NANCY J. EVANS ELLEN M. BROIDO KIRSTEN R. BROWN AUTUMN K. WILKE

# DISABILITY IN HIGHER EDUCATION

A SOCIAL JUSTICE APPROACH

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# A Social Justice Approach

Nancy J. Evans Ellen M. Broido Kirsten R. Brown Autumn K. Wilke



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Published by Jossey-Bass A Wiley Brand One Montgomery Street, Suite 1000, San Francisco, CA 94104-4594—www.josseybass.com

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#### Library of Congress Cataloging-in-Publication Data

Names: Evans, Nancy J., 1947– author. | Broido, Ellen M., 1965– author. |
Brown, Kirsten R., author. | Wilke, Autumn K., author.

Title: Disability in higher education: a social justice approach / Nancy J. Evans,
Ellen M. Broido, Kirsten R. Brown, Autumn K. Wilke.

Description: San Francisco, CA: Jossey-Bass, 2017. | Includes
bibliographical references and index.

Identifiers: LCCN 2016044997 | ISBN 9781118018224 (cloth) | ISBN 9781118415689 (epub) |
ISBN 9781118418543 (epdf)

Subjects: LCSH: People with disabilities—Education (Higher)—United States. |
College students with disabilities—United States.

Classification: LCC LC4813 .E83 2017 | DDC 378.0087—dc23

LC record available at https://lccn.loc.gov/2016044997

Cover design: Wiley

Cover image: ©binik/Getty Images

Printed in the United States of America

FIRST EDITION

HB Printing 10 9 8 7 6 5 4 3 2 1

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# **ACKNOWLEDGMENTS**

Collectively, we thank the students and colleagues who gave life to this book and who supported us as we researched and wrote it. Throughout our journey as educators and student affairs practitioners, we have been inspired by and learned from you. We are also grateful to our partners and spouses who cooked dinners, shoveled snow, scanned documents, edited drafts, moved houses, drove to coffee shops in different states, and tolerated all the time we spent on "that damn book." This book would not exist without our talented editor, and we thank Alison Knowles, at Jossey-Bass, for her unwavering patience with this project. The writing and editing process can be isolating, frustrating, time-consuming, and hard—yet through all of this, our silly, playful cats invaded the weekly author meetings, jumped on keyboards, and kept us company, sitting on our laps during the solitary hours. We acknowledge their warmth and sense of humor, and we are grateful for the connection they brought to our team.

We thank Susan Rankin, who graciously provided her data and analyses to support our chapters on campus climate for faculty and staff (Chapter 7) and students (Chapter 9) and championed our completion of the book. We also express our thanks to the campus disability professionals we met with while researching this book. In particular, we thank Michael Hudson and his staff members at Michigan State University, Jennifer McMahon at the San Diego Community College District, Paula Doss and Fred Bellinger at the University of California at San Diego, Jeff Vernooy (now deceased) at Wright State University, Joyce Stern and Angie Story and the staff members at Grinnell College,

**xii** Acknowledgments

and the participants who requested that we not identify them or their institutions. They were exceedingly helpful in informing us about how campuses might best serve students, staff, and faculty with disabilities. We also thank the numerous participants of the multiple individual research studies that underlie much of the writing in this book. Note that all individuals' names used in this text, other than those of the authors, writers and professionals to whom we give attribution, are pseudonyms. Finally, we acknowledge the reviewers who contributed to making this book a stronger final product, in particular Maria Peña, who provided multiple rounds of feedback and expanded our thinking. Nancy Evans thanks her partner, Jim Trenberth, for his constant support during the preparation of this book, Ellen Broido thanks her partner, Jo Campbell, for her patience and support over the years spent working on this book; her former research assistants, Kirsten Brown and Katherine Stygles, for their assistance in locating material for the book; and Kirsten especially for stepping into a coauthorship role. Kirsten Brown is grateful for the love and support of her family: Jack, Hellen, Karen, Jeff, Lynn, Pete, baby Jack, and partner Kevin Wyne; she is also thankful for the opportunity to learn from this wonderful team of coauthors. Autumn Wilke thanks her partner, Alesha Magee, for the long hours spent at coffee shops and support throughout the writing process, her former faculty adviser and mentor Nancy Evans for inviting her to participate in this project, and the other disability staff at Grinnell College for their collective wisdom.

