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Disability and Aging: Learning from Both to Empower the Lives of Older Adults

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Contents

<i>Preface</i>	ix
1 The World of Late-Life Disability	1
2 Contextualizing Aging and Disability	19
3 Learning from Gerontology	47
4 A Life Course Perspective	73
5 Adventurous Aging Through International Travel	95
6 Managing the Physical Environment	115
7 Enhancing Care in the Nursing Home Environment	133
8 The Experience of Disability at the End of Life	153
9 Toward Better Public Policies	179
10 The Promise of Convergence in Gerontology and Disability Studies	201
<i>Bibliography</i>	219
<i>Index</i>	243
<i>About the Book</i>	251

The World of Late-Life Disability

*Disability can be stigmatizing—or it can be liberating. Such are the opposite connotations of a term that is immensely difficult to define and is so broadly inclusive as to encompass those with profoundly different impairments and levels of impairment. The first description derives from Erving Goffman's 1963 anthropological work *Stigma*; the second from Irving Zola's 1982 memoir, *Missing Pieces*.¹ That Goffman was writing from the outside looking in, and Zola from the inside looking out, bears noting. When those who are not disabled define and analyze *disability*, they often reach quite different conclusions than the descriptions and meanings that people with disabilities give to the term.*

What accounts for such opposite definitions of the term *disability*? It is not simply the vantage point of the observer, although that surely colors the perception of disability and its personal and social meaning. Rather, it is culture and policy—and the shifting ways that time affects perception—that determine the meaning of disability and the social place of people living with disability. Society does not create the physical and psychological impairments that are associated with disability. But whether society perceives people living with disability as outside the prevailing norm or as different but within the norm can make all the difference between stigma and liberation. In his 1993 historical account of the disability rights movement, *No Pity*, Joseph Shapiro captures a key feeling that to be disabled is not to be pitied, but to live—and demand the right to live—in the fullness of life.²

In this book, we are concerned with disability in old age—and with the processes that shape the understanding and experience of disability in late life. A key theme animating our work is that people experience disability differently in old age than they do in youth or middle age. Moreover, disability for the young-old (ages sixty-five to seventy-five) and the old-old (ages eighty-five and over) represent distinct experiences—which is why we focus separately on each period, drawing different conclusions about

the challenges of the adventurous traveler versus the courageous resident of the nursing home.

Disability and Aging

Growing numbers of older adults worldwide are living well notwithstanding varied physical and cognitive impairments. These individuals have the potential to reshape how society views and understands the concept of disability. Old age brings with it a higher incidence of chronic illness, impairments, and limitations in functioning. Despite such conditions, many elderly persons live robust lives. They manage their illnesses and impairments, enjoy good-to-satisfactory health, and retain an optimistic outlook.³

What does this new old-age paradigm portend for the rapidly growing aged population that no longer fits within a narrow and medicalized notion of disability? What does this paradigm mean for how sociologists and gerontologists define the life stage or stages of aging? And what are the political and social implications for countries with a growing population of disabled elders? These questions lie at the heart of the social transformation that is the graying of disability.

In our common language and culture, we are surrounded with the terms *old age* and *disability*. Yet these terms, and the social identities they signify, tend to remain separated based on age cohorts. We tend to reserve the term *disabled* for young and middle-aged people and instead use *sick* or *ill* when we talk about older individuals. And that is how old people view themselves; rarely do they accept the identity—and social personae—of persons living with a disability.⁴

Understanding the divide between disability and old age is the overarching goal of this book. But our path forward is complicated by our very terminology. Like *disability*, the words *aging*, *old age*, and *the aged* are not easy to define. What—and whom—do we mean when we use these terms? When we speak of “the aged,” are we referring to people over a certain age or to people over a certain age whose specific characteristics—health, retirement status, socioeconomic status, gender, family role, or some other social factors—define them beyond their chronological age alone as “old”? Thus, to analyze our terminology is to raise the question of whether old age is a social role rather than a chronological milestone.

For much of the twentieth century, chronological age defined the onset of old age—largely because this milestone was linked to Social Security (and later Medicare) as well as employer-mandated retirement policies. Beginning around the new millennium, however (but with earlier roots, as we will discuss), commentators on aging began to reappraise the social and cultural meaning of growing old. They discovered that they had to view old

age in a new light, as it had been transformed by a “longevity revolution”⁵ and a new cohort of seniors who were redefining the social expectations and political agenda around aging. It is no coincidence that the new gerontology—with its vision of aging as a time of growth, productivity, happiness, and fully articulated success—emerged just about the time that baby boomers were reaching mature adulthood or early old age.

This new vision of aging was that it could be done without disease or disability. The architects of the new aging viewed the idea of retirement with suspicion; even AARP (formerly the American Association of Retired Persons) removed the word from its organizational name. The new aging did not entail a path to sunny senior communities—replete with bingo, horseshoes, and days of endless relaxation. Most importantly, it equated a longer life with a more youthful one. Personal development through activities and engagement—travel, learning, work, new careers, and new romantic relationships—was a theme that scholars studied and the press popularized. The baby boomers were, after all, a generation with a penchant for being part of an age—whether of Aquarius in the 1960s or the Third Age in the twenty-first century—but not part of *old age*, and certainly not an old age lived with the limitations imposed by disability.

