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Editors

Occupying Disability: Critical Approaches to Community, Justice, and Decolonizing Disability

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© Neil Marcus
Tent City 2011, Oakland, California City Center. Image Description: Somewhat battered protest posters, "Occupy Colonize" and "Everything Oakland," line a subway stairwell behind a metal hand rail. A bike wheel protrudes from the right, seeming to climb the stairs. The space is not accessible, yet it is claimed.

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Foreword

The editors of *Occupying Disability* have given us a book that is bold, critical, and radical. Its core project consists in “decolonizing disability.” Toward this end, the editors offer a synthesis of three disparate kinds of sources:

- Occupational therapy, **a health profession** concerned with prevention and remediation of barriers to function and social participation of people with disabilities
- Anthropology, **an academic discipline** concerned with understanding the global and local forces—the discourses and practices—that reproduce cultures but also produce cultural transformations
- Disability studies, the intellectual side of **a social movement** that demands full citizenship and personhood for people with embodied differences

These disparate sources—their languages, perspectives on the human condition, conventional modes of action, and practical concerns—can overlap only partly, not fully. They also collide, threatening to careen an unwary visitor into the “discomfort zone,” a term the editors use to describe the bumpy, multiuse terrain of this book. What is so potentially uncomfortable or discomforting about this place? Why should anyone—anthropologist, disabled activist, occupational therapist—choose to go there?

The answer has to do with the idea of **occupation**. To be colonized is to have control taken away, to have the cultural and material foundations of our homeland seized by an occupying power. But the politics of liberation—with pain and joy—encourages us to do what is necessary so that we ourselves and everyone else can meet our human potential for individual growth and social participation. We insist on occupying the places where we belong.

Among the editors, contributors, and readers of *Occupying Disability* can be found anthropologists who are disabled and produce research on disability; critical occupational therapists who endorse disability rights over medicalization; and disabled artists and activists who aim to unsettle and transform exclusionary cultures. None are waiting around for others to agree with them or to give them permission to act. We are at a point of passage beyond stigma and inclusion. We are engaged and occupied.

Tensions do exist, however, among these multiple positions, standpoints, and intersections. For some of us to experience colonization, others of us must be colonizers, at least in some times and in some places, as situations shift. So the discomfort zone comes with a certain amount of risk. Identifying or being identified strongly with a profession, discipline, or disabled viewpoint may easily put one at odds with others in the collective project. In fact, it may put us maddeningly at odds with ourselves.

Welcome, then, to the discomfort zone. Prepare to read a post-disciplinary manual about occupation. You will find yourself in a place where a certain intellectual anarchy—the refusal to fit into set boundaries—restores a missing wholeness. What a challenging and liberating place to be.

Gelya Frank
Author of *Venus on Wheels: Two Decades of Dialogue on Disability, Biography, and Being Female in America* (Berkeley and Los Angeles: University of California Press, 2000)

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Acknowledgments of Partnerships

There are many intersecting networks here that describe our collective and individual pathways: our literal and intellectual geologies. Editors Pamela, Devva, Akemi, and Nick would like to thank Maria Milazzo for her assistance in copy-editing chapter drafts. We must thank our contributing authors, too many to list here. And then there are the people who influenced all of us—albeit differently considering our varied ages and life histories—some as mentors, some as colleagues, some as friends, and some as partners in struggle. The lists are long. We thank Neil Marcus for setting the most productive and welcoming tone to the project and providing us with our cover image, and Leroy Moore and our many activists and artists collaborators for their knowledge, perception, wit, and juice. Then we would like to thank the people who straddle anthropology and occupational therapy: Anne Blakeney, Gelya Frank, Amy Paul Ward, and Sherri Briller. We all are also profoundly in debt to the following progressive occupational therapists: Lilian Magalhães, Frank Kronenberg, Dikaios Sakellariou, Mansha Mirza, Sue Magasi, and Sandra Galheigo. We are all influenced and supported by anthropologists of disability including Russell Shuttleworth, Lakshmi Fjord, Sumi Colligan, Gerald Gold, Nora Groce, Elaine Gerber, Michele Friedner, Pamela Cushing, Patrick Devlieger, Karen Davis, Rayna Rapp and Faye Ginsberg. And then there are the founders and definers of disability studies and the Society for Disability Studies (an organization of which both Devva and Pamela are past presidents), many with a foot/wheel in anthropology or a related social science or even occupational therapy: Kate Seelman, Richard Scotch, Mariette Bates, Helen Meekosha, Joan Ostrove, Joy Hammel, Nirmala Erevelles, Alison Carey, Noam Ostrander, Alberto Guzman, Petra Kuppers, Marjorie McGee, and Tammy Berberi.

