DISABILITIES AND THE LIFE COURSE

Edited by Heather E. Dillaway,
Carrie L. Shandra and Alexis A. Bender

RESEARCH IN SOCIAL SCIENCE AND DISABILITY

VOLUME 14

DISABILITIES AND THE LIFE COURSE

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EDITED BY

HEATHER E. DILLAWAY
Illinois State University, USA

CARRIE L. SHANDRA
State University of New York at Stony Brook, USA

And

ALEXIS A. BENDER
Emory University, USA

emerald
PUBLISHING

United Kingdom – North America – Japan
India – Malaysia – China

Emerald Publishing Limited
Howard House, Wagon Lane, Bingley BD16 1WA, UK

First edition 2023

Reprints and permissions service
Contact: permissions@emeraldinsight.com

British Library Cataloguing in Publication Data
A catalogue record for this book is available from the British Library

ISBN: 978-1-80455-202-5 (Print)
ISBN: 978-1-80455-201-8 (Online)
ISBN: 978-1-80455-203-2 (Epub)

ISSN: 1479-3547 (Series)

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LIST OF CONTRIBUTORS

Alexis A. Bender	Emory University School of Medicine, USA
Célia Bouchet	Centre for Research on Social Inequalities (CRIS) and Laboratory for Interdisciplinary Evaluation of Public Policies (LIEPP), Sciences Po, France
Mathéa Boudinet	Centre for Research on Social Inequalities (CRIS) and Laboratory for Interdisciplinary Evaluation of Public Policies (LIEPP), Sciences Po, France
Tess Bowles	Emory University, USA
Robyn Lewis Brown	University of Kentucky, USA
Fiona Burke	State University of New York at Stony Brook, USA
Kiera Chan	Emory University, USA
Heather E. Dillaway	Illinois State University, USA
Nancy G. Kutner	Emory University, USA
Scott D. Landes	Syracuse University, USA
Kenzie Latham-Mintus	IUPUI, USA
Louise C. Palmer	Virginia C. Crawford Research Institute, Shepherd Center, Atlanta, Georgia, USA
Anna Penner	Pepperdine University, USA
Anne Revillard	Centre for Research on Social Inequalities (CRIS) and Laboratory for Interdisciplinary Evaluation of Public Policies (LIEPP), Sciences Po, France
Carrie L. Shandra	State University of New York at Stony Brook, USA
Hillary Steinberg	AJ Drexel Autism Institute, USA

ACKNOWLEDGMENTS

We would like to thank all of our colleagues who donated their time to serve as peer reviewers for pieces in this volume and provided valuable feedback to the authors. We also would like to thank Kiera Chan and Riley Hunt for their assistance with the final edits for the volume. Collectively, we also thank all study participants showcased in this volume for sharing their stories with our esteemed colleagues so we can understand their lived experiences across the life course. Finally, we thank Barbara M. Altman, Sharon N. Barnartt, Allison C. Carey, and Sara E. Green for leading the charge on this book series and allowing us to be part of the legacy.

INTRODUCTION: DISABILITIES AND THE LIFE COURSE

Heather E. Dillaway, Carrie L. Shandra, Kiera Chan and Alexis A. Bender

AUTHOR BIOGRAPHIES

Heather E. Dillaway, PhD, is a Professor of Sociology and Dean of the College of Arts and Sciences at Illinois State University. Her research focuses on women's experiences of menopause and midlife, and the reproductive health experiences of women with physical disabilities. Her research on women's experiences of physical disability appears in a range of journals and book volumes, including *Sex Roles, Disability Studies Quarterly, Disability and Health Journal, American Journal of Occupational Therapy, The Journal of Spinal Cord Medicine, Research in Social Science and Disability*, and *The Oxford Handbook on the Sociology of Disability*. She also coedited a special issue of *Gender & Society* on intersectionality, gender and disability.

Carrie L. Shandra, PhD, is an Associate Professor in the Department of Sociology at Stony Brook University. Her research focuses on work (broadly defined) and life course inequalities in the United States, particularly as they occur during the transition to adulthood and among individuals with disabilities. She has held fellowships from the Russell Sage Foundation, Sciences Po, the National Institute on Disability, Independent Living, and Rehabilitation Research, and the National Academy of Education/Spencer Foundation. Select work has appeared in *Social Forces, Journal of Marriage and Family*, *Social Science Research*, and *Sociological Perspectives.*

Kiera Chan, MPH, is a senior research interviewer and research associate in the School of Medicine at Emory University. She is a qualitative researcher whose work centers around stigma, chronic illness, patient care, and women's empowerment. She aims to progress patient-centered care via research, advocacy, and community engagement. She applies a sociological lens toward public health topics by studying the social determinants of health and illuminating key barriers

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Disabilities and the Life Course
Research in Social Science and Disability, Volume 14, 1–10

ISSN: 1479-3547/doi:10.1108/S1479-354720230000014001

in the healthcare system. She conducts both global and domestic research emphasizing the role of stigma in health among vulnerable populations. She currently works on patient-centered care related research on topics of HIV, substance use, dementia, and disability.

