

# NEW NARRATIVES OF DISABILITY

# RESEARCH IN SOCIAL SCIENCE AND DISABILITY

Series Editors: Sharon N. Barnartt and  
Barbara M. Altman

## Recent Volumes:

- Volume 1: Expanding the Scope of Social Science Research on Disability – Edited by Sharon N. Barnartt and Barbara M. Altman, 2000
- Volume 2: Exploring Theories and Expanding Methodologies: Where We Are and Where We Need to Go – Edited by Sharon N. Barnartt and Barbara M. Altman, 2001
- Volume 3: Using Survey Data to Study Disability: Results from the National Health Interview Survey on Disability – Edited by Barbara M. Altman, Sharon N. Barnartt, Gerry E. Hendershot and Sheryl A. Larson, 2003
- Volume 4: International Views on Disability Measures: Moving Toward Comparative Measurement – Edited by Barbara M. Altman, Sharon N. Barnartt, Gerry E. Hendershot and Sheryl Larson, 2006
- Volume 5: Disability as a Fluid State – Edited by Sharon N. Barnartt, 2010
- Volume 6: Disability and Community – Edited by Allison C. Carey and Richard K. Scotch
- Volume 7: Disability and Intersecting Statuses – Edited by Sharon N. Barnartt and Barbara M. Altman
- Volume 8: Environmental Contexts and Disability – Edited by Sharon N. Barnartt and Barbara M. Altman
- Volume 9: What Did We Know and When Did We Know It – Edited by Sara Green and Sharon N. Barnartt
- Volume 10: Factors in Studying Employment for Persons with Disability: How the Picture Can Change – Edited by Barbara M. Altman and Sharon N. Barnartt

RESEARCH IN SOCIAL SCIENCE AND DISABILITY  
VOLUME 11

**NEW NARRATIVES OF  
DISABILITY:  
CONSTRUCTIONS,  
CLASHES, AND  
CONTROVERSIES**

EDITED BY

**SARA E. GREEN**

*University of South Florida, USA*

**DONILEEN R. LOSEKE**

*University of South Florida, USA*



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

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

First edition 2020

Copyright © 2020 Emerald Publishing Limited

**Reprints and permissions service**

Contact: [permissions@emeraldinsight.com](mailto:permissions@emeraldinsight.com)

No part of this book may be reproduced, stored in a retrieval system, transmitted in any form or by any means electronic, mechanical, photocopying, recording or otherwise without either the prior written permission of the publisher or a licence permitting restricted copying issued in the UK by The Copyright Licensing Agency and in the USA by The Copyright Clearance Center. Any opinions expressed in the chapters are those of the authors. Whilst Emerald makes every effort to ensure the quality and accuracy of its content, Emerald makes no representation implied or otherwise, as to the chapters' suitability and application and disclaims any warranties, express or implied, to their use.

**British Library Cataloguing in Publication Data**

A catalogue record for this book is available from the British Library

ISBN: 978-1-83909-144-5 (Print)

ISBN: 978-1-83909-143-8 (Online)

ISBN: 978-1-83909-145-2 (EPub)

ISSN: 1479-3547 (Series)



ISOQAR certified  
Management System,  
awarded to Emerald  
for adherence to  
Environmental  
standard  
ISO 14001:2004.

Certificate Number 1985  
ISO 14001



INVESTOR IN PEOPLE

# CONTENTS

<i>List of Tables</i>	<i>ix</i>
<i>About the Contributors</i>	<i>xi</i>

<b>Introduction: Exploring Narrative as a Social Science Framework on Disability and Disabled People</b> <i>Donileen R. Loseke and Sara E. Green</i>	<i>1</i>
---------------------------------------------------------------------------------------------------------------------------------------------------------	----------

## PART I CULTURAL STORIES OF DISABILITY AND INDIVIDUAL LIVES

<b>Chapter 1 Reframing the Story of Helen Keller and Anne Sullivan: Resisting (Dis)ability Stereotypes through an Analysis of Children’s Literature</b> <i>Cheryl Najarian Souza</i>	<i>11</i>
-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	-----------

