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RESEARCH IN SOCIAL SCIENCE AND DISABILITY
VOLUME 11

NEW NARRATIVES OF DISABILITY: CONSTRUCTIONS, CLASHES, AND CONTROVERSIES

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emerald PUBLISHING

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

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

First edition 2020

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: 978-1-83909-144-5 (Print)
ISBN: 978-1-83909-143-8 (Online)
ISBN: 978-1-83909-145-2 (EPub)

ISSN: 1479-3547 (Series)

CONTENTS

PART I
CULTURAL STORIES OF DISABILITY AND INDIVIDUAL LIVES

PART II
CULTURAL STORIES OF DISABILITY AND ORGANIZATIONS

PART III
CULTURAL STORIES OF DISABILITY AND SOCIAL POLICIES

PART IV
CULTURAL STORIES OF DISABILITY AND RESISTANCE

LIST OF TABLES

Chapter 3

Chapter 7

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INTRODUCTION

EXPLORING NARRATIVE AS A SOCIAL SCIENCE FRAMEWORK ON DISABILITY AND DISABLED PEOPLE

Donileen R. Loseke and Sara E. Green

This eleventh volume of *Research in Social Science and Disability* explores questions about the use and value of narrative theoretical and methodological frameworks in disability research: What do we learn about disability and disabled people[1] from looking through the lens of narrative? How do narratives shape both the personal experience and the social organization of disability? How are narratives implicated in the inequalities and injustices associated with disability? How can narratives be a tool for social change?

Ancient philosophers such as Plato and Aristotle talked about the importance of narratives (an academic term for what are called "stories" in daily life), and narratives long have been of interest to literary critics as well as to scholars of religion (see, for example, Frye, 1957; Polkinghorne, 1991). Yet, social scientists all but ignored how narratives work and the work narratives do until the 1980s. Until this time, there were perceived irreconcilable differences between social science and narrative. While social scientists were focused on understanding the objective world by methods that reduced complexity, narratives are about subjective meaning and emphasize complexity. While social scientists typically were interested in discovering truths that were objective and measurable, narrative truth is experiential, emotional, and moral. Multiple antecedents led social scientists in a variety of academic disciplines to challenge typical beliefs that narratives were not worthy of their attention and then to discover the importance and value of narrative as a subject of social scientific inquiry. Within academia, for

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New Narratives of Disability: Constructions, Clashes, and Controversies
Research in Social Science and Disability, Volume 11, 1–8

ISSN: 1479-3547/doi:10.1108/S1479-354720190000011002

example, there were increasing criticisms that "objectivity" was an ideological mask for social science complicity in supporting inequalities; outside academia rapid change, globalization, mass migrations, urbanization, and technology were creating social environments where people shared little in the way of personal characteristics, experiences, life chances, or ways of understanding and morally evaluating the world. This raised new questions, an important sub-set of which centered on *meaning*: How can people make sense of self, others, and experiences when there is so much disagreement and so little shared meaning? How is it possible to know how to navigate a rapidly changing and increasingly complex social world when so little of it can be known through practical experience? Simply stated, characteristics of the current era encourage a multitude of problems surrounding meaning (see, for example, Alexander, 2017; McCarthy, 2017) that cannot be adequately addressed with traditional social science methods. Together, these various trends produced what is called the "narrative turn" throughout the social sciences as well as within the professions of law, education, medicine, and social work (see Loseke, 2019 for a review).

Narratives are omnipresent in all levels of social life because narrative is a meaning-producing communication form and relatively shared meaning is necessary for individual well-being and for social organization. Narratives produce *cognitive* meanings when plots transform what otherwise might seem random events into patterns; they produce *emotional* meanings when plots and characters encourage feeling; they produce *moral* meanings when plots and characters encourage reflections on what is right and wrong. Narrative meaning also is both *cultural* and *personal*. Meaning is cultural because narratives can be evaluated as important and believable by more than a few people only when story contents reflect culturally circulating systems of meaning; narrative meaning simultaneously is personal because the unique experiences of individuals influence what meaning is meaningful to them.

Scholarly discourses are systems of meaning that can also be viewed as narratives entering the public imagination through social policy and activism. Three genres of narratives of disability are the most common. The *medical narrative* of disability is a story of disability as an individual tragedy best ameliorated through the application of professional interventions (medical, social service, education, etc.); the *social narrative of disability* equates disability with oppressive structural barriers and attitudinal constraints that are part and parcel of a capitalist world organized around ableism; emerging narratives of disability including *crip* and *critical realism* problematize and destabilize the very idea of "normality" or portray disability as a complex and nuanced intersection of bodily, social, and cultural disadvantages. While these narratives tend to prevail in separate areas of social science scholarship and are often framed in opposition to one another, less well understood is how these seemingly disparate views of disability may simultaneously be enacted in the lives of individuals and the social systems with which they interact.