Alexis A. Bender, PhD, is an Assistant Professor in the Department of Medicine at Emory University. Dr. Bender completed her PhD in Sociology with a concentration in family, health, and the life course and an interdisciplinary certificate in gerontology. Her research broadly focuses on aging with disability and chronic disease with an emphasis on relationships over the life course. Dr. Bender is a fellow in the NIMH-funded UCSD Sustained Training in Aging & HIV Research (STAHR) program and receives funding from the National Institute on Aging and the National Institute on Drug Abuse. Select work has appeared in *The Gerontologist*, *Journals of Gerontology, Social Sciences, Journal of the American Geriatric Society*, and *Journal of Applied Gerontology*, where she also serves on the editorial board.

INTRODUCTION

Keeping the Focus on Disability

Over 1 billion people – approximately one in six individuals – currently report "significant" disability across the world (World Health Organization [WHO], 2022). In the United States, one in four adults has a disability: 14% of the population reports physical disability, 11% cognitive disability, 6% hearing difficulties or deafness, and 5% vision impairments or blindness (CDC, 2022). Although there is no definitive list, disabilities can be categorized as (1) congenital or acquired, (2) physical, cognitive, or sensory, (3) visible or invisible, and (4) severe, moderate, or mild. Higher rates of disability worldwide are largely attributed to the aging of populations, higher incidence of chronic health conditions and noncommunicable diseases such as cardiovascular disease and diabetes, and greater risk of accidental injuries such as motor vehicle accidents (CDC, 2022). Furthermore, according to the World Health Organization (WHO, 2002), almost everyone will be temporarily or permanently impaired at some point in life because of eventual acquired disabilities (see also Dillaway et al., 2022). Considering the increasing inevitability of disability acquisition across the lifespan and increasing rates of disability in general, it is important to understand how individuals experience disabilities over time and place – particularly because disabilities vary in how they manifest and affect individuals' lives.

The International Classification of Functioning Disability and Health (ICF) defines disability as not just an attribute or fixed property of a person but, rather, a state that results from the interaction between a person and environment (WHO, 2002; see also Naples et al., 2019). Therefore, while disability may be based loosely on the existence of an underlying impairment of some kind, impairment alone does not determine experience (WHO, 2002). Disability studies scholars in the social sciences have tried to keep the focus on disability as the embodied experience of impairment, as well as the structural barriers that individuals with disabilities confront (Mauldin & Brown, 2021; Naples et al., 2019). As different authors note in this volume, individuals with disabilities report discrimination in all areas of their lives: employment, education, healthcare, relationships with others, etc. (Frederick & Shifrer, 2019; MacInnes, 2011; Maroto et al., 2019; Mauldin & Brown, 2021; Naples et al., 2019; Pettinichio et al., 2021; Shandra, 2018; Shifrer & Frederick, 2019). Indeed, individuals with disabilities are "subject to ableist processes that result in their exclusion and marginalization" (Naples et al., 2019, p. 5; see also Frederick & Shifrer, 2019; Pettinichio et al., 2021; Shifrer & Frederick, 2019). This means that disability status is an axis of inequality, similar to race, class, gender, sexuality, and age, that reflects larger systems of oppression (Frederick & Shifrer, 2019; Mauldin & Brown, 2021; Shandra, 2018; Shifrer & Frederick, 2019). As social scientists who seek to deepen our understanding of impairment and disability, we must continue to interrogate how individuals with disabilities navigate embodied experiences and confront macro-level barriers across the lifespan.

