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Disability Worlds

Faye Ginsburg and Rayna Rapp, Guest Editors

Disability/Anthropology: Rethinking the Parameters of the Human
The Politics of Disability Performativity: An Autoethnography
Disability Expertise: Claiming Disability Anthropology
Disability, Anonymous Love, and Interworldly Socials in Urban India
Kinship Destabilized: Disability and the Micropolitics of Care in Urban India

Autism, "Stigma," Disability: A Shifting Historical Terrain
Activism, Anthropology, and Disability Studies in Times of Austerity: In Collaboration with Sini Diallo

Prosthetic Debts: Economies of War Disability in Neoliberal Turkey
Torture without Torturers: Violence and Racialization in Black Chicago

People as Affordances: Building Disability Worlds through Care Intimacy

The Ability of Place: Digital Topographies of the Virtual Human on Ethnographia Island

The Skilling Journey: Disability, Technology, and Sociality in Postconflict Northern Uganda

In the Long Run: Ugandans Living with Disability
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Disability Worlds
Wenner-Gren Symposium Supplement 21

Danilyn Rutherford

When we take disability into account, nothing seems the same. The cobblestones in the driveway leading to the palace in Portugal, where Wenner-Gren has held so many of its symposiums. The speed, volume, and cadence with which the participants in these discussions spoke to one another. Whether they turned to face their interlocutors, or not. The embodied biases of their metaphors. All those times they referred to “perspectives,” “gazes,” and “points of view.” Anthropology is supposed to be the discipline that makes room for difference. But the spaces we have created have often been cramped and inhospitable, wrongly configured for the work we aspire to do.

From March 9 to 15, 2018, at the Hacienda del Sol Guest Ranch in Tucson, Arizona, the Wenner-Gren Foundation hosted a symposium that brought together 17 scholars from seven countries around the world (fig. 1). Their goal was to investigate the worlds that have arisen around disability, the socially experienced state of difference and disadvantage experienced by people with nonnormative bodies and minds. It was a week of unexpected resonances and spirited debates. The political became the practical, as participants drew connections between the limits that confront disabled people and those that hamper our field. We used CART, a communication system that projected a written version of the conversation as it unfolded. The group included a reveicer to help those unaccustomed to atypical speech. These improvements in access fostered sharper thinking, with the participants paying close attention to what was being said. Even as the symposium focused on disability worlds, it created one of its own, shifting the stakes and norms of academic debate.

In their opening essay, Faye Ginsburg and Rayna Rapp (2020) draw on a long tradition of scholarship to trace the ground covered in the meeting (see also Ginsburg 2013; Rapp and Ginsburg 2011). And this ground was wide: it extended from the way we imagine, study, and inhabit families, to how we analyze structural violence and inequality, to our grasp of disability, modernity, and the human around the globe. Ayo Wahlberg explored the temporality involved in living with different varieties of chronic disease. Other participants wove broad themes through closely observed details: Arseli Dokumaci’s observation of the resignation with which an old man in a wheelchair trying to board a bus waited for “a gesture of recognition that never came” (see Dokumaci 2020); Cassandra Hartblay’s description of the ease with which an ethnographer’s disabled collaborator explained how to put on the kettle, pour water, and arrange cookies on a plate, making an affordance out of the very visitor she was offering tea (see Hartblay 2020).

When it comes to disability, the language we use shapes what we can do (see Grinker 2020; Kasnitz 2020; Ralph 2020). This understanding proved crucial, given the symposium’s emphasis on developing the new lexicons called for by what Michele Friedner and Tyler Zoanni (2018) have called “disability from the south.” In Uganda, as described by Herbert Muyinda and Susan Reynolds Whyte, the category of disability has opened the door to training programs and a chance to participate in “distributional labor” that brings resources to people living with disability in the long run (see Muyinda 2020; Whyte 2020). The category has closed the door to racial justice in Chicago, where city administrators faced with hundreds of legal settlements have provided therapy for traumatized survivors rather than calling their torturers to account (see Ralph 2020). It quickly became clear that disability rhetoric has the power to exclude. Salih Can Açıksöz writes about Turkish disabled veterans who have donned their prosthetics in a dramatic protest against the government, evoking the figure of the wounded warrior to whom the nation owes a debt of gratitude (see Açıksöz 2020). But this figure casts in shadow the predatory lenders who profit from their injuries, not to mention a much broader population of people who lack the ideological

Danilyn Rutherford is President of the Wenner-Gren Foundation for Anthropological Research (655 Third Avenue, 23rd Floor, New York, New York 10017, USA [drutherford@wennergren.org]). This paper was submitted 18 IX 19, accepted 18 IX 19, and electronically published 12 XII 19.
backing needed to press their claims. In Chicago, the victims who attend the clinic Laurence Ralph (2020) describes are but a small subset of those injured by police violence in the city. They in turn are an even smaller subset of the black people who have been harmed by the debilitating effects of racialization in all its forms.

Whether we were talking about the woman Renu Addlakha describes, who would rather stay in the hospital than with a family that struggles to provide for her (Addlakha 2020), or the deaf young people Michele Friedner worked with, who have traded “anonymous love” for the “interworld” provided by the Deaf church (Friedner 2020), the stories told in Tucson refused to settle into predictable plots. Tom Boellstorff led a tour of the virtual “builds” constructed by Ethnographia Island’s disabled residents, who have important things to teach us about what it means to be embodied in space (see Boellstorff 2020). Pamela Block examined the consequences of “unplanned survival” under conditions of austerity, where medical advances are helping vent-users survive into adulthood, but without the resources they need for a safe and fulfilling life (Block 2020). Roy Richard Grinker showed us how the emergence of autism as a diagnosis has spawned an industry that profits from the “disease,” at the same time it has opened a space in society for people with atypical skills (see Grinker 2020). Taken together, the contributions exposed the richness and complexity of a range of disability worlds.

In the end, the challenges posed by this symposium were both ethical and analytical. “Disability by definition is remarkable,” Devva Kasnitz reminds us. “Disabled people live with the reality that the public wants to define that remarkableness and the knowledge that if they do not manage their human relationships carefully, their remarkableness will be used to control them” (Kasnitz 2020; see also Hartblay 2020). The encounter between disability and anthropology needs to involve more than simply a search for scholarly insight; it calls for new kinds of collaboration and care. The stakes are high, as Ginsburg and Rapp (2020) insist. “Disability worlds, we argue, are essential to understanding not only what it means to be human . . . they also offer a crucial diagnostic on the future that confronts us all.” This special issue points the way toward a discipline that is better equipped to create knowledge that matters and is shared.
The Wenner-Gren symposium program has a history of charting new directions in anthropology. We have hosted conversations on militarism, masculinity, Atlantic slavery, and the Anthropocene, to name just a few of the topics covered in recent years (Gusterson and Besteman 2019; Tsing, Mathews, and Bubandt 2019). One of the strengths of this symposium lay in the encounter it staged between anthropology and disability studies, a field whose commitments differ in subtle ways from those of anthropology. In the future, we are planning to host symposia that strengthen ties between anthropology and other disciplines in the humanities and social sciences. If you know of a topic with the potential to move forward conversations in anthropology, while demonstrating our discipline’s value to scholars working in very different traditions, please let us know.

References Cited


Disability/Anthropology: Rethinking the Parameters of the Human
An Introduction to Supplement 21

Faye Ginsburg and Rayna Rapp

As an analytic and an object of study, disability provides a powerful lens to refocus and potentially transform thinking about new and enduring concerns shaping contemporary anthropology. At its most basic, the recognition of disability as a universal social fact helps us to understand the cultural specificities of personhood and to reconsider the unstable boundaries of the category of the human. This special issue of Current Anthropology is based on a 2018 Wenner-Gren international symposium on disability addressing this underrepresented area of research. The articles published here demonstrate the transformative value of critical anthropological studies of disability for many of our discipline’s key questions regarding kinship, biopolitics, the life course, inequality/racism, war and violence, technology and materiality, and the importance of disability to decolonizing perspectives in anthropology.

We have to recognize that disablement is not merely the physical state of a small minority of people. It is the normal condition of humanity. (Sutherland 1981:18; emphasis [second sentence] in original)

Anthropology is well known for its capacious, ever-expanding framework and its embrace of diversity. Yet, the universal circumstance of being disabled—how the realities of embodied, cognitive, and emotional impairments are understood in different sociocultural contexts as part of the human condition—has too often been neglected in our field, as we argued in our 2013 Annual Reviews chapter “Disability Worlds” (Ginsburg and Rapp 2013). Ethnographic studies remain incomplete and under-theorized without the consideration of disability. This holds true for accounts of embodiment, kinship, gender/sexuality/reproduction, race/ethnicity, and violence and its disabling aftermath, as well as citizenship, biopolitics, and precarity (environmental and otherwise). As an analytic and an object of study, disability provides a powerful lens to refocus and potentially transform thinking about new and enduring concerns shaping contemporary anthropology. At its most basic, the recognition of disability as a social fact helps us to understand the cultural specificities of personhood and to reconsider the unstable boundaries of the category of the human.

In the words of pioneering British disability activist Allan Sutherland, quoted above, disability is the normal condition of humanity.

This special issue of Current Anthropology is based on a 2018 Wenner-Gren symposium on disability we organized to address this underrepresented area of research in our field. The articles published here demonstrate the transformative value of critical anthropological studies of disability for many of our discipline’s key questions. We are particularly grateful to the Wenner-Gren Foundation not only for embracing but also sharing the excitement of expanding the boundaries of anthropology to include this form of human diversity. Beyond the intellectual and financial support that it so generously provides, the foundation took on every detail of infrastructural support, accommodation, and affordances to ensure the full inclusion of all attendees. These included everything from ramps to revoicing assistants for those with atypical speech to Computer Aided Real-time Transcription (CART) for participants with hearing impairments. The foundation’s attentiveness to this underrecognized aspect of disability’s materiality was essential to the success and creativity of our symposium. At our gathering, everyone enthusiastically crowdsourced and hacked whatever was needed. The group offered spontaneous audio description for film clips and provided one another with support when walking over rough terrain. Indeed, affordances—the ways that people modify their environments and social relationships to serve their embodied needs, as in providing ramps for wheelchairs (Gibson 2014 [1979])—is the subject of a number of papers in this issue. They are a reminder that a distinctive focus of disability scholarship and advocacy always involves struggles over the material and social support crucial to full inclusion in our institutional homes and associations.

As disability scholar Tanya Titchkosky reminds us, the question of access is an ever-moving horizon for our subjects, ourselves, the universities and communities we work in, and our professional organizations (Titchkosky 2011). As engaged scholars studying disability worlds, we have a particular responsibility...
to advocate for access in all the locations that we inhabit. How might our work individually and collectively contribute to building the kind of access that is essential to an “ethics of possibility” (Appadurai 2013:295) in the construction of disability worlds? For example, we invite all readers to explore the buildings in which they are now reading this introduction: are they accessible to wheelchair users, blind and deaf students and colleagues, and those with other sensory impairments? Is there a gap between signage and actual accommodation, as we have continually discovered while building a disability studies program at New York University where we work? Someday in a utopian future, we anticipate the routinization of such successful “bodymind” considerations in all public venues and events (Harblay 2020; Price 2015; Rothschild 2000; Schalk 2018). For now, the question of access remains open, an incitement to close the gap between theory and practice.

Historically, anthropological studies of disability were relatively rare until the late twentieth century, often intellectually segregated into the realm of medical and applied anthropology. Yet, the international spread and uneven impact of the disability rights movement from the 1960s forward, as well as cross-cultural work in anthropology, show that what counts as a disability in different cultural settings is not obvious. The need for wide-ranging research and theorization cannot be underestimated, given that approximately 80% of the world’s 1 billion people with disabilities reside in what is glossed as “the Global South” (Friedner and Zoanni 2018; Grech and Soldatic 2016; Staples and Mehrotra 2016; World Health Organization 2011).

One of the key disciplinary critiques emerging from non-Western studies of disability, for instance, interrogates the limits of a Western model based primarily on individual rights. Such work examines the presence or absence of disability as constructed by diverse epistemologies regarding “normalcy” in familial, community, religious, and political life (Zoanni 2019). In classic anthropological fashion and in harmony with disability studies, this scholarship reveals that disability is not a category of difference unto itself, challenging the individualizing model central to scholarship and activism in many liberal democracies. Rather, disability is profoundly relational and radically contingent, (inter)dependent on specific social and material conditions that too often exclude full participation in society. Beyond such exclusions, a focus on disability also reveals creative cultural production. Unexpected sites of innovation, inclusion, and the reframing of “the normal” are continually producing new kinds of “disability worlds,” a point to which we return below.

In organizing our Wenner-Gren symposium and editing this resulting special issue of Current Anthropology, we and our authors have an ambitious and shared agenda: disability perspectives can and should expand and transform anthropology in the widest sense. This special issue is intended as a contribution to that goal. The articles assembled here focus on the social, political, experiential, narrative, and phenomenological dimensions of living with particular impairments in different cultural locations and circumstances across the life span. They range from the micro-affordances of the everyday to circumstances of extreme violence.

We build on the prior efforts of those anthropologists who first incorporated a critical disability studies perspective, an approach that “considers how institutions, cities or societies ‘dis-able’ people systemically and socially as well as looking into how the body and impairment can critically be incorporated into the discussions of disability and disablement” (Chapman, n.d.). In other words, this approach, used by many of the authors in this special issue, shows how the promissory note of inclusion (as well as barriers to it) shapes the world-making of people living with disabilities and their allies. Collectively, these writings articulate how the experience of disability—that named or unnamed—is reshaping understandings of the person as well as the boundaries of the human in broader social contexts that both enable and constrain it (Minich 2016). Disability is always intersectional, shaped by race/ethnicity, class, gender, religion, and national location. This entails anthropological attention to essential forms of embodied, cognitive, or sensory difference, whether one studies the intimacy of kinship and sexuality or public activism and social movements.

Additionally, disability can provide a critical anthropological perspective on “everyday life with a difference” (Ginsburg 2016). Disability is always intersectional, shaped by race/ethnicity, class, gender, religion, and national location. This entails anthropological attention to essential forms of embodied, cognitive, or sensory difference, whether one studies the intimacy of kinship and sexuality or public activism and social movements.

2. The field of critical disability studies in and beyond anthropology is founded on a social model of disability and its auto-critique. Developed in the 1970s by British activists in the Union of the Physically Impaired against Segregation, the social model of disability replaced a traditional “medical model” that focused on deficits in the body with an understanding that problems arose from prejudice as well as a built environment for the able-bodied (Shakespeare and Watson 2002). In other words, the social model made clear that disabilities are produced by modernist attitudes, environments/technologies, and discourses that are disabling in their lack of recognition and accommodations for a range of bodyminds. By 2002, Shakespeare and Watson offered an auto-critique of this important concept, arguing that the social model oversimplifies the issues and does not lend itself to dealing with the complexity of problems people face due to their disabilities, some of which do not disappear just by removing environmental barriers (Shakespeare and Watson 2002). This last point became particularly evident as disability studies scholars have increasingly engaged issues of cognitive, behavioral, and intellectual disabilities, long marginalized.

1. “Mad studies” scholar Margaret Price describes her use of “bodymind” thus: “because mental and physical processes not only affect each other but also give rise to each other—that is, because they tend to act as one, even though they are conventionally understood as two—it makes more sense to refer to them together, in a single term” (2015:268). She credits trauma studies scholar Babette Rothschild for inventing the term (2000). In her 2018 book Bodyminds Reimagined, Sami Schalk, a scholar of disability and gender, acknowledges Price as the source for the term, “a materialist feminist disability studies concept . . . that refers to the enmeshment of the mind and body” (2018:8).
and Rapp 2013), often experienced in the shadow of a selectively globalizing neoliberal economy. Disability is implicated in circumstances of precarity, exacerbated by the erosion and privatization of resources as well as toxicity and environmental degradation in this latest stage of capitalism, widely labeled the Anthropocene. Moreover, we have entered a new demographic era. The increasing survival of fragile infants and those with chronic disease, along with the expansion of people living into extreme old age, challenges not only the scarcity of social labor for caregiving across the life cycle but also the failure of contemporary social institutions to provide the structures to accommodate these demographic shifts. At our conference, Ayo Wahlberg characterized these transformations as “chronic living,” while Pam Block introduced the complementary term “unplanned survival” (Block 2020). These disabling conditions are experienced differentially across the enduring inequalities of racial/ethnic and class/caste divides and state-sponsored neglect and violence (Açıklıkçı 2020; Devlieger, Albrecht, and Hertz 2007; Ralph 2020).

Such shifting experiences of disability across the life course intersect expansive social movements for disability rights that make powerful ethical and political claims on the public sphere for growing recognition and disability inclusion. At the same time, the modernist drive toward perfectibility fuels culturally seductive medical interventions now routinized in everyday biopolitics, notably genetic testing for selective abortion of fetuses with potential disabilities. Once confined to rich countries, this technology is now rapidly diffusing to middle- and low-income countries. Such interventions raise utopian hopes of individual control over bodyminds without consideration of the crucial role of kinship, community, and religion that may or may not offer resources for support and inclusion. Of course, biotechnologies not only are potentially exclusionary but also are often supportive of people with disabilities, essential to the interdependence on which disability integration ultimately is built. Media, prosthetics, social networks, infrastructure, and assistive communication devices along with attendant therapies are all examples of such rapidly transforming technologies, at times producing life-changing opportunities for people with disabilities and their supporters.

We have called this paradoxical tension “the doubled telos of modernity” (Rapp and Ginsburg 2001). Telos is Aristotle’s term for the ultimate aim or inherent purpose of any entity. For us, the doubled telos signifies two alternative trajectories or imaginaries, each shaped by broad visions of collective social life in the present and near future. Disability is imbricated in both. On the one hand, we have the telos of the technoscientific imaginary of bodily enhancement, and on the other, there are the growing demands of the utopian imaginary invoked by social movements for democratic inclusion of new constituencies too long excluded, including people with disabilities. While these two vectors are often held in profound tension, we have come to understand that there is no absolute line separating these two orientations. These emergent formations—both public and intimate—require political will as well as a recognition that disability worlds are projects of cultural creativity and reinvention that routinely intersect other biopolitical regimes.

Disability World-Making

In prior work, we used the idea of “worlds” to stress how experiences of disability may incite everyday creativity, provoke new ways of understanding human difference, and take place in specific locations. Indeed, we are not the first anthropologists to suggest a model that embraces this idea of disability worlds as sources of potential creativity with distinctive features in different sites. Belgian anthropologist Patrick Devlieger, a foundational disability scholar and a participant in our Wenner-Gren conference, worked with an interdisciplinary group of European scholar/advocates to convene disABILITY MUNDUS (mundus is Latin for “world”) in 2012. This was the first in a series of summer doctoral schools they organized “to support research efforts on disability with a focus on the European continent,” addressing human rights, societal innovations, and critical issues that pertain to culture and society (DisABILITY MUNDUS 2013).3

For Devlieger and coeditors, the term “disABILITY MUNDUS” was also the unifying concept for a 2013 edited volume, Rethinking Disability: World Perspectives in Culture and Society (Devlieger et al. 2013).4 The editors underscore that disABILITY MUNDUS “has the potential to create transformations,” offering

the radical presentation of disability as a resource, and a creative source of culture, that moves disability out of the realm of victimized people, or as an insurmountable barrier. . . . [Rather,] the experience of disability provides the opportunity to enter into networks that recognize strengths of different abilities and that include considering resilience, survival, vulnerability, body knowledge, and performativity as resources. (Devlieger et al. 2013:19

The idea of “disability worlds” clearly supersedes a framework that too easily pathologizes people with disabilities as

3. Sheila Jasanoff and Sang-Hyun Kim write that “imaginaries are instrumental and futuristic: they project visions of what is good, desirable and worth attaining for a political community; they articulate feasible futures. Conversely, imaginaries also warn against risks or hazards that might accompany innovation if it is pushed too hard or too fast. In activating collective consciousness, imaginaries help create the political will or public resolve to attain them” (2013:123).

4. The group included Dan Goodley, Hans Reinders, Alice Schippers, and Isabelle Ville.

5. This work was supported by the ALTER European Association on Disability Research and Disability Studies in the Netherlands.

6. This book was a substantial update of an earlier 2003 compendium focusing on “the emergence of new definitions, concepts, and communities” regarding the lived experience of disability (Devlieger, Rusch, and Pfeiffer 2003).
“suffering subjects,” instead embracing the creative challenges that disability brings to social life, despite enduring difficulties. Beyond “victimology” lies disability’s world-making creativity, central to critical disability studies, as discussed in essays in this issue by Tom Boelstorff (2020), Arseli Dokumaci (2020), Cassandra Hartblay (2020), and Devva Kasnitz (2020).

Many come to research on disability because of personal knowledge and commitment to “living life with a difference” themselves, often in alliance with disability advocates and activists working on a range of projects dedicated to some dimension of disability justice (Rapp and Ginsburg 2011). Their embrace of a critical disability studies perspective in particular entails a reflexive understanding of the complexities of the research/activism nexus. These might include institutional advocacy, contributing to disability studies, working with NGOs, and extending support to individuals and local communities. In that sense, work in this area invokes many of the same commitments and strategies that have characterized decolonizing anthropological efforts in studies of gender, race, and postcoloniality (Hartblay 2020; Kasnitz 2020).

A positive sense of imaginative world-making has also been broadly incorporated by anthropologists in science studies, medical anthropology, critical urbanism, and beyond (e.g., Geurts 2015; Gursel 2016; Roy and Ong 2011; Zhan 2009). In the introduction to her coedited book *Worlding Cities,* for example, Aihwa Ong clarifies why the concept of worlding can be of use to ethnographers. “We stay close to heterogeneous practices of worlding that do not fall tidily into opposite sides of class, political, or cultural divides. Rather, a non-ideological formulation of worlding as situated everyday practices identifies ambitious practices that creatively imagine and shape alternative social visions and configurations” (Ong 2011).

More recently, the idea of “worlds” has been deployed by anthropologists Michele Friedner and Emily Cohen, working at the convergence of our discipline and disability studies. In their introduction to a series of essays for the online journal *Somatosphere,* they explain their title “Inhabitable Worlds: Troubling Disability, Debility, and Ability Narratives.”

We see “inhabitable worlds” as both analytic and material worlds, worlds that have existed, that do exist, and that will exist. And perhaps most importantly, we see inhabitable worlds as worlds that people themselves inhabit and aspire towards. . . . People also transform these discourses through political advocacy and personal tactics they develop to navigate the material realities of bodily differences and built environments. (Friedner and Cohen 2015)

They underscore the aspirational and even utopian aspects of active disability world-making, as do many of the authors in this special issue of *Current Anthropology.*

Ethnographic research is particularly well suited to analyzing how disability worlds are both made and unmade by families, communities, NGOs, religious institutions/ideologies, and medical and other technologies, along with state policy. It is our argument that disability world-making presents a constant ethical, political, and cultural challenge, deeply embedded in everyday contexts yet profoundly shaped by larger geopolitical processes.

A Genealogy of Disability Worlds in Anthropology

The work of the authors in this special issue is built on the accomplishments of those who first made this field visible in anthropology, laying groundwork for our present efforts over the last half century and more. For example, Robert Edgerton’s 1967 monograph, *The Cloak of Competence,* was groundbreaking both for its insights and its attention to a historical paradigm shift surrounding the place of disability in American public life; he showed how different disability worlds are produced in proximity to one another, shifting perspective from the individual to broader social networks (Edgerton 1967). The title of his book highlights the strategies deployed by those diagnosed with “mental retardation” (now, “intellectual disabilities”) who learned to “pass” when the impact of an international movement for the closing of asylums settled them in local communities after long-term institutionalization. In the 1990s, Michael Angrosino, after a decade of fieldwork at Opportunity House with adults with intellectual disabilities, demonstrated the value of collaborative research. He worked with his respondents to author their own life stories (Angrosino 1994, 1997). In that tradition, Nakamura’s engaged research at

7. The concept of worlding has roots in various philosophical lineages that address world-making. Many draw on Martin Heidegger’s concept of worlding, a neologism introduced in his 1927 book *Being and Time;* there he explores the experience of “being in the world.” In Heidegger’s work, worlding is a concept with a less than clear definition of how we experience the making and unmaking of the world as familiar. His ideas of worlding and reworlding were rearticulated by Spivak (1999) in her postcolonial attempt to recuperate subaltern subjects. A second lineage derives from philosopher Nelson Goodman’s book *Ways of Worldmaking,* which considers the role of both representational and material structures in building and reshaping the realities in which we live (Goodman 1978).

8. Regardless of its modest yet growing presence within the field, an anthropology of disability has powerful allies in neighboring disciplines that have picked up on these themes. Yet interactions between anthropology and critical disability studies is spotty at best, despite the long history of robust interdisciplinary work in both fields. Perhaps this is due to the emergence of disability studies in Anglophone countries that stressed valuable agendas addressing the concerns of those living in the Global North: qualitative sociology in the United Kingdom and the humanities in the United States.

9. The phrase “mental retardation” has fallen out of favor since 2009 when the “Spread the Word to End the Word” movement was first established by American youth with and without intellectual disabilities during the Special Olympics Global Youth Activation Summit. Advocates to end the “R word” reject the use of the word “retard” in colloquial and everyday speech as hurtful and dehumanizing to individuals with intellectual and developmental disabilities. According to R-word.org, “The R-word hurts because it is exclusive. It’s offensive. It’s derogatory.” [https://www.spreadtheword.global/](https://www.spreadtheword.global/) (accessed June 29, 2019).
Bethel House with a community of people with psychiatric disabilities in rural Japan also used a collaborative approach that honored her interlocutors’ stories, as portrayed in both her documentary film and her compelling ethnography (Nakamura 2010a, 2010b). *Loneliness and Its Opposite*, a pathbreaking study of sexuality and intimacy among disabled adults with significant cognitive impairments, compares their distinct situations in Sweden and Denmark (Kulick and Rydström 2015). The book is exemplary of the recent broadening of the field to include those who cannot easily represent themselves. Likewise, articles in a 2018 special issue of the *Cambridge Journal of Anthropology* offer anthropological interpretations of living with cognitive differences in diverse settings (McKearney and Zoanni 2018).

Other ethnographies focus on different aspects of disability, including the sociology and phenomenology of embodied difference in a less-than-accommodating world. Medical anthropologist Joan Ablon, for example, was a pioneer, publishing several key studies on the social consequences of living with genetic differences, beginning in the 1980s. Her important books on short-statured people, their communities of support, and strategies of normalization began with *Little People in America* (Ablon 1984) followed by *Living with Difference: Families with Dwarf Children* (Ablon 1988) and *Brittle Bones, Stout Hearts and Minds* (Ablon 2010). As Shuttleworth and Kasnitz point out in a cogent review of her work, “Ablon’s methodological rigor, privileging of informant voices, and participatory approach is an exemplary ethnographic model for the anthropology of impairment-disability” (Kasnitz and Shuttleworth 2001; Shuttleworth 2012).