Disability in Old Age

Our specific interest in this book is the graying of disability—the contemporary societal transformation that is taking place as people live to older ages and experience the varied physical and psychological impairments that lead to disability. Disability in old age is an issue that could theoretically unite two distinct communities: those who are aging and those who are disabled, plus the scholars who study these communities and the activists who advocate for their rights. Yet so far, this has not happened. We hope our book will begin to make that connection.

Alzheimer’s and Parkinson’s disease leave no ambiguity about the effects that aging can have on the body. These diseases are associated with old age, but there are many others—cancer, heart disease, diabetes, arthritis—that disproportionately impact older people. And it is not just disease that causes impairment in old age. The body experiences physiological losses of function that are compounded by other nonphysical losses, including diminished social and financial resources as well as new barriers to enjoying past fixtures of comfort and independence (such as the family home and car).

Our efforts to understand disability in late life should begin with an appreciation of the individual person—and specifically, how the later stages of life are more than just a period of loss. Instead, they are a highly significant part of the life course that gives meaning to the previous stages of life.

The forty-one essays in Phillip Berman's *Courage to Grow Old* poignantly explore this idea, allowing the reader to see how people address multiple layers of loss throughout old age. Berman notes in his introduction:

Unless we are very lucky, aging inevitably entails increasing physical disabilities, whether it's the slow shift, as Henry Heimlich puts it, from a "cane, to a walker, then to a wheelchair," or the more rapid decline of an individual suffering from Alzheimer's. But whether we age slowly or rapidly, none of us can escape decline. . . . What we can control is the way we choose to deal with our infirmities, and this is where courage—and a healthy dose of humor—works wonders.⁶

The essays in Berman's volume are a window into the world of old age as a time of greater proximity to, and awareness of, death. Yet this concern with death does not diminish the other dominant aspect of the aging experience in late life—that is, the desire to continue, to propel forward, to banish fear, and to embrace what is left of life. Along with adopting a more spiritual orientation, many older people find strength in practicing gratitude. This is especially true for those with disability. In this framework, appreciation and contentment are not merely well-worn sentiments, but can actually become buffers that moderate the effects of loss and disability. During this period of late life, people's subjective understanding of their own health—and their attitude in the face of health challenges—is a predictor of future well-being. A positive attitude and continuous social engagement improve the quality of an older person's remaining life.⁷ Disabled persons of all ages can benefit from appreciating how those who are aging with disabilities have adapted over time to changes in their life circumstances.

Gerontology and the New Aging

Readers of the series in which this book is included are well aware of the trends and trajectories in the rich field of disability studies. Works by Ronald J. Berger, Rosalyn Benjamin Darling, Dana Lee Baker,⁸ and others in the series—along with output from other publishers and periodicals—highlight the dynamism of disability studies. Yet few books or articles have sought to connect disability and aging—perhaps because of the different languages and cultures that define the respective disciplines. We do not see our project as attempting to reconcile the two different approaches, as much as to begin a dialogue between them.

Most work in disability studies emphasizes the positive aspects of life lived in the context of disability. Gerontology, in contrast, has focused on the negative aspects of disability in the context of an idealized course of

healthy aging. Indeed, disability is often treated as undermining a newer vision of old age as a time of productivity, happiness, and rejuvenation. Gerontology as an interdisciplinary field has been built on discrediting an older view of aging as a period of decline, illness, and isolation. On college campuses, young people are drawn to study this new aging. They are intrigued by, and wish to learn more about, the final stages of life. A generation in search of meaning, millennials want to understand how time impacts us all—so that they can plan how to live meaningful lives.⁹

This positive redefinition of old age has many implications, the first of which is that people need not fear growing old. By celebrating old age, we may even discover an answer to the question posed by Robert N. Butler in his Pulitzer Prize-winning *Why Survive?*¹⁰ However, this reinvigorated version of old age has located the aging experience away from disability. The term *disability* has negative connotations in the aging literature and is used to describe an undesirable condition that, at best, should be limited in scope and compressed in time. In this revised formula for a well-centered old age, disability is simply a burden. There is little emphasis on how to live well—and seek support—as a disabled older person.