Pamela: In addition to those mentioned above, Pamela would like to thank her mentors in disability studies (Christopher Keys and James Rimmer), in occupational therapy (Vera Jean Clark Brown in memoriam), and anthropology (Richard G. Fox) who influenced her emerging scholarship and helped her along this journey. She would also like to thank Dean Craig Lehman of the School of Health Technology and Management at Stony Brook University as well as Sue Ann Sisto, Deborah Zelizer, Eva Rodriguez, and Richard Johnson for supporting her scholarship and initiatives to build disability studies programs in our school and across campus. A special thanks to the growing list of disability studies colleagues at Stony Brook,

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Part I

Decolonizing Disability

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Occupying Disability: An Introduction

1

Pamela Block, Devva Kasnitz, Akemi Nishida, and Nick Pollard

Abstract

Inspired by disability justice and the fall 2011 "Disability Occupy Wall Street/Decolonize Disability" movements in the US and related activism elsewhere, we are interested in politically engaged critical approaches to disability that intersect academic fields—principally occupational therapy, disability studies and anthropology—as well as community organizing and the arts. The "occupy" international movements claim collective identities as does *Occupying Disability: Critical Approaches to Community, Justice, and Decolonizing Disability*. International disability movements claim disability as a collective identity rather than a medical category and recognize the political and economic dimensions of disability inequity as it intersects with other sources of inequality. Different political positions have evolved within different disability perspectives, all of which demand audience. Working with them and understanding them

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requires broader social critiques not usually part of most clinical educations. Some activists would not, as a matter of principle, engage clinicians because of their unfettered access to agency and operations of power. Negotiation of separatist consciousness is a stage to forming identities in many political movements. Yet we, as editors and authors strive to move beyond simple binaries: the goal is true participation, meaningful occupation, and disability justice.

Keywords
Occupation • Occupational • Occupying • Occupational therapy • Occupational science • Disability • Disability studies • Anthropology • Theory • Practice • Activism • Justice • Decolonize • Community • Movements

1.1 Anthropology, Disability Studies, and Occupational Therapy

This book provides a discursive space where the concepts of disability, culture, and occupation meet critical theory, activism, and the creative arts. There are books that challenge occupational therapists to engage in innovative, community-based and politically relevant practice, however, there are no books that draw from anthropology and disability studies together to push the boundaries of how occupational therapy/science approaches disability. Similarly, the "Occupational Therapy without Borders" literature has great relevance to anthropology and disability studies—offering (as Gelya Frank has been telling us for many years) innovative ideas about what to *do* with all this theoretical training—but this literature is regrettably not known to most anthropologists and disability studies scholars (Frank et al. 2008). Even the use of "occupational science" and "applied anthropology" nomenclature has not served to bridge contested and negatively value-loaded academic and professional boundaries that variously characterize occupational therapy as clinical and atheoretical, anthropology as an esoteric soft science, and disability studies as an interesting self-indulgence for the disabled.

Our contributing authors come from a variety of professional, academic, and activist backgrounds in order to include perspectives from theory, practice, and experiences of disability. The authors are premiere scholars and practitioners, as well as emerging theorists and activists drawn from all three fields of study and from around the globe. Our principal themes include: all the permutations of the concept of "occupy;" disability activism and decolonization work; marginalization and minoritization; technology; and struggle, creativity, and change. Moving well beyond traditional clinical formulations of disability, this book will engage clinicians, social scientists, activists and artists in dialogues about disability as a theoretical construct and as lived experience. In other words, the goal of this volume is to consider disability, not in terms of pathology or impairment, but as a range of unique social identities and experiences that are shaped by a full spectrum of always visible—sometimes perceivable—usually invisible—diagnoses/impairments/embodied differences, connected to socio-cultural values, assumptions, and environmental barriers. We try to look at disability analytically but without confining it to any particular definition. We allow authors to define their own terms appropriate to their purpose. Terminological definitions should be tied to theoretical positions, and these in turn should be chosen not only by what intellectually satisfies, but by what supports action toward human flourishing. We probe deeper and broader than usual visible/invisible, physical/psychiatric, acute/chronic binaries.

