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# Critical Approaches to Community, Justice and Decolonizing Disability: Editors' Summary

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## Abstract

This chapter is a reflection on the whole book. It looks back to the themes from the introduction and forward to the conclusions. We reintroduce our themes, discuss how the sections and chapters approach the themes, and develop the ideas in the chapters in more depth. Taken together, Chaps. 1, 25, and 26 are an expression of our development of the not unproblematic ideas evoked by the phrases occupying disability and decolonizing disability.

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## Keywords

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

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## 25.1 Decolonizing Disability

Disability is contested territory. In the Aramaic Hebrew bible while there is no collective word for “disability,” it is a matter of fact—only sometimes noteworthy. Moses’ speech impairment becomes a foil for God’s voice, the irony very deliberate as Aaron becomes an example of revoicing as developed and used by Devva Kasnitz and her long-term anthropology colleagues Russell Shuttleworth and Pamela Block; an example of the human microphone as Neil Marcus coins it in this volume (Chap. 24). In the Christian bible disability is not a matter of fact but now it is a foil for Jesus to demonstrate divinity by making miraculous cures. Disability is observable, a sign of evil at worst and pity or powerlessness at best. While the Viking warrior’s missing leg may be a sign of triumph over both enemy and death, in anyone else it is more likely a sign of punishment or a test of faith. If colonies exist for the benefit of the colonizers, disability exists for the benefit of and in contrast to the non-disabled. However wretched your life, you are “lucky” you are not one of us.

The metaphor of an identification between disability and colonialism emerges as a *strategy* when disability becomes more medicalized and medicine more ableist. As Ben-Moshe describes (Chap. 4), the use of “colonialism” as a metaphor is problematic. We acknowledge that while colonization and decolonization are not true metaphors, the lived experience of disability and the continuing struggle under ableism with intersecting social injustices interactively overlaps with colonialism. We contemplate how such settler colonialist mechanism is used on our disabled bodies, and some chapters do literally look at postcolonialist populations. Disability was/is the observable and incurable failure of medicine. Medicine continues to create disability as people survive with changes that were once not survivable. Medicine creates disability as more and more behavior becomes a sign of “something wrong.” As the colonizers view the colonized as needing order, the medical industrial complexity needs the disabled to need medical order, starting with a diagnostic label. As anthropologists, disability studies scholars, and occupational therapists, all also activists, we as editors of this book, ardently hold “decolonizing disability” as our necessity and our goal. “Occupying disability” is our method.

We eschew exaggerated academic binary models. The medical/social model binary is oversimplified along with disabled/non-disabled, scholar/activist, and perhaps the most difficult illness/disability. We look broadly at the conceptual layers of disability scholarship from the bio-physical world to impairment to disability to community to participation to justice. We borrow from many disciplines and theoretical models shamelessly, we borrow from many disciplines and theoretical models shamelessly and apply them to our topic and goal. We seek to decolonize ourselves in order to occupy disability in many ways. Disability is an experience as is colonization. With the recognition of these experiences they become an attitude, a dance, our source of strength, a community. As Neil Marcus says “Disability is an ingenious way to live” (see Chap. 24).

Devva Kasnitz tells us “I knew from quite young that you may forget my name or my face, but you won’t forget my body,” but somehow she didn’t “claim” disability

until she was 20, after spending a year in the 1970 student strike resistance to the 4/30/1970 invasion of Cambodia. She truly “came out” vocally as disabled in 1981 after 10 years of gestating her anti-war activism. She had designed costumes for her first 25 years and then owned a clothing store for 15 years. She costumed herself, she realized. “If people were going to stare at me, I might as well give them something to stare at.” Quite amazingly “people gave me hundreds of thousands of dollars to dress them!” Crip style trumped cookie-cutter mass-market style. Coming out disabled is not easy. But, once you realize the alternative, change happens.

To refresh the progression of the book, we remind you here of the themes from our introduction (Chap. 1) and then review the other chapters, a second introduction! We start with Sunaura Taylor et al. (Chap. 2) who demonstrates the radicalizing, strengthening process so well and so started us off. Describing process is important. We put Mami Aoyama’s work on Minamata Disease next (Chap. 3). We almost didn’t include this chapter. We struggled with was it about justice for disabled people or environmental justice? Was it about disease or disability? Did it focus too much on suffering rather than resistance, a focus on death instead of living with disability? Environmental injustice creates disability all around it, human and otherwise. And this was a case of conscious and criminal disablement. We present it in that context.