Many of the works cited above were initially conceived as broad cultural projects, offering a critique of medicalization, jointly articulated by both ethnographers and their subjects. Paradoxically, this work was nonetheless often embraced by medical anthropology, one of the few anthropological locations that offered an intellectual home to disability until recently. Indeed, the first Disability Research Interest Group in the American Anthropological Association took shape under the auspices of the Society for Medical Anthropology in the 1980s (Kasnitz and Shuttleworth 2001). Now, medical anthropologists themselves have appropriately called for ethnographic research on disability to move beyond the confines of their subdiscipline (Mattingly 2010). At the same time, as disability has become a more prominent topic in and beyond anthropology, medical anthropologists increasingly are recognizing a disability component in their research while bringing a critical analysis to the social framing of enduring disease and disorders (Inhorn and Wentzell 2012; Manderson 2011). For example, disability and chronic illness are deeply intertwined in Carolyn Rouse’s sobering work on sickle cell anemia in the lives of young African Americans and Julie Livingston’s important studies of chronic illness, debility, and cancer in Botswana (Livingston 2005, 2012; Rouse 2009).

Ethnographers with a disability have made good use of reflexivity in their fieldwork, whatever the focus of their research. Sumi Colligan, for example, discusses the epistemological value of her own embodied difference, suggesting that every ethnographer, whether or not disabled, consider how “their own bodies potentially enrich anthropological insight and experience” (Colligan 2001:9). This point is powerfully addressed in Kasnitz’s piece in this issue (2020). Some have used an autoethnographic lens to offer rich insights into their own experience, illuminating the broader terrain they inhabit. For example, the blind ethnographer John Gwaltney’s rich and underappreciated *Drylongso: A Self-Portrait of Black America* (Gwaltney 1980), highlights his own experience with traditions of blind culture in the African American community. Anthropologist Barbara Myerhoff’s extraordinary film *In Her Own Time* shows how fieldwork carried out while seeking a cure for her lung cancer in fact opened up research possibilities with her ultra-Orthodox Jewish subjects, revealing their cultural approaches to her dire circumstances that would never otherwise have emerged (Myerhoff 1985). Robert Murphy’s influential classic book *The Body Silent* offers a gripping narrative of his battle with a spinal cancer that left him quadriplegic. His was among the first works to interrogate how American norms of independence can dis-able identity, status, and social relations, revealing the cultural and existential dynamics of marginalization (Murphy 2001 [1987]). This theme also surfaces in works on chronic pain, a notoriously hard-to-define and often-dismissed disabling condition discussed in both *Camp Pain* (Jackson 2000) and *Under the Medical Gaze: Facts and Fictions of Chronic Pain* (Greenhalgh 2001). Similarly, Emily Martin’s 2007 *Bipolar Expeditions* is grounded in both her first-person experiences of and ethnographic research on bipolar disorder. She traces the cultural life of mania and depression beyond diagnostic categories, arguing that the notion of mania in particular became a master trope in American society linked to a period of market exuberance at the turn of the twenty-first century (Martin 2007). Other first-person ethnographic accounts address the experience of invisible disabilities such as learning differences. A trio of anthropologists used their own life histories of living with “brain difference” and its attendant stigmas, arguing that this circumstance made them more sensitive to “the kinds of intuition and other such skills that are adaptive in non-writing-nor-reading-focused cultures” central to anthropology (Raphael, Salovesh, and Laclave 2001). Some authors also place themselves reflexively in relation to the lives of their disabled subjects. Gelya Frank uses experimental/experiential writing to explore the long-term psychodynamics of her relationship with Diane DeVries, a woman born without arms and legs. In *Venus on Wheels*, fieldwork blurs into friendship and mutual care (Frank 2000).

Many have been particularly attentive to different communicative practices entailed in impaired hearing (Becker 1980) and sight (Deshen 1992; Gwaltney 1970), stressing management tactics as well as the creation of communities, whether inclusive or exclusive of difference. Nora Groce’s *Everyone Here Spoke Sign* was and remains a vanguard study of the long-standing intertwined Deaf and hearing lives, languages, and communities on Martha’s Vineyard, setting a standard for
future Deaf studies (Groc 1985). Later anthropological work has made it clear that "Deafhood" (Ladd 2003) is shaped by national contexts as well as educational, linguistic, and identity politics. For example, in her work on what it means to be deaf in Japan over three generations, Nakamura shows the historical rise of deaf activism and language wars as her deaf subjects increasingly chose to identify as a linguistic minority (Nakamura 2006). Michele Friedner reminds us of the significance of national contexts in shaping different forms of Deafhood in her ethnography of sign language—using young adults in urban India, showing how new regimes of value are emergent at the intersection of "deaf development" and Indian modernity (Friedner 2015, 2020). Friedner and Helmreich reposition phonocentric models of speech, arguing for attention to the diversity of what they call "sensory socialities" (Friedner and Helmreich 2012). Clearly, what constitutes Deaf politics varies widely across contexts, often depending on the status of minoritized identities in different national and international settings, historically changing circumstances, technologies, and notions of the sensorium (Blume 2009; Green 2014; Kusters 2015; Mauldin 2016). In short, all these works make clear that disability worlds are shaped by the intimate and broader contexts in which they evolve.

Local/Global Thinking

Our brief history of the intersections of anthropology and disability would be remiss without acknowledging the landmark collections edited by Benedicte Ingstad and Susan Reynolds Whyte that refocus attention on the Global South. Their two very influential edited collections, Disability and Culture and Disability in Local and Global Worlds remind us that the vast majority of people living with disability reside outside the wealthy “developed” countries of the so-called Global North (Ingstad and Whyte 1995, 2007). Their first volume showed “how cultural circumstances (such as assumptions about personhood and social ones (such as the existence of disability institutions) shape the meaning of disability in different local worlds” (1995:1). The second volume makes “disability connections, weaving links of relevance between located worlds, and between them and imagined ones of different scale . . . underlining the primacy of the local in the heuristic opposition of local and global worlds” (2007:2). While it is clear that the United Nations Convention on the Rights of Peoples with Disabilities has had an enormous impact on policy recognition at the national level for many signatory countries, Ingstad and Whyte point out that “the challenge is to see how much—or how little—the world has changed for the majority of disabled people and their families living in a great variety of particular situations . . . The conditions of life for most people with disabilities may not be changing as rapidly as political awareness” (2007:5). It is important to highlight the value of these groundbreaking volumes. Collectively, the authors/activists whose work is published in these two books taught our field that disability is relational, intersectional, and constantly transforming in its social and political presence, and above all is crucial to understanding the human condition.

The legacy of the Ingstad and Whyte volumes is felt in the growing attention to local/global entanglements outside the West. For example, Helen Meekosha argues that the “dominance of the global North in . . . writings about disability has resulted in the marginalisation of these experiences in the global South. This constitutes an intellectual crisis for disability studies in the periphery” (Meekosha 2011). Attention to North/South distinctions likewise characterizes the aforementioned 2013 volume Rethinking Disability (Devlieger et al. 2013) and the 2014 launch of the journal Disability and the Global South, edited by Shaun Grech, “an interdisciplinary platform prioritising material that is critical, challenging, and engaging” and that “encourages contributions from disabled activists and theorists from the global South” (Grech 2014). In 2016, Grech collaborated with Karen Soldatic to edit the volume Disability in the Global South: The Critical Handbook. They make a strong case for the disproportionate presence of people with disabilities in “the southern space” due to the “violent colonial and geopolitical asymmetries sustaining the current condition of coloniality” (Grech and Soldatic 2016:3). The collection highlights the contributors’ “ethical commitment to move beyond the restraints of hegemonic global North epistemological, discursive, ontological and practical foundations to look towards and prioritise instead situated local knowledges” (xxvi). The last section of the book, “Activism and Research across Cultures,” focuses on “disabled people’s rights and their struggles for recognition, redistribution and representation” (xxvi), offering a welcome decolonial stance that is increasingly central to the work we are discussing.

Most recently, Americans with Disabilities Act–generation disability scholars Michele Friedner and Tyler Zoanni curated a 2018–2019 Somatosphere series, Disability from the South: Toward a Lexicon. They build on the Ingstad and Whyte

10. Friedner and Zoanni spell out the important if under-recognized politics of prepositions. "We deliberately don’t write about disability in the Global South because such a spatializing preposition connotes encapsulation, containment, fixity. Of course, from has its own challenges. For one, we are conscious of the fact that many of the contributors included in the series are not from the locations in which they conduct research, and this matters. Second, as is true for more general proposals about theory from the South, there is always the danger that from-ness takes on an extractive nature, in which the lives of disabled people in the majority world are appropriated as data or evidence for the theory- and career-making of Northern scholars" (Friedner and Zoanni 2018).

11. We are grateful to Cassandra Hartblay’s discussion (2020) of the so-called ADA generation, a reference to "those who have come of age after the passing of the Americans with Disabilities Act, landmark civil rights legislation, that deeply shifted the ways that people with disabilities participate in public life, and changed the material landscape of the country . . . reflecting increased disability visibility following activist movements in the second half of the 20th century." She draws on the work of Forber-Pratt (2019) and Harkin (2014).
The papers they assembled for a series in *Current Anthropology* offer persuasive ethnographic cases from Brazil, China, India, Mexico, Uganda, and Vietnam addressing a range of intersecting topics. These include the temporarities of disability and inter-generational relationships of care as well as the limits of kinship in the absence of other supporting structures (Whyte 2020). Zoanni calls our attention to “care in the middle voice”—when distinctions between subject and object are obliterated—and the reciprocity that emerges in long-term interdependent caregiving. Scaling up, Vandana Chaudhry (2019) addresses the relational epistemologies of personhood, materiality, and structural divides by theorizing disability from the perspective of rural lives in India. We learn how families occupy a critical role in the lives of their kin who are psychiatric patients in China, giving distinctive shape to disability worlds in the shadow of Chinese state paternalism (Ma 2019). She points out that family-focused configurations of disability seem to be the rule rather than the exception for much of the South, suggesting that we analyze family as “a cultural ideological construct, a unit of survival, a product of intimate politics, and a source of generative disruption to the hegemonic normativity.” The essay by Friedner, Ghosh, and Palaniappan (2019) offers a critique of how cross-disability formations in India (and elsewhere), while linking different disabilities for political purposes, can also obscure the distinctive needs of those with particular impairments. They end with a call for more research “on the kinds of social and political work in which disabled people across impairment categories engage in order to make themselves legible to each other and to actualize some kind of universalizing ‘disability identity’.” The articles in this special issue, discussed below, offer a range of perspectives on the “cross-disability” question that has been central to the politics of disability rights in the West since the late twentieth century.

Nothing About Us Without Us: Decolonizing Disability

Since the 1990s, “Nothing About Us Without Us” (NABUWU) has become a well-known slogan unifying disability activists identified with the international Disability Rights Movement (DRM), “in order to push back against the inclination of parents, social workers, medical professionals, and pretty much everyone else to patronize and infantilize us by making decisions about our lives without our input or consent” (Carter-Long 2019). Disability activist James Charlton popularized the slogan as the title of his groundbreaking 1998 book; he first heard the term from South African disability activists who had adopted it from East European colleagues (Charlton 1998). As Ed Roberts, one of the leading figures of the international DRM in the twentieth century, quipped, “If we have learned one thing from the civil rights movement in the US, it’s that when others speak for you, you lose” (Driedger 1989:28, quoted in Charlton 1998:1). Recently, US disability activist Lawrence Carter-Long in 2018 rephrased and shortened the slogan to make a timely intervention: “Nothing Without Us.” This perspective also informs the collection *Occupying Disability: Critical Approaches to Community, Justice, and Decolonizing Disability* (Block et al. 2016), where the concepts of disability, culture, and occupation meet critical theory, activism, and the creative arts.

These activists remind us that for too long, people with disabilities have found themselves represented by “expert others,” as has often been the case for many other minoritized constituencies studied by anthropologists. We argue that recent efforts to decolonize the discipline in the spirit of *anthropologie partagée* (Rouch in Feld 1989) invite us to ask, How do we decolonize disability, especially given resistance to the topic of disability in our discipline historically and into the present? This issue was powerfully raised at our conference by anthropologist/disability scholar and activist Devva Kasnitz, whose article launches this special issue: “Anthropology’s institutions have failed to embrace disability studies despite the feminizing, browning, queering, and now the crip-ping of anthropologists. Perhaps this is because for some, these developments, like applied anthropology, suggest a loss of status for the discipline. How can we think about the decolonizing of disability given the historical resistance to the topic in our discipline?” (Kasnitz 2020).

Kasnitz’s moving and witty autoethnographic account of disability performativity is a reminder of the significance of disability to anthropology, despite its recurrent marginalization (2020). Similarly, Cassandra Hartblay’s reflexive ethnography
produced with her disabled Russian interlocutors points out the importance of taking seriously what she calls their “disability expertise”: the deep quotidian knowledge produced by people with intimate experience of disability (2020). Such knowledge can emerge from disabled subjects and/or their allies, proficiency gained by what Kasnitz calls “disability exposure”—a concept similar to Rutherford’s living with “proximity to disability” (Rutherford 2018). Like all forms of local knowledge that are central to anthropology’s project, the insights of both Kasnitz and Hartblay once again bring our attention to sites of creative cultural production, unexpected innovations, inclusion, and the reframing of “the normal,” producing new and ever-expanding kinds of “disability worlds.” Along with Lawrence Carter-Long (2019), we argue that creative work across the arts—film, dance, theater, diverse forms of media—has provided powerful and compelling projects, many developed by disability arts activists globally. All help to forge the road forward by expanding the imaginary and wide-ranging impact of disability worlds.

New Kinship Imaginaries and Their Limits

Attention to kinship is one of anthropology’s key contributions to the analysis of social life in general and, we argue, should be more consciously deployed in critical disability studies. How does anthropological research on disability bring an appreciation of new and alternative kinship imaginaries and their limits to both anthropology and critical disability studies? For people with disabilities across the globe, “family,” however defined, is usually the initial locus of intimate connection, care, and claims on resource distribution, as well as a potential site of coercion and exclusion. The social relations that emerge around the fact of disability, whether negative or positive, give rise to what we have called “new kinship imaginaries,” as family members refashion their expectations, caregiving responsibilities, daily lives, discourses, and temporalities around “life with a difference” (Phillips 2010; Rapp and Ginsburg 2001, 2011). Our use of the term “new kinship imaginary” underscores the reality that families are not only flesh-and-blood collaborations. They also engage in acts of cultural imagination to encompass the fact of disability as part of a family narrative. Kinfolk may feel compelled to rewrite pre-existing cultural scripts that relied on seemingly stable notions of normative kinship. Indeed, the famous American psychologist Erik Erikson institutionalized his newborn son with Down syndrome, telling other family members that the child had died, literally writing him out of the hegemonic family kinship narrative (Grinker 2020). In the process of incorporating or rejecting disability, family members often find themselves transforming temporal, spatial, and caregiving arrangements they may have previously taken for granted. Kinship imaginaries require continual reinvention, from the rearrangement of responsibilities in the household to the production of transformed family narratives, as conference participant Beatriz Miranda-Galarza has made clear in her research on how intellectual disabilities are woven into family life in Ecuador (2015). Such dynamics—both negative and positive—are central to Renu Addalkha’s article on the caregiving dilemmas of adults with disabilities in India (2020), in this issue. Her analysis reveals in careful detail how adult children may be mobilized to care for a mother with chronic schizophrenia, whether in or out of hospital care, as her husband’s family refuses any responsibility. Refusal is also central in her case of another adult, a man with cerebral palsy, whose kin no longer care for him; instead he finds a home with an NGO where he was first educated and then employed. Michele Friedner’s work (2020) with deaf young adults in Bangalore, India, again underscores how her interlocutors find alternative community, in this case in the Christian churches that reach out to them, teaching Indian Sign Language, providing spiritual “alterworlds,” while supporting their social integration in ways that their natal families often do not.

Biopolitics and Their Discontents

The biopolitics of medicine and social policy have been central to anthropological work on disability over the last 3 decades or more, especially under the influence of medical anthropology/science studies. How do we understand the increase and plasticity of diagnostic categories affecting the disability experience in relation to the social history of capitalism and its present neoliberal moment? For example, the “unplanned survival” of those diagnosed with once life-threatening vulnerabilities and increasing recognition of neurodiversity and chronic conditions are rapidly transforming the presence of disability and demands of caregiving across the life course (Livingston 2012; Mattingly 2010, 2014; Rouse 2009; Wahlberg and Rose 2015). Roy Richard Grinker (2020) offers a view of the **longue durée** shaping the intertwined transformations of capitalism with the emergence of mental illness as a category. He focuses on changing understandings of autism in particular, from its evolving medical diagnostics in the late twentieth century to the rise of the twenty-first-century neurodiversity movement, in concert with a more flexible economy and a growing “autism industrial complex.” How might these intersecting developments contribute to more nuanced understandings of the spectrum of human capacity? In her reflexive account of two dramatic cases of “unplanned survival,” Pamela Block shows how the advocacy of friends and colleagues provide fragile networks of support for two men whose struggles are exemplary of the complexities of chronic conditions over the life course (2020). She places their aspirations for independent living in the context of the punishing marginality produced by state and institutional negligence, while chronicling the demise of support for disability studies at her own university.

Structural Violence and Inequality

Many experiences of disability emerge at the intersections of race, ethnicity, gender, and dis/privilege (Holmes 2015; Ralph...
The question of technology’s relationship to quotidian body-mind activities has rich genealogies in both anthropology and disability studies, among other fields. Recently, the explosion of digital devices, online media practices, and virtual social worlds and networks has been celebrated for their liberating potential for people with a range of disabilities, although the availability of such technology is highly stratified across the globe. How do anthropologists make analytic use of concepts such as affordances, accommodations, and prosthetics drawn from disability studies? Arseli Dokumaci’s work (2020) eloquently focuses on how disabled people and their allies creatively manage everyday life. In her fine-grained fieldwork in Turkey, Canada, and Wales, she discovered the widespread creation and deployment of quotidian microactivist affordances: when accessible transport is not available, a Turkish father uses his back to carry his child who cannot walk to school; in Canada a husband carefully arranges kitchen supplies and groceries for his arthritic wife. As Dokumaci writes, these can be understood as forms of “microactivism.”

Historically, media have often been exclusionary of participants with disabilities; blind and deaf people rarely imagined that they could be part of audiences for popular cinema, for instance, until the advent of audio description and closed captioning. Recently, digital technologies are increasingly providing infrastructures of possibility for the creation of new disability imaginaries, virtual and otherwise (Elkesser 2016; Ellis, Goggin, and Haller 2019; Schalk 2018). Tom Boellstorff’s (2020) ethnographic examination of embodied placemaking focuses on the experience of disability in the immersive world of Second Life. He demonstrates how people with disabilities build and imaginatively inhabit alternative “disability worlds” on Ethnographia Island, the experimental space he built for his research. There, his interlocutors create avatars that may or may not reflect their impairments “in real life.” This systematic blurring of experiential realms—a hallmark of the digital age—offers new horizons of opportunity for people with disabilities who have access to these technologies.

In the Long Run: Disability and Vital Conjunctures

Anthropology teaches us that the experience of disability—like all social relations—changes over the life course and through historical time (Kohrman 2005; Langness and Frank 1981; Livingston 2005; Myerhoff 1980; Phillips 2010). Susan Reynolds Whyte (2020) describes the different temporalities experienced by her disabled interlocutors in eastern Uganda over their complex life courses. Her article provides a grounded perspective on what it means to live as a disabled person in Uganda, a country well-known for its progressive legislation supporting the rights of people with disabilities and robust donor support for special education and community-based rehabilitation programs. Despite this national context and commitment, those living outside urban centers find themselves frequently scrambling for resources. Whyte’s knowledge of “the long run” builds on her lifetime collaborative research with rural villagers (Whyte 2014). She calls attention to the vital conjunctures she has witnessed of humanitarian “development project time” and “global health time” as these temporalities intersect with disabled people’s life projects in under-resourced circumstances. Her research demonstrates how aid projects may come and go; their impact is often minimal in the long run of lifetimes in which everyday concerns of making a living and making families predominate. Working in Northern Uganda where the impact of civil war has been enduring, Herbert Muyinda traces the significant presence of people with disabilities (PWDs). In rehabilitation camps, they are offered training for potential employment, acquiring skills that are often irrelevant to village life when they return. Instead, he shows how people use their entrepreneurial savvy to establish networks and niches that provide appropriate work. In his analysis, their success or failure depends on existing forms of sociality such as kinship and friendship networks as well as new technological developments; these sometimes open unexpected work opportunities as skills are constantly transforming to meet new circumstances in postconflict Uganda. As he writes: “In this skilling journey . . . sociality seems to be the highway, technology the vehicle, and a PWD’s life condition the destination” (Muyinda 2020).
The Ecological Future of Disability Worlds

Our week-long gathering took place in the stunning Tucson desert, at an accessible hacienda. Yet, a particularly disabling environment lies just beyond and below the exquisite beauty we all enjoyed; we learned about this hidden toxicity from the work of Sunaura Taylor, an extraordinary disability artist/activist/writer/painter and scholar (Taylor 2017). Her current research on “disabled ecologies” points to the significance of disability as an aspect of environmental justice. Taylor questions conventional understandings of both disability and nature by exposing the costs of a contaminated aquifer in Tucson, the city where she was conceived. Sunaura and her sister Astra wrote about their family’s exposure to toxic industrial military waste and its disabling consequences.

In 1982 our family was living on the Southside of Tucson, Ariz., in a primarily working class and Latino neighborhood not far from the airport. That year Sunaura was born with a congenital birth defect known as arthrogryposis, a condition that severely impedes muscle growth and requires her to use an electric wheelchair. On nearby blocks, women were giving birth to babies with physical disabilities and neighbors were dying of cancer at worrisome rates. Over time, we learned that our groundwater was contaminated. Most of us are vaguely aware that war devastates the environment abroad. The Vietnamese Red Cross counts 150,000 children whose birth defects were caused by their parents’ exposure to Agent Orange. Cancer rates in Iraq are soaring as a result of depleted uranium left from the Gulf War. But what about closer to home? (Taylor and Taylor 2006)

The polluted aquifer feeding Tucson’s water supply was contaminated by the US Department of Defense, one of the biggest polluters on the planet (MacLeish and Wool 2018). As Sunaura explains:

While disability is commonly understood as a complex relationship between a person’s embodiment and their environment that leads to limitation and lack of access, and nature is largely perceived as a delicate web of life vulnerable to human interference, my work suggests that new and generative understandings of these words emerge when we center impaired environments and the people made ill or disabled by ecological damage “disabled ecologies” [are] . . . manifested and produced between and among human and non-human entities. . . . The Tucson International Airport Area Superfund site is a contaminated military industrial zone, locally notorious for having polluted the drinking water of Tucson’s largely Black and Latinx South Side as well as portions of the Tohono O’odham Nation, leaving thousands of people with a variety of cancers and congenital disabilities. The story begins in the 1950s when Tucson became the home of Raytheon, a major player in postwar US military industries. . . . The impacts of pollution on the residents went unacknowledged even after the area became a registered Superfund Site in 1981 . . . the epoch we live in, what some call the Anthropocene is as much a story of disability as it is of racism, colonialism, capitalism, and anthropocentrism. Turning to disability activists, artists, and scholars—people who have long learned how to adapt to loss and limitation and celebrate vulnerability and interdependence—might offer invaluable insights into how to live with ecological disablement. (Taylor 2018)

Her insights are similar to those of critical disability studies scholar Helen Meekosha: “The production of impaired peoples continues as a result of a multiplicity of phenomena including: war and civil strife, nuclear testing, the growth of the arms trade, the export of pollution to ‘pollution havens’ and the emergence of sweatshops” (2011).

When moved from margin to center in social theory, disability’s significance becomes ever more apparent: it emerges in analyzing the human costs of environmental toxicity, war, racism, and structural violence as well as gendered relations of kinship and intimacy. Indeed, the study of biopolitics, the life course, technology, and media are all incomplete when disability is erased. Disability worlds, we argue, are essential to understanding not only what it means to be human (Rapp and Ginsburg 2010), the classic remit of anthropology; they also offer a crucial diagnostic on the future that confronts us all.

References Cited

Ginsburg and Rapp  Disability/Anthropology


Zhan, Mei. 2009. Other-worldly: making Chinese medicine through transna-


The Politics of Disability Performativity
An Autoethnography

Devva Kasnitz

Disability is a concept that grows as we think about it, forcing us to adjust our conversations in vocabulary and rhetoric depending on which disability world we inhabit or address. Understanding disability starts with exposure to disabled people’s bodyminds in their own spacetime and an appreciation of disability expertise. The disability justice movement pulls the intersectional performance of disability out of the intimate sphere so that it can play a role in policy, an analytic where anthropology should shine. This article is particularly addressed to anthropologists with a new interest in disability and critical disability studies scholars with a frustration with anthropology. I use exemplary analysis of actual dialogues drawn from an autoethnographic record of my own perceived mobility and speech impairments to explore my biopolitical positioning as disabled. Anthropologists have the capacity to move disability theory forward, feeding it with ethnographic fuel. While the anthropology of disability uses insightful ethnographic methods to understand specific impairments in specific contexts, the reflexive turn in anthropology has not yet embraced disability. We are still better off remaining individual disability experts; our collective efforts are still an “embarrassment to power.” This article, as part of a collective special issue, aims to change that.

Disability is an ingenious way to live. (Neil Marcus)

Coffee Cups

At the diner my husband likes because the locals come in wearing overalls and talking cows, the waitress comes with her coffee pot and starts to serve us in the old-fashioned cups and saucers from which I slurp as they are much too top heavy and flat for me to pick up. She says, “I’ll just pour you a half a cup, so you don’t need to worry about spilling it. I’ll come round and keep refilling it.” I respond, “Oh, thank you, can you make it the top half?” (From my autoethnographic field notes, October 2015)

Disability is one of those concepts that grows as you think about it, forcing you to consider related concepts: identity, impairment, illness, health, intersectionality, and more. Were it not complex, the emergent field of disability studies could not be sustained. As an academic and political exercise, disability studies reframes disability to bring out the nuance appropriate to different projects.1 We adjust our conversations in vocabulary and rhetoric depending on which disability world we address.

1. Here I use “nuance” as others might use “critical.” I postulate that at this time, all new good anthropology or disability studies is “critical” in its subjectivity. Pure description is an impossibility. We expose our biases in both what we say and do not say. Sins of omission of discussions of relationality and power constitute serious faults. See Meekosha and Shuttleworth (2009) and Harblay (2020) for more on critical disability ethnography, a product that, like all of disability studies, centers the expertise of the disabled and exposes the relationality of the writer.

Disability Justice Is Good to Think

Understanding disability starts with exposure to disabled people’s bodyminds in their own spacetime and an appreciation of disability expertise. The disability justice movement pulls the intersectional performance of disability out of the intimate sphere so that it can play a role in policy,2 an analytic where anthropology should shine. Disability by definition is remarkable. Disabled people live with the reality that the public wants to define that remarkableness and the knowledge that if they do not manage their human relationships carefully, their remarkableness will be used to control them. This was noted as “the Management of Spoiled Identity” as early as 1963 in Goffman’s 1963 sometimes forgotten classic and rephrased by Rosemarie Garland-Thomson (2009) writing about how disabled people recognize, at least intuitively, that it is their role to set non-disabled others at their ease. There is significant pushback to this from the exasperation of disabled people tired of that effort, to people who consciously refuse to do it—or who do it in their own and unexpected ways. Someone like artist/writer/performer Neil Marcus, who has the same diagnosis of dystonia that I have, always does it with kindness and humor.3 I have more anger, but we meet in our recognition of the risks

2. We are all indebted to our colleagues of color for articulating “disability justice”: see Mingus (2017).

Devva Kasnitz is Executive Director of the Society for Disability Studies (PO Box 5570, Eureka, California 95502-5570, USA) and Adjunct Professor at the City University of New York (devva@earthlink.net). This paper was submitted 11 XI 18, accepted 8 VII 19, and electronically published 5 XI 19.
and the power of in-your-face disability performativity (Marcus, Kasnitz, and Block 2016).