Negotiation of separatist consciousness is a stage to forming identities in many political movements. In this evolving dialogue there may be some issues of coherence, it is not an arena where everyone speaks in the same academic language, because it is a space shaped by inequality—in access to places and platforms, in opportunities for education and expression, and in struggles for resourcing and a right to daily existence. The languages used are themselves determined by these experiences and at times there will be no consensus about appropriate terms, no clear agreement. An emergent discourse is not an easy one to follow. We have had to step back from taking the traditional academic editorial role, which in this project would have stifled the authors. It is not appropriate here to correct the way people have written in their own words what they have wanted to say, except perhaps to make some adjustments for clarity. Instead, we hope we have tried to let the conversation flow. We're excited about working with the authors to present these discussions in the same volume, and look forward to the arguments and debates that we hope it may stimulate the reader to take up. In the course of editing this book, we have had some of those debates ourselves and so feel at first hand that it is an emergent discourse. As editors and authors we strive to move beyond simple binaries: the goals are true participation, meaningful occupation, and justice for disabled people.

The concept of "occupation" is also intentionally a moving target in this book. Some authors will discuss occupying spaces as a form of protest or, alternatively, protesting against territorial occupations. Others will discuss occupations as framed or problematized within the fields of occupational therapy and occupational science and anthropology as engagement in meaningful activities. Others will frame it, as Friedner (Chap. 14) does explicitly, in terms of occupying time and space in or out of the workplace.

There are marked tensions about just who occupies disability in the sense that countless professional jobs have been created to "support" disabled people across the life course in educational, rehabilitation, and service fields, while disabled people themselves struggle for employment. There are disabled occupational therapists and anthropologists, but they are pretty rare and barriers are legion: from licensing specifications or expectations of exotic fieldwork that can be used to exclude students from these fields, to the inaccessibility of national conferences that deter the participation of all disabled professionals—a new and particularly disturbing experience for those with late onset disability (Murphy 1987). "Independence/interdependence" and "meaningful occupations" remain real unmet goals in which occupational therapy has an important but too often unrecognized or unrealized role. We seek to explore critical reassignment of those terms. At present the occupational therapy profession seems to consider "occupation" in ways that underpin the professional relationship to medicine and other health roles. It has yet to demonstrate—even in its foundation theoretical field of occupational science—how occupation is experienced as a human quality encompassing all behaviors in all varied cultural contexts. In terms like productivity (Wilcock 2006) there is a tendency for the meaningfulness of occupation to be separated from the positive meanings that many people experience in occupations that lead, for example, to sexual intimacy, fun, taking action, or, negatively, to exploitation or drudgery. As a "service" field, occupational therapy tends to be focused on individual experiences of meaning rather than supporting collaborative growth through interdependence, or being facilitative such as in the generation of spaces where people can experience each other and joint occupations. This latter approach is explicit in the application of disability studies and anthropology.

Our specific aims are to:

- Give occupational therapy scholars, students, and practitioners more complex theoretical approaches to disability using anthropology and disability studies,
- Give disability studies and anthropology scholars, students and practitioners examples of occupation-based practices of direct relevance to disability studies and anthropology,
- Engage students, professionals and academics with disability activist concepts as articulated directly by the activists themselves, with the goal of preserving the power and authority of activist voices.

Too often scholars of disability studies and anthropology are content to observe, document and theorize. Examples of this include the *Disability Studies Reader* (Davis, 3rd edition 2010) and *Disability in Local and Global Worlds* (Ingstad and Whyte 2007). Meanwhile, occupation-based practices focus on active engagement but are often under-theorized. Disability studies has emerged as the multi/inter-disciplinary home to incubate theoretical and methodological perspectives toward disability in society, not just any disability content. Anthropology and disability studies can inform and enhance critical reflections on the nature of occupation-based engagement with disabled people and disability communities. Occupational therapy can focus theory on the content of human occupation. Our goal is a dialogue that is balanced among the people who study, practice, and work for justice: some of us utilize these "occupations" of occupational therapy, anthropology, and disability studies, while some contest these occupations with our lived experiences as disabled people. In documenting various means of translation from theory to practice we span the spectrum from clinical practice to activism and performance.