Survey data may help explain the dearth of professional interest in the topic: they show that older individuals are reluctant to view themselves as having disabilities. The labels *disability* and *disabled* threaten their core identity as empowered and autonomous individuals. Many older people simply eschew *disability* as a label, category, or specific consciousness. And because they do not self-identify as disabled, older persons with disabilities are not disposed to advocate for themselves. Thus, they make limited claims for specialized programs.¹¹

The divergence between disability studies and gerontology goes beyond how to characterize disability. Disability advocates and scholars have been most interested in the subject of rights—specifically, how to breach the barriers to social, political, and economic inclusion. The issues of health and sickness are not considered central to the disability experience.¹²

For gerontologists, however, disability does tend to be associated with disease—and thus poses a threat to health, which is considered an aging person's greatest asset. For this reason, gerontology scholarship has focused on the loss of health in old age. Writing from an epidemiological perspective, Christina Victor notes that “the importance of health is a key feature of many studies of the experience of age and ageing, and health is seen as central to the experience of and maintenance of quality of life in old age.”¹³

Disability thus poses a challenge to the field of gerontology as people live longer and therefore may spend a greater part of their elder years managing disability.¹⁴ Few older persons have any prior experience living with a disability—and with its emphasis on health, the field has provided little in the way of guidance about how the disabled elderly can lead a rewarding life. In

his preface to *The Cambridge Handbook of Age and Ageing*, British gerontologist Malcolm Johnson acknowledges this trend: “From its inception the core area of gerontology has been health,” with the leading concern of the past thirty years being “apocalyptic demography.” What this focus has obscured, Johnson reports, are studies “on the social features of life in the Third and Fourth stages” that “explore the positive potentialities of being an older person.” Even when such studies appear, he argues, they “are overwhelmed by the sheer weight of inquiries about illnesses—physical and psychological—and the interventions that might ameliorate their consequences.”¹⁵

The origins of aging research as a social science may help explain the way gerontology engages—or does not engage—disability. The field began largely as a multidisciplinary project in the years after World War II, with an aim to approach aging as a topic worthy of scientific investigation and a cultural phenomenon appropriate for social and philosophical theorizing.¹⁶ Its main growth came after 1960, and by 1976 it had matured to the point at which the first of many *Handbooks of Aging* were published to showcase the new discipline’s accomplishments. Given gerontology’s early focus on the social aspects of aging and how they influenced the aging process, the issue of disability might have been expected to attract the attention of scholars. However, this has not been the case.

In the first edition of the *Handbook of Aging and the Social Sciences* (1976), the sociological domains of structure (e.g., population, stratification) and systems (e.g., family, work) received careful attention, as did modes of social intervention (e.g., politics, research).¹⁷ Yet from the first edition through the eighth edition in 2015,¹⁸ the subject of disability has been studied only as a minor note—and chiefly as it relates to the loss of health and rarely from the standpoint of the personal experience of those living with disabilities or caring for persons who have disabilities.¹⁹

To understand this orientation within the field, it is useful to explore the paradoxical issue of ageism. On the one hand, the term *ageism* suggests grounds upon which to seek common cause with the disability rights movement in fighting discrimination and securing a protected minority status for the aged. On the other hand, ageism has spurred a movement to reject old age as a time of limits imposed by either society or physiology. One might say that ageism has led to a curious antiaging stance on the part of the aged and those who study them.

The Problem of Ageism

To appreciate the development of the field of gerontology and the relatively low priority of disability as one of its concerns, it helps to consider the field’s intense concern with ageism. “Beginning in the late 1960s,” writes Thomas

Cole, “America witnessed a formidable effort to eliminate negative stereotypes of and prejudice toward older people.”²⁰ But unlike disability advocates who embraced the lived experience of disability, these advocates for the aged took their project to be debunking myths about old age. In the process of doing so, however, they created new myths centered on an antiaging ideal.

This project of reassessing the meaning of old age was built on an older research foundation that saw limits in studying aging as a function of age alone. Since the 1940s, some gerontologists had been arguing that age itself was a poor indicator or predictor of behavior and that older people adjusted to late life and its challenges in many different ways.²¹ Increasingly, the key question in gerontology turned on the issue of personal adjustment in old age—with the individual’s ability to adapt to his or her environment seen as the centerpiece of the aging experience.²² The field recognized from an early date that society structures the life prospects for the elderly—and that it was the responsibility of these older persons to optimize their responses to these conditions and social limitations.²³

Gerontologists did not view the problems of aging in terms of “changes in physical and mental capacities but in changes in social opportunity.”²⁴ Thus, understanding the shrinking of social opportunities—what would later be called “ageism”—became central targets for the field of gerontology in its early days. But unlike the disability rights movement, the aging community did not make gaining rights its chief priority. Rather, it focused on finding ways for individuals to adapt to and integrate with their environment—a largely personal act of evolution and coping.

One form of adaptation that goes beyond the individual is gerontology’s effort to reframe the aging experience so that age itself is less relevant as a category of analysis. This movement to minimize the relevance of age was a response to an earlier period’s definition of old age as a key marker for disengagement from economic and social activities. From the 1930s through the 1960s, age itself had assumed a high degree of importance. The bookended policies of Social Security (1935) and Medicare (1965) provided older persons with a guaranteed income and access to medical care on the basis of age alone. Retirement also emerged as a new period in the life cycle, when workers were required to leave work and seek fulfillment in other (often less fulfilling, leisure-based) activities.