# **PREFACE**

social justice approach to disability in higher education means beginning with the assumption that people's abilities and rights to contribute to and benefit from higher education are not dependent on their bodies or psyches conforming to dominant norms. It means that we believe the barriers to success in higher education lie in the structural, organizational, physical, and attitudinal aspects of our institutions. In this book, we deliberately approach disability from a social justice perspective, recognizing the multifaceted nature of disabled people's lives, while attending to the contributions and potentials of students, staff, and faculty with disabilities. We also pay attention to the attitudinal, organizational, and physical barriers impeding success; to history, law, and policy; to functional limitations and the challenges posed by people's minds and bodies; and to advocacy, struggle, and social change. In particular, we recognize that the experience of disability is mediated by other social identities people hold and the many roles they take on, both within and outside higher education. In addition, in this book we examine the role of people who are not disabled in creating and maintaining social systems, policies, and norms that circumscribe the lives of individuals with disabilities, as well as the ways that those with and without disabilities can reduce or eliminate those barriers.

Our approach differs from most other writing on disability in the context of higher education, in which disability commonly is understood as deficit, limitation, or inability. Even those who work to create an inclusive, socially just society frequently use metaphors that reinforce perceptions of the incapacity of people with disabilities (e.g., using "color-blind racism" to describe people

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who say they are unaware of racial differences; Nocella, 2009). As Mingus (2011) noted,

People usually think of disability as an individual flaw or problem, rather than as something partly created by the world we live in. It is rare that people think about disability as a political experience or as encompassing a community full of rich histories, cultures, and legacies (para. 1).

In this book, we strive to do just that. In addition, this book differs from other texts on disability by recognizing and exploring diversity within disabled communities. Moreover, we take an intentionally interdisciplinary approach, drawing on both the research and experiential literature from a variety of disciplines, while noting the paucity and dated nature of disability research that foregrounds the experiences of people with disabilities in higher education (E. V. Peña, 2014). Finally, we approach disability as a campuswide issue rather than the sole province of disability resource providers.

We need a better approach to understanding disability in higher education for multiple reasons. First, the numbers and percentages of people with disabilities entering college are rising, with 2011 data indicating 11.1% of college students having a disability (National Center for Educational Statistics, 2016b), almost double the numbers from the mid-1990s (although there is considerable variability in disability statistics, as discussed in Chapter 4). Second, despite the increasing enrollment of disabled students into higher education, people with disabilities continue to be underrepresented in the workforce, including at colleges and universities, as we expand on in Chapter 7. These two dynamics are compounded because few staff or faculty members know how to work effectively with people with disabilities as students, colleagues, or supervisees. Finally, few colleges or universities have systematically identified and eliminated institutional and cultural barriers to the success of their constituencies with disabilities. In this book, we provide the information necessary to begin to create campus environments supportive of the success of all their members.

### **Audience**

The primary audiences for this book are disability resource providers and student affairs practitioners who work with students with disabilities (i.e., all student affairs practitioners), faculty and academic affairs administrators, and master's and doctoral students who are studying social justice and disability issues. We believe the book will be particularly useful to scholars and faculty who teach courses on social justice and/or disability, both inside disability

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studies programs and in education, health and human services, social work, and human development programs. Scholars studying disability also will find this book to be an important resource because we bring together material from multiple disciplinary perspectives; present new data and interpretations; and integrate history, theory, and practice from a social justice perspective. This book will be of help as well to scholars who are pursuing new and important areas for future disability research, practitioners seeking a reference manual written from an intersectional perspective, faculty interested in course textbooks and supplementary material, students who are entering the field wanting disability-specific knowledge, and individuals without disabilities looking to deconstruct ableism on their campuses. Finally, we believe this book will be useful to those working to help students with disabilities make the transition from high school to higher education.