A Journey into Autoethnography

This article is particularly addressed to anthropologists with a new interest in disability and disability studies scholars with a frustration with anthropology. Its goal is to further conversation by using exemplary analysis of actual dialogues drawn from an autoethnographic record of my own perceived mobility and speech impairments. I use both phenomenology and systems theory as analytic grist to this data to explain my biopolitical positioning as disabled.

As a student in the 1970s I was hesitant to study disability and to write what came to be called autoethnography. It remains professionally dicey. Many current anthropology faculty still have trouble seeing a disabled student doing anything but autoethnography.

Why autoethnography (Block 2020; Forber-Pratt 2015)? To bring out nuance. I moved from Australia to Sicily over 3 years of studying reproduction and immigration for my dissertation, but my best data on the Sicilians of studying reproduction and immigration for my dissertation by using exemplary analysis of actual dialogues drawn from an autoethnographic record of my own perceived mobility and speech impairments. I use both phenomenology and systems theory as analytic grist to this data to explain my biopolitical positioning as disabled.

As a student in the 1970s I was hesitant to study disability and to write what came to be called autoethnography. It remains professionally dicey. Many current anthropology faculty still have trouble seeing a disabled student doing anything but autoethnography.

Why autoethnography (Block 2020; Forber-Pratt 2015)? To bring out nuance. I moved from Australia to Sicily over 3 years of studying reproduction and immigration for my dissertation, but my best data on the Sicilians’ conception of female physiology came from kitchen table and bathroom conversations about whether or not it was a good idea for me to have a baby. Sumi Colligan (2001) also reports this experience of our disabled bodies being the conversational foil to understanding general ethno-embodiment.

How autoethnography? As in “Coffee Cups,” because of my speech impairment, I use chat, text, and email as others use the telephone and face-to-face conversation. I have verbatim transcripts of all my classes and most meetings I attend from employing Computer Aided Real-time Transcription or CART as an accommodation. As data, I mine these texts altered only to protect others’ anonymity. I make no claim to generalization. Today I am content to demonstrate how anthropological tools make my life more meaningful to me with verbatim electronically captured data.

Anthropology’s Contributions to Disability Studies

Anthropologists have had a significant impact on the development of critical disability studies, as is evident in various reviews and curricular interventions. In the twenty-first century, some anthropology graduate students are embracing disability studies from the beginning of their careers, while seasoned anthropologists have turned to this subject as an active part of their later personal and professional lives. However, too often institutionalized anthropology eschewing a perceived “service” thread in disability studies misreads the field’s theoretical and methodological contributions as “only applied.” Anthropology is also wary of autoethnography and its place in cultural studies (Forber-Pratt 2015), as if participant observation was ever successful without intense and even risky, if unexpressed, self-reflection, a hallmark of the early disability and anthropology engagement tradition I follow here (Frank 2000; Murphy 2001).

Interrogating the shared category and experience of disability is, I argue, what separates disability studies from simply the study of disability. It distinguishes disability anthropology or anthropological disability studies from simply the “anthropology of disability” (Shuttleworth and Meekosha 2013) and it welcomes autoethnography. Disability anthropologists excel at describing others’ points of view in context. We make theoretical contributions to disability studies about demedicalizing and decolonizing disability, highlighting indigenous meanings.

Despite a growing disability anthropology, most anthropologists of disability are only now discovering disability studies. Anthropology’s institutions have failed to embrace disability studies despite the feminizing, browning, queering, and now the crippling of anthropologists. Perhaps this is because for some, these developments, like applied anthropology, suggest a loss of status for the discipline. How can we think about the decolonizing of disability given the historical resistance to the topic in our discipline? Yet there has been at least one anthropologist on the board of directors of the Society for Disability Studies (SDS) for 27 of its 35 years, serving as president for 28% of that time. Disability studies has welcomed ethnography in all of its permutations, yet anthropology’s bureaucracy has remained profoundly ableist, even when three disability ethnographers sat together on the executive board of the American Anthropological Association (AAA).

4. See a description of this in Kasnitz and Block (2012).
5. I believe some unresolvable discomfort with the disabled or racial other sparks inappropriate anger because people hate feeling embarrassed. See Ralph (2020). In American disability worlds, a polite “No, thank you” to proffered help is often met with indignant anger: “Well, be that way about it!” People need to be needed. However, when others decide what you need, when you need it, and how you need it, it becomes oppression.
6. There are many reviews of disability anthropology. See Kasnitz and Shuttleworth (1999, 2001), Battles (2011), and Rapp and Ginsburg (2013) to start.
7. Here I thank Lucy Cohen, Alice Kehoe, and Jay Sokolovsky for their gift of conversation.
8. Most reviews look at publications; I will simply list names of anthropologists not in this collection who have been active not only in early disability scholarship but also in institutional organizing. A partial list would include Irving Zola, Joan Ablon, Louise Duvall, Gerald Gold, Joseph Kaufert, Russell Shuttleworth, Carol Goldin, Jessica Sheer, Nora Groce, Robert Murphy, Sumi Colligan, Karen Nakamura, Gaylene Becker, Linda Mintenness, Gelya Frank, Cheryl Mwaria, Lois Keck, Mathew Kohrman, Zev Kaliphon, Elaine Gerber, Olga Solomon, Susan Gabel, Pamela Cushing, Gail Landsman, Miki Iris, etc. The Society for Disability Studies started under Irving Zola’s mentoring in the early 1980s with three fresh anthropologists—Groce, Sheer, and Kasnitz—on the founding board. Despite 35 years of the Society for Medical Anthropology’s (SMA) Disability Research Interest Groups, which never failed to organize AAA meeting sessions, “disability” as a keyword in the AAA meeting program guide is new.
Anthropology’s four-field division has not helped. We talk to each other less and less. Medical and educational anthropology both study disability but rarely talk because of the disproportionate size of the Society for Medical Anthropology within the AAA not only renders it hegemonic but also makes it difficult to DE-medicalize and hence destigmatize disability. Linguistic anthropologists have embraced the study of signed languages, nonstandard speech, and autistic communication (Ochs et al. 2004). The subfield of bioarchaeology has also recently engaged disability’s long-standing significance for the species (Byrnes and Muller 2017). The growth of interest in disability within anthropology holds important potential, but without knowledge of disability studies, many confound disability, illness, debility, impairment, and chronic illness. Some medical anthropologists of chronic illness are careful NOT to claim disability expertise because they are aware of this critique. In this work, it is also essential that we tease out ageism and ableism both separately and in interaction, but not collapse them. My deliberate personal strategy to further institutional disability anthropology has been to seek out these colleagues, present with them at meetings, encourage joint publication, and create email list conversation threads.9

Anthropologists have the capacity to move disability theory forward, feeding it with ethnographic fuel. While the anthropology of disability uses insightful ethnographic methods to understand specific impairments in specific contexts, often from a western or indigenous medical diagnostic perspective, this approach often fails to deploy a dynamic relational concept of disability. A perusal of recent presentations at AAA meetings shows that family and care provider voices are privileged, sometimes in the service of “studying up.” However well done, this risks silencing disabled subjects, particularly people who are nonverbal or speech impaired and who have nonstandard voices to which the ethnographer must literally learn to listen.10

Words Matter beyond the Word Police

My ideas depend on a largely temporal distinction between impairment and disability, although not in a classic biology/society dualism.11 Both are socially constructed. Here I do differ from others, including in this issue, who collapse or interchange disability and impairment because their community does. In disability studies we debate, or passionately refuse to debate, binary word choices such as the long-standing argument between “disabled person” and “person with a disability,” or “people” versus “identity-first” language. Students learning about disability studies want to be told which is correct. I eschew the “word police” in favor of conversations about meaning. To avoid offense, we can talk about disability without using either “disabled people” or “people with disability.” If the focus is connecting to a social movement, writing this article, or teaching, I use words that I hope will best communicate my ideas. None of my choices are for variety, “honoring,” or not offending. I understand I am a “person first.” I have embodied anomalies that are socially marked as “impairments” because of “discrediting attributes” as perceived by others, not as lived by me.12 Once perceived, impairment is a route to disenfranchisement; I am “disabled” by that perception and disenfranchisement. Impairment may not trigger an experience of disability oppression; but when it does, I become a “disabled person” precisely because my personhood is disabled by attitudes toward my perceived “impairments.”

I also eschew all of the overused wordplay such as dis/ability, dis/ableism, able-disabled, and challenged, even if it is not gratuitous. I do not use “disability” in its noun form comfortably except as a name for a perceived demographic category (Friedner 2020) and as a name for an experience. I particularly avoid “disabilities.” Concretizing disability as something plural or with a range of severity seems so divisive that I will restructure a sentence entirely to avoid it. I would rather destabilize the disability/not disability binary than explode disability into the plural. I acknowledge that my socially perceived “impairments” are multiple, as are the barriers I face and the contextually appropriate accommodations I expect, but disability is a unifying experience.

Bigger Is Not Better

I find marginal utility in definitions of disability that inflate it to the largest minority or in reminders that anyone can join our ranks at any time. I do, however, join Lakshmi Fjord, Lenore Manderson (2009), and Sunaura Taylor (2017) in a broader view of the value of disability theory to understand the production of disabled social and environmental ecologies and disasters, be it family or forest. An expanded notion of “disability” can provide a better understanding of “affordances” as opportunities (Gibson 1966) and “accommodation” as enabling. For example, one way to reframe the need for radical inclusion in professional organization meetings would be to mark accommodation needs as relational and interactive. Everyone should fill in the “Accommodation Request” box with notes such as “I don’t sign. I’ll need an interpreter for any presentations by deaf participants,” or “I’ll need a revoicer for Devva at these times when I hope to meet with her.”

I think of this strategy—which I call “community-based accommodation”—as exemplary of Danilyn Rutherford’s (2018) idea of how nondisabled people who are family or allies have “disability proximity.” Significant disability proximity is a part

9. See archives of AAA meetings.
10. See Hartlay (2020) for a discussion of how as an ethnographer, she slipped into an altered sense of time to interview someone with extremely slow language production.
11. See early British social model theorists such as Michael Oliver, whom we just lost (Malhotra 2019).
12. Thanks to Goffman (see Shuttleworth and Kasnitz 2004) and the still-useful stigma model.
of what I describe as a larger societal “disability exposure” that allows a “cross-impairment synergy,” a recognition that we share a unique and heightened energy across specific impairment labels that we cannot access separately, to emerge from a disability justice perspective and to hold powerful group advocacy potential.

**Apprehension of Disability**

In American culture, disability—like race, gender, nationality, and any other imagined identity characteristics—are situated in a world where it shifts from background to foreground in our quotidian lives. This is not without risk. Certain experiences cause perceived impairment to pop into the foreground as problematic, the “light bulb” moment when an impairment becomes a disability, a spacetime out of spacetime experience. This starts from or can lead to embarrassment and then to the apprehension of disability status. When repeated often enough in multiple contexts, embarrassment as a tool of ableism wanes and a consciousness of ableism and of disability identity emerges as a strategy to manage the categorization of disability as a social vulnerability or risk. Chronic illness, temporary injury, and all kinds of bodymind anomalies in contextual spacetime can trigger the apprehension of disability status. It takes repetition and some reflection to create the disability identity “access intimacy, interdependence, and disability justice” that disability advocates express (see Mingus 2017).

When people have significant exposure to disability, they can become adept at recognizing disability expertise and helping in a way that makes disability background and other activity foreground. Applying the concept of “affordance” (Dokumaci 2017), which I think of as openings in social structures that create opportunity or well-being, I may choose to gracefully accept help I neither need nor want, but I am clear that it is not my affordance but my helper’s. This experience is what I want to share in my micro-autoethnography here where “microaffordances” are but tiny cracks. That is why I started with my “Coffee Cups” vignette above. I allowed the waitress’s need to feel kind lead me to truthful humor.

**Blank Faces**

I tell my students:

I just met someone in the hall who introduced himself and told me what our connection is, that he teaches the intro disability studies course and attends SDS. I said, “Oh, nice to meet you.” I started to actually talk to him, that blank face. “Oh, okay. Okay, let’s try again,” I thought. I tried again very slowly. Blank—where others would say “Again?”—he gives me only a frightened rabbit expression with no clue to let me know where he lost me—and this person knows me from disability studies! That makes the situation a little sticky. I thought, “He was clearly embarrassed.” I thought about embarrassment, and I realized that I don’t have the luxury of being embarrassed.

If I get embarrassed, I can’t get my needs met. I can’t do anything. It is completely immobilizing. Embarrassment is just not on my agenda. Having the luxury of being embarrassed is ableism. I know that the best care providers just naturally dispel embarrassment. It doesn’t accomplish anything and is an e/motion that puts you out of motion. (Class CART transcript, 2/28/2018)

In the next vignette, like “Coffee Cups,” I again show how disability pops into my own consciousness and intrudes on my life while I am otherwise engaged because of a social interaction. Remember, my impairment reality is obviously uncommon, but my chosen accommodation is not. I can drink/slurp the top half from most cups without picking them up or even touching them. The bottom half I can only splash over the room should I try to pick it up and I tend to burn my tongue with straws in hot coffee. The other common solution to the “Devva” problem waitresses assume they/I have is to offer a disposable cup so they/I need not be concerned about breakage. I can’t even touch such a cup without knocking it over because it is too lightweight.

**Alone?**

This foregrounding of disability caused by the actions of clueless others has little relevance to my activities except to block them (Shuttleworth 2002). Perhaps my marching gait is a bit off, but my endurance is not.

I “*Me Too*” marched in snowy and poor Cincinnati—my first time in the city. I had a blast except for the woman who came up to me and blocked my path when I jumped up on the sidewalk to quickly get a better view of the crowd to guesstimate the size. She said, “Are you alone?” Of course, I instantly knew I’d been hit with crap, again. Was she embarrassed for me that I seemed alone? Did she think I needed better care? Was I too “ugly” to be out alone? Here is where I resent my speech impairment. Here are the snappy answers to her silly question that I would have liked to say: “Oh yes, (grabbing her arm) I’m all alone—will you help me? Will you buy me lunch?” “They just let me out of the hospital/jail.” “No, but my friends can go without my supervision for a short while if you need help.”

I muttered something about gross paternalism and infantilization that she neither heard nor would have understood as my friend said, “NO, she’s with us.” After I ran to get back in place, I marched backwards and stared at her.

13. See Ralph (2020) for more on how violently acquired disability experience medicalizes vulnerability and risk in exchange for services and “care.”

Then I did a few pirouettes and started to skip. (Class CART transcript, May 16, 2018)

Embarrassment and Disability Apprehension

I am indebted to Hughes and Paterson (1997) for their classic phenomenological elevator spacetime disability conundrum vignette. They describe how when the elevator doors open, and someone gets on and asks Hughes a question that does not have a yes/no answer, he can at best stick the footplate of his chair in the door to give his CP (cerebral palsy) mouth time to answer. I know this “innocent” questioner well. S/he is usually embarrassed that they have made a disabled person go through the effort to answer; they may break into profuse apology, asking more rapid-fire questions we do not have time to answer. Or they may be disturbed that their time is now engaged past the usual elevator spacetime. Although tiresome, we “crips” are accustomed to this. Some of us get the setting-people-at-their-ease, however much we wish for the reverse courtesy. When spacetime permits, I do the setting-at-ease by assuring people “I know I’m hard to understand, this is NOT news to me.” If I want any kind of relationship with the embarrassed, I must help them over it. The need for others to join me in employing communication accommodative microaffordances, such as turning a face toward me or putting down a phone, is often central to such conversations. With a recognition of cross-impairment synergy, this is true whether we “present” with “expressive” impairments, strange voices, mechanical voices, proxy voices, confused voices, signed voices, slow voices, and/or with “receptive” impairments, sound processing, hearing, listening, contextualizing, or combinations.

There is, however, a darker side to embarrassment and disability when someone is embarrassed for someone else. While I have realized I do not have the luxury of feeling embarrassed, to assume I am embarrassed, or that anyone is or should be embarrassed for me is profoundly ableist. I may need help with many things, but being embarrassed by my experience of disability is not one of them. Embarrassment over the mere existence of disability is oppressive. In these cases, my interlocutors feel free to ignore public norms of word and deed to invade physical and psychic space to “assit” me in my self-presentation to minimize the disability stigma their own unbridled perception of disability has bestowed on me. They are both the author of the problem and seek to be its solution. They can and will, without asking, either seek to “fix” me or to control me so “my” disability is minimized according to others’ views. This loss of self, this “management” of personality, is ableist intrusion. In the case of people who used to be called “retarded,” this phenomenon is magnified. While I endured that R-word epithet only from spitball-throwing boys on the school bus, others were and still are not that lucky. They experience an extreme ableism for which I still use “handicap.” Someone encounters “handicap,” as I use it, when oppression goes beyond a disabling of personhood to remove it altogether. Philosopher Eva Kittay (2001) addresses this circumstance when she writes of the joy she takes in her daughter Sesha’s affective expressions. At the same time, she acknowledges Sesha’s profound care needs; although Sesha is nonverbal, Kittay highlights a reciprocity others do not see.

Although I experience both mobility and speech impairments, sometimes people are aware of both and sometimes not. My experience of disability oppression is, however, singular when it is foregrounded in my vignettes. Sometimes my mobility issues surface in an unusual gait; other times it is my inability to write in small blanks or carry certain things. For example, at the bank when I limp in, I am offered a desk and a chair; this is very nice except I can only handwrite standing up or kneeling on the floor. Then, after I start to speak, I am offered a pen and paper. Sometimes I wave my crisp fingers at them. Sometimes I answer no to “Can you write that down?” Sometimes I say okay and kneel on the floor, as I do at home. Perceptive tellers learn to think twice before asking a limper and mushy-speaker crip to write. These autoethnographic vignettes reveal the subtle variations in how speech impairment becomes speech disability, and how mobility impairment becomes mobility disability in mainstream life. Like others, I continually invent microaffordances and direct accommodations. There is a reason I accentuate my odd gait and hold my ticket in my “bad” hand when boarding a plane: I want the preboarding affordance.

On the Accommodation Octopus

The concept of accommodation currently enshrined in American regulation is a problem. It both over-individualizes and overgeneralizes. Ignoring community accommodation, it places the burden on the individual to give up some affordances in order to get others, while it generalizes building codes as if all wheelchairs were the same height. It is about others demanding that you change to be disabled their way. For example, in academia, a student’s most common accommodation is extra time. What is the most valuable thing we have in life? Time. What is the last thing most employers want to offer as an accommodation? Time.

The health care system has become a gatekeeper to accommodation. This exacerbates its place as an inappropriate economic engine, creating an accommodation industry. Starting in childhood, medicine is entangled in the provision of basic education. In order to get or get out of “special education” services, you have to invoke the power of medicine. I remember asking my pediatrician to get me out of gym and get me into advanced placement French instead. My mom wrote the letters

15. Thinking about these apprehensions of disability is a continuation of a conversation between me, Pam Block, Neil Marcus, Russell Shuttleworth, Mathew Wangeman, and Susan Fitzmaurice.

he signed. Later, at 30, when I decided to try learning to drive, I needed a letter again. I asked my neurologist for a letter saying I could drive. He asked, “Can you drive?” I said, “I don’t know; I need a learner’s permit!”

In this multilayered system, in the conceptualization of the problem in the moment, in the way in which you look for help, or advocate for change, if you are in the realm of disability or the domain of illness, you do it differently. People move through these domains in life; you cannot act on all of them all at the same time. That is why I am so careful to describe “my” disability as an experience of a certain kind of exclusion, as opposed to describing it as dystonia, which is the diagnosis, or as speech and mobility impairment, which is the realm of functional limitations. I seek accommodation because of disability; the specifics are because of how impairment as a social category manifests in different contexts.

**Week One Introductions in an Online Class**

How do I greet an online class? How do I make them allies? I use humor and performance to introduce disability in person. I want to perform disability online in a way that I cannot avoid doing in a face-to-face class. I want to disrupt students’ notions of disability and impairment. I start by posting a video of myself spinning wool surrounded by a living room strewn with dozens of skeins of prize-winning yarn I have spun. I show them something that they cannot do and that no one expects me to be able to do. I look for that “pop,” a kind of culture shock as a way of introducing myself. I started talking during the filming.17 About halfway through I realized I was unintelligible and started speaking nonsense, real English words, but nonsense. The prankster in me wondered, would they notice? Then I posted this introduction.

Well, my arms ache from clicking Blackboard buttons. The software is really not designed for a crip like me with too many repetitive movements of my constantly moving spaz hands. Can’t type in wrist braces at all. The base of my thumb is swollen, the heel of my mouse hand calloused.

Online teaching is both a boon and a disaster for crip faculty. No ramps to the environment and we hope that you have not yet expended extra energy fulfilling this particular request.” (Email correspondence, 2/1/2018)

If I, as disabled faculty, found this communication rude, how must others feel? This is not how I want disability represented. I received a reply.

We review our messaging templates at regularly scheduled intervals and your recommendations will be taken into consideration at this time. (Email correspondence, 2/2/2018)

At this school, as is common, disabled student accommodations are met by one office and disabled staff needs by another. Luckily, these two offices DO talk to each other in this case. While as a new disabled faculty member I was not clued in about the faculty office ahead of time, and was sent to the wrong building twice, for one hard of hearing (HoH)/deaf student’s request, I was told, it MUST be negotiated weeks ahead in a phone call, despite the fact that phone calls are inaccessible to me as any HoH/deaf student would surely understand. The business of student accommodation provoked faculty disability. This possibility was outside their disability world imaginary, causing my experience of disability to pop again into that foreground of embarrassment and vulnerability, and I seethed.

For the first class, I had a captioner trying to revoice; that was my idea, a bad one. She felt embarrassed and exposed, standing beside me instead of sitting in a corner behind her machine.

17. See [https://www.youtube.com/watch?v=c887SWOJR2c](https://www.youtube.com/watch?v=c887SWOJR2c) (“dr devva spinning and talking”).
preprogrammed to type “inaudible” with a single stroke. From the back of the room, students with advanced knowledge of the field feed her the vocabulary. It helps but also confuses as disembodied voices come at her. This captioner is not a good revoicer, but others might be. The Chinese students flee, some during and some after the class. They may be seniors, but this is a test of their English skills they do not dare take.

The second class has captioning, CART projected for all to see. Most captioning in class is “closed,” available only to eligible students via Wi-Fi to their laptop. My request that it be “open,” that is, projected, hit a glitch. It seems the software does not allow a font size large enough to be seen from the back of the room.

The accommodation office also takes the initiative to call in a pair of ASL (American Sign Language) interpreters who get Deaf Culture. Doesn’t take them more than a few moments to see they are in Crip Culture land with me. It takes them most of the first class to get the protocols and hand signals for HOW they are supposed to revoice. Recognizing kindred souls, I stop them when they begin to paraphrase instead of revoice. Looking deep within their eyes, hands on cheeks, in performance mode for the students, “Your voice is mine, word for word. You don’t need to understand. Listen, repeat, forget; listen, repeat, forget; listen, repeat, forget; listen, repeat, forget. That’s your job. (In fact, if they relax about trying to understand, they will.) Your mouth is MINE,” punctuated with a kiss. Everyone cheers. Lesson one in “Embodiment and Disability” is delivered.

I tell the students to take note of how meaning emerges from, or is muddled by, the sheer physical and joint mental effort our communication accommodations absorb, and to be aware of the role they play individually as solution or barrier. Not paying attention goes beyond being a bad student; it is ableist. I do not expect them to work as hard as we four: two interpreters, a captioner, and me, all of us at least 20 years older than they. But meet us halfway.

My Listener’s Brain

I give the students a piece of disability apprehension theater I have developed over the years. Just as I performed my ASL interpreter turned revoicer’s brain above, I perform my naive listener’s brain mindstream when it first encounters my live speech. I tell the students that I know they are thinking:

Oh, my goodness, look at her talking. Look at how her face CONTORTS. Who could ever understand her? She just keeps talking. Oh no, she is looking at me. What will I do if she asks me a question? How will I even know it’s a question? What should I do? Do the others understand her? Am I alone?

(Class CART transcript, 2/9/2018)

Good humor and intellectual surprises work to dispel embarrassment. The class is still awake at 9:15 p.m. The HoH student only learning ASL is happy as she lip-reads the revoicing interpreter and then checks the captioning. One interpreter must stop putting her hand over her mouth when she is embarrassed if she does not understand me. Maybe later the two of them, both big women, will figure out how to join the circle rather than sit in the middle of it. The students with sound processing problems are happy with the captioning. Everyone likes the idea of getting the transcript. Later it will dawn on them that because attendance is required, a student may miss class but make it up by reading the transcript and posting comments to the class website, a task much harder than just showing up.

It is a constant dance to both manage all these classroom affordances and accommodations AND to teach. I tell myself that the mere routine exposure to so much proximate disability expertise to apprehend IS the lesson. I explain my cross-impairment synergy process to the class.

I have a thought and I look over there at you and that changes my thought a little. Then I look at the revoicer, and I say half the thought, and then she gets it wrong. That changes my thought. Then I say it again. And because this is all so slow, there is lots of time to think. Then one ASL interpreter feeds the other in ASL the words she missed in English. At times the HoH student feeds it in ASL to the interpreter because her disability studies vocabulary is better than the interpreter’s. Meanwhile the captioner may get what the revoicer misses, but for me to know that, I must turn around with my back to the class to see the screen. (Class CART transcript, 2/7/2018)

I try to curb students’ thumbed conversations with people not in the room. It breaks the one-person-talking-at-a-time rule. After all perform their brain, students respond well when told,

“I know how hard I am to understand. My bargain with you is that if you still your inner voice (and put down your phone) to give your brain more space to listen, I promise to be funny, to dance and mime, to keep you awake, and to say things that are memorable.”

(Class CART transcript, 2/7/2018)

Zooming to GoToMeeting

Technology is blessing and curse as it intersects my accommodations. We meet in real time via a combination of voice and chat. I feel pressured to type into chat fast and not fix typos, and the chat is not all mine. Other people interrupt me even when I am giving a formal report. My current solution is to prepare ahead such a good written report that I anticipate any questions and to also develop a close enough working relationship with the correct committee chairs that they are prepped to answer if there are questions. A good meeting is one where I do not need to talk. If I do, I fear the uncorrected chat will be judged and I will be found inarticulate—my audience will apprehend a “disability” I do not have! How

18. I love the contradictions between my speech impairment and verbal art. See Bauman (1975).
do I manage my need for patience with the predominant culture that may even privilege some hyperactivity (Nishida 2016)?

**Independent Living Removement?**

I am in a play, a farce, it seems. I have Skyped into an important most-of-the-day meeting. Because of my speech, we always have chat open so I can type. We have two-way video and speakerphones at both ends. We start with a brief formal meeting; the chair solicitously asks for my vote and I unmute and resume for them to give my “Aye.” Then we have a guest, and the camera for my visual is just a few inches from our presenter’s butt. They improve my sightlines and we all laugh. After our speaker leaves, it is time for the six of us to get to work. My virtual self appears to be about 10 feet from everyone else. I have a great view of backs. (Later I learn no one thought to move the table closer to the outlet.) My chat messages go unseen. I interrupt the conversation via speakerphone and try to say, “Please read the chat.” The leader gets up, walks over to me and reads—no, actually paraphrases—my typed words in the third person, as if I were not there, for the others. She only sees the most recent of my typing as it scrolls off the screen. With her nose inches from the camera, she stands inches over my laptop self. She asks me to be quiet while SHE types TO ME. I type:

[12:57:50 PM] Devva KASNITZ: can you put the chat close to yhou
[12:58:13 PM] Devva KASNITZ: I can hear huow. Why r u typing to me? (Skype chat transcript, April 2016)

Now, I HATE to send such bad typing out, but my customized typing software does not link with chat, and there is no time to correct a chat the intended audience seems loathe to read. This would be funny if the organization involved was not a 30+ year old disability service and advocacy one. Should I be surprised?