This dialogue has taken place over the past decade in spaces like the Society for Applied Anthropology, the Society for Medical Anthropology, the Society for Disability Studies, and the Society for the Study of Occupation, and in the 2008 special issue of the Journal *Practicing Anthropology* (edited by Block, Frank, and Zemke). There are books that challenge occupational therapists to engage in innovative, community-based and politically relevant practice. Examples include *Occupational Therapy without Borders* (Kronenberg et al. 2005, 2010), with a planned second edition to these first volumes, *A Political Practice of Occupational Therapy* (Pollard et al. 2008), and *Politics of Occupation-Centered Practice* (Pollard and Sakellariou 2012). However, there is no book that specifically discusses how occupational therapy engages with disability studies *and* anthropology. It is time to move the conversation forward through a book project allowing for a deeper and more richly comprehensive exchange of ideas.

1.2 The Discomfort Zone

We are aware of our responsibilities in creating a collection that includes critical scholarship, research reports, and activist narratives. We must remain accountable to all the participating communities both in terms of regional power dynamics and tensions between therapeutic, scholarly, and activist modes of representation and practice. For example, Petra Kuppers (Chap. 5) cautions that anthropologists and occupational therapists would do well to join "[w]estern disability researchers [who] need to take better heed of the concept of sovereignty and culturally specific knowledge, and allow these understandings to complicate universal human rights frames and ways of conceiving of aid," (p. 70). Activists also confront western scholars about elitism and the lack of accessibility in academic formulations of disability. For example, activists heatedly protested the original framing of a call for proposals (CFP) for a forum on gender and disability issues for the online publication called *The Feminist Wire* (TFW). After receiving numerous complaints about the inaccessibility of the CFP, the program committee responded with the following statement:

> Given the sustained exclusion and economic vulnerability of those with disabilities, the academic language of our call was pointed to as yet another method of exclusion. Reduced access to formal higher education works to perpetuate a cycle of ableism. The unfortunate reality is that there's a disjuncture between disability studies (and academia at large) and disability justice organizing. We honor that many communities on the frontlines of oppression regard the academy itself as a major site of violence, trauma, and ableism. While TFW seeks to blur the demarcation between activism and scholarship, it is also an "academic-ish" publication. We are committed to making our forum widely accessible, and we also want to acknowledge and politicize the location from which we ourselves are located and form critical analysis.
>
> (The Feminist Wire Call for Submissions 2013, http://thefeministwire.com/2013/08/call-for-submissions-tfw-forum-on-disabilities-ableism-and-disability-studies/, retrieved 7/20/2014)

The TFW forum organizers were in a fertile but disquieting space that we term "the discomfort zone," (Block et al. 2011). Unrelated to Jonathan Franzen's (2006) book of the same name, our concept of "the discomfort zone" was first introduced in a panel *The Discomfort Zone: Exploring juxtapositions of Applied and Theoretical DS in Research and Practice*, organized by Pamela Block and moderated by Pamela Cushing, at the Society for Disability Studies in 2009, Tucson Arizona (Block 2009) which included the following presentations: "The Discomfort Zone: Collaborative

Disability Studies Research with Clinicians, Activists, and Youth with Multiple Sclerosis" (Block et al. 2009), "Using the Discomfort Zone to Create a Disability Studies Informed Rehabilitation Practice" (Magasi and Kramer 2009), as well as presentations by Kasnitz (2009) and Cushing (2009).

This *discomfort zone* is where we acknowledge and respect boundaries while at the same time pushing them. This is an ongoing struggle when moving between activist versus scholarly, clinical, and professional formulations. And from the other end, in some contexts, scholars fear the appropriation of disability studies for partisan political purposes, as Mello and Block discuss (Chap. 20), as well as the appropriation of disability activism by academia as just described above. Similarly, the discomfort zone emerges when engaging topics that highlight the intersectionality of race, sexuality, nationality, and disability as it has been articulated in Bell (2012), Erevelles (2011), and by many others. Such a discomfort zone actually prepares and continues to nurture the ground for critical theories, activist practices, and art to sprout. This is where this book idea first emerged; readers will witness the ongoing struggle when moving between and interweaving activism, artistic, scholarly, clinical, and professional spheres.