Public understandings of disability tend to follow the medical narrative of disability story line. This story imagines disability as a physical, visible, constant feature of experience; it imagines disabled people as inadequate actors. Within this narrative, disability is a personal tragedy and disabled people deserve the emotional response of pity. This story reflects and perpetuates a range of cultural values reflecting a gendered culture prizing independence and productivity as traditionally conceptualized and measured (self-sufficiency, employment). This story is powerful in its consequences because it shapes public policy, organizations, perceptions of self and others, as well as influences which stories are encouraged and which are discouraged. Yet because this story is a woefully inadequate image of the complexity of the experiences/characteristics of disability and disabled people, it is routinely and strongly challenged/resisted by disabled people and their supporters (family, organizations, and academics).

Scholars in disability studies and sociology have tended to argue against the medical narrative of disability and in favor of the story line of the social narrative of disability portraying social structures, social forces, and social attitudes as the problem to be resolved. Yet a growing chorus of voices has been raising concern that a strict adherence to the social narrative of disability may neglect, or even repress, the telling of disability stories that do not neatly conform to the primacy of social oppression central to the social narrative plot (Darling, 2013; Shakespeare, 2014; Siebers, 2006). In seeking to emphasize social, economic, and cultural barriers, social narratives of disability may underemphasize or even repress stories of pain and bodily suffering. Additionally, wholesale rejection of the medical narrative of disability may lead to overlooking, harshly criticizing, or actively silencing stories about the search for medical intervention or cure. Still further, the voices of family members, caregivers, and allies may also be neglected by strict adherence to a social narrative that, justifiably, privileges voices of disabled people themselves. Such critiques call for new and more complex narratives that include voices and experiences missing from the social narrative of disability.

This volume seeks to answer this call by exploring how a focus on narratives might lead to richer and more diverse understandings of disability. While the interdisciplinary field of disability studies has embraced narrative approaches such as literary criticism, biography, and memoir generally associated with the humanities, social scientists interested in disability as a topic of scholarly concern have been slower to embrace narrative as a theoretical and methodological tool. In this volume, we explore the work that disability narratives do in the social world, as well as the potential of narratives to encourage and support social change. Chapters in this volume explore relationships between narrative and a diverse array of questions about the social organization and personal experiences of disability. Chapters are about how narratives create and ideologically support disability-related meanings and social structure, as well as how they encourage particular cognitive and emotional responses to disability and disabled people.

In multiple ways, these manuscripts demonstrate the ability of narrative theoretical and methodological frameworks to speak across what often are boundaries limiting social science deliberations. These authors approach their studies from multiple disciplinary perspectives including anthropology, disability studies, education, gerontology, government and public affairs, mental health counseling, sociology, and women's and gender studies; they rely on a variety of data including interviews, blogs, websites, children's books, and social policy documents. Their particular interests range from questions about individuals' understanding of their own disabilities and the disabilities of others, to questions about the organizational processing of disabled people, to questions about relationships between socially circulating stories of disability and culturally central systems of meaning such as individualism, gender, race, and class. Finally, these manuscripts demonstrate how narrative frameworks can be useful in exploring questions about disability experiences that are often ignored such as those associated with cognitive or emotional impairments, chronic pain, or contested illnesses.

Despite significant differences in topic, question, and data, each of these chapters explores relationships between culture and disability as both social organization and personal experience. Conceptualizing culture as socially circulating systems of ideas (see Gertz, 1973; Swidler, 1986), authors engage various questions about cultural narratives of disability, which are stories known by relatively large segments of the population and used by social members to make sense of experience as well as to justify cognitive, emotional, and moral reactions to disability and disabled people. Manuscripts in this volume support six general conclusions about such cultural narratives of disability.

First, typical contents of cultural narratives of disability reflect – and thereby perpetuate – other socially circulating systems of meaning. Carmen Britton and Laura Mauldin, for example, demonstrate how expectations surrounding disability and the disabled person in Sri Lanka reflect ideas about both gender and ethnicity. Heidi Steinour and Sara Green show how fathers of adult sons and daughters with life-long needs for care and assistance draw on cultural narratives of fatherhood, even as they engage in caregiving tasks that are at odds with this narrative. Several chapters pertain specifically to the Western world where the primary value of *individualism* promotes the importance of self-reliance and labor productivity as well as encourages assuming individual responsibility for problem resolution. The cultural value system of individualism is particularly important for questions about disability because it is the foundation for the medical narrative which features disability as tragedy and the disabled person as deficient (Oliver & Barnes, 2012; Shakespeare, 2014). So, Nickie Coomer and Kenzie Latham-Mintus demonstrate the ways in which medical models of disability as individual deficiency underlie higher education settings; Stephanie Lau and Aliza Weiss examine the consequences of deficiency narratives on postsecondary education; Melinda Maconi argues that, despite the fact that there are many talented artists who are disabled, deficiency narratives lead to assumptions that art programs for disabled people are valuable primarily for their "therapeutic" value rather than for developing artistic talent.