<b>Chapter 2 “It’s Not That Way You Know, She Has a Good Future”: Women’s Experiences of Disability and Community-based Rehabilitation in Sri Lanka</b> <i>Carmen Rebecca Britton and Laura Mauldin</i>	<i>27</i>
------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	-----------

<b>Chapter 3 Test Anxiety: Participation and Exclusion beyond the Institution</b> <i>M. Nickie Coomer and Kenzie Latham-Mintus</i>	<i>43</i>
---------------------------------------------------------------------------------------------------------------------------------------	-----------

<b>Chapter 4 Narratives of Care and Citizenship: Mothering “Precariously Normal” Adult Sons and Daughters in an Age of Inequality</b> <i>Linda M. Blum</i>	<i>59</i>
---------------------------------------------------------------------------------------------------------------------------------------------------------------	-----------

<b>Chapter 5 “More than a Parent, You’re a Caregiver”: Narratives of Fatherhood in Families of Adult Sons and Daughters with Life-long Disabilities</b> <i>Heidi Steinour and Sara E. Green</i>	<i>75</i>
----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	-----------

**PART II  
CULTURAL STORIES OF DISABILITY AND  
ORGANIZATIONS**

- Chapter 6 “You Won’t Tell That You Have Schizophrenia, Right? You Should Say You Have a Small Depression”:  
Organizational Narratives of “Adjusted” Workers with  
Disabilities and the Rhetoric of Reassurance in France**  
*Lisa Buchter* 93
- Chapter 7 “I Want to Go Places on My Own”: A Case-study  
of Virginia Commonwealth University ACE-IT in College**  
*Stephanie J. Lau and Aliza H. Weiss* 107
- Chapter 8 More than Therapy: Conformity and Resistance  
in an Organizational Narrative of Disability and the  
Performing Arts**  
*Melinda Leigh Maconi* 123

**PART III  
CULTURAL STORIES OF DISABILITY AND  
SOCIAL POLICIES**

- Chapter 9 Narrative Productions of Problems and People in  
the Americans with Disabilities Amendment Act**  
*Melissa Jane Welch* 139
- Chapter 10 Institutional and Personal Narratives of Chronic  
Pain Management: Interrogating the Medical and Social  
Models of Disability**  
*Loren E. Wilbers* 151
- Chapter 11 Stuck in Transition with You: Variable Pathways  
to In(ter)dependence for Emerging Adult Men with Mobility  
Impairments**  
*J. Dalton Stevens* 169
- Chapter 12 Conflicting Narratives of Corporeal Citizenship:  
Medicaid Personal Care Attendant (PCA) Policy and Program  
Users’ Experiences of Cross-state Moves**  
*Brian R. Grossman* 185

**PART IV**  
**CULTURAL STORIES OF DISABILITY AND RESISTANCE**

<b>Chapter 13</b> Neither Victim nor Superhero: Reflections on Disability and Mental Health Counseling <i>Richard A. Chapman</i>	203
<b>Chapter 14</b> Self-study of Intersectional and Emotional Narratives: Narrative Inquiry, Disability Studies in Education, and Praxis in Social Science Research <i>Lisa Boskovich, Mercedes Adell Cannon, David Isaac Hernández-Saca, Laurie Gutmann Kahn and Emily A. Nusbaum</i>	215
<b>Chapter 15</b> Neoliberalism and the Fight for the Child: Narratives of Queer Mothering <i>Ahoo Tabatabai</i>	231
<b>Chapter 16</b> Sick and Tired: Narratives of Contested Illness in Chronic Fatigue Syndrome Blogs <i>Morgan V. Sanchez</i>	245
<b>Chapter 17</b> “We Love Each Other Into Meaning”: Queer Disabled Tumblr Users Constructing Identity Narratives through Love and Anger <i>Justine E. Egner</i>	261
<i>Index</i>	277

# LIST OF TABLES

## Chapter 3

Table 1.	Sample Characteristics.. . . . .	48
----------	----------------------------------	----

## Chapter 7

Table 1.	Descriptive Codes and Sub-codes. . . . .	113
----------	------------------------------------------	-----



## ABOUT THE CONTRIBUTORS

**Linda M. Blum**, PhD, is a Professor of Sociology at Northeastern University, USA. She is a Past Chair of the American Sociological Association Sections on Sex and Gender and Body and Embodiment and received a book award from the Section on Disability and Society. She has served on the editorial boards of *Gender & Society* and *Signs*.