Language differences exist across cultural and regional boundaries but also across disciplinary, professional and activist ones. In June 2013, Block gave a presentation in Brazil about neurodiversity and her family experience growing up as the concept of autism changed dramatically over a 45 year period from the late 1960s to the second decade of the twenty-first century. She used autistic-first language as is preferred in autistic self-advocacy contexts in the United States and many northern countries. However, Brazilian activists and scholars embrace the people-first language of the Convention on the Rights of People with Disability (CRPD), long-ratified in Brazil. Even though Block was careful to explain in detail why she made her language choices, she could see the audience cringing every time she used disability-first language. Though jarring to readers used to other formulations based in other political realities, the respectful language choices in individual chapters, such as Aoyama (Chap. 3) who refers to Minamata Disease survivors as "victims," accurately represent the sometimes politically-charged language choices made by specific disability groups from around the world. In addition, the academy often specifies how knowledge should be expressed and privileges certain writing styles. This constriction of diverse and creative expression narrows our understanding of people's experiences. Instead, this book embraces various writing styles that are authentic to the authors and topics and we also include a few images to expand how the authors' wisdom is communicated. We have tried to edit the chapters in this book in ways that are sensitive to how different experiences are described by different people and that allows the authors' perspectives to be shared unobscured.

We are indeed in *the discomfort zone*, and this is where we want to be. Not all contributors are in agreement on how the concept of occupation should be used and how occupation works in practice. Not all contributors agree with how disability should be defined and spoken about, what language to use, and even who is allowed to join the discussion. Some use "people first" language and some do not. Because our chapter authors represent UK, US, and Australian English speakers, as well as many for who English is a second or third language, we preserve local vocabulary and syntax while trying to communicate intent. Retaining the creativity of the discomfort zone is work in need of doing and one of our occupations for this book.

1.3 Decolonizing Disability, Disability and Community, and Struggle, Creativity and Change

These are the three *Parts* of this volume. Any and all of the chapters can stand alone and be understood separately. In fact, in our new era of publishing flexibility, the chapters may be purchased separately. The *Parts*, while not specifically chronological, do have a mood of temporality about them—past, present, future.

Part I: Decolonizing Disability, does take as its focus disability in the context of oppressive social structures of power that create and recreate disability out of difference in part as a system of control—methods of settler colonialism of the past or that which we hope is past. It is not pessimism, just that to come to a point of proactively decolonizing, we must first recognize the state of being colonized or how the settler colonialism deeply intersects with the mechanism of ableism. This section title as well as the book title is a direct reflection of the second half of the "Occupy Wall Street" movement: "Decolonize Wall Street." We strongly agree with indigenous scholars' statements that "Decolonization is not a metaphor" (Tuck and Yang 2012). While not all chapters directly engage with the work of decolonization, our intention for the use of this word is in order not to stop our conversations at Occupy disability and in order to acknowledge and join the work to decolonize and occupy wall street, the ableist medical industry, and many other spaces." This *Part* spans from the personal to the statistical—from Taylor et al. (Chap. 2) life change narrative from sites of US activism against class injustice, to Geddes (Chap. 9), a formal analysis of post-colonial inequality in the Caribbean. As in Geddes, decolonization is directly relevant to Kuppers' view of disability in Aboriginal Australia (Chap. 5), while Aoyama's (Chap. 3) story of Minamata Disease in Japan, and Yergeau's (Chap. 6) of autism are examples of decolonization reinterpreted intraculturally. Ames (Chap. 7) and Perez et al. (Chap. 8) are both about art funded as therapy for colonized cultures—Wales and Brazil respectively. Without denigrating art as therapy, and good therapy as art, both of these chapters ask "who benefits?" Perhaps the essence of understanding disability in colonialism is to ask that question.

Part II: Disability and Community, takes as its starting point that disability can be a basis for community. This is the present in our quasi-temporal order. Community is a deceptively simple word and concept. We think we know what it is, particularly if it is intentional. We speak of multiple kinds of intentionality. There is the extreme intentionality of planned or "Intentional Communities" such as utopian experiments that have and will seduce those with a touch of escapism (Zola 1982). Disabled people could be ripe for this kind of future if we were not so diverse. However, current trends in intentional communities that involve disability are either still nursing-home-esque, single-impairment, defined by others, and often involuntary; or, they are loosely structured and fluid and based on the collective experience of disability, not on the individual experience of impairment. The *community* we explore here can be based on social identities or occupational activities. Whether the community we discuss is “real” or “imagined” or “wishful,” whether it is defined from within or without or both, whether it is physical or “virtual,” it is contemplated, from a structuralist point of view, because someone found the idea “good to think.”