Liat Ben-Moshe (Chap. 4) untangles intricate anti-occupation struggles and disability activism: from the hierarchy of disability to diversity within these movements. Thus, Ben-Moshe depicts the limits of disability rights and peace activism in the context of the Israeli military occupation. As she states, “[d]isability is always inherent in anti-occupation and anti-war and vice versa,” (p. 56); disability and occupation take on particular and ominous meanings in this context of Israeli-Palestinian struggles. This chapter carries a particularly devastating power for us, since missiles were falling in Gaza and Israel when we were writing this in July 2014.

We next take you to Australia to Petra Koppers’ (Chap. 5) beautifully optimistic meditation on decolonization via art and trained listening. Here she honors the experience of hundreds of years of colonization. She turns her method internally—not unlike the best ethnography—and learns about others by studying herself in others’ places, in interaction. Other chapters use her same method but more often unconsciously. It is paradoxical that this deep ethnography comes from a non-anthropologist in a book rich with anthropologists. She reflects on truth in knowledge upon which we all need to reflect. Use her example.

Melanie Yergeau (Chap. 6) similarly gives voice to people deemed voiceless. She clearly describes a group of people whose difference—autism—has just recently, but thoroughly, been claimed and appropriated, if not colonized, by others from family services, to the educational sector, to medicine. She gives us an example of a growing body of autobiography of autism. This remarkable and accessible literature is a perfect example of Petra’s decolonizing methodology of art and deep ethnography. It also prepares us to look at other examples of communication disability as is discussed later in the book (Chap. 13) by Turnbull and Stoddart and (Chap. 24) by Marcus, Kasnitz, and Block. To risk overstatement, communication

impairments are some of the internally scariest, particularly when coupled with other impairments that make you dependent on instrumental help from other people. If we err, let's err on the side of assuming competence. Do *not* let protectionism focused on presumed incompetence allow colonization. Risk too is a human right.

Margaret Ames (Chap. 7) adds to this message. She too talks about liberation from colonization through art. She also works with a population of presumed incompetence—learning disabled in United Kingdom English—cognitive or intellectual disability in United States English usage. She also contends with another layer of colonialism, that of Welsh culture and language in the UK. She describes how claiming both disability and Welsh identity provides meaning if not escape from colonization. Art training is commonly deemed an appropriate occupation for people with “learning disability,” but as a part of “therapy” or a holding pattern against other more instrumental and remunerative activities they “can’t” do, not as a true occupation to be celebrated and shared in the larger art community and valued and compensated by the art-consuming public.

Marta Simões Peres et al. (Chap. 8) again looks at the role of art in disability, in this case as practiced in psychiatry in a total institution. Here the colonization of disabled art is even more explicit than in Wales. The Welsh program is mainstream, voluntary, community-based, respectful, and empowering compared to the Brazilian example. The institution-based art therapy approach in Brazil would be more acceptable if it were called therapy and left at the institution. However, the described endeavor points out how the international renown of the “therapists” is the true desired outcome, which could only be enhanced by its therapeutic efficacy if it led to improvement in the mental health of some patients, but does not require that outcome as a measure of the program's value. Here decolonization is explicitly dual: the colonization of Brazil by Europe and European “Art Therapy,” and the colonization of psychiatric disability within Brazilian institutions. Here decolonization needs a local refocus.

Annicia Gayle-Geddes (Chap. 9) on Jamaica, Trinidad, and Tobago closes *Part I Decolonizing Disability*. Her work is a departure from a focus on art and autobiographical methods, but no stranger to the politics of colonization, both in its common political sense and as applied to disability experience as a colony within larger society. We need reminding that disability correlates with most of what is least admirable in modernity: strict notions of the value of labor; inequity in metrics such as wealth, health, longevity; barriers to participation; isolation and unhappiness. Disability has yet to be decolonized by development in most of the world.