A Life Course Perspective

Emerging first in the 1960s, the life course perspective is a theoretical framework developed to examine "continuity and change of human lives in relation to interpersonal, structural, and historical forces" (Elder et al., 2003, p. 4). Sociologists, anthropologists, social historians, demographers, social workers, economists, political scientists, and developmental psychologists, among others, have worked to advance this paradigm across disciplines. They have called attention to myriad topics: the significance of historical events and social change in shaping individual lives; cohort, period, and generational differences in lived experience; varied pathways to adulthood and older age; typical life transitions and turning points; the timing and sequencing of personal events and decisions; and how individuals can employ human agency across the life course (Elder, 1994; Elder et al., 2003; Harrington Meyer, 2014). Life course scholars propose that "depending on the exact life stage, different factors or issues take on differing degrees of importance" and become significant in shaping identity and experience as well as an individual's ability to accomplish certain typical life transitions and trajectories (Dillaway et al., 2022; Elder et al., 2003; Roehling et al., 2001, p. 146). Life course analysis also enables researchers to observe how individuals navigate a particular identity or experience within one single moment as well as to consider how individuals negotiate a particular identity or experience over time (Harrington Meyer, 2014). An emphasis on the life course, therefore, allows us to see the immediate, cumulative, and/or longstanding effects of individuals' and groups' experiences.

As Robyn Brown appropriately notes in this volume, "the life course paradigm is not a single cohesive perspective, but a combination of perspectives guided by … principles and methodological considerations." As many other authors in this volume also note, a life course lens is guided by four main themes that researchers and practitioners utilize in different ways as they engage in the "long way of thinking" about human lives and social pathways (Elder, 1994, p. 5): (1) "the interplay of human lives and historical times," (2) the timing of life transitions and events, (3) how individuals lead interdependent or "linked lives," and (4) how individuals use agency as they make choices across the lifespan. Elder et al. (2003) detail a fifth theme in later publications, reminding life course scholars that human development and aging are "lifelong processes." In emphasizing timing, transitions, and trajectories, as well as how historical forces and social institutions can shape day-to-day life, life course scholars focus on connections between the macro- and micro-levels of experience and examine both continuity and change in people's identities and experiences across time.

Our Project: Applying a Life Course Lens to the Study of Impairment and Disability

All individuals, with or without disabilities, have storied lives that unfold across time and place. Impairments and disabilities also have varied meanings and implications depending on time, place, and other life contexts. That is, an individual's identity and experience of an impairment or disability at one moment could be quite different from their identity and experience at another moment. At the same time, an entire cohort or generation of individuals with the same type of impairment or disability may face similar lived experiences in key moments, depending on historical context and the opportunities created by technologies, institutions, or policies. Alternatively, individuals could experience the same moment very differently depending on their social locations, types and levels of impairment or disability, past experiences, and current life contexts.

In this volume we aim to broaden the application of the life course perspective to explore the multiple ways in which impairments and disabilities factor across the lifespan and have diverse impacts in assorted life stages. In addition, we aim to highlight how individuals might think about, maneuver, and encounter impairments or disabilities, in a variety of ways depending on time, place, and life contexts. Consequently, the primary purpose of this volume is to expand our knowledge of impairments and disabilities across the life course, both in terms of how they can change in form, meaning, and experience across time and life stage and how certain life course transitions and events can manifest differently or carry new meanings because of impairment or disability status. We hope to prioritize explorations of individuals' lived identities and experiences as well as the macro-level structures that shape these identities and experiences. Finally, we seek to highlight commonalities and differences in identity and experience with special attention to intersecting social locations and the diversity of impairments and disabilities.

Layout of This Volume

As expected, authors in this volume adopt a wide range of methodologies and approaches to studying disability using a life course perspective. Depending on the chapter, the reader will encounter analyses of data drawn from reviews of existing literature, in-depth case studies, individual interviews, and nationally representative survey data. Authors in this volume specifically contribute to our knowledge of the effects of macro-level contexts on individuals' identities and experiences, linked lives, timing and time use, human agency, cumulative disadvantage, and the intersections of disability with other social locations. Overall, all authors expand our understanding of the continuity and change in both identity and experience, and the ways in which a life course lens can improve our considerations of impairment and disability across the life course. We organize the chapters to reflect authors' different foci and contributions. We begin with chapters that are more conceptual, that consider generally how a life course perspective may help us comprehend disability identity and experience. We then move to pieces that explicitly tackle issues of stigma and identity across the lifespan. Later chapters help us understand disability-related educational experiences, the effects of disability on familial relationships, employment trends for people with and without disabilities, spouses' entry into and negotiation of caregiving roles, and interrogations of specific concepts such as diagnosis pathways, spoiled identity, doing disability, policy reception, work precarity, and time use.