But almost as soon as age cemented its relevance in policy and social consciousness, a reaction against age as a category of analysis found a ready audience amid the cultural changes of the late 1960s and 1970s. The generational tide of the baby boomers, with their attendant challenge to authority structures and normative behavior, began a shift in outlook toward an old age that was diverse and youthful—a view that may be seen in retrospect as sanctioning the social current of the times. In 1976, prominent University of Chicago gerontologist Bernice Neugarten and Norwegian sociologist Gunhild

O. Hagestad surmised that we “seem to be moving in the direction of what might be called an age irrelevant society; and it can be argued that age, like race or sex, is diminishing in importance as a regulator of behavior.”²⁵

At around the same time, Butler also was questioning the utility of thinking about aging according to chronological age. In *Why Survive?* he argued that “the idea of chronological aging (measuring one’s age by the number of years one has lived) is a kind of myth.” Butler, of course, was not denying that age has physiological consequences, but he contended that the differences in how old people aged were more significant than their actual ages. “Physiological indicators show a greater range from the mean in old age than in any other age group. . . . Older people actually become more diverse rather than more similar in advancing years.”²⁶

Butler addresses this issue in a section of his book called “Myths and Stereotypes About the Old” in which he enumerates a series of negative but unfounded societal attitudes toward the elderly—attitudes that promote ageist conclusions. These myths and stereotypes include “unproductivity,” “disengagement,” “inflexibility,” “senility,” and “serenity.” After considering each, Butler notes that “insufficient contact” with older persons was one cause of these myths, but he maintains that “there is another powerful factor operating—a deep and profound prejudice against the elderly which is found to some degree in all of us.” Butler explains that he “coined the word ‘ageism’” to describe this prejudice, defining the term to mean “a process of systematic stereotyping of and discrimination against people because they are old, just as racism and sexism accomplish this with skin color and gender.”²⁷

Rejecting the social meaning of chronological age had a lasting impact on gerontology. If being old means many different things, then what does it mean to engage in a study of older persons? The diversity of the aged as a group has led Richard A. Settersten, a specialist in life course studies, to worry that although “gerontologists now assume that there is [great] variability among old people, . . . only rarely do we consider the things that old people may have in common.”²⁸

This attitude is in contrast to the approach of disability studies, which unites many impairments and social environments under the broad umbrella of disability. Aging has presented less of a common experience. As we show in this book, disability in old age is marked by variability and disparities rather than by a common consciousness or unifying policy agenda. The many typologies of disability are thus grafted onto the multiple scaffolding of the aging experience.

The work of social historian and gerontologist Tamara Hareven points to the need to integrate life course research with an understanding of the family and its relationships over time. In the social contexts of aging and disability, the role of the family is central—specifically, whether the family is available to support an elder or child with a disabili-

ity. Few families are untouched by either aging or disability—and our own lived experiences show the connections across three generations in this regard. It is often a person's social networks, within and beyond the family, that define what it means to be “disabled,” as much as any impairment or public policy.²⁹

If old age is to become a more meaningful signifier of a period of change in the life course, the impact of disability must figure prominently in our analysis of the aging process. Understanding how age intersects with disability on the individual level will also help us see how disability impacts the cross-generational role of the entire family in late life. Today, an entire generation of middle-aged and young-old persons (mostly women) are providing unreimbursed care for parents, grandparents, and even siblings whose lives are affected by disability.³⁰

Disability in old age not only matters at the individual and family levels, but it may also lead to a shift in the way that gerontologists think about aging. Many leaders in the aging field, including Powell Lawton and Malcolm Johnson, have observed that the field is rich in empirical knowledge but limited in theoretical perspectives. There are, to be sure, varied theories that have dominated the field (e.g., successful aging, stress and coping, continuity, activity, and quality of life). Yet according to Elias Cohen, an elder statesman in the field, we are “in need of some kind of theory about aging, at least some kind of social theory.”³¹ To generate such a theory will require substantive dialogue among academics across the disciplinary lines of aging and disability. It will also require input from those whose lives are affected by both aging and disability as well as from those who are engaged in what Cohen describes as the “public administration of services designed to mitigate the insults of old age.”³²

Such a new theory of aging and disability may, in part, find support in an older framework called “disengagement theory,” which posits a view of old age as a time of slowing down and withdrawing—disengaging—from previous social interactions.³³ Few gerontologists have been willing to embrace this theory since its introduction in 1961—and one can see how it runs counter to the ideal of an active and sustained lifestyle for those who are aging. But disengagement need not be considered in only this narrow way. There may be, as Cohen suggests in his forthcoming monograph, a process of “successful disengagement,” especially in very old age.³⁴

A theory of aging and disability would examine how individuals can continue to live long and meaningful lives—especially as the long-term processes of disability in late life take effect—even if these lives are different from what they were in middle life and young old age. This new theory would address the reality that, in old age, the previous organizing framework of life recedes as people exit the workforce, lose their spouses, have fewer ties that bind them to place, and experience more difficulty getting

out and making new ties. Such a theory would not need to reject activity—and could even be pro-activity. It would, however, need to offer a vision of activity on a smaller scale, addressing the challenges of maintaining life and managing the tasks of day-to-day living that can be daunting to elders, especially when they are living with disability.