# **Positionality**

As we begin a book that takes a social justice approach to understanding disability in higher education, we recognize the importance of locating ourselves as authors. We believe that readers need some understanding of the experiences, influences, and values we bring to our own approaches to disability and the ways those approaches shaped the content of this book.

We hold several social locations in common. Each of us is a White, cisgender woman with a great deal of education. All of us were raised and have lived most of our lives in the United States. We each identify as having one or more disabilities. We all have cats. We each have worked in student affairs (although in different functional areas). We all have extensive histories in social justice work, view ourselves as advocates, and view student affairs work in general and disability work specifically from that perspective. While we all have served as college instructors, for two of the four of us (Nancy and Ellen), this was or is our primary professional role. Autumn and Kirsten have taught in addition to their main employment. In addition, we have unique histories that have shaped how we came to write this book and how we conceptualize disability, both personally and as a theoretical construct. Below, each of us explains her history.

#### Nancy J. Evans

I had polio as a four-year-old during the last big polio epidemic before development of the polio vaccine. I grew up in a poor family: my father was a tenant farmer who left school after the sixth grade, and my mother was the daughter of Norwegian immigrant farmers. My first memories are of my parents leaning **xvi** Preface

over my bed at the medical center an hour from my home, where I was treated by a prominent orthopedist, nationally known for his work with polio patients. Still, my mother experienced lifelong guilt feelings because (a) she was sure I had caught the polio virus on a trip to her family home in Minnesota just before I became sick, and (b) our family's financial status made it impossible for her to take me to the Mayo Clinic in Minnesota for treatment. My back and legs were paralyzed, and I spent nine months in a rehabilitation hospital learning to walk with crutches and the back and leg braces I have worn since I was four years old. I also had many surgeries between the ages of 4 and 13 to straighten my legs and feet, which required hospitalization, rehabilitation, and periodic home schooling.

I had my last major surgery at age 13 and was home-schooled during my eighth-grade year by a young teacher who also taught at the local school. She spent a great deal of time with me and was a major influence on my life, encouraging me to excel in my schoolwork and go on to college. My father was killed in an accident when I was just starting ninth grade. My mother, who was not used to making decisions, was overwhelmed and unsure of her role as a single parent with two teenagers. Since she worked first evening and then night hours, we were left on our own a lot. Because of my teacher's influence and my mother's lack of self-confidence, I became an independent and resilient teenager, making my own decisions, ignoring my impairment for the most part, and focusing on the aspect of my life in which I could excel: academics.

Because of my disability, the New York State Department of Vocational Rehabilitation would pay my college tuition and costs as long as I attended an in-state college. However, the private college I had my heart set on attending "discouraged" me from enrolling because they did not think I could handle its rather hilly campus. Devastated, I instead attended SUNY-Potsdam (now Potsdam State University), where I felt welcomed. Potsdam provided an excellent environment in which to expand my horizons, become involved in the civil rights and antiwar protests of the 1960s, and become a student leader, including student government president.

Immersed as I was in student government and protest, I had no clue what I would do with my life after I graduated from college in 1970. Based on the advice of my student government advisor, I finally decided on a career in student affairs, completed a master's degree, worked in the field for several years, completed a PhD, and became a faculty member. Throughout these young adult years, I rarely thought about my identity as a disabled person, other than the affect I assumed my disability had on my social relationships, particularly with men. Another belief my mother passed on to me was that men would not be interested in me romantically. That belief was dispelled when I met my life partner while we were both teaching at Western Illinois University. Together

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we worked through many of the issues and false messages I had regarding my appearance and ability to contribute to a relationship; we were married in 1997.