We purposely begin our volume with a conceptual chapter by Kenzie Latham-Mintus and Scott Landes, as these authors focus readers on key concepts and themes of the life course perspective. Latham-Mintus and Landes apply Elder et al.'s (2003) five principles to "reconsider" the life course lens while centering disability status as an axis of inequality and paying close attention to macro-level contexts. *Time and place* play a crucial role in the disability experience, including historical period, geographic location, and birth cohort – as well as policies and social movements that expand or restrict opportunities for disabled populations. *Timing and age effects* should consider how disability, timing and duration of disability, and structural ableism shape life transitions, social trajectories, and cumulative dis/advantage. *Agency* is bounded by social policies, institutionalization, and administrative burden, and is inseparable from the concept of *linked lives* and interdependence. Finally, the resilience and adaptation that accompany *lifespan development* should be considered in tandem with the unique social, environmental, and structural contexts faced by people with disabilities. Latham-Mintus and Landes offer both theoretical and methodological suggestions for aging and disability scholars to "better attend" to issues of disability across the life course.

Louise Palmer reviews existing research on multiple sclerosis (MS) to integrate core concepts of life course theory with an intersectional feminist disability perspective – two equally critical frameworks for understanding disability experience. Palmer highlights the dearth of comprehensive research on the variation in MS trajectories and outcomes, especially by social locations such as race, ethnicity, class, gender, sexual orientation, nationality, age, and disability. Introducing the concept of "diagnosis pathways," she suggests that time from symptom onset to diagnosis determines MS illness trajectories, and that these pathways are shaped by overlapping systems of inequality. Certain groups therefore experience delays in diagnosis which create further disparities in health outcomes across the life course. Individuals' abilities to use relationships with others or their own agency to influence the diagnosis process are also shaped by social locations. Palmer draws from the limited research on racial-ethnic disparities in time to MS diagnosis to show readers how to discern the effects of macro-level inequalities on health outcomes across time. This author ultimately explains how we might miss the importance of this variation in diagnosis pathways if we are not pairing a life course lens with an intersectional perspective. In this way, Palmer illustrates the flexibility of life course theory, in that it can be easily paired with other conceptual frameworks to understand disability and chronic health experiences.

We next turn to issues of disability identity and the French national context with Célia Bouchet and Mathéa Boudinet's chapter. These authors present data from 65 biographical interviews from two separate qualitative studies to examine how individuals with disabilities affiliate and identify with different social groups as they interpret reasons for the disadvantages they face over time. Respondents in this study invoke their disability as a primary cause of negative experiences in a variety of circumstances. In particular, interviewees who had been labeled as "disabled" for a longer period of time were socialized to understand that this identity is more salient than other social locations such as gender or race. However, those who acquired a disability later in life often attributed negative experiences primarily to another social location or identity. The authors also track certain "turning points" in the ways that participants make connections between their identities and the inequalities they face. For example, Bouchet and Boudinet propose that participants reinterpreted the underlying causes of disadvantages they faced as they learned more about their own intersecting social locations and the history of macro-level inequalities over time. Most participants still named a single identity and affiliation as the primary cause of a negative experience, however, even if they defined their experience as based in multiple social locations. This chapter allows readers to contemplate the ways disability identity might be more or less salient over time and how certain types of socialization and education may affect one's sense of identity. These authors also help us understand the reasons why the concepts of time, agency, and linked lives matter, and why and how disability identity and experience might vary across the life span.

Furthering our understanding of disability identity and experience in particular life stages, Nancy Kutner and Tess Bowles interview young adults living with kidney failure about dimensions of young adult development. While all individuals, regardless of disability status, must make the transition "to and from young adulthood," Kutner and Bowles' participants were dependent on medical treatments to manage their conditions. These treatments, in turn, impacted independent living, regular employment, and community involvement – three indicators of "successful" development reported by participants. From their interviews, Kutner and Bowles identify the theme of perceived condition-related stigma and apply Goffman's (1963) notion of spoiled identity, discussing how "different" participants felt in comparison to those without chronic conditions. Finally, they show how participants felt isolated from peers, with limited opportunities to share experiences and identify with others. The authors note that relationships with others and participation in specialized "transition clinics" or other developmentally appropriate programming may benefit young adults who might have difficulty making "on-time" life course transitions because of disabling chronic conditions.