These chapters raise issues about how we train for collaborative work. We need collaboration that is cross discipline and transformational. It needs to discuss data all people involved value and understand. Community organizers have their own problems being collaborative with their “community.” As occupational therapists, anthropologists, and disability studies scholars we all have our professional machismo. As researchers, even as we participate, we watch the doers. Anthropology teaches us to triangulate. We look at what people say they do, what they say they should do, and what we see them doing—Petra's deep auto-ethnography (Chap. 5). Occupational therapy trains people to watch what and how people do what they do and to help them do it better. They study impairment—

they may or may not study disability. Anthropologists are careful to not only study “down,” e.g., focusing on those with less social status. So studying “up” to study a stabled clinical profession such as occupational therapy is an option, one that medical anthropology has embraced. Of course in the hierarchy of health service providers, occupational therapists don’t perceive themselves as having high status in comparison to doctors, for example. Also, providers don’t necessarily like being the object of study. Collaboration is key. Disability studies has a more problematic relationship with studying providers. It is a valuable approach. We need to study power. But, if you study the people who “take care of disabled people” from their point of view, is that disability studies, or is it the anthropology of work? If it is the latter, just as work on therapeutic approaches to impairment, it is rarely disability studies. Although, we do indeed agree that reappropriation of disability should follow the slogan: *Nothing about us without us!* So, medical work on impairment should include disabled clinicians. However, not everything about us, even with us, is disability studies. Question all labels.

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## 25.2 Disability and Community

For a long time community has usually been perceived as a positive word (Williams 1976) but it is a term which often masks differences. People often belong to different groupings within the communities they inhabit and inhabit multiple communities. Such groupings frequently constitute differences concerning social identities and occupational activities. In order to identify themselves they may operate entry and exclusion criteria, so while communities might be about who is included in a group, they also concern rules about who is ineligible, or about facilities and spaces which might only be used by some but not all. The interpretation of group membership might be formal or informal, it might rely on criteria determined by the group in a narrow way, or accorded in some form of consensus amongst community members. All of this might be necessary to enable people to maintain their distinctive identities, develop their consciousness, knowledge, or skills, but it can often bring about injustices where many communities are also characterized by their diversity, or where distinctions are related to the occupation of territories and the maintenance of physical boundaries.

In the second set of chapters (Part II) authors explore the connections between disability and community, viewing them through the lenses of different impairment and disability experiences and intersecting identities such as race and gender. What disability makes evident is that there are many extra layers to the membranes which may form patterns of exclusion. The term disability was not explored by Williams (1976), and it has only been since the 1970s that the significance of the experience of disability has been pushed forward through bottom up encounters which occur in, or despite, or in the disputes about, access and rights to community settings. As the authors in *Part II* reveal, both the concepts of disability and of community are complex, but they are prone to being made too simple to be useful. Occupation is also a complex term in its relationship of activity to territory and place as well

as the act of being physically present in a particular space. These complexities can produce obstructions and also provide creative and strategic opportunities that challenge disabling structures.

Akemi Nishida (Chap. 10) examines the impacts of neoliberal academia on those who participate in it—particularly through a disability studies lens. This chapter reveals physical and psychological consequences of various demands, such as hyper-productivity, under which scholars are often put. Thus, what does neoliberalization of academia (e.g., corporatization, individualization of responsibility, and increasing inter-colleagues, –departments, and -universities competitions) mean to disabled people, while academia is historically contested for its ableist and saneist foundation and practices. Finally, the chapter critically discusses the accessible and more inclusive academic justice activism and significance of interdependent relationships as a micro resistance among those who work to change academia from inside-out.

Mansha Mirza, Susan Magasi and Joy Hammel (Chap. 11) look at the risks which may stem from an over simplistic understanding of participation and narrowed practice of occupational therapy. A clinical perspective which does not reflect the wider economic and social environment, the real context of disability, cannot expect to meet the needs of people who are more likely to be marginalized because of their multiple issues. They suggest the introduction of a more interdisciplinary approach to professional education to tackle and counter the reproduction of a middle class privileged normative culture in clinical assessment, and thence the perpetuation of disabling practices.

Denise M. Nepveux (Chap. 12) reveals the way that a normative culture impacts community facilities when it is combined with real estate interests in the gentrification of run-down neighborhoods. She charts the resistance organized by the members of a senior center to its relocation under the guise of a public-private partnership between the Syracuse city council and the Salvation Army. The members were the last people to find out about the plans for their center and through their actions have persuaded local politicians of the need for a more participatory approach to local decision making.

Rick Stoddart and David Turnbull (Chap. 13) take another look at these kinds of divisions in relation to the occupational communities of professionals and the occupational communities in the wider social environment. They chart Rick's history of trying to find a job and operate his life roles in ways which reflect his level of capacity rather than being forced into a position of being a person with disability who has to accept other people's operating practices and rules in his private space. Arguing from Rick's experiences in asserting his dignity, they critique the ethical underpinnings of professional care services.