How Age Matters

Ironically, the acceptance of disability as part of the aging process may serve to bolster the significance of age as a scholarly construct within the discipline of gerontology. Few people would discount the importance of old age as a time with its own special meaning. In the past half-century, however, this traditional meaning has increasingly been called into question—and as we have seen, the field of gerontology has challenged the very idea that old age *qua* old age matters.³⁵

Attention to disability offers gerontology a way of looking at old age as both a diverse and a discrete period in life. Acknowledging the role of disability in old age reveals the ways in which disability restructures how people see themselves and are viewed by others throughout the aging process. Recognizing old age as a key life period reveals the dynamic ways in which disability is accepted (or rejected), internalized (or externalized), and managed (or not managed). For many disabled younger people, disability has always been part of their lives or has been from an early age. For older people, however, the transition from a state of not being disabled to one of being disabled is a process that provides a valuable window into a lesser-understood aspect of the human life course experience.

In addition, disability may unlock the mystery of why and how age matters. The fear of losing health and experiencing disability is a dominant concern for older persons, even outpacing their fear of death. This mindset—the fear of loss—is central to the consciousness of being old and distinguishes this period of life from earlier ones. This consciousness delineates a time frame when individuals find themselves changing gears and refocusing their attention on how to survive in late life. Yet this period also presents unique opportunities to develop the self by attaining a level of wisdom and peace that may allow for the journey forward—and permit many years of continued growth, though not necessarily by any conventional standard of success or productivity.

This point of view recognizes that we cannot defy age indefinitely; we will all grow old. The question is how we can retain our sense of self—who we are—while accepting changes in health and the inevitable disabilities and barriers that come with advanced age. This recognition and acceptance of aging broadens gerontology's well-known focus on healthy lifestyles to

include support for all older persons and those who care for them. As Malcolm Johnson urges, such support should be in the form of a public-private partnership that values individual autonomy—the opportunity to exercise control over one’s own life.³⁶

But even with government and private entities working together to provide this support, older people need something more: they need to find a community. The role of community—as both a place and a group of people who care for one another—can play a key role in minimizing disability. Elders who participate in community programs (e.g., senior centers), who volunteer to help others, and who retain a group of friends are more likely to continue to manage independently as they age and encounter disability. In contrast, older people who are not integrated into a community, who have not cultivated a practice of helping others, and who have few friends are more likely to find themselves isolated and without support in late life. Even if these individuals do not have many or significant physical impairments, they are at great risk for losing their independence.

Bodies and Minds in Time and Place

Old age and disability exist in a relational framework. Both the young and the old may experience disability—it cannot be defined by age alone. In this sense disability is analogous to space, its contours constantly shifting and uncertain. Similarly, we are all suspended between states of living and dying in a broad continuum of life. The idea that disability is not a state that is distinct from normal life was a prime claim for sociologist Irving Zola. He believed that disability is not an external and unnatural state, but one that at some point in time affects all people, though in degrees that can be as varied as the population itself.³⁷

The present reality is that disability is more often framed as a particular situation whose relevance is given meaning in relationship to others. This is why historians—who are the scholars most focused on time and context—have in recent years championed disability as an example of the “other” and what it means to speak of historical “otherness.”³⁸

This notion of the relational other has resonance for gerontologists’ views of aging and disability. What we mean by “health” and “wellness” in old age is often constructed in relation to those who are ill; how we construe “old” is often in relation to those who are young or young-old; and seniors we view as “disabled” are considered so in relation to seniors we perceive as able and capable. In each case, the strength of the positive modifier—the healthy old, the young-old, and the able old—is given meaning by an often unmentioned other, and this is the negative modifier: the sick old, the old-old, and the disabled old.

The concepts of aging and disability are not only relational, but also quite inclusive. Both are social categories with core and noncore members. In the first category, that core group consists of people over age eighty-five, who are considered by gerontologists to make up the old-old. In the second category, that core group consists of people whose disabilities have long been recognized by society as markedly distinguishing (as real or core disabilities): those who are totally blind, those who experience fundamental mobility impairments, and those who are deemed mentally impaired. In both the aging and disabled categories, the noncore groups are more varied in functional abilities as well as self-perceptions.³⁹

Navigating the borders of what we mean when we speak of someone as “aged” or “disabled” is not merely about semantic constructions. These are also categories that enlist claims on the public, its resources, and the social expectations of those currently neither aged nor disabled. The very old and those persons with core disabilities share certain common themes in public policy, including society’s paternalistic attitude toward them. These groups are viewed with sympathy and pity—such that they are deemed worthy of support and assistance. For much of our history, the old-old and the core disabled were indeed set apart. The very old and the very disabled often found themselves in special institutions, where their days were subjected to disciplined regimes designed to promote order and stability. Neither group had much prospect for inclusion in society writ large. Their world was—and, in the case of many, still is—an other world.