Clearly community can be geographic and permanent, but its physicality can also be temporary and episodic. A community can be communicative or linguistic, a type, a style, a mode of intersecting networks of information and feelings. Many combine both aspects: geography and communication, such as the Welsh case, but this is changing. Nepveux (Chap. 12) and Friedner (Chap. 14) are the most geographically bounded discussions of community. They both talk of the unrecognized importance of a place to be that is fluid in how people can use it as a site for interconnection and communication. Both are examples of geographic communities that continue to exist, at least partially, due to service providers’ all-too-precarious support. “Naturally” occurring US Deaf communities using American Sign Language (ASL) are clearly communicative, but usually share proximity only episodically and with sustained effort.

Some chapters, like Nishida (Chap. 10) and Mirza et al. (Chap. 11) speak to a clash, or potential clash, of communities, in these cases communities directly related to occupation in its most formal sense—what you do for a living. Nishida introduces the idea of occupational “hyper-productivity” and applies it to academia. Hyper-productive occupational expectations can in themselves exclude many groups of people and are inherently ableist and saneist everywhere and in any field. Nishida demonstrates that in academia, where knowledge is supposedly created and shared, the disability community, in particular as it intersects with other minoritized communities, conflicts with the academic. Mirza et al. look at the occupation of being an occupational therapist and of how this occupational community can conflict with that of “their” not always so “patient” customer (although we can argue that insurance providers are the actual customer). They suggest a more open and interdisciplinary approach to *training for collaboration*, a recurrent theme, as one corrective for the narrowness of monocular clinical occupations. This myopia is a direct foil for the creation of the community described in de la Haye (Chap. 16): the service users’ movement. She wants to see this community visible in a policy world and active in research. Will reaching out to the professionals be accepted as true participation?

Three of the chapters in this *Part II: Disability and Community*, tell a story of how an individual negotiates communities. Stoddart and Turnbull (Chap. 13) relate Stoddart’s journey as someone denied a professional occupation by a speech impairment who tries to create an occupation as a trainer in how to communicate with people with speech impairments. With Turnbull as his university-based partner, he succeeds conceptually, but not yet fiscally. However, while Stoddart does not embrace disability as a collective identity, Dupree (Chap. 15) most explicitly does. Is this related to their different experience of satisfaction? Dupree seeks out community in one of the most densely populated places on earth, Manhattan, NY. As a ventilator user he demonstrates true physical risk as part of the business of building community. He is an example of how luck and life can meet disability and create activist communities in the process. This is not to idealize Dupree's lived experience, which includes life-threatening struggles, discomfort, pain, and weariness. Accompanying the triumphs come roller-coaster rides of hope and disappointment. Perhaps the most optimistic picture of emerging disability community is that of Eva Rodriguez (Chap. 17). She relates how simple but profound changes in how an educational planning meeting is structured, centering the priorities of family and disabled child, may make a huge difference in the child's future. We want to educate for choice and collaborative communities that enshrine the needs, hopes and opportunities of all children.

Part III: Struggle, Creativity and Change is the future in this quasi-temporal schema and our many paths to a cautious optimism. This endeavor is not academic, it is not a sequestered case study, nor is it a random sample. It is the best of what we know that drives us to know more. It is the best of what we have seen that works and satisfies. *Part III* also resides in the discomfort zone as reader and writer both struggle in ways that bring the kind of creativity that sparks substantive change. All are underrated. Some of these chapters capture us in their unusual formats: with a poem, a dialogue, an image, we promise creativity. We close the effort on the upbeat with Marcus et al. (Chap. 24) which uses all of these creative formats. However, even here the pain to arrive at such a hopeful place is just below the surface. Hecht (Chap. 19), among other dark chapters, is perhaps the darkest foil to Marcus et al.'s optimism. It is a discomforting but riveting short story by Hecht upon which Mello et al. (Chap. 20) reflect, as they do a groundbreaking job of discomforting English language disability studies specialists with a surprising sibling, Brazilian disability studies. Our message is simple: change and grow—collectively, it is both possible and necessary.

