed called for the rejection—not the expansion or

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revision—of successful aging as a concept and ideal. They challenged the concept's portrayal of aging and health as personally controlled through behavior and lifestyle choices. From the early critique of successful aging by the late social gerontologist Matilda Riley (1998) for its neglect of structural factors that influence aging, to Sarah Lamb's (2017) recently published anthology, *Successful Aging as a Contemporary Obsession*, scholars for more than two decades have written about the successful aging concept's inability to attend to the social, environmental, cultural, and structural contexts of aging.

Many of these critiques also called out the ageism and ableism embedded in successful aging ideals. As Holstein and Minkler (2003) argue, "Normative terms such as successful aging are not neutral; they are laden with comparative, either-or, hierarchically ordered dimensions." This in turn reinforces negative views of older adults with disabilities or disease that, importantly, are often internalized by them. Korotchenko and Hurd Clarke (2016) found that "cultural expectations of the successfully aging body," along with inaccessible envi-

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ronments, contributed greatly to the disruption of life and identity experienced by new users of motorized scooters.

Toni Calasanti (2016) similarly found that middle-age study participants feared aging and implicitly blamed themselves or others for fail-

The dominance of the medical model contributes to U.S. spending priorities that limit social supports.

ing to age successfully. As Hurd Clarke and colleagues (2008) found in their study of older adults with chronic conditions, "Health issues both include and extend beyond the impact of identity and lived experience to include core feelings about the body and one's place in the physical world." Gender and heteronormative expectations create conditions in which women are particularly susceptible to disapproval and selfblame that may threaten their sense of value (Walker, 1999), a phenomenon that Hurd Clarke discusses further in this issue (see article on page 104). Successful aging norms can thereby leave those who do not meet the standardsstatistically, the majority of older adults and, disproportionately, women-with negative perceptions of their own bodies and identities.

The Difference a Model Can Make: Medical and Social Disability Models

To further explain how ableism is embedded in notions of successful aging, we compare two ways of conceptualizing disability: the medical model and the social model of disability. The medical model of disability defines disability as individual deficiency and bodily or mental deviation from a desirable norm that creates difficulties in one's life and must be prevented or cured. By contrast, the social model of disability makes a critical distinction between impairment and disability. Impairment is considered an individual characteristic of the body, while disability is contextual and describes the disabling interaction of individuals and their social and physical environments (Hayward, 2004).

The medical model of disability

The medical model prescribes the prevention and cure of bodily impairments through medical intervention on the individual, while the social model positions institutional norms, discriminatory attitudes, and physical structures that create disability as locations of change. Identifying the social and physical contexts that disable individuals allows for strategies to decrease barriers to participation through, for example, universal design, employment accommodations, education, and legislation to decrease discrimination and social stigma against disabled people, as well as adequate funding for financial and service supports, including access to respectful, quality healthcare.

When individual impairments are medicalized, the urgency to address the oppressive social causes and consequences of disabling environments is diminished. One such consequence is the segregation and isolation of disabled people, which further entrenches the social fear of disability and contributes to ableism.

The social model of disability

A person becomes disabled not because of an impairment (a medical model viewpoint), but because the social and physical environments make living with the impairment challenging. From this social model comes the often preferred language of "disabled person" (identity-first language) rather than "person with a disability" (person-first language), as the former names the person in terms of how the environment has influenced them and fits with other ways of identifying (e.g., Asian American, queer woman, etc.). Disability activists and scholars developed the social model on the heels of the Civil Rights Movement as a critique and corrective to the medical model, which has dominated ways of treating disability for many decades.

Notably, the social model of disability identifies the medical model of disability itself as part

of the disabling environment because its individualized and negative view of impairment reflects and perpetuates institutionalized and interpersonal ableism.

Overall, the disability movement continues to fight against underlying assumptions that disabled peoples' lives are tragedies (or sources of inspiring stories of heroism), and that inferior status is justified.

Successful Aging Is Rooted in a Medical Model

Viewing successful aging through these two models of disability reveals its adherence to a medical model and its stark contrast to the social model. Successful aging conceptualizes and measures disability within the individual and not by the broader contexts named by the social model. Through its criteria of the avoidance of disability and the maintenance of mental and physical function, successful aging has disqualified people based on medicalized views of disability and function. Even the recently revised wording of one criterion to the "low risk of disease and disease-related disability" (Rowe and Kahn, 2015) maintains this medicalized view and measures success accordingly. Furthermore, it excludes disabled people who may fail the function criteria but consider themselves to be functioning quite well with assistance and accommodations (Minkler and Fadem, 2002).