**Aaron the Revoicer**

People who use a revoicer often develop an oratorical style. We hear our own words repeated—a unique feedback loop. They may, like me, put the punchline at the end of the sentence so that people do not try to speculate what they think I am going to say. Speculation takes over from listening to what I do say. Truly listening is rare among our culture of multitaskers. Perhaps Moses broke the first set of tablets in frustration not so much over the Golden Calf but that they did not LISTEN to him. Perhaps Aaron’s shame was not allowing the Golden Calf but failing to revoize Moses’s words to the multitudes firmly enough?

What makes a good formal revoicer? Like Aaron, someone who is not too shy, who speaks up. Someone who, if invested in the topic, is not insecure about their own ideas, and does not need to be the one leading the discussion all the time—

they need to focus on what the speaker is saying and HOW they are saying it rather than on what they would say or how they would say it. A good short-term memory helps. One protocol with strangers’ revoicing is: listen, repeat, forget; listen, repeat, forget; whereas people who know you well use that knowledge. A good revoicer is also someone who looks directly at the speaker with an expressive face so that the moment they lose the speaker, the speaker knows it. Understanding is interactive and must trump any embarrassment felt when it is wrong and must be corrected.

Families have been the center of communication access for both early- and late-onset speech impairment. Families have had to conceptualize meaning and express it to the outside world. Only recently have speech therapy, signed language interpreting, and alternative and augmentative communication become recognized sciences or activities. As these fields professionalize and services are reimbursable as medical costs, there is lucrative territory to defend with significant processual and emotional clashes among scientific, familial, service sector, and disabled people over validity and process.19 Within the family, these needs figure into the micropolitics of care. In many cases communication “care” never goes beyond the family. Where it does, we see the development of social and professional accommodative strategies very different from the family. My first-choice accommodation is revoicing. Institutionalized by the work of Segalman (2009) in national telecommunications law, it is a little known but required “speech to speech” relay service for all speech-impaired people where their words are repeated (revoiced) to their listener by a trained third-party “communication assistant.” This is now gaining national recognition using my term as “revoicing” in remote and, more often, face-to-face communication.

As people with speech impairments develop clearer ideas of using revoicing as a tool, their perception of what constitutes best practices may be very different with family, friends, or strangers in that role. Because communication is so fundamental, it can form the basis of alternative families that develop in disability contexts (Friedner 2020). Part of this difference has to do with who owns the problem. In India or in Africa, anthropologists are asking whether it makes sense to talk about the disabled family (see Addlakha 2020; Friedner 2020; Whyte 2020). Clearly, there are differences between revoicing as a family strategy where intimate knowledge of the speaker is primary; social revoicing where friends are usually the gatekeepers to participation, and relationships must be carefully managed to avoid misunderstanding and fatigue; and professional settings where accuracy is critical but there may be no prior interpersonal relationship. In the last case, the revoicer probably has been trained as an ASL interpreter or captioner. She might be a generic personal assistance-provider

19. Alternative and augmentative communication strategies are both individual and concretized in some sectors. Hot debates over techniques such as facilitated communication and rapid prompting method are current and beyond the scope of this paper.
with idiosyncratic experience of clients who need revoicing or help with alternative and augmentative communication devices, along with other mobility apparatus.

**Small Talk Communicative Personality**

As an anthropologist and as someone with a changing speech impairment, the data collection process for my ongoing autoethnography has revealed some of my own strategies. I had to give up small talk a long time ago. Like so many stigmatized people, I do best when I am funny; I put on a show and use physical humor. Embarrassment, again, can lead to a breakdown in communication. My disability imaginary is a communicative world free of disruptive embarrassment and its consequences: anger, confusion, guilt, and withdrawal. I want to avoid loneliness and promote its opposite (Kulick and Rydström 2015). I want my relationships unconstrained by disability in general or by preconceived notions of a disability hierarchy in addition to real differences due to specific impairment. Anecdotally, I can say that all my friends with generalized and even painful movement disorders that also affect their speech report that their speech impairment is their most troubling disability experience. Along with Alison Kafer (2013), we work toward an accessible future as one where familial, social, and professional revoicing blend and all support participation.

**What Do Allies Get?**

Allies understand that disability is not about health and that disabled people can be the healthiest in the room, living and dying well. They assume competence and seek comprehension. They offer appropriate assistance based on proximity and exposure to disability that values our disability expertise. They see the complexity and the dynamics among and between impairments and cross-impairment synergy. They understand the project of grasping disability process in all bodysminds and spacetimes with meaningful insight into our variation as well as the ever-changing environment. Our academic allies “get” the sophistication of disability studies. Those in anthropology understand that the time is up for an anthropology of disability. We occupy disability (Block et al. 2016). We beg the service sector to see us as we want to be seen. We use the metaphor of “decolonizing disability” carefully. I have been called an infrastructure activist within anthropology and disability studies as I perform disability for different purposes. Within the American Anthropological Association, we have reached a crossroad. We perform disability for different purposes. Within the American Anthropological Association, we have reached a crossroad. We understand the dominant discourse in disability studies, the Americans with Disabilities Act, and “reasonable accommodation,” but as a discipline we are missing a deeper understanding and have not yet operationalized our knowledge to make a more accessible profession.

**Concluding with Microaffordances into Future Imaginaries**

Disabled people care about place. When we enter a room, we scan it. If I’m in that corner and then I can do this, but I can’t do that, that chair is too low, but if I get this chair, it will be too high. This is work that goes on just to figure out what is around you, how it may or may not limit you or extend you, and how much you can manipulate it. We may do this consciously or tacitly. My micro-ethnographic role is my ability to witness and explain this process. Creative accommodation demands it. Call it a reframing of disability pride. It is something missing in much disability-related design. Disabled people rarely commission design. Designers design what they want to design for a purpose they want to meet. Disabled people are the colonized consumers. Too often, it is assumed that there are not enough of us for economic viability of design products without medical reimbursement. This makes the reimbursement source the true customer to please. The voice recognition software once developed for people who could not type used to be trainable to nonstandard voices. As it has gone mainstream, that feature is gone. Features in Microsoft Office 2010 offered flexible possibilities, while the 2016 version introduced a barrier to its use as it became more standardized.

We occupy disability (Block et al. 2016). We beg the service sector to see us as we want to be seen. We use the metaphor of “decolonizing disability” carefully. I have been called an infrastructure activist within anthropology and disability studies as I perform disability for different purposes. Within the American Anthropological Association, we have reached a crossroad. We understand the dominant discourse in disability studies, the Americans with Disabilities Act, and “reasonable accommodation,” but as a discipline we are missing a deeper understanding and have not yet operationalized our knowledge to make a more accessible profession.

We cloak disability exposure and expertise in “individual confidentiality.” Members who call out errors do so at considerable personal risk. The reflexive turn in anthropology has not yet embraced disability. We are still better off remaining individual disability experts; our collective efforts are still an “embarrassment to power.” This article, as part of a collective special issue, aims to change that.

21. Google’s Project Euphonia is currently seeking to expand paired speech recognition: “Google likely to unveil Project Euphonia at I/O 19 to give the speech-impaired ‘their voice back.’” Kyle Bradshaw, April 26, 2019, 1:47 p.m. PT @SkyledDev. https://9to5google.com/2019/04/26/google-project-euphonia-io-19-speech-impaired/.

22. The American Anthropological Association has hired an access coordinator as of June 2019. There is hope.

20. Speech impairment is quite common among people with generalized movement disorders such as CP, dystonia, and stroke.
Acknowledgments

I want to acknowledge Fanya for this opportunity. I must thank all my “Disability World” colleagues. Pamela Block and Russell Shuttleworth have been my long-term collaborators and Neil Marcus and Matthew Wangeman my muses. Tanya Anderson revoiced my 24/7 disability world words with grace. I thank the Society for Disability Studies which is both my baby and my home. My teachers Jim Blaut, Bill Lockwood, Skip Rappaport, Art Vander, and Joan Ablon are always with me.

References Cited


Disability Expertise
Claiming Disability Anthropology

Cassandra Hartblay

This paper stakes out a space for a critical global disability anthropology that considers disability not as a medicalized classification of impairment but as a relational category. Disability expertise, I argue, is the particular knowledge that disabled people develop and enact about unorthodox configurations of agency, cultural norms, and relationships between selves, bodies, and the designed world. Disability expertise is a descriptive domain, that is, a container into which ethnographers might enumerate observations about how disabled people enact personhood and moral agency in diverse cultural settings. To illustrate what I mean by disability expertise, I draw examples from one interlocutor’s experiences, described in interviews conducted during broader ethnographic research in Russia. I elaborate one particular domain of disability expertise: managing perceptions of disability, especially the tendency of nondisabled people to view disability through the tropes of suffering and pity. I call for anthropologists to claim disability anthropology as a space for critical, interdisciplinary knowledge production.

Disability anthropology is not new. Sociocultural anthropologists’ accounts of disability have a long history in our discipline and in qualitative ethnographic inquiry (Ablon 1981, 2002; Benedict 1934; Frank 2000; Ginsburg and Rapp 2013; Ingstad and Whyte 1995, 2007; Kaslitz and Shuttleworth 2001; Klotz 2003; Murphy 2001 [1987]; Shuttleworth and Kasnitz 2004; Staples and Mehotra 2016). Disability, typically defined as a chronic impairment that significantly impacts the daily life of a given individual, is a complex category with culturally contingent political and social meanings. Over the past 3 decades, new scholarly work in critical disability studies has shifted the broader transdisciplinary conversations in which anthropologists engage (Ginsburg and Rapp 2013), refocusing attention to how the category of disability emerges in social relations.

This paper calls for ethnographic reflection on a domain of human practice that I call “disability expertise” and offers my vision for a robust “disability anthropology” that both engages the existing canon and proposes new questions. Throughout, I focus on examples drawn from interviews with one research participant whom I call Anya. I begin by clarifying some definitions, then offer background about fieldwork in Russia. Next, I provide an ethnographic example of how Anya enacts disability expertise. I then elaborate more broadly on what I mean by disability expertise, developing one example by showing how Anya manages the way that nondisabled others perceive disability in interactions with her. In closing, I consider directions for future research in disability anthropology.

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1. The words we use to describe disability remain a point of contention. Some advocate for “person first” language (“people with disabilities”), while others call for claiming diagnostic identities, preferring language that presents a given disability as an adjective rather than a “thing” that one “has” (“autistic person” instead of “person with autism”). As scholarly and popular conversations about identity shift, ethnographers must at once track changing language styles that impact how disability might be understood and use language that signals participation in current disability justice conversations.

2. For a discussion of the so-called ADA generation, see Forber-Pratt (2019), Harkin (2014), and Harkin Institute (2017). The phrase refers to those who have come of age after the passing of the Americans with Disabilities Act, landmark civil rights legislation that deeply shifted the ways that people with disabilities participate in public life and changed the material landscape of the country. For many older millennials like myself, growing up in the United States in the 1980s and 1990s, earlier legislation concerning inclusive education was already in place and (imperfect) inclusive public education was a fact of life from earliest childhood. While the “ADA generation” moniker is deeply United States centric, generational conversations reflecting increased disability visibility following activist movements in the second half of the twentieth century are present in other countries, though the legal contexts and the disability studies conversations are distinct.

3. This article focuses on sociocultural anthropology and ethnographic research. However, my definition of disability anthropology works across the four fields, including the existing important transdisciplinary disability studies work by biological anthropologists, archaeologists, and linguistic anthropologists.

Cassandra Hartblay is Assistant Professor in the Department of Anthropology of the University of Toronto and the UT Scarborough Interdisciplinary Centre for Health and Society (19 Russell Street, Toronto, Ontario M5S 2S2, Canada [cassandra.hartblay@utoronto.ca]). This paper was submitted 11 XI 18, accepted 19 VII 19, and electronically published 4 XI 19.

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the foundational ethnographic project of investigating cultural differences across and within societies.4

In order to demarcate this transdisciplinary orientation, I differentiate “disability anthropology” from an “anthropology of disability,” wherein the latter suggests a subfield of medical anthropology in which disability is the subject matter. In contrast, I define disability anthropology as work that engages the distinctive theoretical concerns and methodological approaches of transdisciplinary critical disability studies, enacted through a citational politics that foregrounds disability studies texts and scholars.5 We might also think of disability anthropology as anthropology that draws on and contributes to disability theory and that starts from what Simi Linton has called the “disability studies perspective” (2005).

Let me clarify this point further. We can differentiate between an anthropology of disability and disability anthropology using these criteria: (1) Is the work part of a transdisciplinary conversation with scholars of critical disability studies, in terms of both theoretical approach and citational practice? (2) Does the work start from, and maintain focus on, the point of view of people with disabilities themselves? These distinguishing questions may be useful in thinking through the intellectual genealogies and political commitments of a variety of ethnographic works and can serve to parse whether a scholar finds affinity with an anthropology of disability, disability anthropology, or both. Take, for example, João Biehl’s Vida (2013 [2005]). This important book focuses on the life experience of one woman with disabilities, living in a makeshift community of disabled people who have fallen through the cracks of the Brazilian health care system, in order to make observations about the dynamics of care in the neoliberal state. In this way, the work is clearly an ethnography of disability. However, Biehl’s citational practice largely leaves out transdisciplinary disability studies as an area of scholarly concern. In contrast, works such as Karen Nakamura’s ethnography of a community for people with mental illness in northern Japan (2013), Sarah Phillips’s work on citizenship and adults with spinal cord injuries in post-Soviet Ukraine (2011), and Michele Friedner’s work on middle-class deaf people in the business and technology hub of Bangalore (2015) all take disability studies as central to the orientation of the ethnographic project.6 Thus, these can be understood as works of disability anthropology.

In calling for scholars to claim disability anthropology, I do not seek to detract from the important scholarship in medical anthropology and other subfields that tracks the numerous ways in which people with disabilities are systematically dispossessed, incarcerated, injured, impoverished, disenfranchised, denied legal voice, abused, and neglected. Rather, I seek to further the conversation between sociocultural anthropology and disability studies. The fields are shaped by divergent ethical and political assumptions (Kulick and Rydström 2015:14–15).7 The hallmark of the ethnographer’s project is a quest to translate a cultural insider’s point of view, showing how a cultural world is comprised and how the cultural insider lives and makes decisions as a savvy moral actor. Meanwhile, disability studies—across several waves of scholarship over the past 30 years—is defined by (1) a commitment to pursuing more just futures for people with disabilities, (2) foregrounding the point of view of people with disabilities, and (3) contributing to a disability studies canon (Linton 2005). Scholars working across these conversations combine study of the local lived experience of people with disabilities in diverse global contexts with the theoretical drive of critical disability studies to analyze how people with disabilities mobilize power in the context of diverse cultural configurations of pervasive systems of compulsory able-bodiedness.

Thinking in this translational space has led me to consider how people with disabilities perform social expertise in daily life. Disability expertise is enacted knowledge specific to disabled people, acquired through life experience in non-normative bodyminds.8 The concept emerges from ongoing conversations in critical disability studies and feminist science and technology studies. In a manifesto in the journal Catalyst, critical disability studies scholars Aimi Hamraie and Kelly Fritsch write that “disabled people are experts and designers of everyday life” (2019:2). Along with others, they argue that disabled people, as users of designed technology, are systematically discounted as nonexperts whose knowledge is not worthy of compensation or recognition, while designers of the infrastructure of built environments (ramps, sidewalks) or assistive technology (wheelchairs, ASL-to-speech software) are frequently depicted as bearers of professional expertise (Boys 2017; Hamraie and Fritsch 2019; Jackson 2018; Williamson 2012a, 2012b). Furthering this charge, Friedner situates her own work as disability studies (2015). Claiming deaf studies as part of disability studies is controversial; in many regards the fields are distinct. The foundational claim of US deaf studies—that deaf identity that is linguistic and cultural, and deafness therefore, should not be viewed as an impairment—has sometimes been used to argue that deaf people are not disabled and have little in common with disabled people.

4. Critical disability studies is a heterogeneous and changing field. Setting aside distinct international conversations, North American disability studies has been defined by numerous shifts—from developing the social model of disability, to critiques of the social model, to the emergence of crip theory, to recent turns toward transnational decolonial and antiracist reconsiderations of the field’s core questions, and to a new focus on what unites critical disability studies methodologically across disciplines (see Davidson 2016).

5. This formulation follows that of historian Catherine Kulick, whose seminal article defined “disability history” as distinct from “historical studies of disability”; in her formulation, disability history engages with and contributes to disability theory (2003). I thank Kulick for suggesting “disability anthropology” as a phrase during a discussion following Karen Nakamura’s (2015) presentation at the 2015 Society for Disability Studies conference.

6. Friedner situates her own work as disability studies (2015). Claiming deaf studies as part of disability studies is controversial: in many regards the fields are distinct. The foundational claim of US deaf studies—that deaf identity that is linguistic and cultural, and deafness therefore, should not be viewed as an impairment—has sometimes been used to argue that deaf people are not disabled and have little in common with disabled people.

7. “Compulsory able-bodiedness” is a cultural system that not only privileges nondisabled people but systematically seeks to eliminate disability. The term references a queer/crip genealogy (Kafker 2003; McRuer 2010; Rich 1980). “Compulsory able-mindedness” represents an important extension to clarify the inclusion of neurodiversity.

8. The term “bodymind” works against persistent mind/body dualism in understandings of ableism (Price 2015; Schalk 2018).
Sara Hendren calls for attention to the “virtuosity” of disabled users in negotiating their worlds. Hendren asks: Why does a skateboard rider cruising a ramp provoke a response of awe at skill, while a wheelchair user’s expertise at navigating the same ramp gets read as limited or limiting? (2013, 2017). In fact, people with disabilities are already engineering and designing in their daily lives, engaging everyday expertise to navigate their environments, minimize pain, and facilitate capacity (Hendren and Lynch 2016; see also Fritsch and Hamraie 2019:9). Thus, the notion of disability expertise builds on scholarship theorizing disability and design, and I offer the concept as one that ethnographers might find good to think with.9

Background: Framing the Research

This analysis draws on an ethnographic study of the daily lives of adults with disabilities in contemporary Russia as well as the ways that the idea of disability access travels globally (see also Hartblay 2015, 2017). Between 2010 and 2014, I conducted over 12 months of fieldwork in Petrozavodsk, Russia, the capital city of the northwestern region of Karelia, bordering Finland. This research centers on interlocutors with a range of apparent physical disabilities and speech impairments including cerebral palsy, traumatic brain injury, and progressive conditions. The research language was Russian, and research participants are native Russian speakers. Methodologically, the research included participant observation in a social group for unemployed adults with disabilities; one-on-one qualitative ethnographic interviews with some people from that group as well as local advocates and activists; informational interviews with journalists, academics, and social workers; participation in two local social theater projects; and participation in the daily life of the city.

Here I focus on one interlocutor, Anya, a woman in her 30s with a progressive muscular disorder. This is not intended to present her as representative of all fieldwork interlocutors but, rather, to allow an in-depth analysis of how a single person enacts one kind of disability expertise in her cultural world.10

Rather than select participants with a particular diagnosis, I sought to uncover locally meaningful categories of disability and observe how disability as a category comes to matter in the world.11 While many adults with disabilities in Russia live in institutions (see Klepikova 2018), this research focuses on those who live at home in family apartments. For this group, post-Soviet rhetorics of democratization and inclusion have put the idea of social integration with nondisabled peers rhetorically within reach: numerous disability advocacy nonprofits were founded and funded in the early years of the post-Soviet transition. These developments occurred during a long period of economic instability but growing civic investment in disability inclusion throughout the 1990s and early 2000s. However, by the end of the first decade of the 2000s, the Russian Federal government took measures to reconsolidate centralized administrative power, expelling foreign-funded projects and leaving many independent disability advocacy organizations that had relied on international funding unfunded. Meanwhile, social service providers funded through municipal administrations worked to fill in these gaps. Thus, my interlocutors with disabilities had experienced three distinct periods of disability social services by the time they reached their 30s. This generation is similar to those whose childhood was depicted in research about mothers of children with disabilities in the immediate post-Soviet years of the 1990s (Iarskaia-Smirnova 1999) and somewhat younger than the Ukrainians with disabilities described by Sarah Phillips (2011).

Enacting Expertise, Observing Minor Virtuosities

In Russian households in the region of Karelia, it is customary to offer a guest—whether a stranger, relative, or close friend—tea. The phrase “to drink tea” (pit chai) is a euphemism for visiting with a guest, and serving tea is a quotidian gesture of hospitality. The practice of sitting down, usually in the kitchen of a family apartment, and preparing a hot drink—usually black tea, but sometimes instant coffee or herbal tea—creates a formal basis for social exchange. Typically, the host offers a sweet or dessert, a fruit or a serving of prepared food that happens to be on hand, to eat k chaiu (with the tea). Conducting research with people with mobility impairments in a city with inaccessible infrastructure meant that I (as an ethnographer who does not have a mobility impairment) often visited interlocutors at home in family apartments. Many of my interviews took place in kitchens or living rooms, over tea. On these visits, I brought a small offering—a chocolate bar, rice cakes, or a few pastries from a bakery kiosk—k chaiu, in anticipation of the ritual. Once I had handed over the small edible gift as I crossed the threshold of the apartment and removed my shoes, the snack would become the purview of the host to arrange, present, and serve. Even those of my interlocutors who did little kitchen labor in their homes,

9. Here, “expertise” is insider knowledge that may not be recognized outside of the disability community. This is different from an “anthropology of expertise” that traces expert practices of professional intellectuals (e.g., Boyer 2008). Disability expertise does share some concerns developed under the banner of anthropology of expertise, including understanding expertise in relation to communities of practice and apprentice relationships, as a practice or “enactment” (Carr 2010). Disability expertise reclaims the idea of expertise for disabled people, who have frequently been excluded from the professional class and cast in the role of patients or user-recipients of technology designed by professionals. For a discussion of ideologies of professionalism in institutional care for disabled people in Russia, see Klepikova (2011).

10. I do not consider interlocutors in Petrozavodsk to be representative of some essential “Russian” experience. Russia is a vast geographic territory, with rich ethnic, linguistic, and cultural diversity. Petrozavodsk is a regional capital in a European region with a contested ethnic heritage and close ties to Scandinavia.

11. Considering the work that the “category” of disability does in social worlds is reminiscent of and influenced by David Valentine’s “ethnography of a category” (2007).
leaving it to other family members for expediency or in observance of gendered expectations, took charge of serving tea to me as their guest.

Anya is distinctive among my interlocutors in that she is one of the most professionally accomplished, with two master’s degrees and a professional job. Her impairment is progressive: her body seemed normal until late childhood, but her muscle tone and strength have decreased over time, so that when I met her when she was in her early to mid thirties, she used a battery-powered wheelchair and needed help with many of the tasks of daily living, from getting dressed, to some aspects of eating and drinking, to bathing. She has bobbed brown hair, a neat and sophisticated taste in clothing, and a sharp sense of humor.

The first time I had tea with Anya was at her parents’ apartment; after chatting in her room, we moved to the kitchen, where she recruited her mother to put on the teakettle and set out cups. But her mother was busy with other things and soon hurried off to another room, leaving Anya and me alone in the kitchen. Without missing a beat, Anya began to give me instructions as to when and how to pour the tea, where to find a spoon, which bag of cookies in the sweets bowl to untie and serve, and so on. As a first-time visitor in her home, of course I did not know my way around the kitchen, nor would I have presumed to make myself at home. By giving me specific, direct instructions in a neutral, even tone, Anya enacted the role of host, serving me tea and sweets by instructing me to follow instructions as to when and how to pour the tea, where to find a spoon, which bag of cookies in the sweets bowl to untie and serve, and so on. As a first-time visitor in her home, of course I did not know my way around the kitchen, nor would I have presumed to make myself at home.

In deploying this practiced virtuosity—managing my reaction to her own bodily relation to the kitchen—Anya enacted a kind of disability expertise. By anticipating my need to be introduced to her access needs and guiding me through the logistics of a ritualized interaction in which Anya’s impairment prevented her from fulfilling the culturally expected role, she opened a possibility for us to build what disability justice advocate Mia Mingus calls “access intimacy,” the comfort that emerges when access needs are known and accounted for in a relationship (Mingus 2011, 2017). Because “people are disabled in endless different and specific ways,” access is never a foregone conclusion but an unfolding negotiation, a learned manner of relation (Moser and Law 1999). I was cast in and accepted my role as her apprentice, learning the ritual of “having tea with Anya” from the expert, Anya herself.13

Domains of Disability Expertise

The specific social knowledge of people with disabilities has been an important focus for disability studies since its inception. In 1998, reflecting on the formation of the field, Simi Linton (1998) observed that in claiming the moniker “disability studies,” scholars and activists created an intellectual space for “a knowledge base that explains the social and political nature of the ascribed category, disability” (117). Over 3 decades, Linton has continued her field-defining work, arguing that disability studies takes the point of view of people with disabilities to examine disability as a category and explore the social structures that produce disability (2005). From this foundation, scholars have sought to understand how the dominant north/western cultural dialogues about disability work to reproduce stigma and social exclusion of people with disabilities (Kasnitz and Shuttleworth 2001; Linton 1998; Mitchell and Snyder 2001; Snyder and Mitchell 2010; Zola 1989).14 Disability studies scholars have called for analyses of configurations of ableism across cultures, endorsing the important work that anthropologists have done to extend the disability studies perspective globally (Davidson 2016; Inngstad and Whyte 1995, 2007). Recent writings have developed new theories of bodily difference that do not privilege a liberal political orientation to entitlement and rights, instead centering on justice, and the entanglement of ableism with imperialist, colonial, and racializing systems of oppression and highlighting non-Western perspectives (Erevelles 2003, 2011; Friedner and Zaoanni 2018; Meekosha and Soldatic 2011; Puar 2017; Wiedlack and Neufeld 2016). Engaging these conversations, ethnographies of disability experience document and theorize particular modes of social expertise that disabled people deploy in managing the perception and practice of disability.

Disability expertise might also be understood as a type of “situated knowledge” as developed in the feminist science studies tradition (STS). Hamraie and Fritsch (2019) draw on this canon, asserting that disabled people are uniquely situated to gain skills as tinkerers and bricoleurs, encountering a persistent mismatch between themselves and the designed world. In spite of a medicalizing gaze that systematically devalues their knowledges, disabled people persist in asserting themselves as “experts and designers of everyday life” (2019). In this usage,

12. Mingus (2017) writes: “Access intimacy is that elusive, hard to describe feeling when someone else ‘gets’ your access needs. The kind of eerie comfort that your disabled self feels with someone on a purely access level . . . Access intimacy between disabled and able-bodied people . . . has been the hardest for me to build. This is a huge part of my life because most of my access depends on able-bodied people and because I don’t have paid or formal attendants, I am often relying on friends, coworkers and strangers for my access, as is the case for so many disabled folks.”

13. Anya’s invitation to develop access intimacy indexed shared possible futures, suggesting an interpersonal strategy of building crip kinship “as a political strategy” (see Kondakov 2018:77).