Struggle is such a recurrent theme. Even Seelman (Chap. 18), as she embraces technology, worries not only about the politics of economic access, and of the unhappy consequences of surveillance potential, but about what creates daily meaningful occupation with low or high tech help. Chaplin (Chap. 22), a Deaf/blind author, welcomes us into his everyday world. Occupational therapists will appreciate how he analyzes his own experience of participation. His greatest instrumental need is for people to relax their hyper-productive drive for constant simultaneity. The use of focus in time recurs as a theme in all discussions of communication impairment. Kasnitz has noted conflicts of reality in this area. She describes to us all how blind interlocutors who have not touched her, held her hand, or stroked her cheek as she speaks, often don't realize the effort her speech entails nor body language cues of conversational turn taking. A chapter such as Chaplin's fills some of the "Now I got it!" gaps in our experience of each other's struggle and how creative we need to be to have voice.

The poems and text of the Stevenage Survivors (Chap. 23) do this explicitly. There should be no real surprise that art, particularly preformed or written word art, is a powerful vehicle for psychiatric survivors. As Moore, Garcia, and Thrower (Chap. 21) demonstrate, the written word also reveals often overlooked violence—police brutality against disabled people of color or political gentrification by mainstream activism—as well as challenges it and sheds a light on the path to justice. Ben-Moshe's (Chap. 4) perspective as a disabled Israeli illustrates how violence manifests at the intersections of ableism and other social injustices when living with a legacy of military occupation. In other parts of the world, we are not so close to death, but neither is it as far away as we would like. The Stevenage group call themselves "Survivors" appropriately, and the term could just as well be applied in Dupree (Chap. 15) or Peres et al. (Chap. 11) or withheld in Moore et al. (Chap. 21) or Hecht (Chap. 19). Many disabled people experience a lack of *voice*. Whether autistic (Chap. 6), a psychiatric survivor (Chaps. 11, 16 and 23), learning disabled (Chaps. 7 and 17) or speech impaired (Chaps. 13 and 24), we are haunted by a sense that no one is listening, we are silenced, misrepresented, or erased. Is it any wonder that we hone our performance skills to hold an audience's attention, once we have won the battle to get them to still their inner chatter and really listen—a reborn art we demand of our environment?

1.4 Recurrent Themes and Open Futures

This book is not a random collection but it is very diverse. Two of us, Block and Kasnitz, are American Jews who sit here in solidarity with Liat Ben-Moshe (Chap. 4), safe, and feel horrified but powerless to stop the death and disability-making going on at this moment (August 2014) in Israel/Palestine except in our voices of protest recorded here. This war time disability-making is of course not new. In *Moving Violations* (1995), Hockenberry describes it in haunting accounts of his experiences as a wheel-chair using journalist in the Middle East between 1988 and 1992. He describes dark times, and these tales seem prescient to our post 9/11 era and the current war in Gaza. Moore et al. (Chap. 21) describe the disability-making of police violence. Minamata Disease (Chap. 3) is the disability-making of corporate greed. The colonization of Australia created disability from difference as seen by Kuppers (Chap. 5). And being people of color in white supremacist societies, brings disability closer to them, whether it is through racial violence or over- and under-diagnosis.

Once made, disability is best lived in community. Any struggle for community is worthwhile. A creative struggle is the most satisfying. This volume is rife with contributions by people who consciously engage in word art as an act of resistance. We really want to see these and the other innumerable skills of disability recognized and taught. However satisfying these occupations may be to spirit, we also want to break through the barriers to formal *occupations*, what we are remunerated for, how we support our families. Everyone needs to be paid for what they can do, not warehoused for what they can't. We have not yet scratched the surface of disability as an ingenious way to live.

We close this introduction with a note about our style. As this book developed, and with such dramatic changes in publishing, many of you may never hold this volume in your hands. You won't feel its weight or flip its pages. You may not even have the whole thing. You may have just purchased chapters. Well, if you are reading this, we invite you to also read Chaps. 25 and 26, the last two. Like this chapter they are also written by the four of us and in serving as introduction, development, and conclusion are the three legged stool on which we sit thinking about the problems and delights of the ramifications of "occupying" and "decolonizing" disability.