Second, typical contents of the cultural narrative of disability shape understandings of what disability *is*. Most often, this story imagines disability as a physical, visible, and constant feature of experience, which discourages thinking of disability as cognitive, emotional, invisible, or fluid. Questions about what should "count" as disability can become a formal topic of debate in social policy hearings (Melissa Welch). As demonstrated by chapters in this volume, this matters because those whose disability experiences do not conform to the typical story can find their problems ignored and their needs denied. Chapters in this volume present such evidence for those with intellectual/developmental disabilities (Stephanie Lau and Aliza Weiss), disabilities that are social-behavioral-emotional (Linda Blum), or involve the contested problems of chronic fatigue (Morgan Sanchez) or chronic pain (Loren Wilbers).

Third, the primary character in cultural stories of disability is the disabled person and this story *character* patterns expectations about *real* people who are disabled. Disability scholars have explored the characteristics of disabled characters in fiction, fairytales, and film (see Berger, 2013, and Oliver & Barnes, 2012, for reviews), yet while there has been a "proliferation of publicly circulating representations of disability" (Rapp & Ginsburg, 2001), the most commonly circulating stories remain those depicting the disabled person as either deficient because of disability or heroic in motivations and attempts to overcome disability. In this volume, Linda Blum demonstrates how this matters as she found mothers sometimes evaluate their own adult sons and daughters with social–behavioral–emotional disorders using the yardstick of cultural stories of "normal" adults as independent and economically productive. Cheryl Najarian Souza argues that the contents of children's books about Helen Keller and Anne Sullivan reflect – and therefore perpetuate – cultural stories about disability and disabled people.

Fourth – and predictably – chapters in this volume show how the actual experiences of disability are far more multi-dimensional than imagined in cultural stories and ways in which this matters. J. Dalton Stevens argues that while social services for transitioning to adulthood for disabled people are embedded within a social policy assuming "independence" is the preferred goal, actual experiences and desires of disabled people transitioning to adulthood are far more diverse; Brian Grossman shows how the state-by-state organization of Medicaid community-based services reflects a notion that disabled people are place-bound rather than wanting to explore opportunities in other states; scenes from Richard Chapman's life show how he is neither the tragic character featured in the cultural story of disability nor the socially prized superhero overcoming problems associated with his impairments.

Fifth, regardless of multiple failures of cultural stories of disability to adequately describe real people and real experiences, manuscripts in this volume show the power of stories to shape the content of public policy and social service organizations. Melissa Welch, as well as Loren Wilbers, directly examine how stories of disability and disabled people shape social policy; Lisa Buchter demonstrates how cultural stories of disability as understood within the French cultural importance of "indifference to difference" resulted in particular kinds of worker recruitment practices in ongoing organizations.

Finally, but absolutely critically, chapters in this volume demonstrate that while narratives can reflect and perpetuate negative constructions of disability, they also can be used as strategies of resistance. Several chapters explore instances of *active resistance*, both to widely circulating narratives of disability as tragedy and to narrowly constructed academic and activist discourses on disability that fail to take into account the complexity of disability experiences and their intersection with other categories of social exclusion. Justine Egner analyzes how LGBTQ + disabled people of color construct narratives of care in ways that counteract their experiences of exclusion, invisibility, and stigmatization; Morgan Sanchez studies how people with the contested illness of chronic fatigue syndrome use public blogs in ways resisting cultural stories of illness that diminish or even dismiss their suffering; Ahoo Tabatabai shows how mothers raising children with disabilities can actively question ideals of "normalcy" and resist definitions of "success" that are limited to independence and labor productivity.

Such are examples of the myriad relationships between cultural stories, social structures, and personal experiences of disability. We have organized the chapters in this volume into four basic categories representing the intersection of cultural stories of disability with individual lives, organizations, and social policy and resistance to such cultural narratives. The chapters included in each part address themes that are inter-related and reflexive; the arguments and supporting evidence in many chapters easily demonstrate two or more of the general themes described above. Each part of the book, then, addresses several interrelated themes related to the complex interplay of disability and narrative.