The story of modern disability policy has been the breakdown of the separate silos that had previously marked each of these groups as distinct. The impulse toward democratization at the turn of the twentieth century, during the Progressive Era, led to a typology approach to disability. New policies in special education and rehabilitation, along with alternating fears and hopes for those deemed disabled, started a course of state interest in addressing differences based on dependency and ability. Although the resulting policies were often confused and oppositional, they focused on addressing an ever wider range of issues—educational, work related, medical, and financial—that surfaced in a new society, economy, and polity. The typology approach to disability—with its distinct groups of the blind, the deaf, the crippled, and the mentally impaired—increasingly gave way to viewing disability as a larger social and economic issue. A broader spectrum of disability emerged that occupied policymaking at the state and, beginning with the New Deal, federal level. This elastic notion of disability as a broad catchall would find its most complete statement in the 1990 Americans with Disabilities Act (ADA).

The understanding that aging posed a similar set of issues that mattered to the public also has its roots in the Progressive years—albeit during the seemingly immoderate Roaring Twenties. Many states organized

commissions to consider the “problem of aging” as the percentage of older people grew in relative and absolute terms.⁴⁰ The modernizing economy—and the transformation that new technologies and efficiency systems promised to bring about—won the approbation of many who praised the “divinity of machinery.”⁴¹ This was a decade when “labor-saving methods” were imposed through “what Thomas P. Hughes has called ‘Networks of Power’”⁴² and older workers had a harder time keeping up. In this environment, policymakers increasingly focused on the issues posed by superannuated workers as well as older people who had worked throughout their lives and in old age found themselves without work, resources, or family. The fear was that, without the help of the state, these individuals could not survive.

The concepts of disability and old age retain core elements that are based on this similar history of dependency and need (framed within a compass of public virtue) that distinguishes the plight of each group’s members and makes them attractive recipients of assistance.⁴³ But this support diminishes when the rights and privileges that are granted to a blind person or a person who requires a wheelchair or an individual with profound mental challenges are extended to the malleable lists of disabling conditions that are recognized under law. In such instances, it seems that the very meaning of *real* disability is diluted in a sea of special interests.⁴⁴ A similar diminution in attitude toward programs for the aged has been ongoing since the late 1970s and early 1980s. As the size of the federal budget devoted to aging—through Social Security and Medicare—continues to increase and as many beneficiaries of these programs receive far more than they have contributed, those older persons who are not truly needy are increasingly eroding society’s sympathy for the senior cause.⁴⁵

The futures of disability policy and aging policy are thus caught in a paradox. As these policies have become more generalized and greater numbers of individuals are included in benefit programs, the specialness of the disabled and the aged—as dependents who are deserving of support based on their unique conditions—has diminished. There is much talk of benefit seekers who abuse the classification of disability and of greedy geezers who receive disproportionate benefits. How can public policies for these groups evolve in response to a twenty-first-century society that will both be older and experience higher rates of disability for all age groups? How can these policies best serve an inclusionary model that fosters dignity, promotes care, and avoids the excessive benefit seeking that imperils public support? As we contemplate the growing number of seniors who will age with disabilities in the coming decades, these questions demand our attention. We can begin to answer them by understanding the interconnections between the concepts of aging and disability.

Notes

1. Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity* (Simon and Schuster, 2009); Irving Kenneth Zola, *Missing Pieces: A Chronicle of Living with a Disability* (Temple University Press, 1982).

2. Joseph P. Shapiro, *No Pity: People with Disabilities Forging a New Civil Rights Movement* (Three Rivers Press, 1994).

3. Gerontologists have studied this process of age-associated disease within the framework of the “cascade of disability.” See Lois M. Verbrugge and Alan M. Jette, “The Disablement Process,” *Social Science and Medicine* 38, no. 1 (1994): 1–14.

4. These words resonate with most people, yet most of us do not realize that *old age* and *disability* relate not just to others, but also to ourselves—if not now, then at some point in our lives. We are all aging, and we all fear the loss of ability—although we do not always feel these fears at a conscious level.

5. Robert N. Butler, *The Longevity Revolution: The Benefits and Challenges of Living a Long Life* (PublicAffairs, 2010).

6. Phillip L. Berman, *The Courage to Grow Old* (Ballantine Books, 1989), xii.

7. Eva Kahana, Tirth Bhatta, Loren D. Lovegreen, and Boaz Kahana, “Altruism, Helping, and Volunteering: Pathways to Well-Being in Late Life,” *Journal of Aging and Health* 25, no. 1 (2013): 159–187.

8. Ronald J. Berger, *Introducing Disability Studies* (Lynne Rienner, 2013); Rosalyn Benjamin Darling, *Disability and Identity: Negotiating Self in a Changing Society* (Lynne Rienner, 2013); Dana Lee Baker, *The Politics of Neurodiversity: Why Public Policy Matters* (Lynne Rienner, 2011).

9. Not too long ago, few undergraduates showed any interest in older persons. Today, classes in aging-related subjects—even courses on death and dying—are quite popular, and the Gerontological Society of America (GSA) has a burgeoning student membership. The *millennial generation* is defined broadly as those born after 1980. See William Strauss and Neil Howe, *Generations: The History of America's Future, 1584 to 2069* (William Morrow, 1991); Neil Howe and William Strauss, *Millennials Rising: The Next Great Generation* (Vintage Books, 2009).