Some proponents of successful aging have heeded the concerns about the model's exclusion of people with disabilities by proposing expansions to the criteria. Freedman, Kasper, and Spillman (2017) call for a successful aging model that includes disabled people who have *successfully accommodated*, which they define as using assistive devices without reducing activity or needing assistance from others. While more inclusive of disability, the conceptualizations of accommodation (using technology, not people) and independence are still situated within the individual (a medical model approach) rather than allowing for accommodation that involves help from others—including, importantly, honoring the very real interdependence between generations. This stands in contrast to a social model of disability that values human assistance and relations of care.

Some successful aging researchers have taken a more ecological approach by considering environmental supports, policies, practices, and resources needed by people with disabilities and care needs to age "successfully." Rowe and Kahn (2015) proposed a "Successful Aging 2.0" research agenda with the goal of developing institutional interventions to facilitate successful aging for more people. While these efforts seek to expand the individualized model, their adherence to an ideal of successful aging that is defined by medicalized criteria, and suggests that some will fail, aligns with a medical model of aging.

Furthermore, even expanded models of successful aging are ill-equipped to shift our focus from personal responsibility to inequitable power relations that create inequities and influence experiences of aging (Katz and Calasanti, 2015). Successful aging's medicalized focus leaves unattended strategies to protect the critical supports that can make society less disabling and otherwise challenging for many older adults. We currently face congressional threats to Medicaid funding. More than 6 million older adults and more than 10 million children and adults with disabilities rely on Medicaid annually. Women make up two-thirds of Medicaid beneficiaries, and these women are more likely to be poor, in poor health, less educated, and women of color.

Also, 66 percent of family caregivers and 90 percent of direct care workers are women who are often unpaid or underpaid, and are at greater risk for illness and disability (Hooyman, 2014). How relevant is successful aging to Medicaid recipients and caregivers—mostly women—who do not meet the criteria and who face effects of poverty and related social determinants of health? How does successful aging serve us in the face of these gender, race, and class inequities?

To put this in broader perspective, this medi-

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cal model dominance contributes to U.S. spending priorities that limit social supports. We spend twice as much on healthcare as we do on social services, but have worse health and social indicator outcomes than those European countries that have the reverse ratio: spending twice as much on social services as on healthcare (Bradley and Taylor, 2013). There is something amiss when, under threats of budget tightening, daily meal services delivered by volunteers can only be justified if they show a cost-savings through reduced healthcare use—and, if not, they are replaced by the more impersonal option of frozen meals, delivered once a week.

This economic logic has become so engrained that it may not even strike us as odd. Under the dominant political philosophy of neoliberal capitalism, with privatization, deregulation, and individualized risk at its core, state programs that mitigate collectivized risks are dismantled. As political theorist Wendy Brown (2005) has argued, under neoliberalism, "all dimensions of human life are cast in terms of a market rationality" and social problems—including ageism—are de-politicized, as we are encouraged to seek our own individual advantage.

Jasbir Puar (2013) further explains that this ever-present market measure concerns us all, whether we are disabled, non-disabled, or somewhere in between, because all bodies are "being evaluated in relation to their success or failure in terms of health, wealth, progressive productivity, upward mobility, [and] enhanced capacity."

As critically thinking gerontologists, we must be aware of how this neoliberal system continually assesses "which debilitated bodies can be reinvigorated for neoliberalism, and which cannot" (Puar, 2013). We must consider how gerontological discourses may unwittingly play into this assessment and leave older, ill, or disabled women unseen or leveraged in the name of successful aging.

By defining aging in relation to individual medical needs that require economically justified solutions, and not in relation to important social supports (such as Meals on Wheels) that provide sustenance and connection as they relieve isolation, successful aging is entangled in efforts to privatize risk. This leaves unattended the growing differences in life chances, the inequities that contribute to those differences, and the needed supports and structural changes that can help mitigate and prevent those differences. Our models of aging need not be complicit in this partial way of thinking.