I learned about the concept of social injustice as an undergraduate during the civil rights and antiwar movements and developed close friendships with several gay men in graduate school and my first professional position. When I began teaching, it was apparent to me that the student affairs literature base was focused almost exclusively on students whose backgrounds were privileged. Believing that student affairs professionals needed to know about minoritized students as well, I began adding information about these students through panels, assignments, and discussions. Later, I focused my scholarship on the experiences of lesbian, gay, bisexual, and transgender (LGBT) college students and social justice in general. Reflecting now, I believe that I was doing this work related to other marginalized individuals because I was not yet ready to explore the issues I personally faced as a disabled person.

It was not until I began teaching at Iowa State University (ISU) that I needed to address my identity as a disabled person. I had gradually lost strength in both my legs and my arms and I began experiencing significant pain. I was at a point of needing to make the transition from walking with crutches to using a wheelchair at work. This decision felt like "giving in" to my disability, and I agonized over it. At that time, ISU's disability resource coordinator, who was also taking classes in the student affairs program, became an important ally in the process of turning my feelings around to the point where I was not only comfortable with myself as a disabled person who used a wheelchair, but could also openly share my experiences in classes, presentations, and writing. I am so grateful that he constantly confronted the oppression people with disabilities experience and modeled speaking up for one's rights in professional settings.

Currently I am experiencing the challenges of post-polio syndrome, which most polio survivors experience as they reach their 60s. I went on permanent disability leave in 2013 since I no longer had the energy to manage my faculty role effectively. I continue to learn and grow by immersing myself in the disability and social justice literature, and I bring social justice and critical realist positions to my personal and professional work.

#### Ellen M. Broido

My diagnosis of diabetes as a four-year-old profoundly shaped multiple aspects of my experience and identity, although it has taken me many years to recognize those influences and I am sure there is more to learn. I grew up in a family in which I was encouraged to treat diabetes as "no big deal" and to ensure no

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one was inconvenienced by it. I also had the socioeconomic privilege to access quality health care and cutting-edge treatment. I had contact with other kids with diabetes while attending a camp for diabetics for two weeks each summer; that experience was a counterbalance to the rest of the year, where diabetes was a solitary, isolating experience I was taught to treat as a mild annoyance and a manageable medical condition. I absorbed the message to minimize others' awareness of the impact of diabetes on my life, accept the myth of being able to do it all, and never considered myself to have a disability. However, due to diabetes, I lost my vision in one eye while a master's student and was told to expect to lose my remaining sight in the near future. Shortly after, I was exposed to material about disability in the context of a course on social justice, and for the first time I recognized the commonality between my own experiences and those whom I had previously considered to be "other" people with disabilities.

This dawning understanding of a social justice perspective on disability, work with others who shared social justice approaches, and research on other aspects of social justice grounded my professional work in higher education in social justice. Later, as I began to do research on disability in higher education, my thinking was influenced by multiple theorists and researchers who were using critical approaches to disability.

My other social identities, as a person who has racial, economic, educational, and cisgender privilege, and someone minoritized because of my sexual orientation, gender, and religious affiliation, also influence how I experience disability. My understanding of disability and approach to the material in this book is shaped by the combination of my own identity and experiences as a disabled person, my other social identities, my contact with others doing social justice work on disability and other issues, and theoretical and empirical literature.

#### Kirsten R. Brown

From a very young age, being dyslexic was an inescapable part of my self-identity. In grammar school, some of my most embarrassing memories involved spelling exams. As an adult working in academia, I constantly struggle to produce written work that others might interpret as grammatically correct. Yet my identity and positionality are more than just a monolithic picture highlighted by learning differences; culturally, I inhabit a space where my white skin, able body, cisgender appearance, advanced education, heterosexual relationship, and middle-class position provide some cover for my dyslexic grammatical blunders. The privilege that these positions afford, coupled with an immersion in disability research and an empathetic family,

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allows me to occupy a space where writing is a practice, not a perfection. As a social justice advocate, I view my spelling errors as an opportunity to deconstruct stigma associated with disability by making the hidden visible to students in my classes and colleagues.