10. Robert Butler, *Why Survive? Growing Old in America* (Harper and Row, 1975).

11. An adverse view of disability is not without foundation in experience. A leading historian argues that in Western cultures, social “hierarchy depends on the threat of disability always lurking as the ultimate living catastrophe.” See Catherine J. Kudlick, “Disability History: Why We Need Another ‘Other,’” *American Historical Review* 108, no. 3 (2003): 765. It should be noted that disability scholars view the concept of disability as “a key defining social category on a par with race, class, and gender” rather than as “an individual characteristic.” *Ibid.*, 764–765. Disability also serves an emancipatory function as “an effective weapon in contests over power and ideology.” See Kim E. Nielsen, *A Disability History of the United States* (Beacon Press, 2012), xiii.

12. It should be noted, however, that internal stigmas have existed toward people whose disability includes a degenerative component, as opposed to those whose disability is in conjunction with stable health. Sociologist Irving Zola explores this notion in his account of Het Dorp, a residential community for adults with severe physical disabilities in the Netherlands. Zola observed the distinctions that community members drew between the “diseased” and the “handicapped.” As one longtime resident told him: “To be handicapped is to be stabilized, to be diseased is *not*”

[emphasis in original]. Irving Kenneth Zola, *Missing Pieces: A Chronicle of Living with a Disability* (Temple University Press, 1982), 53.

13. Christina Victor, "The Epidemiology of Ageing," in *The Cambridge Handbook of Age and Ageing*, ed. Malcolm L. Johnson, with Vern L. Bengtson, Peter G. Coleman, and Thomas B. L. Kirkwood (Cambridge University Press, 2005), 95. A natural corollary to this focus on health is the imperative to avoid disability in old age. John W. Rowe and Robert L. Kahn, "Successful Aging," *The Gerontologist* 37, no. 4 (1997): 433–440.

14. The view that longer life entails a greater period of more severe disability is suggested by Michael Marmot, *Status Syndrome: How Your Social Standing Directly Affects Your Health and Life Expectancy* (Bloomsbury, 2004). The exact relationship between extended life and disability is not clear—specifically, whether disability will constrict or expand as people live longer. For a review of the literature on population trends and late-life disability, see Vicki A. Freedman, "Disability, Functioning, and Aging," in *Handbook of Aging and the Social Sciences*, 7th ed., ed. Robert H. Binstock and Linda K. George, with Stephen J. Cutler, Jon Hendricks, and James H. Shulz (Elsevier/Academic Press, 2011), 66–68.

15. Malcolm Johnson notes that research on health and illness in old age "is more methodologically and technically proficient" than it was in the past but "there is no parallel development in our conceptualising. Theoretical work remains a remarkably neglected area of gerontological work." See Malcolm L. Johnson, "Preface," in *The Cambridge Handbook of Age and Ageing*, ed. Malcolm L. Johnson, with Vern L. Bengtson, Peter G. Coleman, and Thomas B. L. Kirkwood (Cambridge University Press, 2005), xxi–xxiii. W. Andrew Achenbaum, the respected historian of old age and gerontology, has likewise shown how physical decline and its connection to old age are the preeminent concerns of the field. See W. Andrew Achenbaum, *Crossing Frontiers: Gerontology Emerges as a Science* (Cambridge University Press, 1995).

16. Achenbaum, *Crossing Frontiers*; see also W. Andrew Achenbaum, *Old Age in a New Land: The American Experience Since 1790* (Johns Hopkins University Press, 1978).

17. Robert H. Binstock and Ethel Shanas, with Vern L. Bengtson, George L. Maddox, and Dorothy Wedderburn, *Handbook of Aging and the Social Sciences* (Van Nostrand Reinhold, 1976).

18. Linda George and Kenneth Ferraro, *Handbook of Aging and the Social Sciences*, 8th ed. (Academic Press, 2015).

19. Another factor that has anchored aging research in health has been the funding mechanisms established by the National Institute on Aging (NIA), which is part of the larger National Institutes of Health (NIH). Funding in the basic sciences of aging has been health oriented—how to promote a biology of wellness in old age, largely through clinical trial research designs—and projects that are more socially based generally must show a connection with the goals of health promotion and disease prevention. There is limited funding to explore how life with disability in old age can be made more meaningful or satisfactory to those living with disability. See Timothy J. O'Leary, Jean R. Slutsky, and Marie A. Bernard, "Comparative Effectiveness Research Priorities at Federal Agencies: The View from the Department of Veterans Affairs, National Institute on Aging, and Agency for Healthcare Research and Quality," *Journal of the American Geriatrics Society* 58, no. 6 (2010): 1187–1192.

20. Thomas R. Cole, *The Journey of Life: A Cultural History of Aging in America* (Cambridge University Press, 1992), 227.

