

Commentary

Reframing Resilience for Aging, Disability and Longevity

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This commentary reimagines a society with increased longevity and greater likelihood of disabling conditions, from an environment of fear to one of resilience and possibilities. In a world where aging baby boomers - and all who may experience a longer life span - worry that their old age may be one with chronic conditions, limited mobility and various impairments that destroy their sense of healthy aging, we may need to reframe how we view and plan for an aging process that will, in time, spare no one from the vicissitudes of longevity. This piece seeks to reframe how we accept and adapt to the likelihood of limitations, with the goal of incorporating the concept and practice of resilience in preparing for early and late onsets of disability, as well as for aging with a disability.

Why is this important, and how might the concept of resilience be the “next critical turn” [1] in reframing attitudes, narratives, policies and programs? In the next three decades, more of us can live longer and look forward to increased longevity. But as we look around at our contemporaries facing strokes, hip replacements, impaired mobility and the need to use walkers, the visceral reaction tends to be one of “OMG, I don’t want to go there!” We may also generally avoid the topic of diminished abilities as we age until the realities set in. We find this avoidance in media, public narratives and professional approaches to aging, as well as in terms such as “successful aging,” “purposeful aging,” “healthy aging” and “walkable communities.” Photos of 70- and 80-year-olds in glamorous settings with youthful, vigorous and physically fit appearances add to a view of aging with a disability as somewhat pathological.

Considering the use of this conceptual dimension of resilience in gerontology and social policy can enable researchers and policy analysts to incorporate the more positive complex layers of society that are welcoming and that can be used to create new support for aging

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adults with disabilities and marginalized groups in aging societies. We define resilience as “the process of adapting well in the face of adversity or significant sources of stress” that “involves bouncing back from these difficult experiences and profound personal growth” [2]. Resilience encompasses several components, such as well-being, mastery, self-efficacy, flexibility, inner strength and optimism [3,4]. In addition, the APA definitions’ purposeful emphasis on process, rather than personality trait enhances the inclusivity of the term in that it suggests individuals of all socioeconomic status, personal backgrounds and environments are capable of cultivating resilience [5]. These definitions and how we shall use them in this piece allow us to go beyond individual protective characteristics and incorporate both the environmental and social contexts in which older adults and disabled persons are placed [6].

Perhaps one detriment for the helping professions - social work, public health, nursing, medicine, physical and occupational therapy - and their mission to serve vulnerable clients may be the neglect or minimalization of resilience as an important tool in their protocols. Social work, for example, trains professionals to help, rescue, advocate for, and otherwise use victimhood and vulnerability to describe their clients and thus save them from difficult circumstances. Yet the extent to which our broader definition of resilience is incorporated into social work practice may allow for modifying the policy, physical and infrastructure environment. And the attitudinal strengths of this concept may enable individuals to expand their sense of independence and empowerment, even with a variety of disabling conditions in old age. This is not to say that individuals should “tough it out” but rather that assessing the broader context of what may hinder resilience can be a turning point in adapting and adjusting.

This ecological model of resilience states that contextual and sociocultural resources and an individuals’ ability to utilize such resources can help them enhance their problem-solving abilities and maintain a sense of purpose and hopefulness, which acts as protection against adversity [7,8]. These socioecological concepts invite studies that explore how mechanisms at social and societal levels interact with an individual’s capacity to cope with the challenges of disability in later life. Building a new generation of studies based on the concept of resilience may provide innovative research and intervention opportunities aimed at older adults with disabilities without stigmatizing or excluding them from research on what it means to age successfully. The concept of resilience in later life is gaining momentum in gerontology, with recent publications focusing on the mediating effects of resilience on adversities experienced in later life and its function as a buffer to disability, multimorbidity and depressive symptoms [9-11]. These studies have found moderating effects of resilience on negative life events that affect the quality of life among older adults, reinforcing the belief that resilience effectively shapes an individual’s capacity to navigate these events. While there is much left to be discovered, such as the risks and protective factors of resilience, a notable shift in the way we view aging and disability has unlocked potential for developing policies and services that actively support resilience.

It is these public policies that have brought civil rights to persons with disabilities, older adults and those aging with a disability but heretofore have not legislatively drawn on the concept of resilience [12]. The 1990 passage of the Americans with Disabilities Act (ADA) grants broad protections and access for persons with disabilities. The Rehabilitation Act of 1973 (and its Section 504) prohibits discrimination against those receiving federal funds. The 1990 Individuals with Disability Education Act (IDEA) mandates mainstream education for all children with disabilities. And most impactful, the Olmsted Decision by the US Supreme Court in 1999 determined that all people with disabilities, regardless of age, deserve some modicum of independence and should not be forced into institutional settings. These important public policies set the stage for access, protections and opportunities for younger and older persons with disabling conditions to mainstream in social life. Yet at the time of their enactments, the concepts of empowerment, self-sufficiency and hence resilience had not entered the body politic of policy analysis. Perhaps as these laws and regulations are amended in the future, our evolving understanding of this concept can be added to these foundational safeguards.