#### Autumn K. Wilke

Disability was not an aspect of my life that I began to fully embrace until I was an adult in my first full-time job. As a graduate student, I was diagnosed with generalized anxiety disorder, panic disorder, and an adjustment disorder. I attended weekly therapy sessions with an individual therapist and weekly group therapy sessions to attempt to manage my symptoms, and I told no one about my struggles. Anxiety had been a constant part of my life, but it had not affected me in such a pronounced way until graduate school. As a teenager, I had internalized many of the messages regarding mental health that are prevalent in society, and I continued to view my mental health through this lens. I saw my daily struggles with anxiety as an internal flaw that I had to manage. I did not seek accommodations or support from my faculty or supervisors even though I was familiar with the accommodations process, having received academic accommodations for severe migraines as an undergraduate student.

In my first full-time position, I had the pleasure of working with a number of incredibly talented students who also experienced a myriad of struggles with mental health, and as I challenged their own internalized perceptions of their mental health, I began to challenge my own. I sought a new therapist and added a new diagnosis, obsessive-compulsive personality disorder—which helped to explain many of my experiences that were not fully encompassed by my anxiety disorders. I also began to recognize the ways in which my other privileged identities as a white, cisgender, middle-class woman affected my access to not only health care resources, but also to accommodations in the work-place and professional legitimacy even with the stigma many people attach to mental health disabilities.

# Organization of the Book

We deliberately organized this book to move from foundational philosophical, historical, theoretical, and legal concepts; through exploration of the albeit limited literature on the interaction of disability with other aspects of identity and experience; to a focus on environmental issues; before focusing on very practice-oriented chapters. We believe that effective, socially just disability

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work requires understanding why particular strategies do or do not work in particular settings and with particular individuals and groups, and that "why" comes from philosophy, history, theory, and laws. While we recognize that some readers may want to jump directly to strategies for particular functional areas of campus, we encourage all readers to engage with the preceding chapters so they can best tailor their work in light of the foundational material.

This book begins with an Introduction in which we discuss our social justice framework, language that we have chosen to use in this book, and the additional theoretical perspectives that underlie the text. The book has four parts: "Foundational Concepts" (chapters 1 through 4, addressing history, theory, law, and ways of classifying disability); "Population-Specific Experiences" (chapters 5 through 7, focusing on social identities, diverse populations and campuses, and faculty and staff with disabilities); "Environmental Issues" (chapters 8 through 12, focused on the campus environment, campus climate, universal design, assistive technology, and instructional issues); and "Serving Students" (chapters 13 through 15, on disability resource offices, student affairs units, and transition-related topics). Each chapter starts with a vignette or quote from one of us or from students, faculty, or staff who offered invaluable contributions to our research for this book. Each chapter closes with discussion questions that serve as tools for reflection and practical application of the issues and concepts described in the chapter. The Conclusion to the book presents a new framework for a socially just approach to disability in higher education and strategies to implement the framework.

#### Introduction

In the Introduction, we describe what we mean by a social justice approach to disability, frame the language we use in the book, discuss language to avoid, and provide a rationale for the material we have chosen to include. We close by suggesting that a social justice approach accepts that bodies and minds come in a wide variety of forms and advocate that all people are deserving of respect and equality regardless of how they function (Nocella, 2009).

#### **Part 1: Foundational Concepts**

In the first chapter, we provide an overview of the history of disability in the United States. We review both the social context in which the education of people with disabilities took place and the major events in the development of higher education that affected disabled individuals. In Chapter 2, we present the various models of disability that have guided society's understanding

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and treatment of people with disabilities over time and currently. We also examine how disability models can inform student affairs professionals and faculty who work with students with disabilities.