Michele Friedner's (Chap. 14) account of deaf young adults in Bangalore is an ethnographic investigation of the ways in which vocational training programs offered by NGOs provide trainees with opportunities to develop social skills, networks, and share learning. These exchanges occur through the social relationships deaf people have worked out for themselves. The extramural outcomes are more valuable than the limited scope of the repetitive training, and as they inhabit the

spaces of a world which is unheeded by the trainers and their employers Michele identifies alternative ways in which occupation figures in their lives.

Nick Dupree (Chap. 15) describes his adventures in taking his ventilator from Mobile, Alabama to New York City, getting out of Medicare to live with his partner and so to participate in the events around the Occupy Wall Street movement. Drawing on aspects of the protest movements across the globe at the end of the first decade of this century, his chapter asserts the position of disability activists in the current political struggle against corrupt and corporate power and its social and economic consequences.

Stephanie De La Haye (Chap. 16) explores ways in which the service user movement can address health policies, particularly with regard to asserting their inclusion in the development of research processes that influence them. She sets out examples of cultural change amongst professional groups initiated through service users which enable more inclusive practice, but warns against the loss of service user independence.

The concluding chapter in *Part II*, by Eva Rodriguez (Chap. 17) is on self-advocacy self-determination and access to the US education system for disabled students. She describes how some of the assessment processes are administered and experienced in ways that do not involve students or their families. As a result, parents may be unaware of how their children are denied opportunities because of the assumptions made by educational professionals.

These experiences reveal some of the disabling obstructions which range from the huge and obvious to the nuances of administrative prejudices to be uncovered in the negotiation of everyday life and the expression of the right to live in communities. There are practical things to implement, strategies to adapt and follow, questions to ask, both rules to break and to make, powers to seize and tools to use in the communities that we are about to develop.

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### 25.3 Struggle, Creativity and Change

In Part III we continue our exploration of difference, meanings, and experiences related to disability, culture, and occupation by focusing on extremes and continuities of struggle, creativity, and change. As a species, we careen into the future, as that which was once distinct becomes blurred, societies and peoples collide and intermingle, we find distinct forms of oppression as well as new ways to work together and enjoy each other. Technology provides us with toys for elite enjoyment, assistive technologies for those who can afford them, and opportunities for enhanced survival and quality of life. It also provides us with weapons of mass destruction, and, for many, the realities of oppression. In many ways we are under surveillance, observed and policed by militarized systems of control that regulate our bodies and behaviors in the context of (with the excuse of) administering bodies politic. These systems are amongst the prime means of generating new forms of disability either through the consequences of using them or having them



used against us, being involved in manufacturing them, or through living amid the polluting wastes they produce.

Through the mechanisms of surveillance systems, regulation, control, and the use of militarized technologies, humans are distinguished into “us” and “them.” These are powerful and seductive tools which encourage us to accept controls and even participate in our own surveillance, but our relationship with them is complicated, with positive elements as well as negative aspects. Also it is critical to note how usage of technologies is deeply related to the market force: creating demand for technologies and those concerned with surveillance are designed to protect the propertied from the property-less. Because we appear to benefit from the technologies and the marketing of them, we do not always recognize how much we are enslaved to them. It becomes unthinkable not to have these technologies, many of the industries and processes which support our society and at the same time endanger it. Despite the extent of these capacities for the abuse of power and the limitation of rights, disabled people’s struggles against ableism and saneism demonstrate the inventiveness that comes with resiliency, and some of the strategies people have developed depend on the access provided by new technological environments and facilities. We explore opportunities for resistance and creative change, while recognizing that across the globe, and in our own communities, there are struggles for the most basic human rights and survival.

Disability communities’ struggles for liberation and against ableism and saneism can take many forms. In the sociocultural context of Hecht (Chap. 19), we have a short story in which disability and ableism encounter racism, sexism, and classism as the disabled character, the Crab, solicits prostitution. In the eyes of the child prostitute Conceição, observing the Crab in the street and in his home, he has a freedom of physical and social movement as well as security of home and foods that she longs for. He has a certain freedom of movement, seeming to fly suspended just above the ground, but progressing with a smooth rapidity as if “possessed of an urge to move faster than they,” (p. 274). At the same time, his physical differences and sexuality are heavily questioned and examined. To Conceição, the Crab’s life is a life of privilege, even though the ending of the story takes a dramatic turn and complicates her observation. Who is on top is all a matter of perspective. While Conceição’s perspective is fictional, the series of events depicted in this story are based on interview data collected by anthropologist Hecht while he was conducting ethnographic research in Northeastern Brazil.