Hillary Steinberg's chapter is an additional analysis of disability identity and performance, yet with attention to how individuals "do" disability and gender simultaneously within ableist environments. This author uses a life course approach to illuminate how early socialization to gender expectations and ableist expectations may have implications for how individuals with disabilities perform gender and disability in later life stages. Specifically, Steinberg focuses on how interviewees, regardless of gender, learn that ableist expectations encourage "feminine" behavior. While some (especially women and nonbinary individuals) may explicitly resist performing gender in feminine ways, such as worrying about others' discomfort over their own when dealing with a disability in a public space, all interviewees reported knowing that emphasized femininity is expected of them. Additionally, interviewees who identified as men also noted the benefits of emphasized femininity in interactions with others about their disabilities. Data presented in this chapter confirm that expectations for gender and disability performance cannot be separated. Steinberg also proposes that living with disability is, itself, a gendered process that impacts both gender and disability identity and performance in all life stages. In reviewing this chapter, then, readers will understand the ways in which different macro-level structures intersect to enforce certain gendered behaviors among those who confront ableism across the lifespan.

Anne Revillard subsequently emphasizes the importance of thinking about how macro-level forces – in this case, changes to disability-related educational policy in France – impact individuals with disabilities on the micro-level. That is, the author clarifies that the study of policy making and policy change must include an evaluation of how policy is received by the individuals targeted by such policy. Studying policy reception through qualitative interviews with individuals born and schooled in different time periods, Revillard shows that policies can have differential effects on individuals depending on personal contexts and one's ability to enact agency. In analyzing the narratives of a woman born in 1942, in the era of separate schooling, and a man born in 1985, in a period of school integration, Revillard compares and contrasts the ways in which policy both limits and expands individuals' opportunities. Thus, public policies have "both a constraining and an enabling effect on individuals." Studying policy reception via a life course lens means focusing on the micro-level effects of policy-making across time periods, cohorts, and generations. Revillard outlines the complexities in studying how macro-level forces impact individuals across time and place.

Anna Penner applies the life course concepts of linked lives and social pathways to evaluate the long-term impact of disabilities – specifically, the effects of growing up with a disabled sibling. Penner utilizes nationally representative survey data to examine the likelihood of college completion among individuals with a disabled sibling, finding that women with disabled siblings are less likely to complete college than women without disabled siblings. However, having married parents eradicates this gap in college completion. Penner indicates that there are invisible costs of having a child with disability within a family unit, but the exact impact on family members varies by social location and parents' relationship status. Readers are reminded that applying the concept of linked lives to the lived experience of disability means studying the effects of disability on both those with disabilities and those within their social networks.

Also concentrating on the effects of disability on the family unit, Alexis Bender explores couples' transitions after one partner incurs a spinal cord injury. Following 18 couples through rehabilitation care and the subsequent transition home, Bender examines how the noninjured partner becomes involved in caregiving and the types of caregiving roles they adopt. She tracks how couples enter, negotiate, and adjust to or exit caregiving relationships across time, and finds three main groups of caregivers in the process: naturalized, constrained, and resistant. Bender examines how healthcare institutions (particularly rehabilitation settings), social class and employment status, and gendered cultural constructions of women as caregivers all influence couples' transitions to the caregiving relationship. Data presented in this chapter reaffirm how important it is to pay attention to the relationships between individuals with disabilities and their partners and/or caregivers, as well as the influence of those in healthcare settings. Bender further urges us to pay attention to individuals' social locations as well as the macro-level ideologies that shape people's perceptions of disabilities and their impacts. Inevitably, individuals and couples will experience disability and life course transitions and trajectories differently depending on these external factors.

Robyn Lewis Brown uses longitudinal, nationally representative data to consider how individuals with disability experience cumulative disadvantage in two types of outcomes: work precarity and involuntary job loss. Results for the first outcome indicate that having a disability in 1986 was positively associated with work precarity (as measured by job and income insecurity) after the start of the Great Recession. Further, people with disabilities who experienced early income insecurity were more likely to experience later income insecurity than people without disabilities. Results for the second outcome show that having a disability in 1986 increased the hazard of involuntary job loss two decades later. Finally, the adverse effects of early job precarity on later job loss were significantly larger for people with disability, compared to those without disability. People with disabilities are disproportionately impacted by early work precarity, despite the passage of the Americans with Disabilities Act during the study period. Brown argues that quantitative researchers must attend to continuity and change over time when studying people with disabilities. In considering both age and period effects across five waves (and 26 years) of data, Brown is able to decipher the employment consequences of living with a disability more fully than with cross-sectional data alone.

Finally, Carrie Shandra and Fiona Burke also use nationally representative survey data to consider how daily time in activities of daily living, instrumental activities of daily living, and other social activities varies by age, gender, and