**Lisa Boskovich** is a Doctoral Candidate with an emphasis in Disability Studies in the Donna Ford Attallah College of Educational Studies and a Research Assistant at the Thompson Policy Institute on Disability and Autism at Chapman University, USA. Her dissertation research focuses on fathers of children on the Autism Spectrum.

**Carmen Rebecca Britton** is a Doctoral Candidate at the Department of Human Development and Family Sciences at the University of Connecticut, USA. Her areas of research include disability, and community-based rehabilitation programming, practice, and development in relation to socially marginalized groups, particularly in the Global South.

**Lisa Buchter** is an Assistant Professor at Emlyon Business School, Lyon, France, and a Doctoral Candidate in a joint program at Northwestern University and the Center for the Sociology of Organizations, Po Paris. Her areas of research include disability, the fight against discrimination, and social movements' strategies to improve inclusive laws and policies.

**Mercedes Adell Cannon**, PhD, is an Associate Director of Adaptive Educational Services, an Administrator in the Division of Diversity, Equity, and Inclusion, and an Adjunct Faculty Member in the School of Education at Indiana University Purdue – University Indianapolis (IUPUI), USA. Cannon's research examines race, gender, and disability in the context of postsecondary education.

**Richard A. Chapman** is a Licensed Mental Health Counselor, a Certified Rehabilitation Counselor, and a Doctoral Candidate in the Department of Counseling Education at the University of South Florida, USA. His research focuses on mental health, developmental disabilities, the promotion of alternatives to guardianship, and the measurement of self-advocacy and self-determination for individuals with disabilities.

**M. Nickie Coomer** is a Doctoral Candidate in Urban Education Studies at Indiana University – Purdue University Indianapolis (IUPUI), USA. Her areas of research include special education, disability studies in education, teacher

identity and agency, critical pedagogies, and praxis. Her dissertation examines the informal processes of eligibility determination in special education.

**Justine E. Egner**, PhD, is an Assistant Professor of Sociology at the University of Wisconsin – La Crosse, USA, a Program Chair for American Sociological Association Section on Disability & Society and a Co-Chair of the Society for the Study of Social Problems, Disability Division. Egner's research focuses on disability/illness, autism/neurodiversity, sexuality, LGBTQ+ identities, and virtual communities.

**Sara E. Green**, PhD, is a Director of the Interdisciplinary Social Sciences Program and a Professor of Sociology at the University of South Florida, USA, a Past Chair and career award recipient of the American Sociological Association (ASA) Section on Disability & Society, and a Past Co-Chair of the ASA Committee on the Status of Persons with Disabilities.

**Brian R. Grossman**, PhD, is an Assistant Professor in the Department of Disability and Human Development at the University of Illinois at Chicago, USA, a Faculty Affiliate with the Illinois Leadership Education in Neurodevelopmental and other related Disabilities (LEND), and a Past Co-Chair of the Disability Division of the Society for the Study of Social Problems.

**David Isaac Hernández-Saca**, PhD, is an Assistant Professor in the Department of Special Education at the University of Northern Iowa, USA. Hernández-Saca's research focuses on historical equity issues in general education and special education, and current movements for inclusive education from a Disability Studies in Education paradigm.

**Laurie Gutmann Kahn**, PhD, is an Assistant Professor of Education at Moravian College, USA. Kahn's dissertation won the American Educational Research Association Disability Studies in Education Special Interest Group (DSE SIG) Outstanding Dissertation Award. Kahn's research and practice can be located at the intersection of identity, culture, and disability within educational contexts.

**Kenzie Latham-Mintus**, PhD, is an Associate Professor of Sociology at Indiana University – Purdue University Indianapolis (IUPUI), USA. Latham-Mintus' research interests include health and aging with an emphasis on disability, chronic illness, and health disparities across the life course. She is a Fellow of The Gerontological Society of America and serves on several journal editorial boards.