21. Ralph Linton, "Age and Sex Categories," *American Sociological Review* 7 (1942): 589–603; L. S. Cottrell Jr., "Adjustment of the Individual to Age/Sex Roles," *American Sociological Review* 7 (1942): 617–620.

22. See Otto Pollack and Glen Heathers, "Social Adjustment in Old Age: A Research Planning Report," *Sociological Practice* 11, no. 1 (1993): 33–39. See also George Lawton, *New Goals for Old Age* (Columbia University Press, 1945); Nathan Wetherill Shock, *Trends in Gerontology* (Stanford University Press, 1951).

23. Often trained in social work, a cadre of gerontology researchers and professionals soon emerged who would serve as guides to the elderly in how to manage their lives effectively in the later years. See Carroll L. Estes, *The Aging Enterprise* (Jossey-Bass, 1979).

24. Irving Rosow, *Socialization to Old Age* (University of California Press, 1974), 12.

25. Bernice L. Neugarten and Gunhild O. Hagestad, "Age and the Life Course," in *Handbook of Aging and the Social Sciences*, ed. Robert H. Binstock and Ethel Shanas, with Vern L. Bengtson, George L. Maddox, and Dorothy Wedderburn (Van Nostrand Reinhold, 1976), 52.

26. Butler, *Why Survive?* 7.

27. *Ibid.*, 11–12.

28. Richard A. Settersten Jr., "Aging and the Life Course," in *Handbook of Aging and the Social Sciences*, 6th ed., ed. Robert H. Binstock and Linda K. George (Academic Press, 2006), 8. Settersten offered his colleagues a corrective to gerontology's emphasis on variability among the aging by asking them to "be as open to things that are shared by old people, experiences that may persist across time and context, as we are to the things that make old people different and may vary across time and context." *Ibid.*

29. "Collective family requirements and strategies" are central to the study of the life course and have functioned in many capacities throughout history. See Tamara K. Hareven, "The History of the Family and the Complexity of Social Change," *American Historical Review* 96, no. 1 (1991): 106. For example, families have helped secure work and fostered adaptation to the workplace; see Tamara K. Hareven, *Family Time and Industrial Time: The Relationship Between the Family and Work in a New England Industrial Community* (Cambridge University Press, 1982). In rural societies, families have provided for family members in old age as part of an inheritance contract "in which sons agreed to support aging parents in exchange for inheriting property"; see Hareven, "The History of the Family and the Complexity of Social Change," 116. More recently and closer to home, families have helped secure appropriate education for disabled children. What makes the family's place special and deserving of attention is "its bond of 'love' and 'altruism' not generally thought to be found in other groups in our society"; see Hareven, "The History of the Family and the Complexity of Social Change," 117.

30. Robyn Stone, Gail Lee Cafferata, and Judith Sangl, "Caregivers of the Frail Elderly: A National Profile," *The Gerontologist* 27, no. 5 (1987): 616–626.

31. Elias S. Cohen, personal communication with the authors, 2015.

32. Elias S. Cohen, forthcoming work, in possession of the author.

33. See Elaine Cumming and William Earl Henry, *Growing Old: The Process of Disengagement* (Basic Books, 1961).

34. Elias S. Cohen, manuscript in possession of the authors. See also Elias S. Cohen, "The Last 2000 Days," *The Gerontologist* 57, no. 1 (2017): 116–120.

35. Indeed, the newest movement in the field sees the earlier life course as integrated into old age, so that aging is considered more of a lifelong process than a dis-

crete period. According to such a measure, it is the earlier period of the life course that informs much of our understanding of what comes later.

36. Malcolm Johnson, "Dependency and Interdependency," in *Ageing in Society*, ed. John Bond and Peter G. Coleman (Sage, 1993).

37. Zola, *Missing Pieces*.

38. Catherine L. Kudlick argues that the discovery of disability by scholars in the fields of anthropology, sociology, and literature has allowed historians of disability "to rethink what we do." Kudlick, "Disability History," 763–764.

39. The case of the deaf is more complex. See Douglas C. Baynton, *Forbidden Signs: American Culture and the Campaign Against Sign Language* (University of Chicago Press, 1996).

40. Achenbaum, *Old Age in a New Land*, 115–116.

41. Carroll Pursell, *The Machine in America: A Social History of Technology* (Johns Hopkins Press, 2007), 230.

42. Ibid. Pursell is referring to Thomas Parke Hughes's *Networks of Power: Electrification in Western Society, 1880–1930* (Johns Hopkins University Press, 1983).

43. See Harlan L. Lane, *When the Mind Hears: A History of the Deaf* (Random House, 1984).

44. On disability as a special category, see Richard K. Scotch, "Disability Policy: An Eclectic Overview," *Journal of Disability Policy Studies* 11, no. 1 (2000): 6–11.

45. Robert H. Binstock, "The Emergence of the Oldest Old: Challenges for Public Policy," in *The Future of Age-Based Public Policy*, ed. Robert B. Hudson (Johns Hopkins University Press, 1997), 56–73.