In Chapter 3, we discuss how disability law and legal initiatives play a significant role in shaping the educational experiences of people with disabilities. We provide a brief historical overview of four foundational pieces of legislation pertaining to disability and education and then focus on current and upcoming legal issues, including accessible technology, auxiliary aids, standardized testing, barrier removal, housing, emotional support animals, and accommodations for temporary disabilities. We conclude by discussing socially just approaches to interpreting disability law.

Chapter 4 is focused on different individual and social factors that influence how people think about and experience disability. We review the broad variability within and among forms of impairment. We conclude by providing definitions of and reviewing statistics on the prevalence of forms of impairment found most often in college student populations.

#### Part 2: Population-Specific Experiences

In Chapter 5, we address the influences of the multiple identities of individuals with disabilities. We examine as well the concept of disability identity and provide an overview of several theories of disability identity development that can inform student affairs professionals and faculty who work with students with disabilities. In addition, we examine numerous ways that race, gender, sexual orientation, and social class influence the individual experiences of people with disabilities in the college and university environment.

In Chapter 6, we continue the theme of multiple aspects of disabled students' identity and focus on lived experiences that affect different student populations' access to and experience within higher education. We discuss topics salient to disabled students who are also adult learners, community college students, English language learners, first-generation college students, international students, single-parent students, student athletes, transfer students, undocumented students, and students who are veterans.

Chapter 7 has a focus on the specific experiences and context of university staff and faculty members with disabilities. It contains an overview of case law, legislation, and regulations regarding employment and reporting, as well as climate issues specific to faculty and staff, and concludes with recommendations for policy and practice. This chapter will be of particular interest to human resources staff, as well as staff and faculty who have disabilities or who have colleagues with disabilities.

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#### Part 3: Environmental Issues

The third part of the book addresses multiple aspects of the campus environment. In Chapter 8, we discuss aspects of the campus environment and the effects they have on students with disabilities. Specifically, we examine the ways in which the human aggregate (faculty and students), the organizational structure (university policies and practices), and the physical environment (architecture, landscape, and location) affect the performance, satisfaction, and well-being of students with disabilities and recommend ways in which these aspects of the environment can be modified to better address the needs of disabled students.

The focus of Chapter 9 is on how disabled students experience the campus climate and the effects that the climate has on those students. We include in this discussion a summary of a recent multicampus study of campus climate experienced by students with disabilities and a model for transforming campus climates to be more welcoming for this student population.

In Chapter 10, we examine the concept of universal design and its application to various aspects of the campus environment, as well as to instruction. We explore the relationship of universal design and social justice and describe specific programs that provide resources and materials to assist college and university staff in developing universally designed initiatives.

In Chapter 11, we explore how technology can improve the autonomy and independence of many individuals, including those with disabilities. Technology is increasingly present in the day-to-day functioning of colleges and universities, and when it is employed in an accessible manner, it can be a strong tool for the retention and positive experiences of students, faculty, and staff with disabilities. In this chapter we outline categories of technology, tips for usage, and guidelines for reviewing accessibility.

In Chapter 12, we examine current classroom practices for working with students with disabilities, critique existing methods, and explore the implications of universally designed instruction for the education of students with disabilities. We include examples of good practice for instructing disabled students and other nontraditional students who also benefit from universal design.

#### Part 4: Serving Students

In Chapter 13, we focus on disability resource offices and their staff. We describe the administrative, service provision, and outreach roles that are critical to student success and community education and the role of disability resource practitioners in advocating for social justice.

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In Chapter 14, we examine current practices and socially just approaches to engaging and supporting students with disabilities in higher education. We start by discussing current research on retention of students with disabilities and describe the importance of universal design in student affairs. Then we provide an overview of functional areas within student affairs, using specific examples and existing research to demonstrate effective uses of universal design.

In Chapter 15, we address the transitions into, during, and out of postsecondary education for students with disabilities. We also continue the discussion of student affairs functional areas in relation to admissions, orientation, transfer students, study abroad, career services, and graduate school preparation. In particular, we highlight the roles that vocational rehabilitation and K-12 education play in the transition process and call attention to the lack of research focused on the transitions that occur while in college.