Leveraging a Social Model

We echo a handful of other gerontologists who have proposed integrating elements of the social model of disability into our thinking about aging. What could this do for gerontology and, more importantly, for older adults? First, a social mod-

'Successful aging is entangled in efforts to privatize risk.'

el of disability helps us to understand the experiences of disability and disease in all of their complexity. Susan Wendell (2001) asserts that we must see even disease-related disability as being not only about suffering because, "Like living with cerebral palsy or blindness, living with pain, fatigue, nausea, unpredictable abilities, and/or the imminent threat of death creates different ways of being that give valuable perspectives on life and the world." Eli Clare (2017) highlights the idea of brilliant imperfection as "a way of knowing, understanding, and living with disability and chronic illness" that embraces "the nonnegotiable value of body-mind difference" and counters our tendency to hold up differences to constructed standards of "normal" and "abnormal." These perspectives open our thinking to recognize (and value) disability in ways that prevent marginalization.

Disabled older women's lives are about more than just the burdens of sexism, ableism, ageism, and racism that create life difficulties; they also are about the determination for self-worth, acts of resistance, and relations of care and compas-

sion (Morris, 2001). Different ways of being can enable gratitude and appreciation for alternative modes of functioning, a sense of perspective on what is valuable in life, and opportunities for personal development. We urge more research that allows older adults to share and define these experiences fully, without the restricted strictures of a successful aging framework (i.e., "tell us what successful aging means to you").

Recognizing and valuing the experiences of disability and illness in later life does not return us to "decline and loss" stereotypes, but instead reflects the diverse and ecological processes of aging. One of the positive effects of exposing older adults' full experiences is that exposure reduces fear and stigma, both of disability and of aging. A social model of disability shows us the importance of de-pathologizing disability so that it can be seen for what it is-an essential element of human diversity represented by at least 20 percent of the general population at any given point in time, and a larger percentage in older ages. It is important to measure and monitor impairment and chronic disease in old age, but rather than using those measures to determine some measure of success, why not use them to identify and address gender- and racebased inequities, as well as other inequities, to ensure appropriate resources in support of our aging population?

As disability and history scholar Catherine Kudlick (2016) suggests, "If we put as many resources toward fixing hostile environments and attitudes as we do toward finding a Cure [for disabilities], our society would be in a better place for incorporating its full human potential." By acknowledging and valuing disability as part of the diverse experience of aging, we are better able to reveal the human potential of old age.

This orientation toward a social model also allows us to reap the interdisciplinary value of the field of gerontology, with its rich, varied contributions and ways of thinking. While the field comprises numerous disciplinary traditions, it is heavily dominated by medicine and thus by "successful aging" and a medical model of disability. Michelle Putnam (2017) notes that many disability sector professionals and advocates consider this medical model to be patronizing and disempowering, as it presents "an antiquated view of disability that does not align with practices like person-directed care."

Given this ideological rift between the fields of aging and disability, Putnam details an argument to find common ground so that aging organizations can learn from the disability sector and better address the needs of the 12 to 15 million individuals currently aging with long-term disabilities. This kind of cross-sector work requires interdisciplinary research and practice. Gerontology can do this better by working with and drawing more from fields such as disability studies, critical race studies, women, gender, and sexuality studies, the humanities, anthropology, sociology, social welfare, geography, bioethics, and critical public health. This interdisciplinary work covers more ground and can contribute to a broader, realistic, and inclusive vision for aging.

If we continue to promote models of aging that leverage ableism to combat ageism, we leave people fearful of their own and others' aging bodies—hardly a liberating scenario for older adults, and especially for older women, who are particularly disadvantaged by successful aging and the medical model of disability.

A social model of disability provides a lens through which to view aging very differently and reflect on the relationships between ageism and ableism. It upholds the value of disabled peoples' lives, while focusing attention on social determinants of health and impairment disparities. Rather than hiding disabled older adults in our normative models or in certain corners of our residences, we can learn from their experiences and perspectives in the world to support aging processes for them and others. As noted by feminist philosopher Sara Goering (2015), doing so will be truly liberating and better prepare us for the future:

"Presuming that we live long enough, we will all, eventually, be impaired in one way or

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another, if we are not already. Learning to accept this fact will not only perhaps help to eliminate the us/them divide that continues to segregate many people with disabilities in social life, but could be used to diminish the desperation with which many people seek the elusive state of perfect health. Reducing our fear does not mean that we cannot take measures to prevent impairment, only that we recognize how we can learn to live with them when they inevitably come, and how making social accommodations now will be beneficial to all of us in the long term."

While medicine certainly has a place within broader understandings of aging—and equitable health and wellness care is a core matter of social justice—what we argue for here is an approach to "doing old age" that accounts for and prepares for the common experience of aging with disability or chronic illness, and does not hold it up to some measure of success. We ask our colleagues to consider how we might "do gerontology" in a way that acknowledges and *honors* disability as a common part of the human experience.

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