14. The term “north/western” recognizes global cultural hegemony on both north-south and east-west axes (Wiedlack and Neufeld 2016).
Hamraie and Fritsch challenge the notion that expertise is the purview of professionals. An adjacent STS conversation traces how specific disability categories emerge in social relations: these are enacted differently by diverse actors, requiring particular kinds of work to resolve multiplicity and heterogeneity (Mol 2002; Moser and Law 1999; Pols 2005). Tracing situated knowledge as presented in practice refuses typically presumed hierarchies of expertise between disabled people, service providers, and medical professionals.

Numerous ethnographic works can be read for cases of disability expertise. For example, in Gelya Frank’s Venus on Wheels (2000) interlocutor Diane DeVries is treated as the foremost expert of her own experience; the text lays bare conflicts between DeVries and Frank about interpretation and representation. In Carolyn Rouse’s Uncertain Suffering, sickle cell anemia patients’ own accounts of their experiences of pain and the way that medical personnel treat them are presented as definitive interpretations (2009). These and other accounts of the social knowledge and everyday expertise of people with disabilities draw on the core precepts of an ethnomethodological approach. I am not suggesting that disability expertise is “new” to anthropological scholarship, but rather identifying it as a significant domain for scholarly attention. In reading the canon of disability anthropology for examples of disability expertise, we might also begin to catalog types or kinds of disability knowledge. For example, Sarah Phillips (2011) describes how her interlocutors have developed a particular expertise in negotiating a variety of discursive strategies to claim the rights of citizenship in a complex and changing postsocialist context. There are many kinds of disability expertise that disability anthropology might track (see fig. 1). In the analysis of interactions and interviews with Anya that follows, I elaborate one domain of disability expertise, which I call “managing the normate’s perception.”

Managing the Normate’s Perception, Managing Pity

One kind of disability expertise is the skill with which disabled people perform relational repair when others react to their bodies with surprise, pity, or uncertainty. Rosemarie Garland-Thomson writes,

When one person has a visible disability [it] almost always dominates and skews the normate’s process of sorting out perceptions and forming a reaction. The interaction is usually strained because the nondisabled person may feel fear, pity, fascination, repulsion, or merely surprise . . . .

Garland-Thomson coined the term “normate” to refer to “the corporeal incarnation of culture’s collective, unmarked, normative characteristics” (1997:8). Drawing on Erving Goffman’s description of a normal social position that seems wholly without stigma, Garland-Thomson defines a mid-century North American normate as “a young, married, white, urban, [from the] northern [US], heterosexual, Protestant father of college education, fully employed, of good complexion, weight and height, and a recent record in sports” (Garland-Thomson 1997:8). The term is more than a synonym for able-bodied: the figure of the normate shifts across cultures as well as over time.

15. A domain is a unit of analysis that ethnographers use to organize the folk terms or insider experiences of members of a cultural group, a “symbolic category that includes other categories” (McCurdy, Spradley, and Shandy 2004; Spradley 1979:100). The phrase “domains of expertise” also appears in the anthropology of expertise (e.g., Holmes and Marcus 2005:236–237, cited in Boyer 2008:39).
people must learn to manage relationships from the beginning.
In other words, disabled people must use charm, intimidation,
ador, deference, humor, or entertainment to relieve nondis-
abled people of their discomfort. (1997:12–13)

Not unlike Anya’s practiced expertise when instructing me to
make and pour tea, Garland-Thomson observes that many
disabled people are well-practiced in managing not only overt
ableism but also the negotiation of expectations when meet-
ing new people. Garland-Thomson writes, “Most physically
disabled people are skilled enough in these encounters to
repair the fabric of the relation so that it can continue’
(Garland-Thomson 1997:13). In this way, one aspect of dis-
ability expertise entails a series of virtuosities to put the nor-
mal at ease,” reassuring interlocutors who may be uncertain
when encountering the specificity of difference: people with
disabilities become uniquely adept at managing the pitying
gaze. This is not to say that disability does not ever entail some
version of the suffering that those casting a pitying gaze imagine.
Rather, the expertise that Garland-Thomson highlights is a re-
version of the suffering that those casting a pitying gaze imagine.

During an interview in her apartment one afternoon, Anya
shared a story that illustrates this move of recalibrating percep-
tions. She delivered the narrative as a kind of humorous quip
about stereotypes of disability in her city, details rattled off
quickly as the momentum of the telling surged toward the cul-
mination of the event.

So I’m out for a walk, near the front door [to my apartment
building]. I didn’t actually go anywhere, because all my friends
were busy, I just went out to get some fresh air. I’m sitting there
by the entranceway, I had taken a book and I’m reading. And
out of the corner of my eye, I’m watching people: who’s
coming out of our entrance, who’s coming up to it . . . And
this guy goes past me with a spring in his step. He goes in our
entrance.17 I saw him and I’m thinking, “I don’t think he lives
here, he’s probably visiting someone . . .” I’m sitting, I keep
reading. After about 20 minutes, the guy comes out, walks past
me, heading toward the store, and there’s a spot there where
you have to go down some steps to get to the bus stop. So
he gets to the stairs, and he turns around and looks at me. And I
see that he’s coming back, walking back up toward me. And
I’m thinking, “What’s he coming back for?”

And then he comes up to me and gives me 10 rubles!!
So I ask him, “What’s this?”

And he says, “Oh, you’re not asking for change?”
And I go, “What, I look so bad that you’re giving me
handouts?”

So he starts apologizing and then runs away . . . [laughs]
“Not too bad!!” I’m thinking. “But why did he only give
me 10 rubles?18 If he would have given me 100, well that
would have been something! I would have thought twice
about whether to take it or not!” . . . Yuck. It was awful.19

In this transcribed interview excerpt, Anya recalls a story in
which a stranger, passing through the neighborhood, noticed
her sitting outside in a wheelchair, and, assuming that she was in
need of charity, approached to offer her a few pennies. But, in
Anya’s telling, the power dynamic of the exchange shifted when
she quipped that she did not need handouts, and the stranger
retracted, embarrassed. In this retelling, Anya narrates her own
volitional capacity to shift the course of the exchange. Rather
than accept that the stranger had assigned her to the category of
pitiable panhandler, in Anya’s retelling her response forced the
stranger to reconsider the stereotype that motivated his actions.
Although she describes the experience of being publicly pitied
by a stranger as “awful” Anya positions herself as a bearer of
agentive refusal. She refuses the idea that her embodiment and
wheelchair alone make her socially undesirable and character-
izes the stranger’s assumption that she is in need of handouts as
such a judgment. In her narrative, Anya manages the specter of
the stranger’s pity response by casting it as inexpert and unin-
formed; meanwhile, the social expertise to navigate a situation
(which she presumably had encountered in prior variations),
belongs entirely to Anya herself.

19. At the time, 30–35 rubles was equivalent to about 1 US dollar.
Ten rubles was pocket change, hardly enough for bus fare; 100 rubles
would have purchased a loaf of bread at the bakery, a black coffee at an
upscale coffee shop, or a serving of fries at a mid-level cafe.

20. Аня: Гуляю я, значит, около своего подъезда . . . Никуда не
пощла, потому что все мои друзья были заняты, а я просто вышла
подышать свежим воздухом. Сижу у подъезда, вижу книжку и
читаю . . . И вдруг, выходит из подъезда, кто-то смотрит на
меня, и он начинает извиняться и убегает . . . [смеется]...” Сижу, читаю
далше. Минут через 20 этот парень выходит из подъезда, прошел
мимо меня, я вижу на подъезде магазин, и я подумала, что он
подойдет к ней, и она постащит на меня . . . И, заметьте, я не
обращалась к нему. Он говорит: «А я тебе что, так плохо выгляжу, что ты мне милостыню
dашь?»

17. See n. 16.
18. Many apartment blocks have several entrances, each serving a
group of apartments accessed via stairwell. It is common for people
to recognize the neighbors who use their own and nearby entrances. The
word for “entranceway” (pod’ezd in Petrozavodsk, as in Moscow;
paradisaia or lesnitsa in Saint Petersburg) refers to the door and front
stoop, the driveway where a car or pedestrian might access that stoop,
and to an extent, the shared space of the interior stairwell.
The refusal of pity or charity is central to how Anya asserts her own sense of personhood. Critical disability studies observes that one widespread expression of ableism is the stereotype that disabled people are suffering and in need of pity. The pitiying gaze has the effect of representing people with disabilities as automatically suffering, imagined passive recipients of care. Critical disability studies scholars advocate for depictions of disability beyond suffering for reasons similar to the move away from an over-attention to suffering in ethnography more generally: focus on shared human suffering runs the risk of flattening cultural difference (Robbins 2013:450, 453, 455–456). Analyses of disability expertise should not flatten difference, but instead situate minor gestures of expertise in specific cultural contexts.

Anya’s refusal of pity is deeply imbued with post-Soviet Russian logics of social worth and value. While refusing pity is recognizable in Western disability activist ideologies as a kind of “pride” in the sense of identity politics commonly found in liberal democratic ideological configurations. The practice of offering handouts to needy beggars, coded in contemporary Russia as a good deed, emerges from a specific history. During post-Soviet times beggars and “feeble-bodied” and “feeble-minded” people clustered around churches and monasteries where they received charity from passersby. Official Soviet characterizations of disability posited bodies unable to participate in physical labor as morally lesser, further entrenching an idea of disabled people as excluded from the normative labor market (Iarskaia-Smirnova and Romanov 2013; Phillips 2009, 2011). During Soviet and post-Soviet eras, war veterans, often without work and “forgotten” or “abandoned” by the state, took to begging and displaying war-wounded bodies in urban metro stations. This shaped a commonsense perception that the state had failed to care for disabled people, either isolating them in institutions or leaving them without work or official means of income (although scholars demonstrate that many disabled Soviet citizens did work) (Dale 2013; Phillips 2011; Shaw 2017). In late Soviet and early post-Soviet society, to be perceived as a beggar is to be perceived as “needed by nobody,” that is, a human being without the meaningful social ties of personhood (Höjestrøad 2009). Furthermore, people with physical disabilities who were cared for by families were rarely out alone due to the typically inaccessible built environment of the former Soviet Union (Kikkas 2001; Romanov and Iarskaia-Smirnova 2006). This lack of public presence reinforced a perception that physical disability is equivalent to destitution and financial need (though activist groups’ advocacy in newspapers provides a punctuated exception, and in recent years other depictions in popular media have emerged).


This prevalent stereotype linking disability and poverty is well established in the ethnographic record. For instance, sociologist Elena Iarskaia-Smirnova relates an example from a life history interview with a woman named Anna who has an apparent physical disability living in the city of Saratov:

When we, the disabled, come to a welfare agency, we are to be dressed in rags, we must not wear make-up, we have to look poor and bad, otherwise we’d be told: “Are you disabled? Oh, no, you aren’t!” (2001:105)

Like my interlocutor Anya, Iarskaia-Smirnova’s Anna reports receiving change from random passersby:

Often somebody would give us change, for instance, when I was in the corridor, waiting in line in the welfare office, a man gave me some change though I didn’t ask him for it, he just saw me and my crutches. (2001:105)

In this example, as in Anya’s story, Anna suggests that she has repeatedly encountered attitudes from strangers loaded with the stereotypical post-Soviet view that disability is inextricably linked with poverty, degeneracy, and pity. Both Anna and Anya assert themselves as subjects in a moment of objectification. Disability expertise opens the possibility to consider the virtuosity with which Anya and Anna, rejecting the pitying gaze of normate strangers, make minor gestures that turn difference away from categorization and toward immanent relational experience.

Disability, as a category, is real: it does things in the world. This is so even as some interlocutors may refuse to identify themselves with the category, and even though the ways in which the category of disability “appears” may differ from one context or field site to another, or between interlocutors in the same field site (Titchkosky 2011; Zoanni 2019). This is the crux of disability anthropology: asking, What does the category of disability do? What does disability do, here? What are people doing with disability? Disability, after all, is a category of modern nation states (Stone 1984). Thus, disability as a category is a...
technology of governmental power. Therefore, disability anthropology benefits from interrogating disability as a technology, that is, examining what the category of disability does and how it does it. This approach relies on renouncing an individualizing, pathologizing, medical notion of disability—disability as an undesirable individual characteristic—in favor of a relational concept of disability as a category enacted in social relations. “To conceive of something as disability,” Tanya Titchkosky writes, “can be understood as an oriented act of perception, intimately tied to evaluation that guides interaction. This orientation grounds the critical understanding that disability should be regarded as that which exists between people; one cannot be disabled alone” (2011:5). How, then, does disability emerge as meaningful in a given interaction?

What power relations are enacted through the invocation of disability as a category? What does the category mean? By what power is that act characterized? Anya and the young man near her entranceway, thinking of the exchange between strangers as dynamic relations coming into being, let us revisit the way that Anya manages the stranger’s interpretation of meaning. Anya recalled that:

He’s coming back, walking back up toward me. And I’m thinking, “What’s he coming back for?”

And then he comes up to me and gives me 10 rubles!!

So I ask him, “What’s this?”

And he says, “Oh, you’re (V) not asking for change?”

And I go, “What, I look so bad that you’re (ty) giving me handouts?”

So he starts apologizing and then runs away. (Laughs.)

Asking, “What’s this?” Anya challenges the young man to state his intent in offering her, a stranger, 10 rubles, unpro

voked, forcing him to explain aloud that he had assumed that she was in need of charity.

The exchange as reported by Anya not only demonstrates the stereotype in play but tracks the emergent dialogic negotiation of status between Anya and the passerby. There is a sociolinguistic dynamic to the power relations at play between them. In Russian, the second person pronoun (you) requires the speaker to select between ty—informal or singular—and vy—plural, or in dyadic address, formal. Thus, the possible permutations of possible ty-vy relations in spoken Russian—symmetrical ty (intimate), asymmetrical ty-vy (recognizing social hierarchy), and symmetrical vy (formal or unfamiliar)—require interlocutors to make unfolding judgments or invoke designations of social difference when addressing others. While social difference is usually somewhat fixed based on age or status, and most conversations follow a predictable course once established, shifts between ty and vy usage can be deployed by speakers as “a symbol for feelings about the addressee” (Friedrich 1972:297). As strangers gain information about one another, Russian speakers might switch from vy to ty or vice versa, enacting emergent and shifting relations (Friedrich 1972:287).

In general, contemporary Russian speakers in Petrozavodsk use vy in a reciprocal fashion to address adult strangers in public; however, adults may speak to children they do not know using ty. Adults usually use a reciprocal ty to address old friends, spouses, or close family members. In this reciprocal usage, ty signifies familiarity and intimacy. However, a speaker may suggest a status differential by uttering an unreciprocal ty to someone who addresses them as vy (Mayer 1975). For fluent Russian speakers, the decision to use ty or vy belies a judgment that hovers at a threshold of consciousness, enacting relationships through actual speech.

In Anya’s retelling, faced with the question “What’s this?” the young man responds, “Oh, you’re (vy) not asking for change?” using the respectful form of the second person pronoun. That is, the young man recognizes Anya as an adult stranger in the public sphere. Yet Anya recalls her response as an asymmetrical ty, instantiating Anya as superior in a status differential between them. This could be interpreted to mean that Anya was suggesting that she felt herself quite older than the young man, or it can be read as a way of asserting the withdrawal of respect or sympathy for him. This unreciprocal ty casts the event, in Anya’s recollection, as one in which the exchange veered toward her own perspective: the move to ty interpellated the handout-offering stranger as seeking Anya’s respect and approval.

Any a’s use of ty in her response sets the exchange as one in which she expertly negotiated...
available symbolic resources to assert her own status and sense of self-respect, inverting the young stranger’s initial assumption that read Anya’s body and wheelchair as symbolic of suffering and deserving of a pity-drenched handout. Anya’s story serves to highlight her own adept negotiation of anonymous social situations and expertise in inverting ableist attitudes of pity. The exchange not only demonstrates social attitudes about disability but also stands as an example of Anya’s disability expertise.

In sum, disability expertise is the particular knowledge that disabled people develop about unorthodox configurations of agency, cultural norms, and relationships between selves, bodyminds, and the designed world. It is an acquired virtuosity in negotiating the meaning that emerges when disability appears in social relations. It is a descriptive domain that ethnographers might use to understand and interpret how disabled people enact their personhood and moral agency in diverse cultural settings. Disability expertise thus circumvents the ethnographic tendency to focus on suffering, while contributing to broader concerns of transdisciplinary critical disability studies scholarship.

A few qualifiers about disability expertise as a concept are necessary. In arguing for attention to disability expertise, I seek to draw out theoretical possibilities for understanding how personhood and possibilities are enacted otherwise. But in no way should attention to disability expertise and to those interlocutors who appear as “successful” subjects in society detract from the important work of witnessing and working to dismantle the ongoing domination and abuse faced by many people with disabilities, whether incarcerated or entangled in the slow violence of poverty and debilitating biopolitical control. Disability expertise is not “resistance” in the sense of activist agitation against Power with a capital P, but rather the emergent relational enactment of configurations of diffuse power (small p), always coming into being and refiguring heterogeneous possible futures. This kind of creative, relational improvisation matters as anthropologists seek to theorize disability in order to represent the moral personhood of disabled subjects. Disabled interlocutors’ expertise in managing the specter of pity is but one valence of disability expertise that ethnographers might trace.

Conclusion

Disability anthropology embraces disability as an epistemological concern for both empirical ethnographic inquiry and social theory. Disability comes into being through social relations; the attributes of disability in a given moment are not fixed but are negotiated and always changing. Disability anthropology asks what the category of disability does in the world, and in particular, in local disability worlds. Distinguished by the practice of starting from the point of view of people with disabilities, and by a deep and persistent tie to the interdisciplinary scholarly conversations of critical disability studies, disability anthropology can be traced as both an emergent subfield already bearing a canonical tradition and sketched as a project for future scholarship. Throughout the research process and presentation of results, people with disabilities, like all ethnographic subjects, are understood to be experts of their own experience.

Thinking of disability anthropology as a distinctive subfield with its own interdisciplinary conversation opens several questions that at present have only just begun to be addressed in sociocultural anthropology. As Ginsburg and Rapp (2013) have suggested, the methodological implications of starting from a disability studies perspective—in terms of neurodiversity, decolonial racial justice, and conducting work with nonverbal or minimally verbal research participants—suggests an important terrain for further scholarship (Acvedo 2015; McKearney and Zooni 2018; Pols 2005). Disability anthropology is a persistent scholarly project with both an intellectual lineage and a future, offering interventions like those of postcolonial and feminist anthropology. In those examples, thinking from the situated knowledge of interlocutors linked by a conceptually abstracted topic of study—women or postcolonial subjects—opened up the study of naturalized systems of power—gender, colonial domination, racialization—to a reconsideration of how those systems operate in and through the discipline and research practices of anthropology itself (e.g., Abu-Lughod 1990; Asad 1979; Rapp 2016:2; Silverstein and Lewin 2016). It therefore follows that a robust disability anthropology may reveal in-as-yet-unarticulated ways that compulsory able-bodiedness operates in and through anthropology’s disciplinary norms. Applying Rayna Rapp’s formulation of feminist anthropology to a critical disability approach, how might taking disability anthropology seriously require “transforming the subjects, objects, methods, and theories of our entire field” (2016:2)? Disability anthropology’s impact may open possibilities to reconsider anthropology’s empirical practices anew, with implications for how knowledge is produced, including who does research, whose experiences are researched and valued, and what it means to come to know.

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References Cited


Disability, Anonymous Love, and Interworldly Socials in Urban India

Michele Friedner

This essay considers disability studies scholars’ investment in “the social” as a site of rehabilitation, recuperation, and cure in order to argue that in urban India, the case is otherwise: the public often engages with disability through “anonymous love,” which produces opportunities for the concretization of disability as a category, for disabled people to exist socially, and for validation of an existing social. I argue, however, that this conceptualization and enactment of the social is empirically unfulfilling and analytically limiting. I then turn to ethnographic research conducted in deaf churches in order to consider what other forms of engagement might emerge when we include the interworldly—engagements with God, the Divine, or the Spirit—in our analysis of disability worlds. This essay argues that including the interworldly offers an alternative animation of the social as a concept. Overall, attending to the interworldly leads to the creation of nonliberal and nonsecular alterworlds where alternative renderings of the social that are not premised on the politics of biosocial recognition are made possible.

Living Socially

As scholars and activists working on disability are well aware, two of the foundational and interconnected paradigms through which disability as category and experience are analyzed and made known are the medical model and the social model, often considered to be in opposition (Barnes and Mercer 2003; Oliver 1983, 1990; Shakespeare 2002). The medical model posits that disability is an individual impairment to be corrected through rehabilitation, surgery, and other medical interventions. The social model argues that disability is constructed by social attitudes and structures. In contrast to the medical model, the social model locates disability as created out of the intersection of the individual and the environment. However, the social model resembles the medical model in that it is designed to diagnose and recuperate disability, although it does so through intervening in the social as opposed to through medicine. While there have been significant critiques of the social model (e.g., Kafer 2013; Shakespeare 2002), I argue that the social is often considered the site of cure in that transformation in social practices—and society at large—is supposed to result in greater inclusion of disabled people in society. As I discuss, this valorization of the social has significant stakes in that disabled people are interpellated into living socially, and it is through the social that disability has become a legible category. Departing from this celebratory embrace of the social, how might we think of the social as both recuperative and wounding?

Thinking through the social requires that we interrogate social bonds because such bonds are often considered to be constitutive of disabled peoples’ lives, whether through disability community or expanding senses of kinship more broadly (e.g., Rapp and Ginsburg 2001). Disability scholars’ and activists’ focus on the social poses challenges to the connections between precarity and sociality made by social theorists. For example, Butler (2009:14) notes that precariousness means “living socially, the fact that one’s life is always in some sense in the hands of the other. It implies exposure both to those we know and to those we do not know; a dependency on people we know, or barely know, or know not at all.” In foregrounding the social, on the one hand, disabled people are particularly well placed to embrace and speak back to precarious conditions: we see this with the emergence of care collectives of disabled people who interdependently trade and barter care, as Nishida (2017) describes and with recent scholarship on interdependence (Garland-Thomson 2005; Reindal 1999). Kafer’s (2013:6) political-relational model of disability places interdependence front and center in its call for “social change and political transformation.” The social, as an analytical and empirical space for disability studies scholars, includes material infrastructure, policy, and relationships, among other things.

This framing of the social is tethered to a liberal model of disability rights predicated upon disability identification, inclusion and participation in public spaces, and maximizing individual disabled peoples’ agency.1 Disabled peoples’ movements

1. Note that many of these critiques (e.g., Kafer 2013; Shakespeare 2002) have focused attention back to the materiality of the body; in contrast, my critique is interested in the continued investment in the social as a category.

2. There is a growing body of disability studies literature that attends to asociality and different ways of engaging social interactions as a valued way of being in the world. See, e.g., Bascom (2012) and Grace (2013). Price (2011) argues forcefully that the social domain can be fraught for

Michele Friedner is Assistant Professor in the Department of Comparative Human Development of the University of Chicago (1126 East 59th Street, Office 001, Chicago, Illinois 60637, USA [michelefriedner@uchicago.edu]). This paper was submitted 11 XI 18, accepted 12 VI 19, and electronically published 4 IX 19.
for rights and recognition exist alongside claims for accessibility and inclusion: in addition to political claims, these are social claims. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) calls for social rights in addition to political rights: it includes sections on access to and participation in cultural life, recreation, and sports (Article 30) and being included in the community (Article 20; and see Megret [2008] on the inclusion of the category of the social and social rights in the CRPD and how this inclusion marks the CRPD as expansive in relation to previous conventions).

However, this analytical and empirical celebration of the social can be problematized: as Donzelot (1984) and Ferguson (2015) more recently have argued, the social is a relatively new category of control and organization; it has become a catchall framework in which political, economic, and moral problems are remediated through social fixes. According to Ferguson (2015: 67), “The social thus becomes available for a new site of intervention that would be principally technical rather than moral.” Theorists such as Rose (1999) insist that the social has become a new site of governance through which communities take care of themselves. Rose (1996) has argued for “the death of the social,” as conceptions of the social and social institutions have been atrophying and breaking down. Such theorists urge us to be wary of the celebration of the social.

In this essay, I draw from ethnographic research in the Indian cities of Bangalore and Delhi and Indian and international media research to analyze two diagnoses of disability relationality that emerge through the social. I think through diagnosis in light of its etymology, which is to recognize, know, or discern; I am concerned with how nondisabled people know disabled people and how disabled people know each other—and how this knowledge produces emotions as well as (imaginaries of) social forms. (I also enjoy playing with the overdetermined medical connotations associated with diagnosis.) Both diagnoses involve love for a range of disabled actors although I mostly focus on deaf people and deafness; as I have argued elsewhere, deaf people are particularly assimilable and productive of positive feelings (Friedner 2017). My first diagnosis derives inspiration from Stevenson (2014) as I consider nondisabled peoples’ “anonymous love” for disabled others. I examine how anonymous love functions as social glue that validates an already-existing social, as opposed to transforming it, as is often the goal for disability activists and disability studies scholars. I purposely write of love and not care because I am concerned with emotion and not actions, programs, and policies concerned with sustaining life, at least in this first diagnosis.

Diagnosis One: Anonymous Love

The category of disability is increasingly normalized in urban India because of a confluence of political economic and legal interventions as well as disability activism. Consider the following: India signed and ratified the CRPD in 2007; a new disability law was passed in 2016; there is prolific discussion and representation of disability in the mainstream media; an NGO sector and multinational corporations that hire disabled workers have emerged; and the current government has prioritized disability through its heavily publicized Accessible India Campaign, among other things. And while the motto of India’s urban-based mainstream disability movement is “From charity to rights,” which promotes a move toward rational and legislative-juridical engagement (Bhambani 2004), the nondisabled public often interacts with disabled people on the basis of (managed) emotion.

While conducting research with Indian Sign Language (ISL)—speaking deaf people primarily in Bangalore and Delhi, but also in other metro cities, I was struck that hearing people often discussed their feelings for deaf people as involving strong positive emotions that they called “love.” Specifically, hearing people told me that they loved deaf people in general, while deaf people often mentioned specific hearing people who loved them. I learned about such love in information technology offices where deaf and hearing employees worked alongside each other and in schools and other educational settings where deaf and hearing students studied together. I learned that deaf people and signed languages are embraced: I observed ISL classes for new Bangalore metro system employees and learned about similar classes in Delhi for Delhi Metro employees and central government bureaucrats. These were short-term courses in which learning ISL was not discussed in terms of accessibility or rights and appeared to be more about experiencing a new way

people with psychosocial disabilities. McKeen and Zoanni (2018:12) point out that in the case of cognitive disability, “it is harder to see how a severe cognitive disability could be transformed by social conditions to the same extent.”

3. My thanks to Lawrence Cohen for helping me to think through this concept.

4. I use the unmarked category of “hearing people” here intentionally, perhaps in the same ways that my hearing interlocutors discussed “deaf people.”
of communicating rather than actually learning ISL grammar and lexicon or specifics about deaf peoples’ practices or desires. Learning ISL in these settings and in others (see Friedner 2015, chap. 4) functions as means through which attendees come to know and love deaf people at the population level; this is a biopolitics of anonymous love.