**Stephanie J. Lau** is a Doctoral Candidate in the L. Douglas Wilder School of Government and Public Affairs and Transition Training Associate at Center for Transition Innovations at Rehabilitation Research and Training Center at Virginia Commonwealth University (VCU), USA. Lau's research focuses on disability, postsecondary education and employment, health access, and institutional organization.

**Donileen R. Loseke**, PhD, is a Professor of Sociology at the University of South Florida, USA and a Past President of both the Society for the Study of Symbolic Interaction and the Society for the Study of Social Problems. Loseke received the Mead, Cooley, and Mentor Awards from the Society for the Study of Symbolic Interaction.

**Melinda Leigh Maconi** is a Doctoral Candidate in the Sociology Department at the University of South Florida, USA. Maconi's areas of research include disability, health and illness, education, the arts, and identity. She received Honourable Mention in the Society for the Study of Social Problems Disability Division Graduate Paper Award Competition.

**Laura Mauldin**, PhD, is an Assistant Professor in Human Development and Family Sciences and Women's, Gender and Sexuality Studies and an Affiliate in Sociology at the University of Connecticut, USA; a Past Co-Chair of the Disability Division, Society for the Study of Social Problems, and a recipient of American Sociological Association Disability & Society Section book award.

**Cheryl Najarian Souza**, PhD, is an Associate Professor of Sociology at the University of Massachusetts, Lowell, USA. Souza's research and teaching interests include examining disability and ability from intersectional, interdisciplinary, and feminist perspectives. She has written extensively about the deaf community and the challenges deaf women face.

**Emily A. Nussbaum**, PhD, is an Assistant Professor at University of San Francisco, USA. Nussbaum's research focuses on critical qualitative research, disability and disabled researchers, the ideology of inclusive education, and experiences of post-secondary students who are identified as disabled. Nussbaum is a recipient of the AERA Disability Studies in Education Special Interest Group Outstanding Dissertation award.

**Morgan V. Sanchez**, PhD, is an Assistant Professor of Sociology at California State University, East Bay, USA. Her research interests include contested illnesses, illness narratives, and familial experiences of disability. She is currently working on a project using blogs to explore variations in contested illness narratives depending on the degree of medicalization.

**Heidi Steinour**, PhD, is a Visiting Instructor at The University of South Florida. She is also a Learning Experience Designer with Ellucian focusing on integrating educational technology into online learning. Her research areas focus on family, gender, and education with interests in pedagogy and curriculum design.

**J. Dalton Stevens** is a sociology Doctoral Student at Syracuse University, USA. His scholarship focuses on disability, aging and the life course, family, sex and gender, mortality, welfare policy, and qualitative/mixed methods. Stevens received graduate student paper awards from the American Sociological Association and the Society for the Study of Social Problems.

**Ahoo Tabatabai**, PhD, is an Associate Professor of Sociology and the Chair of the Department of Psychology and Sociology at Columbia College in Columbia Missouri, USA, and currently serves on the editorial board of *Sociological Focus*. Tabatabai's scholarship and teaching interests include the study of disability, narratives, and identity.

**Aliza H. Weiss** is a Doctoral Student in the School of Education Counselor Education and Supervision and a Career Support Specialist at the Center for Transition Innovations at Rehabilitation Research and Training Center at Virginia Commonwealth University, USA. Weiss' research interests include disability, postsecondary education/employment, and siblings of individuals with neurodevelopmental disabilities.

**Melissa Jane Welch**, PhD, is an Advocacy Specialist with The Arc of Larimer County, where she works to help disabled individuals and their families navigate systems of support in their communities. Welch's research centers on various aspects of health, illness, and disability, including community engagement and participation, education, social movements, and collective identity.

**Loren E. Wilbers**, PhD, is an Assistant Professor of Sociology and Disability Studies Certificate Program Coordinator at the University of Wisconsin-Whitewater, USA, where she received the Chancellor's Award on Disability Concerns. Wilbers' research and teaching interests include disability, health and illness, and social psychology, with particular emphasis on chronic pain and family experiences with disability.