Struggle can also involve advocating for life-saving or life-changing technologies and the use of virtual media such as the internet for building networks of protest. Surveillance can be a life-saver, as in the case of people on ventilators, who require constant monitoring to ensure breathing, or take life-threatening risks as Dupree recounts (Chap. 15). In contrast, Seelman (Chap. 18) complicates the notion that monitoring can be a form of unwanted surveillance and oppression. As robot caregivers, once the realm of science fiction, may soon be part of systems of disability management, Seelman poses questions on the advancement of technologies in relation to topics of bioethics and disability rights movement principles such as self-determination. Seelman explores the ever-blurring line between human and



technology with the advancement of assistive technologies. Mello, Block and Nuernberg (Chap. 20) discuss the emergence of Brazilian disability studies with its unique intersectional opportunities. They use Hecht's short story to open discussion of some of the complexities of how disability intertwines with gender, race, class and sexuality in Brazil. Moore, Garcia, and Thower (Chap. 21) describe violence enacted by police to disabled people at an intersection of disability, race, class, nationality, and more. Not only do these authors problematize surveillance by police, they also question uses of law enforcement by the Occupy Movements and lend critical analyses on mainstream activism movements from disability justice perspectives. Creative and powerful alternative ways to fight for various layers of justice are introduced by Moore, Garcia, and Thower and are particularly important for us to consider in the wake the movements sparked by Fall 2014 rulings not to indict police officers who were responsible for the deaths of African American men in Ferguson, Missouri, and Staten Island New York. We are particularly haunted by the Staten Island death of Eric Garner, which was caught on audio and video. "I can't breathe" he cried 11 times, as his asthmatic struggle for breath was mistaken for resisting arrest (see Chap. 21). This becomes a new and tragic example supporting Moore, Garcia, and Thower's arguments. "I can't breathe," with hands held high, will become an iconic slogan of protest. Based on his personal experiences as a blind person with hearing impairment, Chaplin (Chap. 22) creatively engages in three layers of occupation. He describes how his daily energy interactively affects his functioning and the importance of interdependency. First, there is the occupational layer of learning life and living skills. Second, is the occupational layer of living, contributing, sharing, leading, and of functioning as an active member of society. Third, is the occupational layer of educating and advocating to advance disabled people's rights as we combine the first two layers of occupation in order to live a fulfilling life. The Stevenage Survivors (Chap. 23) explore the power of the collaborative and generative processes of creating art together and for each other in the community around their Hertfordshire town in the UK, but this is set against and framed by their continuing pursuit of funding to secure the group's survival through each project they develop. Their creativity depends on the hand to mouth process of identifying and applying for various grants, £100 here, and £1200 there. This precarious existence supports their bold mission: "use poetry in all its forms to enable survivors of mental distress to survive more adequately" (p. 335). They have survived their own inner struggles, the economic systems that surround them, and psychiatry's medicalized systems with an understanding that "life is the best poetry there is." Finally Marcus, Kasnitz, and Block (Chap. 24) discuss the occupations of communication, intimacy, dance and art. Who occupies disability? What might be the role of occupational therapists in the context of struggle, creativity and change? What is the role of technology?

Change is an unstoppable force in all these chapters—some choices can never be taken back, and some of the authors depict extreme and violent choices enacted upon or on behalf of disabled people. In some cases, occupational change is the result of technological innovation, or simply aging bodies, or changing states of mind, or slow yet steady steps toward just society. Whether we are talking about changing

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military regimes, economic systems that promote violence, ways that we interact with each other, or political, educational, and artistic interventions to pursue justice at different localities—contained in this book we see hints of dystopian nightmares and utopian possibilities.

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## **25.4 Conclusion**

We have come full circle. Whether you read this chapter right after our introduction (Chap. 1) or after reading the whole book, we brought you back to the themes that are the collection's glue: community, justice, decolonization, and of course occupation. This is where both aspects of the various strains of the international disability rights movements and the occupy movements now stand.

Our goal was and is to bring the tools of academic disability studies, anthropology, and occupational science to the service of future social growth by bringing the voices of non-academic activism into the choir. The next chapter, our last, is where we peek at futures both feared and desired.

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## **Reference**

Williams R (1976) *Keywords*. Fontana, London