A useful technique to enhance the relevance of these conceptual and intellectual ideas is to use personal stories and narratives to viscerally view the role of resilience. The first author, a polio survivor in his mid-70s, often finds his baby boomer friends suddenly facing arthritis, knee replacement, reliance on a cane and other age-related circumstances asking questions such as, “How do you do it with your crutches and mobility scooter,” and “How do you keep such a positive view of life?” And they wonder how a lifetime with a severe disability did not keep me from a fulfilling career, a wonderful family and having fun. I do find it hard to explain that I have a big advantage, having incurred a disability early in life as opposed to a late onset of limitations. This gave me a lifetime of practicing how to adjust and adapt and rearrange my environment to continue enjoying a full and fruitful life into my older years (and with a new phase of adjusting to the post-polio syndrome). And I benefited from a family and a social support system that did not allow me to feel sorry for myself and internalized the value of resilience early in life.

The second author conducted qualitative interviews with older adults who had acquired debilitating disabilities in later life, such as blindness, deafness and dementia, as well as those growing old with a disability from birth. While the common misconception of these subpopulations is that they are frail, helpless and bound by limitations in life, interviews revealed the intricate processes with which these individuals effectively utilized resources at the personal, interpersonal and socioenvironmental level to adapt and be resilient in the face of such adversities. Overall, the second author found that these older adults had come to accept disability and disease as a natural part of their aging journeys rather than something that labels them as having experienced “unsuccessful” aging. These personal stories raise fundamental questions about reframing narratives of a society growing older and with greater levels and categories of disabilities. How can we prepare individuals to be proactive about planning for a lifetime with potential limitations? Have public policies acknowledged the personal resilience and empowerment that individuals can benefit from as they face the vicissitudes of life? How can we balance professional training and practice to mitigate overemphasis on victimhood and dependency and encourage emphasis on infrastructure and environmental changes that enable individuals to have greater freedom and independence as they age with limitations?

The demographic trends compel us to plan ahead and look to the next several decades, when the number of adults in the United States over age 65 are projected to increase from 58 million in 2022 to 82 million by 2050, with their share of the total population rising from 17% to 23% [13]. Moreover, the 85-years-and-older segment, most of whom will have disabling conditions, will more than double from 6.5 million in 2022 to 13.7 million in 2040 [14]. How we define disability will produce various numbers and percentages of those who are germane to this discussion. The ADA defines a disabled person as “a person who has a physical or mental impairment that substantially limits one or more major life activities...or is perceived by others as having such impairment.” This definition, promoted by disability rights movements, creates a big number, with at least one in three persons having a disability. A narrower definition would be those categorized as needing support with Activities of Daily Living (ADLs) such as bathing, dressing, eating, toileting and transferring, and those requiring assistance for Instrumental Activities of Daily Living (IADLs) like managing finances, preparing meals and taking medications. However we define such definitions and their numerical outcomes only highlights the gap in our current understanding of disability among older adults by focusing solely on limitations in daily life. Neither the ADA’s definition nor others incorporate the social model of disability. But disability studies distinguish impairment from disability, the latter being something not resulting from a physical or psychological condition of the individual but created by environmental, social and attitudinal barriers that limit access and inclusion [15].

This commentary suggests that we must bridge these two currently siloed bodies of research by addressing the ageist and ableist views of disability in later life, as well as earlier onsets of disabling conditions, and instead focusing on the dynamic role of resilience and capabilities through a disability studies lens. Integrating insights from both fields could lead to more holistic approaches, where social policy, design of care environments, and interventions are reshaped to strengthen resilience and empower older adults with disabilities, regardless of physical limitations.

In an earlier article, “Reframing Aging and Disability Policy in a World Where Older Adults and Younger Persons Meet Common Destinies” [12], the first author suggested that this reframing requires that we use a life-span perspective to educate and socialize all persons, able bodied and disabled, to merge their fears and concerns about living a long life and facing disabling conditions with looking ahead to a good old age where, regardless of changing circumstances, old age would still provide quality-of-life opportunities and enjoyment. This would assume a sea change in how we view aging and disability and how we bring in the concept and practice of resilience to open the possibility for more nuanced and creative approaches to practice, services and policies that view limitations for older adults as a productive and normal part of life. And it would require a sea change in individuals’ and public - media, film, portrayals, trends - attitudes that having a limitation and use of assistive devices as one ages do not detract from the beauty and appeal of those with disabling conditions. As Gendron, et al., [1] eloquently stated in their seminal article, “The Next Critical Turn for Ageism Research,” by examining the “root anxieties influencing negative attitudes about aging and fears of growing older” and by “examining the intersection of ageism and ableism,” we might, in fact, enter a brave new world of longevity, regardless of circumstances.

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