Part I, *Cultural Stories of Disability and Individual Lives*, focuses on relationships between cultural stories and individual experience. We begin with Cheryl Najarian Souza who explores how themes in children's books about Helen Keller and her teacher, Anne Sullivan, reflect and therefore perpetuate the cultural images of disability and, in so doing, ignore real-life complexity and misrepresent the diverse characteristics of real people. Next, using a feminist disability studies approach, Carmen Britton and Laura Mauldin examine physical and social barriers related to accessibility for disabled women in Sri Lanka and uncover intersections among disability, gender, and ethnicity. We continue with a chapter by Nickie Coomer and Kenzie Latham-Mintus who examine the reflexive interplay of cultural, institutional, organizational, and personal narratives of disability in the lives of college students experiencing immobilizing test anxiety. This is followed by Linda Blum who offers insight into how mothers of children with social/behavioral/emotional disorders sometimes accept, and sometimes challenge, cultural stories. We conclude with stories about fathering in families of adults with life-long care needs by Heidi Steinour and Sara Green.

Part II, *Cultural Stories of Disability and Organizations*, turns to the power of disability narratives in ongoing organizations. Lisa Buchter's analysis of employee recruitment programs for disabled people in France is a concrete example of how multiple cultural narratives – of disability, workers, and cultural value systems – can be translated into specific forms of policies and organizational practices. The second chapter in this section by Stephanie Lau and

Aliza Weiss offers a program evaluation of an inclusive postsecondary education program for students with intellectual/developmental disabilities and shows the potential of stories to identify needs for program improvement. This is followed by Melinda Maconi's examination of how an organization dedicated to producing disabled people as artists navigates the competing demands of fundraising which requires promoting the value of arts education as "therapeutic," and disability advocacy requiring promoting the intrinsic value of disabled artists.

Part III, *Cultural Stories of Disability and Social Policies*, takes up the topics of relationships between cultural stories and social policy. The first two chapters in this section examine how stories shape the process of social policy development: Melissa Welch focuses on debates about what specific impairments should be included as "disability" in town hall meetings for the ADA Amendments Act; Loren Wilbers looks at how stories told by individuals in policy hearings shaped policy surrounding the contested illness of chronic pain. The second two chapters in this section center on practical problems resulting from the shape of policy: J. Dalton Stevens looks at problems created by transition to adulthood social policy that assumes disabled people desire – and are capable of – living on their own; Brian Grossman challenges the organization of Medicaid services that make it all but impossible for program participants to move from one state to another.

Part IV, *Cultural Stories of Disability and Resistance*, examines the ways in which disabled people and their supporters actively resist stories that have so many harmful consequences. We begin with scenes from Richard Chapman's life that highlight the complexity of navigating life as a counselor who has a disability and the ways in which he resists cultural understandings of both disability and counseling. Next, the writing group, Lisa Boskovich, Mercedes Cannon, David Hernández-Saca, Laurie Kahn, and Emily Nusbaum, offers a multi-layered, multi-authored story of the importance of critical friendships in an ablest world. This is followed by Ahoo Tabatabai who examines how mothers of disabled children sometimes use – and sometimes challenge – cultural stories of success when evaluating the characteristics of their own children. Finally, two authors explore how disabled people create online communities that resist toxic stories of disability: Morgan Sanchez directs attention to stories of resistance created by people with the contested illness of chronic fatigue syndrome; Justine Egner's focus is on communities of LGBTQ + disabled people of color.

Together, these chapters offer significant evidence about the importance of narrative in understanding the intersections of bodily difference with cultural environments, social structures, and personal experiences. These chapters variously illustrate that attention to how stories work and the work stories do can uncover and bring to the table voices missing in traditional scholarship, illuminate complex socio-cultural processes, and suggest the potential use of stories about the complexity of disability experiences as tools for resistance and social change.

NOTE

1. Following the social model of disability, we differentiate between impairment and disability. We associate "impairment" with bodily differences currently conceived to be outside of the range of "normal" variation, recognizing that "normal" is also a social construct that varies with social, cultural, and historical context. We associate "disability" with social, cultural, and physical environments that impose layers of disadvantage on people whose bodies do not conform to current concepts of normality. We use "impairment" when we are speaking strictly of bodily differences and "disability" when we are speaking of more complex interactions between bodies and environments. Further, we find value in both the UK convention of speaking of "disabled people" in order to emphasize the ways in which environments act upon people with impairments to disable them and the US convention of using "people with disabilities" in order to emphasize that disability is only one piece of an individual's identity. We alternate between these two conventions in this introduction and have encouraged chapter authors to use the convention with which they are most comfortable, except within direct quotes.

ACKNOWLEDGMENTS

In addition to the chapter authors who served as blind reviewers for each other's work, we wish to thank the following external reviewers: Sharon Barnartt, Michael Dellwing, Douglas Engelman, Carley Geiss, Martin Harbusch, and Kate Scorgie.

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