As noted, this “love” takes place in public domains such as workplaces, schools, and forms of media. These are mostly so-called middle-class spaces (Mazzarella 2005) that have become “open” to disability alongside political economic and legislative reform, as discussed above. Sadana (2018:40) writes of love in India: “Central to my analysis is an understanding of ‘love’ as being culturally and historically determined but also as being a social complex . . . . It is both ideology and institution, emotion and practice.” I see love operating similarly in the case of disability in urban India. I am interested in what love produces in the spaces where I conduct research and more generally in the (middle-class and English-speaking) public sphere. While feelings of love could be analyzed in many ways, including as a sense of concern, responsibility, and regard for deaf people, I attend here to the kinds of politics that are both mobilized and enabled by such love. With this love-as-vector, disabled people are categorically repositories of positive emotions such as inspiration and benevolence but never desire, although there is a desire for a social in which they are present. I see love of disability and disabled people as a form of feel-good politics and publicity in urban India, although there is always a danger of feeling bad, as we have seen with other forms of difference such as caste, religion, and gender (for more on the relation between the disabled body and the national body, see Friedner [2017:678]). While the Indian social is fractured according to class, caste, religious, and gendered lines (Viswanath 2015), I argue that anonymous love of disability serves as reductive glue, although disabled people are themselves not meaningfully included.

The love I refer to here can only be anonymous love in that it is concerned with disabled people as abstract populations. This is a love that in Povinelli’s (2006:191) words “reforms the social” and is perhaps “the sign of a new liberal mystery, a secular religion.” It connects the micropractices of love to the macro-practices of state governance as it attaches to specific bodies in relation to actions, policies, and sentiments that only circulate in public spheres. After all, as Povinelli (2006:175–176) writes: “Love is a political event. It expands humanity, creating the human by exfoliating its social skin, and this expansion is critical to the liberal Enlightenment project.” While Povinelli writes of a Western liberal context, I am interested in the love that disability—as a liberal and modern category—enables in India. This love is an all-knowing gaze that attaches to a population of people as known objects, denying substantial difference both within this population and between the population and others outside. It is anonymous love in that it does not create subjects out of its objects although it creates relations and recognition between nondisabled people who love deaf people, as an enlightened imagined community (Anderson 1983). In this case, I argue that both the political and the social skin are exfoliated, to return to Povinelli’s words. This social varies greatly from previous conceptualizations of the Indian social based on individualism, porous selves, and hierarchies (Dumont 1980; Marriott 1989); disabled people are still kept apart categorically (and often physically), albeit through love.

I analyze two contemporary cases featuring disability as examples of anonymous love. The ways in which these cases are differentially taken up by the media and the public demonstrate disability’s ability to create feelings of love, both toward individual deaf people and toward the nation. In 2015, media attention in India, Pakistan, and internationally turned to the story of Geeta, a deaf young woman in her early twenties who had spent the past 12 years living in Karachi, Pakistan. Geeta had resided with the family who runs the Edhi Foundation, a well-respected Pakistani humanitarian relief organization. Nothing is known about her except that she is from India, which she communicated through gesture upon her arrival in Pakistan. Media accounts noted that Geeta could write in undecipherable Devanagari script and she did not know a recognizable signed language. Geeta seemingly took the train across the border under unknown circumstances and was found by Pakistani soldiers in the Lahore train station. The soldiers took her to a shelter in Lahore and subsequently she was sent to Karachi to Bilques Edhi, the Edhi Foundation’s matriarch, with whom she ostensibly bonded. The Edhises noticed that Geeta was Hindu and built her a prayer room and allowed her to keep a vegetarian diet—although she also fasted for Ramadan. Throughout her decade-long sojourn in Pakistan, she expressed a desire to return to India by making gestures of planes and pointing at maps of India. Attempts to return her through diplomatic channels were unsuccessful and Indian officials living in Pakistan were not motivated to initiate her return (Dawn 2015; Kumar 2015).

5. Other scholars such as Ahmed (2004) have written about the ways that love creates the other or others, and Dave (n.d.), in relation to animal lovers in India, has argued that love is unjust in the way it differentiates.

6. Love as politics here is a different form of politics than that discussed by Michael Hardt (2011), who argues that “a political concept of love would have to be characterized by at least three qualities. First, it would have to extend across social scales and create bonds that are at once intimate and social, destroying conventional divisions between public and private. Second, it would have to operate in a field of multiplicity and function through not unification but the encounter and interaction of differences. Finally, a political love must transform us, that is, it must designate a becoming such that in love, in our encounter with others we constantly become different.”

7. But see Keane (2003) on the ways that objectification can be productive.
Fast forward 12 years later when the blockbuster Bollywood movie *Bajrangi Bhaijaan* was released on Eid 2015. In the film, Salman Khan played an earnest and devout Hindu named Bajrang who is a devotee of Hanuman. Bajrang happens upon a mute (not deaf) little girl from Pakistan named Shahida who is stranded in India after she takes the train with her mother to visit an Indian doctor in pursuit of a cure for her muteness (she is not cured). Shahida and her mother are on the night train back to their remote village in Pakistan when the train stops. Shahida disembarks from the train to play with a lamb and is unable to climb back on before it resumes moving. After meeting Shahida and realizing that she is from Pakistan, Bajrang is determined to return her to her family. The film is about Bajrang’s and Shahida’s ordeals together and sketches out a vision for India-Pakistan unity and a common humanity, foregrounding differences in elements like diet and religion but also demonstrating how these can be managed and negotiated through shared purpose. Geeta’s situation predated the movie by over 10 years—she arrived in Pakistan in 2003—but in 2015, after *Bajrangi Bhaijaan*’s popularity and connections made in the media between her plight and the film, negotiations between India and Pakistan took place and she was repatriated with much fanfare (Chaturvedi 2015; Ghosh 2015). Geeta met prime minister Narendra Modi and was personally escorted around by Bharatiya Janata Party (BJP) minister Sushma Swaraj. (Geeta has been heavily photographed with Indian politicians and in contexts such as an inaugural ride of a new line on the Delhi Metro. No effort has been spared in documenting her return and representing her with symbols of Indian modernity.) Since she has been in India, Geeta has not recognized any of the people that have claimed to be her long-lost family. As she waits for her biological family to come forward, she has been living in a well-respected deaf institute in Indore, the seat of the *Lok Sabha* speaker Sumitra Mahajan. Recently the Indian media reported that Geeta desires to marry, and Sushma Swaraj says that she will preside over the wedding (Sharma 2017). While there is no claim from a natal family, despite the enticement of a cash award, Geeta’s eventual marriage to a Hindu young man will ensure that she will be further absorbed into normative forms of productive Indian life.

Little is known about Geeta. Yet despite or because of this, this case has been notable in the public sphere in the aftermath of the movie’s success and the rise of the Hindu Nationalist BJP government, which has embraced her as a symbol of its benevolence and love for all (or, rather, specific categories of) Indians. Geeta is largely unmarked: she is a Hindu who fasts for Ramadan, we know nothing about her caste or class background, we only know that she is deaf and that she is Indian, and that is enough. She can be interpolated into a normative framework of deaf access (she is learning ISL, and when she is in public she is often with an ISL interpreter) as well as normative heterosexual life. In 2016, for India’s Republic Day, she signed the national anthem and hoisted the flag for a media-covered event (PTI 2016). Through becoming an ISL-speaking deaf Indian and living (and being represented) socially, she has been fully recuperated. Geeta’s case has parallels with women returned to India post-Partition (e.g., Butalia 2000; Kaur 2007), although I argue that what is different is that in the aftermath of Partition, re-incorporation happened in the domestic realm rather than the social.

I see Geeta’s well-publicized story in relation to another recent focus of the media: the Mowgli Girl, as she was called, estimated to be between the ages of 8 and 12 years, who was found in the jungle in Uttar Pradesh living with monkeys. Many articles foregrounded her animal-like characteristics and the ways that she walked, ate, vocalized, and performed other activities of daily life. Photos and videos in popular media showed her engaged in mundane activities in the hospital to which she had been taken and seemingly demonstrated her animal-like qualities (e.g., Worley 2017). However, a few days after its initial sensational surfacing, the story took a tragic turn. Both doctors and the forest department pronounced that she had not been living with monkeys and that she had most likely been abandoned by her human caretakers not too long before she was found (Safi 2017; Saigal and Siddiqui 2017). She was a girl most likely with intellectual and physical disabilities, and presumably, these qualities led to her abandonment. The Mowgli Girl was taken to an institute for children with disabilities in Lucknow where she was (ironically) named Ehsaas, which means “feeling” or “emotion” in Hindi. That is as much as we know about this case. Ehsaas is not loved as Geeta is loved (by the public, the media, politicians, etc.). Is it because loving her would be more complicated? Is it because she is unable to be recuperated and rehabilitated through participating in everyday life? Ehsaas represents the boundaries of anonymous love and demonstrates the borders of the kinds of normative disabled presence that are taken up with enthusiasm in the public sphere and by political figures. Indeed, the case of the Mowgli Girl frustrates the very media narrative that it was primed to follow. Unlike the happy ending of *The Jungle Book*, Ehsaas did not find a home when she returned to society. Cast off in an institute for children with intellectual disabilities, the social does not represent salvation for Ehsaas in the same way that it does for Geeta.

In considering these two cases together, I take inspiration from Das and Addlakha’s (2001) admonition that research on disability has largely concerned itself with the public sphere and ignored what they call domestic citizenship. According to these scholars, focusing on disability in the public sphere ignores aspects of relationality and belonging that operate outside of the public. However, in both of these cases, this young
woman and this child have seemingly been denied domestic citizenship—although Geeta, through future marriage to a Hindu man, will obtain this (note that a prominent point circulating about Geeta is that Bilques Edhi wanted to marry her to a suitable Pakistani Hindu man, but she refused this, in essence refusing both Pakistani domestic and public citizenship). And in the case of Ehsaas, there was an attempt to categorically remove her from the sphere of humanity—to animality—as animality would have provided an acceptable explanatory model for her behavior. Unlike current research such as that by Taylor (2017) on human-animal relationships in the context of disability, no attempts were made to relate to the Mowgli Girl or rehabilitate her as animal or as human. She is unlovable. Geeta can be assimilated into a kind of legible and normative social that Ehsaas cannot.

What kind of engagement is enabled through this kind of anonymous love? This is the love that is professed by saying that, “No matter if we find her parents or not, she is a daughter of India and we will take care of her,” as BJP politician Sushma Swaraj said in the aftermath of not (yet) finding Geeta’s parents. What do we know about Geeta and what knowledge is necessary in order to profess love? And is this love that only accrues because she is a deaf “daughter of India” capable of being rehabilitated? There are often logics of anonymous love at play in the context of disability. Consider public mass camps where hearing aids, prosthetics, wheelchairs, and other auxiliary aids and appliances are disseminated or state-funded cochlear implantation surgery. Note too that corporate social responsibility initiatives and corporate trainings often mirror these state initiatives and find outlet in camps. These camps, often featuring politicians and wealthy businesspeople as loving benefactors, are strikingly similar to Agamben’s (1998) camps turned on their head: disabled people are treated anonymously, through the one-size-fits-all disability objects they are given, as humans to be loved and included. Inclusion as exclusion operates through a state of exception built upon anonymous love. Furthermore, anonymous love emplaces its objects between the categories of bios and zoè; perhaps this potentiality is what is so enticing about anonymous love.

Diagnosis Two: Disability’s Interworlds

In the following section, I turn to another engagement with the social, specifically, disabled people’s engagements with the interworldly. By interworlds, I mean engagements with God, the Divine, or the Spirit. I purposely write of interworlds and not alterworlds with me. What kind of engagement is enabled through this kind of anonymous love? This is the love that is professed by saying that, “No matter if we find her parents or not, she is a daughter of India and we will take care of her,” as BJP politician Sushma Swaraj said in the aftermath of not (yet) finding Geeta’s parents. What do we know about Geeta and what knowledge is necessary in order to profess love? And is this love that only accrues because she is a deaf “daughter of India” capable of being rehabilitated? There are often logics of anonymous love at play in the context of disability. Consider public mass camps where hearing aids, prosthetics, wheelchairs, and other auxiliary aids and appliances are disseminated or state-funded cochlear implantation surgery. Note too that corporate social responsibility initiatives and corporate trainings often mirror these state initiatives and find outlet in camps. These camps, often featuring politicians and wealthy businesspeople as loving benefactors, are strikingly similar to Agamben’s (1998) camps turned on their head: disabled people are treated anonymously, through the one-size-fits-all disability objects they are given, as humans to be loved and included.

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During fieldwork in 2008–2009, I had a discussion that turned into a heated argument with the founder of a prominent NGO in Bangalore. The argument went something like this: she told me that her organization was the only organization that cared about disabled people in the city. I replied, perhaps in reaction to what I perceived to be an arrogant proclamation, that I thought that this was untrue. I told her that I knew that many of the deaf students at her NGO were going to different churches on Sundays and that they had told me that church was very important to them. She replied that churches were just materialistic and that church leaders did not really care—they just wanted to convert them. I responded that I thought that this was insulting and that it was necessary to ask the students why church attendance was important to them. She retorted that churches were just manipulating deaf people, reinforcing what she had said earlier: churches did not really care about deaf people and were just out for numbers of people to convert. In contrast, she stressed that she and her NGO cared. What the NGO director meant by the statement “churches do not care about deaf people” was that churches do not provide deaf and other disabled people with the kind of vocational training her NGO provided.

10. While outside the scope of this essay, the ability to learn language might be key in determining who is able to be rehabilitated and thus loved.
11. See https://latikaroy.org/jo/2019/03/21/disabled-photo-ops/ for images of one-size-fits-all wheelchairs distributed as part of disability camps.
12. I thank Bhrigupati Singh for this point.
such as welding, computer, and electronic skills. In short, she viewed churches as unconcerned with deaf peoples’ livelihoods, futures, and rights. While this NGO administrator was not speaking of love, I believe that her words reflected a discourse of anonymous love, as discussed in the previous section, in that she was treating deaf youth as a known population. Her sentiments certainly reflected a discourse of anonymous care (Stevenson 2014) through which deaf people, as a population with known characteristics, were tracked into specific vocational fields identified for them.

As I have argued elsewhere (Friedner 2015), churches are valued spaces for my ISL-speaking deaf young adult interlocutors. In my research I have found that they have flocked to deaf churches where the majority of participants are deaf and where ISL is spoken, even if their families are not Christian. In Bangalore, where I conducted fieldwork on and off from 2006 to 2018, I learned that there were at least nine deaf churches; many deaf people frequently talked about which churches they were attending and why. They considered churches important for “knowledge” and “development”: the latter category refers to deaf-centric projects that prioritize signed language, creating deaf spaces, stressing economic opportunities, and offering possibilities to become a deaf person oriented toward other deaf people. My interlocutors told me that they learned important skills and ways of relating in church that were unavailable in other spaces.¹⁵

Deaf people also talked about God’s and Jesus’s love for them; in church spaces they stressed that God loved signed languages and that he wanted deaf people to succeed. There was a sense that God was invested in deaf people’s salvation both here on earth and in the future. Moreover, there were hearing church leaders who deaf people said had “deaf hearts” or were “deaf in a hearing body”;¹⁶ these people were typically excellent signers who spent time with deaf people in many spaces. The significance of such interworldly relations are, I suggest, too frequently overlooked; they are not only about forming deaf socialities or selves. Churches and the interworldly attachments and social projects they bring with them play important roles for my interlocutors. I argue that this is a result of “non-anonymous” conceptions of love and care that they find valuable, beyond secular normative teleological disability framings focused on the individual and conceptions of rights.

I have conducted research in deaf Christian churches across diverse denominations; I thus provide a composite sketch of what is at stake in the entanglements of different temporalities, spaces, practices, and discourses that exist outside of secular liberal disability rights and identity frameworks.¹⁷ Additionally, what unites these churches is a focus on cultivating relationality based on mutual care, both individually and collectively. People constantly shared personal and deaf-centered political news, and there was collective monitoring to ensure that everyone present could understand each other. Such attention to whether people could follow and understand was discussed as a form of care. In church spaces, my interlocutors were oriented toward deaf sociality, deaf activism, and ultimately perhaps a “deaf social” based on alternative rights discourses. They were concerned with the right to live deaf lives as they wanted and the importance of valuing deaf ways of living in the world. This includes the use of ISL and the sharing of knowledge and information as well as the creation of interworldly deaf futures.

Importantly, relations in church spaces often occurred via pastoral power through which deaf people relate to each other and to God, offering an under-recognized perspective on deaf sociality that goes beyond the (bio)social or (neo)liberal; nor is it about anonymous love. Unlike pastors in many other church spaces (as perhaps the aforementioned NGO administrator had imagined it), the leaders at deaf churches were not Westerners (although some were from elsewhere in India and one was from Korea). Indeed, church leaders, pastors, missionaries, and Bible translators were often deaf themselves and came from similar backgrounds to those they were attempting to reach. Deaf churches were simultaneously collaborative and hierarchical. Deaf leaders already had experiential knowledge of the kinds of issues faced in their flock’s educational, social, and familial lives.

Hierarchies mapped onto a structure in which leaders—men and women with knowledge about deaf rights and experience learning the Word—cared about their followers who were mostly younger deaf people who knew less about Christianity

¹⁵. Christian organizations have played formative roles in deaf experiences historically and currently in India and elsewhere. See Moges (2015) on Scandinavian missionary efforts in Eritrea and VanGilder (2015) and Aina (2015) on American missionary work in Kenya and Nigeria, respectively. In the United States, the church has built deaf schools, created sign language materials, and provided deaf people with a place to socialize and interact on Sundays (Lane 1984; Monaghan 2007). This is also the case in India where the Roman Catholic Mission established the first school for the deaf in India in Bombay in 1884. Subsequently, the Church of South India established two residential schools in Tamil Nadu in 1896 and 1912 under the auspices of the Zenana Mission Society.

¹⁶. The discourse of “deaf heart” is also prevalent in the United States, where some interpreters claim that they have “deaf hearts.” See https://streetleverage.com/2013/02/sign-language-interpreters-and-the.quest-for-a-deaf-heart/ and http://www.trudysuggs.com/getting-to-the-heart-of-the-matter/ for discussions of this concept in the United States. Deaf people in India use the phrase “deaf heart” to talk about hearing people in India, but in contrast to the United States, where it is mostly hearing people using the concept, deaf people themselves identified hearing people who they thought had deaf hearts.

¹⁷. As I discuss elsewhere (e.g., Friedner 2015), the majority of my deaf interlocutors did not feel that attending Hindu temples or participating in Hindu practices offered them opportunities to develop. There was a deaf Hindu leader (who identified as a Krishna devotee) who traveled to different Indian cities to offer workshops and programs. More recently, deaf Muslim programs have started in the state of Kerala, but I have not yet researched these. From what I have heard from friends and from an interview with a Muslim leader in Bangalore, such programs are a reaction to a sense that Christian churches and organizations are pulling deaf youth away from Islam. Hence the focus on Christianity in this essay.
and deaf rights. They exercised pastoral power in their commitment to caring for the advancement of both specific deaf people and deaf people as a group. Leaders, sometimes referred to as shepherds by deaf church goers, were concerned both with shepherding their flock as a deaf entity and with individual sheep within the flock. They attended to questions of subsistence on multiple levels, in that they were tuned into their deaf followers’ everyday lives in terms of their personal and professional skills, social practices, and vocations. Deaf leaders were also concerned with salvation, a key issue within Foucault’s conceptualization of pastoral power; here this means being part of a deaf social world, working toward deaf rights, and connecting with God (Foucault 2007:127).19 In foregrounding the connections between pastoral power and caring, anthropologist Angela Garcia (2010:31) asks: “I must wonder if, far from excluding the possibility of pursuing ethical ideals of caring, if pastoral power might actually instantiate such an ideal?”

Elsewhere, Foucault (1982:783) notes that pastoral power “cannot be exercised without knowing the inside of people’s minds, without exploring their souls, without making them reveal their innermost secrets. It implies a knowledge of conscience and an ability to direct it.” This is what makes pastoral power so effective (and affective) here: deaf leaders and followers were on the same path and had similar educational and familial experiences. Deaf leaders had often attended the same schools as their followers. Everyone knew intimate details about each other’s lives, spending time together in a variety of spaces, since deaf worlds are often very small. Thus, leaders were both authoritative and familiar. All these circumstances along with shared aspirations for deaf rights produced similar desires. Love is rendered meaningful through intimate knowledge (made manifest as pastoral power) that is connected to deaf embodied experiences and practices; love is also enacted through practices of care.19

In these church settings, deaf leaders and their followers know each other intimately, as both individuals and as members of a deaf collectivity. This is different, obviously, than the kinds of love and social (re)presentation discussed in the previous diagnosis; deaf people are seemingly understood at both individual and population levels. In church spaces, deaf people individually and collectively wanted what was best for themselves as deaf people and for India’s deaf communities as a whole. This was evident in deaf people’s prayers for both individual deaf peoples’ recovery from illness or success on school exams and for the future of deaf rights in India, creating a dense interworldly social.

In short, I suggest that for those who find community in the Indian churches where I researched, the deaf social is a site of salvation that goes beyond liberal recognition premised upon individual desires, identity politics, and group-level representation.20 This kind of sociality can include the interworldly, based upon forms of knowledge, love, and care that are not biopolitical in nature. The significance of deaf churches is under-recognized; the social projects (cf. Povinelli 2011) advanced in them help to create and imagine disability alterworlds, or worlds in which disability is lived, experienced, imagined, and represented otherwise.

Coda

I am drawn to both Geeta’s and Ehsaa’s stories and have been confused that members of the deaf and disabled communities that I spend time with in Delhi and elsewhere in India are not so interested in them. Whenever I bring up Ehsaa’s case, I am told that there are many similar stories. Perhaps there is a sense of fatigue with this kind of sad story of abandonment. Perhaps it does not fit neatly into narrative frames about violations of rights discourses and lack of accessibility. In Geeta’s case, I have encountered many deaf people who have met her and/or who know other deaf people who know her. There is a sense, however, that she is not invested in the same things that they are. Among the complaints and concerns are that she only wants to marry someone who is wealthy, like the aforementioned movie star Salman Khan, and that she wants a big house and other material goods. Also, people say that she constantly seeks visibility and publicity, albeit solely for herself and not for deaf people collectively. There is perhaps a sense that she does not love or care about deaf people in the same way that they do. I was surprised because I naively expected my interlocutors to embrace Geeta because she was deaf like them (Kusters and Friedner 2015). I do not know whether their critiques are true, but I find them revealing of what is at stake in deaf worlds. Perhaps it is a stretch, but I also see these criticisms as a critique of anonymous love and a call for forms of love and care that are both individual and collective, love and care that gesture toward alterworlds.

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References Cited


Kinship Destabilized!
Disability and the Micropolitics of Care in Urban India

Renu Addlakha

In the Global South, disability is often lived as a family experience. The spatiotemporal context in neoliberal India, characterized by rapid social and cultural change disrupting traditional family structures and creating the possibility for the emergence of new and alternative kinship imaginaries. This paper positions disability within families, to explore intrahousehold dynamics around care work and caring. Using a contextual approach to disability and care, it is the purpose of this paper to capture these micro- and macro-level dynamics in the context of urban families in contemporary India through ethnographically informed fieldwork. The discussion is positioned on the cusp of disability and feminist scholarship and activism. Care is considered as a multidimensional polysemous concept that is both universal and specific in definition and scope: labor, affect, and justice are its predominant components as it intersects with disability. Historically, the biological family is most germane to care. It is families that continue to matter as a critical source of survival for disabled people particularly in low-income countries; and in many instances, they also play the dual role of being oppressive toward the disabled family member(s) to whom they provide support. Gender is a critical structuring principle in the organization of care throughout the life cycle, given women’s centrality in procreation, childcare, and the larger domestic sphere.

On the most general level, we suggest that caring be viewed as a species activity that includes everything we do to maintain, contain, and repair our “world” so that we can live in it as well as possible. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, life-sustaining web. (Tronto 1993:103)

Care is an ambivalent concept. On the one hand, it signals love, affection, and trust, while on the other, it often leads to burden, overwork, hardship, and even humiliation for both the giver and the recipient of care. An analysis of care becomes even more complicated when it is configured within the context of disability and poverty. How this interface pans out in a society ridden by intense inequality like urban India, and its implications for the concepts of intersubjectivity and independent living, notions so germane to disability activism, is the overarching analytic frame of this paper. The case material is derived from ethnographic fieldwork that I conducted on the experiences of disability with particular reference to the family in a public hospital during the mid-1990s and a national-level disability NGO (during 2011) in Delhi, respectively. Anthropological methods of participant observation and in-depth interviewing were deployed to engaged with interlocutors in the institutional settings.

This paper explores the complexities of care in a neoliberal context for people with disabilities in India. Here the burdens of caring for dependent members pose unique challenges compelling families, especially women in such families, to develop care strategies that are atypical for the normative domestic cycle, producing a variety of stresses and strains that are not borne by more typical family formations—for instance, sisters and daughters creating a long-term care network for a married female with chronic schizophrenia in a life situation characterized by urban poverty. The situation in under-resourced contexts is more poignant, since care is simultaneously a vital aspect of positive intimacy as well as grueling work that can be both difficult and unpaid. At the other end of the disability-care-family spectrum is the actual absence of the biological family where states and NGOs have to step in to address vital care functions for survival, which are ordinarily the responsibility of families. The second illustration in this paper looks at the lifeworld of an elderly male recipient of care of an NGO where he has been employed for most of his adult life. His story opens up the possibilities of new kinship imaginaries and an indigenous independent living movement in India.

Care, Gender, and Disability: Connections and Contestations

We know that care constitutes the material and moral foundations of life and society and comprises a range of practices necessary for the maintenance and reproduction of society.1

1. At a basic level, caring may be defined as “everything we directly do to help individuals to meet their basic needs, develop or maintain their basic capabilities, and live as much as possible free from suffering, so that they can survive and function at least at a minimally decent level” (Engster 2005:53–54).

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Renu Addlakha is Professor at the Centre for Women’s Development Studies of the Indian Council of Social Science Research (ICSSR) of the Government of India (25, Bhai Vir Singh Marg [Gole Market], New Delhi 110001, India [addlakhar@gmail.com]). This paper was submitted 11 XI 18, accepted 9 VII 19, and electronically published 10 IX 19.
According to Feinberg and Ottenheimer (2001), the reciprocity of care is constitutive not only of individual subjeclhood but also includes the intersubjective world. Since care addresses core biological and developmental needs of survival, cross-cultural research has not found much difference in forms of caring with commonalities outnumbering differences (Levine 1977; Lewis and Ban 1977). It is an integral part of society, critical not only for the biological survival of the human species but also for economic growth and social reproduction. In addition to the bearing and rearing of children, negotiating with the inevitable contingencies of lifelike disease, disability, aging, and death foreground the issue of care at both micro- and macro-levels. Self-care is the logical counterpoint to collective care for survival of society.

In the division of labor, intergroup dynamics and hierarchies have also historically configured care. For instance, the functions of maintaining cleanliness historically have been assigned to Dalits in the Indian caste system, where care is intertwined with ideas of purity and pollution (Douglas 1966). Simultaneously, care is inextricably interlinked with other structures of inequality like race, ethnicity, social class, and even geography. Within the sexual division of labor, association between care work and women is naturalized through ideologies surrounding biological reproduction and motherhood (Daly and Rake 2003; Duffy 2007).