#### Conclusion

We conclude by presenting seven core principles of a socially just approach to disability in the specific context of higher education. We explain how those principles might manifest to create a higher education environment free from ableism.

# **ABOUT THE AUTHORS**

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**xxvi** About the Authors

Evans has been actively involved in ACPA throughout her career, serving as its president from 2001 to 2002, cochair of the 2009 Next Generation conference, chair of Books and Media Board, editorial board member of the *Journal of College Student Development*, and chair of the Commission on Professional Preparation. Her other books include *Student Development in College* (2nd edition), with Deanna S. Forney, Florence Guido, Lori Patton, and Kristen Renn; *Developing Social Justice Allies*, with Robert D. Reason, Ellen M. Broido, and Tracey L. Davis; *Foundations of Student Affairs Practice*, with Florence A. Hamrick and John Schuh; *Toward Acceptance*, with Vernon Wall; *Student Development in College*, with Deanna S. Forney and Florence Guido-DiBrito; and *Beyond Tolerance*, with Vernon Wall. Evans's scholarly interests center around the experiences of minoritized groups, particularly disabled students and LGBT students, on college campuses.

**Ellen M. Broido** is associate professor in Bowling Green State University's Higher Education and Student Affairs program, with an affiliate appointment in Women, Gender, and Sexuality Studies. She holds an EdD from the Pennsylvania State University in counselor education, an MSEd from Indiana University in both college student personnel administration and counseling and counselor education, and an AB from Columbia College of Columbia University in biology. She has held professional positions including coordinator of University Studies/student affairs partnerships and assistant professor of University Studies at Portland State University, residence director and judicial coordinator at the University of Massachusetts-Amherst, and chemistry teacher at the Bishop's School. Broido has received several awards from ACPA, including the Disability Leadership Award from the Standing Committee for Disability, the Annuit Coeptis Emerging Professional award, and recognition as an Emerging Scholar. Bowling Green State University has presented her with the President's Award for Collaborative Research and Creative Work.

Broido has contributed to ACPA throughout her career, serving as a member of the governing board, editor and chair of the Books and Media Board, directorate body member of the Commission on Professional Preparation, and member of the editorial board of the *Journal of College Student Development* and several presidential task forces. She wrote *Developing Social Justice Allies* with Robert D. Reason, Nancy J. Evans, and Tracey L. Davis. Broido's research and writing interests span a range of social justice issues in the context of higher education, including disability activism; experiences of students with disabilities; experiences of classified, administrative, and faculty women; gendered dynamics in faculty service; ally development; and LBG student issues.

About the Authors xxvii

Kirsten R. Brown is a student affairs professional at the University of Wisconsin-Madison and a part-time faculty member in sociology at Madison College. She completed her PhD in higher education administration and student affairs at Bowling Green State University. She also holds a master's in sociology from the University of Wisconsin-Milwaukee and a bachelor of science from Carroll College. Brown was awarded the Disability Leadership Award by ACPA's Standing Committee on Disability in recognition of her research contributions. She is active in several professional organizations and has presented nationally at ASHE, NAFSA, and ACPA. Her research agenda addresses issues of access, diversity, and outcomes in higher education. Specifically, she is interested in practices that support the retention and success of students with disabilities in postsecondary education. Brown's recently published work focuses on neuro and learning diversity, autism spectrum disorder (ASD), and disability research methods.

**Autumn K. Wilke** is an academic affairs professional at Grinnell College working as the assistant dean for disability resources. She completed her MEd in educational leadership and policy studies at Iowa State University. She also completed a certificate in postsecondary disability services from the University of Connecticut. Wilke was awarded the Annuit Coeptis Emerging Professional Award by ACPA. She has been active in the directorate body of the ACPA Commission for Social Justice Educators and AHEAD's Standing Committee on Member Development.