Disability is an Art: This is an example of poster art by Neil Marcus. It is a self-portrait, a loopy rope-like ink drawing of a figure in a wheelchair accompanied by the text: "Disability is not a 'brave struggle' or 'courage in the face of adversity.' DISABILITY IS AN ART (this last phrase in large bolded, ink-stroked text in all capital letters). It's an ingenious way to live." (Drawing by Neil Marcus)

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2 Krips, Cops and Occupy: Reflections from Oscar Grant Plaza

Sunaura Taylor, Marg Hall, Jessica Lehman, Rachel Liebert, Akemi Nishida, and Jean Stewart

Abstract

This chapter includes a collage of reports from disabled (and their ally) occupiers of different cities. The collage is contextualized by Taylor's involvement in Occupy/Decolonize Oakland through journals she wrote while she stayed at the camp site. As much as this chapter acknowledges and celebrates the powerful force of Occupy Movement, it also points out the movement's challenges to make the sites accessible to all. Stewart and Hall illustrate works of CUIDO (Communities United in Defense of Olmstead) and its intersection with the Occupy movement. Nishida introduces KOWS (Krips Occupy Wall Street), the disability community representation at New York City, Occupy Wall Street (OWS), and multiple roles it plays at the site. Liebert reads OWS from radical

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psych perspective, and shares ways people are working to educate OWS to ensure safety for all within the movement. Lehman points out relations between Occupy and general disability rights and suggests mutual education take place between these movements. This chapter ends as Taylor reflects on awareness she gained through her participation in the movement; where she learned the depth of structural police violence and her own privileges in intersection with her disability identity.

Keywords

Community • CUIDO (Communities United In Defense of Olmstead) • Decolonize • KOWS (Krips Occupy Wall Street) • Occupy Oakland • Occupy Wall Street (OWS) • Oscar Grant Plaza • Police brutality

2.1 Introduction

Sunaura Taylor

January, 2012

Inspired by Occupy Wall Street and the numerous other encampments that were spreading across the country, first time protestors and seasoned activists began occupying a public plaza in downtown Oakland, California on October 10, 2011. What began as a relatively small protest on a rainy evening turned into a powerful movement that has had ramifications well beyond the city of Oakland.

My partner and I were there that very first day and it didn't take long before we were hooked–spending hours at the General Assemblies, and (when we could) camping out in our sleeping bags and tent. We were there during countless inspired moments of community building and we were there during many of the (often scary) confrontations with the Oakland police.

Early on I was invited to write my experiences of Occupy for the Occupy! gazette, a project put out by n + 1. What follows are five pieces written for the gazette. They appear here in the order they were originally released. The first three are reflections and updates I wrote on my experiences as a protestor in Oakland. The next is a piece I edited that brought together the voices of other disabled protestors who were participating in the Occupy movement locally and nationally. The last returns to my voice.

Looking back on fall, 2011 I am aware that being a part of the Occupy movement has truly been one of the most remarkable experiences of my life. Of course it has sometimes been challenging, inaccessible, and deeply disappointing—it was and is not perfect. Even the name chosen for the movement, Occupy, has garnered a lot of criticism for the ways in which it uses the language of colonization, leading many to argue for a name change: Decolonize Wall Street (and similarly Decolonize Oakland). Despite its flaws however, the Occupy/Decolonize movement has been inspiring in a way I don't think I've ever felt before.

Occupy Oakland, like the Occupy movement more generally, is not over or dead as the media so often declares. However, it has transformed into something that at least for a time is a lot less visible than the unruly tent cities that were sparking our imaginations last fall. People are busy stopping foreclosures, striking debt and saving their schools. In the past year Occupy Oakland has organized many successful events, it has survived (albeit in a different form) the increasingly intimidating police presence and it has celebrated its first birthday.

My Queer (dis) Abled: Black and white drawing done in pen of a woman with glasses and long hair pulled back by a bandana. She is smiling slightly and wearing a t-shirt with an image and the word Propagandhi in capital letters. She holds up a crutch that is used as a sign post, with a sign saying: “My Queer (dis) Abled Welfare Chicana Ass Demands Structural Change.” “Welfare” is in smaller letters than the rest of the words. “Change” is vertical, in parentheses on the bottom right of the sign, also in smaller letters. (Drawing by Sunaura Taylor)

2.2 Occupy Oakland

Sunaura Taylor

October, 2011: I write this as a participant and admirer of Occupy Oakland.
Not as a representative of Occupy Oakland.

I just woke up in my tent at Occupy Oakland. This is the first night my husband and I (and our dog) have camped out here, and although I can’t say we slept well