Care is actualized in the family through a range of care ideologies and practices. As Martha Fineman points out, “It is caretaking labor that produces and reproduces society” (2004:48). The unique feature of this work is that it is relational in nature, since it emerges in relationships between individuals in contrast to other kinds of labor involving individuals and the material world of objects. Relationality ushers in its wake ideas of reciprocity and exchange attested to by the fact that care labor or care work is embedded within a matrix of both morality and affect. As English usage demonstrates, “caring (for),” “caregiving,” “taking care of,” and “care-taking” highlight the intertwining of the practical with the emotional and the experiential. The care paradigm is framed not only by love, affection, reciprocity, trust, commitment obligation, and responsibility, but it is equally characterized by burden, overwork, hardship, psychological stress, and physical wearing away (Hoyert and Seltzer 1992; Livingston 2005). Indeed, while the literature largely focuses on the psychosocial stress of carers, receiving care particularly from family carers can be equally challenging; consequently, while care is ideally conceptualized as voluntary and altruistic, control and surveillance are as germane to care as selfless concern and compassion. Indeed, any holistic understanding of care has to be located in an intersectional terrain straddling the domains of kinship and family, life course, work, culture, economy, and the state.

As the primary care-providing institution in society, historical changes in family structure and functioning have deeply impacted care theory and praxis in different parts of the world. For instance, the large-scale nuclearization of the family in the West has had a profound impact in structuring the care economy of the developed world, producing a distinct interface between capitalism and the management of deviance and vulnerability. We know that the idea of disability as we understand it today also arose in this spatiotemporal moment. Similar processes are underway in the so-called developing world initiated during the colonial period and spurred on in more recent times by globalization. Indeed, the widespread emergence of the nuclear family in India is a very recent and ongoing phenomenon, coinciding with other macro-level processes like migration, urbanization, and the employment of women outside the home. In this context, the distinction between family or kin care and institutional management comes into sharp relief. In this paper, Sita’s narrative highlights the impact of such change on an urban lower-class “disabled” family in caring for one of its disabled female members.

While at a macro-level it is relatively unproblematic to conceptualize care labor as a necessary survival activity that finds justification within religious teleologies, social contract, and functionalist theories as well as feminist ethics, the micro-level realities of care work are more diverse and ambiguous, raising a range of conundrums and paradoxes. For instance, the idealization of motherhood embedded in particular notions of woman’s nature as caring, nurturing, and self-sacrificing overwrites other dimensions, such as power, control, and selfishness that are equally critical in constructions of motherhood. Similarly, while the management of disabilities needing support in a family member cannot be divorced from notions of love, protectiveness, and loyalty, it also implicates in equal measure negative dimensions like financial hardship, physical fatigue, and psychological stress. In fact, caring in the context of such disability is more often than not a social exigency with very little choice. Like other forms of labor, care work can also be exhausting, burdensome, and unrewarding, especially in contexts where there is no concrete outside support from society and the state. The latter more problematic facets of care in

2. In this paper I use “care work” in connection with all the activities of caregiving within the networks of kinship and the family and “care as labor” as commodification of care work in relation to the macro-reality of society, the economy, and the state.

3. In chapter 1 of the Government of India 2016 Rights of Persons with Disabilities Act 2016 Section 2 (l) “high support” means an intensive support, physical, psychological, and otherwise, that may be required by a person with benchmark disability for daily activities, to take independent and informed decision to access facilities and to participate in all areas of life including education, employment, family, and community life and treatment and therapy; Section 2 (l) defines “person with benchmark disability” as a person with not less than 40% of a specified disability where specified disability has not been defined in measurable terms and includes a person with disability where specified disability has been defined in measurable terms, as certified by the certifying authority.
the context of cerebral palsy are highlighted, for example, by Chakravarti (2008) in her study of urban families in Delhi. She argues that negativity surfaces when conventionally accepted conditions and contexts of caring are breached; for example, caring for a child is normal, but caring for a disabled adult, who needs help with activities of daily living like eating and toileting, exceeds the normative care framework. In the absence of outside support services to families on the edge of survival, experiences of both caregiving and being cared for, under such circumstances, may become burdensome, painful, and humiliating. The nexus between poverty, disability, and care is common in much of the world and even characterizes Western Europe and North America once we look beyond privileged enclaves (Ghai 2001; Grech 2009).

As feminist scholars have long pointed out, gender is central in any discussion on care. Women’s central role in childbearing and rearing has been reinterpreted to include a whole range of activities as the natural domain of women’s work. Historically, this has resulted in the feminization of the whole gamut of care work within and outside the home, be it household, paid domestic work, nursing, school teaching, etc. The concept of compulsory altruism has been put forward to underscore the social constructedness of women’s caring roles (Land and Rose 1985). The grind of daily care work falls squarely on female family members for whom it may become a lifelong “career” (Aneshensel et al. 1995). Chronic psychological stress is a major component (Schulz, Visintainer, and Williamson 1990; Schulz and Williamson 1991), often accompanied by adverse health outcomes for caregivers (Pavalko and Woodbury 2000).

Feminist perspectives on care engage the lens of political economy and feminist ethics, showing how the sexual division of labor puts the burden of care on women, reflecting the patriarchal division of labor in society. Yet, feminist ethics valorizes the work of care, particularly its embodied and emotional dimensions as an important activity: when feminist perspectives are juxtaposed with those of disability studies (Hughes et al. 2005; Kroger 2009; Shakespeare 2000; and Watson et al. 2004, among others), we can see that there is much in common between the two perspectives, if one examines ideas of agency, dependency, and control through the category of interdependence (Kittay 2011; Morris 1993, 2001; Thomas 1993). For example, some concrete commonalities between feminist and disability perspectives include critiques of current care systems and practices, commitment to an emancipatory project, and negotiating choice with control in the care relationship (Erevelles 2011; Kelly 2013).

In light of the above, how does gender configure the disability experiences (particularly the experiences of disabilities with high support needs) in the context of care with reference to the urban Indian context? First, the principal caregiver is most often the mother, sister, daughter, or other women of the household. In the case of joint families, extended female kin, such as grandmothers, sisters, sisters-in-law, and daughters-in-law “naturally” take on such caregiving as part of their normal role as women in the household. Since disability of any kind in a child is often directly ascribed to the mother,4 greater participation of the mother’s natal kin, particularly her female kin, in caring for the disabled child has been observed (Mehrotra 2004, 2006). Mother-blaming discourses often create an almost unbridgeable gulf between the woman and her affinal relatives, with her husband serving as a weak link in this literal face-off. Mehrotra has highlighted how the long term-management of disability, particularly with regard to intellectually disabled women in places like rural Haryana, is socially negotiated through the structural support of siblings, especially sisters. The similar role of natal female networks, particularly the maternal grandparents, has also been highlighted by Chakravarti (2008) in her study of families of adults with cerebral palsy. Interestingly, in the case of adults with disabilities across the joint-nuclear, rural-urban divides, it is again most often daughters and/or daughters-in-law who become the principal care providers.

Biomedical and human rights frames of reference for understanding disability are increasingly salient in urban areas through media campaigns, better access to medical facilities, and the active role of NGOs in the disability sectors. Definitions of disability in rural areas not only are more embedded within sociocultural frames but are more directly connected with issues of production and reproduction in situations where manual labor is more germane in everyday life (Mehrotra 2004, 2006; Mehrotra and Vaidya 2008). For instance, disability is defined more in terms of physical impairment, specifically limb deformity in rural Haryana. Other kinds of conditions that enable individuals to be minimally productive are not defined as disabilities at all. Disabled women, for example, have to show an even higher level of impairment to be excluded from domestic chores and reproductive work (Mehrotra 2004, 2006; Mehrotra and Vaidya 2008). Consequently, there are marked gender differences in definitions of disability, particularly in rural areas. With the exception of severe cases, a disabled woman, even with high support needs in the reproductive age group in particular, is expected to work like any “normal” individual in society and to follow the traditional expectations and norms regarding gender roles, and she is not perceived as having any “special” needs. These women are expected to take on the same responsibilities and perform the same kind of tasks as their nondisabled peers (Addlakha 2015; Harriss-White and Erb 2002; Klasing 2007; Mehrotra 2004). Although in need of care at times, they are mostly the carers of the household. Consequently, the taken-for-granted dichotomy between carer and cared for is not universal when examined through the prism of gender.

The management of any kind of disability in the family occurs in interaction with a range of other social institutions and agencies, including medicine, the state, and civil society

4. Not only are genetic discourses and the principle of heredity implicated, but more importantly, religious notions of karma are more powerful discursive influences in apportioning blame to the mother of a disabled child.
organizations. Empirical observations on the interface between the family and institutions like hospitals highlight how the template of the family configures formal organizations and processes in the care sector, painting the care economy with a strong brush stroke of informality. This points to the messy terrain of actual care work in a social milieu, wherein the idea of the “modern institution” like social welfare services formally taking on care functions does not exist (Addlakha 2015).

Even within formal settings like hospital wards, care is the responsibility of family and informal care networks that are not a part of the hospital legal-administrative structure. For instance, in the context of ambulatory psychiatric care or what is known in India as general hospital psychiatry, I have noted how a chronic paucity of resources, an acute model of treatment, and a family-dominated social system combine to create a treatment context based on continuities rather than disjunctions between hospitalized psychiatric patients and their homes. In its multiple roles of legal guardian, reliable informant, nursing aide, and agent of surveillance, the family foregrounds psychiatric diagnosis, treatment, and its follow-up in settings giving rise to a distinctive hospital-family alliance. This alliance constitutes a pragmatic approach to the management of psychiatric disorders in a situation that rules out long-term institutionalization (Addlakha 2008). The presence of the family in the ward not only protects the patient from the nonperson status that ensues upon admission into a psychiatric facility, but the stay in the ward may also provide a much-needed temporary refuge from a troubled home environment for both patient and family-attendant. The absence of long-term affordable institutional arrangements in the public health system opens it up to a multiplicity of different usages, extending beyond the simple institutional mandate of providing treatment. In the face of multiple exacerbations and relapses during the life course characteristic of ongoing psychosocial disability, the biomedical space became the only and ultimate resort for Sita’s family in the case discussed below.

NGOs provide another interface between different kinds of disabilities and the family. Most of these organizations were started by government welfare departments and charitable trusts for provision of medical, rehabilitation, educational, and vocational services, largely to children with disabilities. The majority of such organizations are also urban based. In the absence of other formal structures for disabled persons (particularly in the case of intellectual disabilities, autism, and cerebral palsy, for which the formal social structure provides no accommodation, unlike the case of special schools for the deaf and the blind), NGOs have become spaces of socialization and psychological support. In such a scenario, a very small number of parent-founded and administered organizations exclusively situated in urban areas have developed to address the multiple needs of disabled persons. While organizations of the deaf and blind have existed for a long time, their functions have expanded in recent times to include matrimonial and job placement services, recreation, and providing care to the elderly disabled, in addition to the traditional tasks of medical treatment, rehabilitation, education, and vocational training. For instance, from focusing on basic skill development and education in the 1980s at the time of its founding, the All India Confederation of the Blind now provides computer literacy, recreation, and job placement services to a significant number of blind persons throughout the country. Again, gender figures the situation: the clients of these NGOs are largely disabled boys and men and their families. Disabled girls and women may be accommodated within the domestic domains of housework and marriage. The compulsions of hegemonic normative constructions of masculinity, with its emphasis on economic empowerment push disabled men into the public sphere; NGOs fill a critical gap, serving as a bridge between the outside world and their homes. In the face of the decline of extended and joint family networks mentioned above, homelessness and destitution are increasing, particularly in urban areas among vulnerable groups like persons with disabilities. This dilemma is highlighted in Ravindran’s narrative, my second case study, showing how an NGO provides ongoing care and support to an ageing man with no family networks, illustrating the emergence of new spaces and visions of care beyond the traditional family.

Case Illustration 1: Coping with Destitution

Sangeeta Chattoo has pointed out how, in the context of the public healthcare system in Kashmir (India), indigent old people who do not have families may use the medical space to lay claims to citizenship. The hospital becomes “a final court of appeal,” the last and only resort for disabled people abandoned by families struggling at the edge of survival (Chattoo 1990:277). An analogous situation prevails in the case of some categories of psychiatric patients whose families are unable to provide them ongoing support. In such cases, the principal aim of hospitalization, that is, treatment, may be relegated to the background. The central concern shifts to the procurement of even more basic needs for survival such as board and lodging. The following case illustrates this process.

Sita is a 40-year-old Punjabi woman with a diagnosis of chronic schizophrenia spanning the past 15 years. Her illness history is punctuated by several acute exacerbations. A resident of Delhi, she has been hospitalized several times in the psychiatry ward of the major government general hospitals in

5. Although “mental disability” and “psychosocial disability” are used interchangeably at times, the United Nations Convention on the Rights of Persons with Disabilities has put forward the internationally recognized term “psychosocial disability,” used to describe the experience of people with impairments and participation restrictions related to mental health conditions in general.

6. For a detailed discussion of this case, refer to Addlakha (2008, chap. 2).
Pratibha explained in the course of an interview that she had dropped out of school in the tenth standard. I interacted with her during one of her hospitalizations in the psychiatry ward of one such public hospital where I was doing fieldwork at the time.

Her elder sister told me that Sita was married about 15 years ago to a man 13 years older. He was also reported to be “abnormal.” The couple have three daughters aged 13, 9, and 5 years. The other members of her marital joint family household are her widowed mother-in-law and two married brothers-in-law and their families. They reside in Central Delhi.

In addition to Sita, my other interlocutors were her two younger married sisters. The eldest, Pratibha, is a primary school teacher living with her husband and two sons in Paschim Vihar, a residential suburb in West Delhi. Sita’s other sister, Bimla, is a nurse in another government hospital in Delhi. She also has two children. Sita’s eldest daughter, Gita, who was her mother’s attendant in the ward, was also very communicative.

My first encounter with Sita was on a hot June afternoon, a day after her admission into the ward. She presented herself, at that time, as a short, stocky, dark-skinned woman dressed in an old and rather unclean nightgown. Her gray hair was disheveled, and her clothes were soaking wet. Pratibha, who had accompanied her to the hospital, told me that Sita had started throwing buckets of water over herself 10 to 15 times during the course of the day. She said, “This is what she has been doing for the past few days. She is also eating a lot and talking nonsense all the time.” After a few days in the ward on psychotropic medication, Sita was calmer and more amenable to communication. She told me of her own accord: “I got this illness when I was in the tenth class. I drank too much coca cola. My throat began to hurt, and then I got sick. Since then, I have been taking Largectil and Magectil.”

This unvarying, etiological explanation for the onset of her suffering was accompanied by such physical complaints as a sinking feeling in the heart, constipation, and general bodily discomfort. During her stay in the ward, she was obsessed by the idea that she had high blood pressure. Whenever she saw any doctor, she would rush up to him imploring him to take her blood pressure, saying, “My blood pressure [badh gaya hai] has gone up.”

In the course of a conversation with Pratibha, some of the family’s management strategies were delineated. Upon my asking her whether anyone from Sita’s conjugal home had come to see her since her current admission into the ward, Pratibha explained in the course of an interview:

Pratibha (P): When she has an attack, she either comes to my house or to Bimla’s. Then we bring her to the hospital.

Renu (R): But when she is all right, then does she stay at her husband’s place?

P: Off and on. Last year, she stayed for 6 months with our brother in Orissa. Her in-laws don’t look after her or her children. We also have to take care of the children.

R: That must be a great burden on you. How do you manage?

P: Yes, it is very difficult. I myself have two sons, and Bimla’s husband died a few years ago. Just food, clothing, and school fees for one more person make so much of a difference. But she is our elder sister: If we don’t look after her, then who will? Gita stays with me, and the other daughter Pooja is in Orissa. Her husband has kept the youngest daughter with him.

R: Is this a permanent arrangement?

P: No, nothing is permanent. Pooja was staying with Bimla before she went to Orissa. If they had been boys instead of girls, then her in-laws would have kept them. After Anju, the youngest daughter, was born, we got Sita sterilized, because they would never have thought of it themselves.

R: And where does Sita stay when she is not with her husband?

P: Sometimes here, sometimes there. She was in Orissa for a year. When she stays either with me or my sister, our brother sends some money for her every month. It has been going on like this for many years. There is also the hospital. Invariably, she becomes ill once a year. Then, she has to be hospitalized for a month or so.

In addition to providing sustenance to Sita, especially during periods of relapse, her siblings (and by extension their conjugal families) are also engaged in the more arduous and long-term task of bringing up her children. Their responsibilities include the provision of basic needs, such as food, shelter, and medical treatment for Sita and the upkeep of her three daughters. This even involves reproductive decision making on Sita’s behalf on the part of her sisters. The hospital emerges as a convenient and necessary resort in this carefully worked out, ongoing family-based system of management and care.

When I asked Sita how she felt about being looked after by her siblings, especially during her illness, she replied in a quiet tone of voice:

7. These are brand names of commonly used psychiatric drugs.

8. Orissa is a state in Northeast India.
If they were not there, who would look after us? My children and I would die. Our bhabhi always fights about me. When I was in Orissa, I lived in the servants’ quarters. She told my brother, “I won’t keep this madwoman in my house!” I cooked my own food on the stove. In Pratibha’s house, they also fight when I go. At least there is no such problem when I am here in the ward. Then, Gita only has to miss school to be with me.

Bimla, who had come to collect her when she was discharged, told me that Sita would stay with her for the time being.

Renu: And after that, where will she go?

Bimla: We will see. Pratibha and I have been thinking of finding her some job as an ayah.10 She can do that sort of work, when she is all right, earn a little money and keep herself occupied. The trouble is that after some time, when she begins to feel okay, she stops taking the medicines; and then she falls ill again.

Sita: [Interrupting] He does not allow me to take the medicines. He sits in the temple the whole day. He forgets things; and he beats me. He won’t let me go out of the house and work.

B: Yes, her husband is also “mental.”

R: Was he also like that at the time of marriage?

B: Yes, they were both of “weak mind.” Otherwise, who else would have married her? But her in-laws should look after her as they look after him.

Although most members of Sita’s conjugal family, including her husband, do not provide either financial or emotional support, her own children come to function as her caregivers, especially when she is hospitalized. Gita looked after her mother in the ward with great solicitude. In addition to reporting on her mother’s condition to the doctors, she cleaned her utensils, ensured that she kept herself clean, and patiently bore with her frequent outbursts of temper. She did not seem to mind the burden imposed on her by this role reversal with her mother.

A sense of alienation is expressed by Sita’s longing for a space of her own. Deprived of a normal home with her husband and children, she often expressed the wish, “I want to build my own house.” It seems that the closest that she could get to the fulfillment of this yearning, in her circumstances, was coming to the ward. Like several other patients, Sita sought refuge in the hospital from her domestic woes. One day toward the end of my fieldwork, I saw her in the Outpatient Department with Pratibha and her youngest daughter. With tears in her eyes, she begged the doctors to readmit her into the ward, saying, “Don’t send me home. I am very sick. I have nowhere to go. They are tired of me.”

When Pratibha was asked what had happened, she shook her head, saying, “I don’t know. So I brought her here. I also think she needs to be admitted. Can Anju be with her in the ward? Gita has to study for her exams.” The poignancy of the family’s plight is revealed by the fact that they had brought along Sita’s 5-year-old daughter to fulfill the hospital’s requirement that a family member must look after the patient at all times. In the absence of a family caregiver, relatives are asked to make arrangements with informal attendants or ayahs who may be hired on an hourly or daily basis.

The analysis of this narrative highlights the crucial role of the natal family in the care of a disabled woman with ongoing psychosocial disability and in the rearing of her children. This continuous support, even after her marriage (when a woman in the Indian context is considered to be largely socially and morally the responsibility of her conjugal family), is not uncommon. Although her siblings, despite adverse circumstances in their own lives, provide Sita and her daughters sustenance and care, underlying economic strains are evident. This in turn creates interpersonal tensions. The conscious seeking out of the hospital by Sita and her family shows the differential appropriation of the biomedical institution more as welfare than as a therapeutic space.

Case Illustration 2: Life without a Family

What does it mean to be a disabled person without a family to call one’s own in a society like India? What are the repercussions of this situation in the declining years of life when some level of impairment is common? What, if any, are the institutional structures available or in the process of taking shape in this emergent scenario, particularly in urban India? Religious institutions like temples, mosques, and churches have been the traditional resorts for survival of the homeless and destitute all over the world, and they continue to be the last unconditional source of succor in such contingencies. But given the rising number of such cases, coming from not only the poorest but even the highest echelons of society, market and civil society organizations have begun to develop a more structured response to this emerging social problem in a situation where the state is withdrawing from social sector financing at a rapid pace. The following case illustrates an ad hoc response to such a situation, which presents both a comparison and a contrast to Sita’s predicament. Indeed, Ravindran’s plight could have been very similar to that of Sita if he still had even a minimally supportive kin network to fall back on.

Ravindran is a 55-year-old unmarried Hindu man with cerebral palsy. He started as a volunteer and then became a

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9. Bhabhi is a sister-in-law, more specifically the brother’s wife.
10. The term ayah refers to a female menial worker engaged in a range of tasks around nursing the ill, elderly, or children. Interestingly, her sisters see no contradiction between Sita’s own status as a chronic dependent patient and slating her in the role of a caregiver.
cashier at AADI (Action for Ability, Development and Inclusion) for over 2 decades, living in a room on top of the AADI office in South Delhi. His salary is INR 4,000.00, less than the minimum wage of a full-time unskilled worker.

He said he was a breech baby, attributing his difficulties of muscular coordination to this difficult birth. Being from a middle-class high-caste (Tamil Brahmin) family, he was taken to many neurosurgeons for treatment as a child. Currently, his mobility is made possible through the use of a wheelchair and crutches. Even though massage and hot water baths were a constant part of his childhood to facilitate muscle coordination and movement, his real treatment began when he moved to the Institute of the Physically Handicapped (IPH) in Delhi at the age of 6 years, where he was given intensive physiotherapy. Ravindran did most of his schooling at IPH in Delhi, where he spent 10 years. Subsequently, he completed his higher secondary schooling through correspondence from Patrachar Vidya Lahaya, a special facility for open schooling under Delhi University; he went on to complete an undergraduate college degree in commerce through correspondence from Delhi University.

Leaving school was a big leap; he had to adjust to living at home with his parents and siblings, who did not understand his needs and capacities. Earlier, he used to only come home once a month. He feels that had he not gone to IPH, he would not have developed a healthy personality. He would have felt inferior, because his parents would have (unwittingly) compared him with his siblings. Talking about the predicament of families with a disabled member, Ravindran said:

There is no help or assistance for families caring for a person with disability. Because they are so unhappy, they feel so much pity for themselves. They are comparing themselves with other families and they feel so helpless. And they say organizations like AADI are fine and very helpful when the child is growing up and all. But after the child has grown up and acquired some skills, the rest of the society is not willing to receive the child. The child, who is now an adult, is sitting at home. The adult person with a disability is now sitting at home with no alternative in life.

Presently, two of his brothers stay in Delhi with their families, but they are old and physically and financially dependent on their children. Ravindran is the eldest of the four siblings.

His youngest sister passed away in her mid-40s due to stomach cancer. His father used to work in a private company and his mother was a housewife. Both have also now passed away.

Discussing the concept of independent living in a social context where the family is the bulwark of care, Ravindran felt that we must give priority to inclusion. It should be there so that people have the choice to decide where they want to go. One should not force you to have to live with the family only, with the parents only, with the brother only: that should not be there. You must have your own choice where you want to live peacefully, so no one should get affected by your presence. And most important is the human relationship. If you are a nuisance to your brothers and sisters, how can you live as a human being? So, everything will be disturbed.

Talking about his life at AADI, he said that he stays there like any other staff member because he has difficulty in commuting to work. Talking about the future after he retires, Ravindran said that there was some plan for group housing on land bought by AADI. He acknowledged that he was totally dependent on the organization for his upkeep because he had no family to go back to. His parents were no more, and his brother was living with his married children. His dependence on AADI was a source of comfort for him, because the organization was a good substitute to the thraldom of the family and a refuge from total destitution.

It must be noted that Ravindran was the only person being given residential support in AADI as a "special case." But it has prompted this and other such organizations to attend to the predicament of disabled persons, particularly those with high support needs, when their families are no longer able or willing to care for them. For other families in similar circumstances to Ravindran’s, such a situation can drive them to seek euthanasia for severely disabled members. In fact, a number of mercy petitions before the President of India on this ground reveal the desperation of parents who are unable to look after their highly dependent adult disabled children. Although the National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act (Government of India 1999) does offer assistance in guardianship after the death of primary caregivers, inadequate awareness about its provisions and limited implementation do not render it a viable option for families on the edge of survival. Besides, it addresses the guardianship concerns of a small specific set of disabilities with high support needs like cerebral palsy but excludes other equally care-demanding conditions like chronic schizophrenia.

One response to this situation seems to be moving in the direction of self-financed group living arrangements in response to the decline of family-based care. Private healthcare and the voluntary sector are increasingly setting the agenda in the care economy at the macro-level in India’s neoliberal context. For those who can afford them, these agencies are setting up

11. AADI is an NGO in Delhi started by a group of prominent citizens who were also the parents of children with cerebral palsy. From a small self-help initiative 30 years ago, it has become one of the most important NGOs in the disability sector in the country, offering a range of services.

12. The reference is to the National Open School which is a school board under the Government of India for providing education to those groups who are unable to access the regular school system through curriculum and methods of flexible learning. Persons living in remote areas of the country and persons with disabilities are major beneficiaries of this system.
institutions for care of the elderly and the disabled. The state’s role is increasingly being confined to social protection legislation intervening directly in the family, such as the Protection of Women from Domestic Violence Act (Government of India 2005) and the Maintenance and Welfare of Parents and Senior Citizens Act (Government of India 2007). Nongovernmental organizations like AADI where Ravindran lives are playing an increasingly important role in mediating the slippery terrain between state regulatory mechanisms and market forces.

With the blurring of the rural-urban divide and the exponential increase in nuclearization of the family, structures of kinship and community that allowed for collective management of adversity, including disability, are breaking down; other mechanisms to cope with aging and debility are emerging. Under these circumstances, urban nuclear households are experiencing a greater burden in the care of disabled members, particularly in the latter phases of the life cycle. Sita’s narrative shows the struggle of families to cope with this changing scenario. The increasing feminization of the care process can be simultaneously interpreted as oppressive to women while also providing women greater freedom to organize the care process in the absence of significant male figures. In Sita’s case, it is her sisters and daughters who constitute her long-term-care network.

The intertwining of the family and hospital regimes in the case of Sita also shows that the hospital space acquires different meanings for diverse participants: patients may experience it as a place of incarceration or refuge, depending on the situation of their respective families. Temporary hospitalization can preserve patients from total destitution, offering them periodic refuge both during normal times and during crises, underscoring a strategic utilization of the formal hospital space. Such innovative approaches also testify to the resilience of families in the face of social and economic challenges over which they have no control.

Conclusion

In this paper, I set up a conversation between different actors in the care complex—recipients of care, significant others who become carers by circumstance, and the larger socioeconomic environment in which the participants are located. In the Indian context, disability continues to be largely managed within the ambit of the family. The caste and class status of the family and family networks determine the well-being of its members, including the disabled members. Prevailing gender ideologies ensure that women are responsible for the nitty-gritty of care work at home. Caring for adult persons with disabilities is particularly challenging not only materially but emotionally as well. As Chakravarti (2008) highlights in her discussions with mothers of adult children with cerebral palsy, feelings of anger and helplessness are expressed as well as apprehensions about the child’s future after their own death. Unfortunately, these concerns—and the attendant personal and social suffering—remain socially invisible.

The realities of care for people with disabilities are highly variable, as the two cases discussed in this paper make clear. Caring is not a static process but an ongoing flow that is constantly constituted and reconstituted by those doing the caring and those being cared for. On the one hand, care work is tiresome and oppressive, with massive opportunity costs for the caregivers, and yet it is essential. On the other hand, caring and being cared for are a source of reciprocity, intimacy, and emotional fulfillment. As the phenomenon of care comes under diverse pressures from a variety of sources, some new, some quite old, ethnographic research offers concrete insights into the future of disability and care not only in India but throughout much of the developing world.

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References Cited


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Autism, “Stigma,” Disability
A Shifting Historical Terrain

Roy Richard Grinker

Erving Goffman’s 1963 foundational discussion of stigma has been both embraced and critiqued in disability studies and other fields. In Goffman’s interactional and historical analysis, stigma was presumed to exist as a natural feature of humanity, deflecting attention away from historical analysis. This article, in contrast, argues that stigma—particularly surrounding “mental illness”—is deeply embedded in historically contingent structural conditions of modern capitalism and ideologies of individualism that shape ideals of the modern worker. Specifically, I use the case of autism—and its commodification in the United States—to show how a stigmatized “mental illness” is intertwined with a range of financial interests that come to depend on the continued production of certain diagnoses. For example, an analysis of the “autism industrial complex” in the United States reveals how economic changes set the conditions for a range of practices that promise to reduce stigma; these include special education, activism/advocacy, and self-representation. These occur in the context of a transition toward more flexible employment and the increasing value of technological and artistic skills often associated with neurodiversity. Despite the fact that a capitalist logic continues to define valuations of personhood, families and autistic self-advocates have been empowered in recent years to use a variety of strategies to decouple stigma and illness and resist conventional definitions of autism as a syndrome of deficits.

In the time since autism was first identified as a “mental illness,” this diagnostic category has undergone remarkable changes. Once considered exceedingly rare and profoundly debilitating, it is now relatively common; once highly stigmatized, it is increasingly accepted under the banner of neurodiversity, invented and promulgated by autistic self-advocates in the United States, many of whom identify as part of the American disability rights movement. Indeed, one reason autistic self-advocates chose to represent themselves through the term “neurodiversity” was to claim ownership of and redefine the currently powerful brain-based model. The claiming of a new identity term—“neurodiversity” and its counterpart “neurotypical”—stands as a strategy to disrupt the stigma long associated with “autism-as-mental-illness.” Assigning this diagnosis a positive social value resembles the strategy of queer, crip, and fat theorists who subverted and disidentified with normative categories and definitions that have subjected them all to stigma for many decades. This article tracks the history of stigma, autism, and “mental illness,” arguing that we cannot understand the emergence of these personhood-shaping categories apart from their long-standing imbrication with the transforming political economy of capitalism and its ideologies of labor.

The Intertwined Histories of Stigma and “Mental Illness”

Stigma is the unwanted shadow of a person, produced when society disdains certain human differences, retaining its ancient Greek meaning as a mark or branding on the body made with a sharp instrument. Often associated in its plural form (stigmata) with Christ’s crucifixion wounds, it has also come to connote a flawed psychological or physical state. Stigmatized people are often seen as incompetent, blamed for their suffering, and socially marginalized in ways that we might now consider “ableist.”

Experts and advocates decry stigma’s persistence. Former directors of the National Institute of Mental Health (NIMH), Steven Hyman and Thomas Insel, have repeatedly called stigma an international “public health crisis” (Insel, Collins, and Hyman 2015). Surgeons general have continually declared war on stigma. According to the US Department of Health and Human Services, stigma is “the most formidable obstacle to future progress in the area of mental illness and health” (DHHS 1999, 2001). However, such advocates and institutions rarely define stigma, identify its causes, or suggest ways to reduce it beyond improving mental health awareness, education, and treatment.

The scholarly literature on stigma—mainly in the fields of psychology and sociology—draws its inspiration from Erving Goffman’s classic work *Stigma: Notes on the Management of Spoiled Identity* (1963), which conceptualized stigma as interactional and performative. Written before identity politics, intersectionality, and the social model of disability were available constructs, Goffman’s ahistorical analysis focused on individuals living in contexts where stigma’s existence is presumed and must be managed. He placed the burden of

Roy Richard Grinker is Professor in the Department of Anthropology of George Washington University (2110 G Street NW, Washington, DC 20052, USA [rgrink@gwu.edu]). This paper was submitted 11 XI 18, accepted 18 VII 19, and electronically published 22 X 19.

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management on discredited individuals who need to hide or mitigate the public exposure of their stigmatizing conditions. Almost all of us, he says, will at some point in time be devalued, if not because we have some discrediting attribute, then because we have social connections to someone who does.1 Due to Goffman’s influence, academic works on stigma deflected attention away from historical and cross-cultural analysis, instead refining a typology of the concept and describing the negative effects of stigma and the cognitive processes involved with classification and stereotyping. Moreover, historically informed sociological analyses tend to emphasize how stigma motivates historical change, as opposed to how historical processes produce particular forms of stigma (see, e.g., Major, Dovidio, and Link 2018).

Yet history tells us that stigma—a culturally specific concept—is highly variable across time and place (Tyler and Slater 2018). It does not derive solely from ignorance or an individual’s failure to navigate the psychological machinations of the presentation of self in everyday life. As Brendan Gleeson puts it, Goffman’s “interactionist fallacy” masks the structural forces that underwrite personal encounters and their meanings (Gleeson 1999:17; Schweik 2014). From its inception, stigma has been bound up with ideas about “mental illness” in Europe and North America; I argue that their two histories can be told as one. Mental illnesses became stigmatized as this label was increasingly deployed as a modern category for the idle, particularly as capitalism developed. Doctors, politicians, and other “experts” on public health isolated people they deemed economically unproductive. Over the past three centuries, neither awareness nor medical and scientific advances have greatly affected the ebb and flow of the stigma of the many conditions classified under the rubric of mental illness, whether explained via conventional psychosocial and psychoanalytic frames or the more recent neurobiological models (see, e.g., Angermeyer and Matschinger 2005; Pescosolido et al. 2010; Reed et al. 2016). Just as ignorance is not wholly to blame for stigma, neither does scientific knowledge erase it. Stigma comes from deep structural conditions, such as capitalism, ideologies of individualism and personal responsibility, and the complicated legacies of racism and colonialism. Our dynamic conceptions of mental illness ride on the waves of broader cultural changes, and when science or medicine does ameliorate the shame of suffering, it does so as the servant of culture.

In this article I examine the dynamics of stigma through the tectonic shifts of economic and political structures and accompanying ideologies of exclusion and inclusion. I argue that stigma emerged out of the structural conditions shaping capitalism, including ideologies of individualism, personal responsibility, and the complicated legacies of colonialism. Stigma must be challenged in the context of those conditions, as the recent and successful efforts of autism activists and autistic self-advocates demonstrate. This is not to suggest that socialist states or noncapitalist communities do not stigmatize difference. The idea that a person should be valued for individual productivity was already in place in communities that later embraced other forms of governance.

Moral judgments about “mental illnesses” reflect what, at certain times and places, people consider the ideal society and person. The same holds true for physical disabilities when communities perceive them as violations of a properly ordered life (Murphy 1987:29) or as “nature’s mistakes” (Bogdan 1988:6). The most stigmatized people tend to be those who do not conform to the ideal modern worker: the autonomous, self-reliant, individual. Indeed, I argue that the burden of stigma changes along with the ideals of the modern worker. At the same time, neurodiversity, which was explicitly modeled on the social model of disability (Shakespeare 2010), has become an exemplar for how economics can play a role in destigmatizing a previously highly stigmatized condition. New accommodations and greater accessibility in work and community life have helped many who identify as neurodiverse make claims on inclusion (Silberman 2013:472–473). As some workplaces become more flexible, valued twenty-first-century workers—including those with autism—might be self-employed, work part-time, combine paid work with family care or volunteerism, interact virtually rather than in person, and continue to live with their parents after the arbitrary ages of adulthood, such as 18 or 21 years of age. As Rapp and Ginsburg (2011) have shown, the “difference of disability” reverberates over the life course, creating “new kinship imaginaries” as many families learn to accommodate atypical lives. Popular representations of contemporary autistic imaginaries suggest that young adults with autism can succeed in the workplace not despite their differences, such as restricted interests in technology and numbers, but because of them. They might enjoy repetitive administrative and technical tasks that neurotypical others eschew, such as filing, inventory management, and animal care. Such flexibility in assessing social and economic worth has made it possible for people like my daughter Isabel, who self-identifies as autistic, to celebrate forms of difference that were once disdained and hidden; they can become valued and visible parts of economic and community life to a degree that was previously impossible.

An increasing number of people with disabilities are being offered more accommodations and job support as alternative work schedules become available to a growing proportion of workers in the United States, the United Kingdom, and most G20 countries (Meager and Higgins 2011). The Organisation for Economic Co-operation and Development (OECD) predicts that “such increased flexibility will provide greater opportunities for underrepresented groups to participate in the labour market, such as women, senior workers and those with

1. Goffman writes that if one seeks to tabulate the number of people who suffer from stigma, including those related to the stigmatized who experience “courtesy stigma,” the question becomes “not whether a person has experience with a stigma of his own, because he has, but rather how many varieties he has had his own experience with’’ (Goffman 1963:129). To make this point, Goffman added a passage that many still find disturbing to read: “There is only one complete unblushing male in America: a young, married, white, urban, northern, heterosexual Protestant father of college education, fully employed, of good complexion, weight, and height, and a recent record in sports” (1963:128).
disabilities” (OECD 2017). The move from factory manufacturing toward flexible production and the democratization of communication via social media and other digital forms have opened up a degree of community integration that was formerly inaccessible for them. Despite these advantages, many scholars and policy makers consider such flexible work to be potentially exploitative of workers through “contingent work,” given that part-time employees are often denied full benefits (Barker and Christensen 1998; Belous 1998; Thomason, Burton, and Hyatt 1998). Yet, more flexible kinds of work schedules make it possible for people with physical and mental disabilities to work, resisting norms that prevent them from becoming integral parts of a community.

Research on the trajectories of autistic adults, and employment opportunities in particular, lag behind research on children and special education (Wehman et al. 2014). Nonetheless, there is a growing body of literature that suggests that people with autism, while continuing to face discrimination, are capable of succeeding in competitive inclusive employment (Wehman et al. 2013), especially if they had work experience as teenagers (Siperstein, Heyman, and Stokes 2014). Workplace changes may valorize those who would previously have been denigrated, like the person on the autism spectrum with a talent for high technology, more comfortable working and interacting with others online. Autistic adults sometimes excel in areas of significant job growth, such as engineering and other professions that rely heavily on mathematics. The Kessler Foundation’s reports on National Trends in Disability Employment (nTIDE) show increasingly positive trends for employment of people with autism, although the number of people with cognitive disabilities employed full- or part-time in the United States has decreased over the past three decades, even after passage of the 1990 American with Disabilities Act (ADA). For autism, even where employment rates remain stagnant, salaries are improving (Hendricks 2010; see also Feinstein 2018).

Psychiatric disorders and developmental disabilities have become increasingly normalized over the past several decades, a stunning reversal of a shameful and stigmatized history. In 1944, for example, one of the most celebrated twentieth-century psychologists, Erik Erickson, sent his infant son Neil, born with Down syndrome, to a residential institution and told everyone, including his other children, that the baby had died at birth (Friedman 1999). In the 1960s and 1970s, children with autism were often diagnosed with childhood schizophrenia or mental retardation, and schools and employers offered few opportunities. With no evidence to back up their accusations, clinicians commonly blamed autism on supposedly unloving “refrigerator mothers” (Bettelheim 1972) and conceived of autism in the framework of psychotic disorders (Tustin 1995). In that context, few parents wanted to disclose that they had a child with autism (Grinker 2007); growing up, I knew no one with autism. But in the twenty-first century, many parents discuss their children’s cognitive, emotional, and behavioral diagnoses, medications and doses, and battles with their school systems, and might even compare them to Bill Gates, Isaac Newton, and Vincent Van Gogh, all mythologized as possibly autistic. Given this dispensation, most people I meet in my social and professional orbit today personally know several people with autism. We are witnessing what Rapp and Ginsburg describe as “the expanding arena of public intimacy around the experience of disability” (2011:395).

This more flexible sense of personhood or citizenship is apparent in almost every aspect of our existence—in the fluidity of our ethnic, gender, and racial classifications, for example—along with “new kinship imaginaries,” in which “atypicality is the norm” (Rapp and Ginsburg 2011:406). Our identities are becoming more fluid and negotiable, and this plasticity goes well beyond recognizing complex multietnic, multiracial personhood. Many forces are contributing to these shifts. For example, globalization encourages forms of personhood consonant with borderless markets and claims for universal human rights, transcending any particular nation or government (Lewellen 2002). Other influential developments include the acceptance of transgendered identities and nonbinary sexual preferences, religious or spiritual fluidity, and new kinds of sociality that transcend the division of species, as with companion animals such as therapy dogs (Solomon 2010). In short, diverse forms of personhood are generally more accepted and considered less threatening today, despite the persistence and resurgence of bigotry, racism, anti-Semitism, and discriminatory immigration reforms throughout the world.

In this context, mental health fields are shifting from contained diagnostic categories, in which one has this disease or does not, to a dimensional view; nearly all disorders are now considered to be distributed differentially across the population. As a result, researchers, including the authors of the Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5), have reframed major diagnoses as spectrum disorders (e.g., schizophrenia spectrum disorders, bipolar spectrum disorder, and the depressive spectrum), as happened with autism more than a decade ago. In this new model, clinicians ideally pay more attention to describing the severity of a patient’s various symptoms than to assessing whether a patient meets every criterion for a specific disorder.

The stigma of “mental illness” is modestly decreasing across many locations, although this is uneven at best. In my field sites in Africa, Asia, and North America, medicalized psychiatric conditions as well as post-traumatic stress disorder among survivors of war, natural disasters, and sexual violence are increasingly accepted as distributed throughout the entire population (Breslau 2004; Grinker and Cho 2013; Grinker et al. 2012). Regardless of these steps toward fluidity and flexibility,
in some parts of the world people with cognitive disabilities are imprisoned in their own homes or in state institutions. Numerous conditions have lost stigma, but other disorders such as schizophrenia and addictions remain in stigma’s shadow. In the United States, Alcoholics Anonymous remains anonymous. The very phrase “mental health” is designed to avoid the connotations of sickness. Even the National Institute of Mental Health, the leading federal agency for research on mental illness, does not call itself an institute of mental illness, though the other national institutes are named for diseases (e.g., the National Cancer Institute).

Nonetheless, greater recognition of developmental disorders, even in low- and middle-income countries, has catalyzed early intervention programs and special education (Grinker, Yeargin-Allsopp, and Doyle 2011). Celebrities no longer hide their mental health challenges; they shine a light on them.4 We have not been able to put it into words, but most of us can sense that something positive is happening. One need only listen to the way millennials speak more openly about their mental suffering. A student in one of my classes described her struggle to find treatment for attention deficit/hyperactivity disorder (ADHD) when she was in high school. Her father told her she did not have ADHD and that she simply was not working hard enough to get good grades. She begged to see a psychiatrist but had to wait until she went to college to act on her own. “Getting diagnosed with ADHD,” she told our class, “was one of the best days of my freshman year because someone actually saw that I wasn’t stupid or lazy, that I just needed treatment to help me do better.” Another student even wore a T-shirt that read “I hate normal people.” In fact, the contemporary term for normal that comes from the neurodiversity movement, “neurotypical,” does not really mean normal. It refers, critically, to people who conform to society’s definition of the normal.

While such acceptance and visibility reflect a change in awareness and education, I would argue that they are epiphenomenal, masking deeper structural and historical forces.

Reframing Mental Illness: From Asylums to Consumer Activism

Capitalism did not cause psychological impairments; rather, psychological impairments acquired new meanings under cap-

4. Lady Gaga and Prince William have disclosed their emotional struggles, she with post-traumatic stress from an assault, he from depression. David Letterman’s psychiatrist joined him onstage in 2017 when he received the Kennedy Center’s Mark Twain Prize for American Humor. Positive autistic characters are present in children’s and adult television. There is an autistic Sesame Street character, an autistic Power Ranger, and other protagonists with obvious autistic traits in the films Mary and Max and Adam and in television shows such as The Good Doctor, The Big Bang Theory, Silicon Valley, Community, Hannibal, The Bridge, Sherlock, House, Mr. Robot, and The Walking Dead, among others. The Tony Award–winning plays Dear Evan Hansen and Curious Incident of the Dog in the Nighttime featured characters with severe social anxiety and autism, respectively.
The asylum was not a hospital for treating illness but a separate world of discipline in which administrators used whatever tools they needed—chains, stakes, cages, for example—to subdue and control the “unreasonable” and, to some extent, inhuman, since reason was considered the essence of humanity. The people represented as “the insane” in many European paintings before the nineteenth century (Gilman 1982, 1988) included those defined by their failure to become proper members of the working class, a definition that persisted in the United States well into the twentieth century. Even as recently as 1960, doctors framed the lobotomy, a drastic measure for discipline and control, in economic terms: as disability studies scholar Jenell Johnson notes, “the ultimate indicator of a lobotomy’s success was its ability to return patients to gainful employment” (Johnson 2011:194). Today, the World Health Organization still includes “productive” work in its definition of mental health.5

Historians have criticized Foucault for providing too little evidence for a “great confinement” or for its uniformity throughout Europe (see, e.g., Middelfort 1980). But the critique misses the point since the numbers are irrelevant (Porter 1990). Exclusion was just as powerful as an idea since the concept of confinement was salient. In London’s oldest asylum, Bethlem (Bedlam), there were generally only about three dozen inmates, yet Bedlam figured prominently as an imaginary in art and literature, in parents’ admonitions to their children, in threats to the disorderly (see Cross 2012; Torrey and Miller 2001:11). Even the humanitarian reform known as “moral treatment” was guided by a capitalist imperative. “Moral” for doctors such as Philippe Pinel (1745–1826) meant “psychological,” not material or physical, a kind of tough love to be exercised in the service of potential liberation and employment of the idle. Folie (madness), Pinel wrote, was alienation from the social order caused by primitive, as opposed to civilized, impulses. An expert on eighteenth-century Francophone literature notes “Folie,” which until the latter half of the eighteenth century had been understood as the general incapacité . . . à suivre les rythmes de la vie collective [inability to follow the rhythms of social life], became through Pinel the bona fide medical condition known as aliénation mentale” (Chilcoat 1998:12). This psychological definition was a major break from the past because, in a sense, a specifically “mental” illness had been born.

The emergence of these seemingly objective concepts in Western Europe was paralleled by another development no less crucial to the stigma of mental illness, in which scientists sought to create stable categories of being and difference: the invention of the female. Just as there were no mental illnesses before the advent of psychiatry, neither were there females, since scientists believed, as they had for centuries, that men and women were part of a single sex—male—of which women were just imperfect men (Laqueur 1990). But by 1800, scientists divided men and women into incommensurable, fixed categories, a categorization that was essential for social order in an increasingly industrialized Europe.

The invention of the female was part of the same process of modern classification as was mental illness. In both France and England, scientists now saw women as defined by their bodies, as beings tied more closely to nature than men. Describing the stigma of being female in the early nineteenth century, one historian notes, “In moral discourse there was hardly any overlap between the active, rational, resolute male and the emotional, nurturing, malleable female. The two sexes were essentialized, and woman was constructed as ‘other’ in a more absolute sense than ever before” (Tosh 2005:336). This separation made it even easier for experts to fix stereotypes of femaleness, including a tendency to equate women with mental illness. It was just a short step to associating mental illness with women through the “nature” of their sex (Chilcoat 1998:13), a development that led to the creation of hysteria as a mental illness category, as well as the development of a pathological model of human sexuality.6

Well into the twentieth century, the association of mental illness with idleness extended to people believed to be inherently inferior, especially the members of colonized populations. During World War I, instead of using the stigmatizing term “hysteria” for officers suffering emotional or unexplained bodily distress, British physicians used the less stigmatizing term “shell shock,” whether the soldier saw combat or not. The term denoted an appropriate, understandable male response to stress, rather than anything inherent in the individual (Mosse 2000:101–102). But doctors retained the feminizing term “hysteria” to describe mental illnesses among working-class soldiers, Jews, the Irish, and colonial subjects, most of whom seldom received treatment (Bogacz 1989:230). Doctors in Germany considered non-elites untreatable because they were considered inherently inferior, weak, and “work-shy,” by virtue of their birth and upbringing (Lerner 2003). Emotional distress was proof of their nature; the diagnosis reinforced their inferior position in a gendered hierarchical system of social classification.

In the United States the stigma of the most commonly diagnosed mental illnesses (such as anxiety, affective disorders, and war trauma) waxed and waned through the first half of the twentieth century in relation to World War I, World War II, and the Korean War.7 Stigma tended to decrease when the


6. For Emil Kraepelin, the great classifier of psychoses, “symptoms of mental illness could be seen not only in women but in undeveloped ‘wild tribal people’ with their demonic and magical beliefs, in children, with their ‘spineless submission,’ and in women with their propensity for extremes of excitement, their volatile mood, and lack of self-control” (Barrett 1996:211).

7. In their book War Neuroses in North Africa (1943), which was known as the “bible” of military psychiatry (Jaffe 2014:139; Shephard 2000:213), Roy Grinker and John Spiegel, in effect, normalized mental illnesses for a time. For them, the more interesting question was not why these soldiers became sick but why so many didn’t become sick. Stigma was reserved for those who failed to enlist or were incarcerated for crimes and severe mental illnesses, including sexual pathology. The New York Times (Laurence 1944:36) prematurely claimed that Grinker and Spiegel eliminated the stigma of mental illness.
military created terms like “shell shock” or “war neurosis” and used the dubious strategy of delaying psychiatric diagnosis and treatment to keep soldiers in combat. The stigma of mental illness then increased postwar when the economic costs of chronic sickness strained government budgets. Despite more than a century of concerted attempts by advocates (such as Dorothea Dix during the nineteenth century) and ex-psychiatric patients (like Clifford Beers and Rachel Grant-Smith in the early twentieth century) to resist dominant discourses on mental disability, mental health advocacy emerged in earnest only during the 1960s, along with other kinds of civil rights advocacy. By 1973 gay rights and veterans’ rights leaders, along with ex-patients and young, progressive psychiatrists, were able to persuade the American Psychiatric Association to remove homosexuality from its list of mental disorders and to begin serious consideration of a new concept of post-traumatic stress disorder (Borus 1975; Haley 1974; Kutchins and Kirk 1997; Young 2008). But with the exception of those two groups—homosexuals and veterans—the so-called mentally ill were still relatively silenced. The experts still assumed that suffering individuals could not speak for themselves about stigma and discrimination. This assumption was especially salient for individuals with physical disabilities (Epstein 2007; Funk et al. 2006).

Working within the framework of the market, patients adopted an economic language by calling themselves “consumers” or “consumer/survivors” (Tomes 2006) and appealing for the right to be heard less on the basis of their rights to health care as citizens than as consumer-citizens. Patients, condescended to and feeling disempowered by the medical professions (and by what was sometimes referred to as the medical industrial complex), aimed to resist medical paternalism by appropriating the discourse of the market. In the consumer narrative, doctors should not only heal but use their resources rationally; patients should be able to shop not only for doctors but also for providers who practice outside the medical establishment—those providers that physicians want to marginalize from the medical marketplace. Government protections for the patient increasingly came not from constitutional law but from consumer regulation protections (Tomes 2006:86–87). Patient advocacy and federal laws to protect the “mentally disabled” (e.g., the 1963 and 1965 Community Mental Health Centers Acts) together posed a serious threat to psychiatrists’ monopoly on mental health care. Patients who had once been characterized as passive (literally “patient”) and irrational, in contrast to the active, rational doctor, were now not only wise shoppers but people who could represent themselves (Halpern 2004).

8. There is a similar push today by transgender advocates to eradicate any category of gender identity disorder from the DSM, though it is unlikely to be successful since removing it would eliminate the possibility for transgendered individuals to get access to reimbursable medical services, such as hormone therapy and surgery (Byne et al. 2012; Reed et al. 2016).

Doctors once considered psychiatric nosology of little concern to the public at large. As one of the editors of the DSM-IV and DSM-5 told me, “The DSM used to be just for doctors.” After publication of the DSM-III in 1980—the first diagnostic manual to define mental illnesses constitutive of the person and in terms of chronicity rather than as temporary reactions to environmental stressors—psychiatric classification became an integral part of psychiatric training, research, and care. DSM categories became essential to a range of practices, such as advocacy and lobbying, global health outreach, pharmaceutical advertising, and of course, insurance reimbursement for clinical care and other services (Kutchins and Kirk 1997). Just as importantly, the DSM began to resemble a dictionary that provided the public at large with a language of seemingly legitimate and objective mental illness categories.

The extraordinary growth in the number of psychiatric diagnoses in the United States and throughout the world resulted in an apparent “epidemic” not only of autism but other conditions as well, most of which are linked to extensive financial interests. Insanity in the nineteenth century was a financial matter largely for churches and government, but in the twenty-first century the private business income generated by mental illnesses exceeds $135 billion a year, about one-quarter of that amount in prescription drug fees. Mental health care costs constitute about 20% of all spending for physician and clinical services in the United States. The US Centers for Disease Control and Prevention (2005) estimates that approximately 11% of the 51 million children ages 4–17 years in the United States have at one time been diagnosed with ADHD and that half of those individuals have at one time taken stimulants as a treatment (e.g., Ritalin). The number of ADHD diagnoses and prescriptions of stimulants is increasing outside the United States as well (Polanczyk et al. 2007). Sales of stimulants for the treatment of ADHD produce more than $12 billion in income for pharmaceutical companies. A similar pattern can be found for adults. At least 9% of Americans have depression, for example, in any given year, and 10% of Americans are taking antidepressant medications, the same proportion of Americans who take statins, the medicines that lower cholesterol. The point is not that children and adults are being overdosed and overtreated—that is a subjective judgment open to a range of interpretations—but that a particular diagnosis became embedded in a financial system that has come to depend on that diagnosis for its sustainability and growth. For example, the FDA recently approved Roche’s drug balovaptan for fast-track clinical trials as a treatment for social communication impairments; other companies are banking on finding breakthrough medications in the near future. Given the absence of any medical intervention, autism is a dream frontier for the pharmaceutical industry.

Because autism is a childhood-onset condition, it falls within the domain of school systems, where the diagnosis thus has had the most financial significance. Between the 2000–2001 and 2010–2011 school years, autism classifications in the American public school system rose by 331%, but the proportion of children in special education programs in the public schools remained static (Polyak, Kubina, and Girirajan 2015). A static special education rate and an increase in autism can occur only if other classifications drop. Indeed, numerous classifications that parents have found uncomfortable if not stigmatizing, such as intellectual disability and specific learning disability, declined as autism became a more common, less frightening, and less shameful diagnosis. The expansion of autism into a spectrum, the decline of mother blame, and the temporary inclusion in the DSM of Asperger’s Disorder as a way to describe people with autism who were intelligent and educable (1994–2013) all reduced stigma and made autism increasingly desirable as a replacement for other diagnoses, especially for children with identifiable genetic syndromes in which autistic features were one part of the syndrome. Some clinicians and researchers now distinguish between nonsyndromic autism (idiopathic) and syndromic autism. For example, syndromic autism is increasingly a term of clinical utility for individuals with Down, Angelman, Cohen, Williams, fragile X, Rett, Cornelia de Lange, 22q11 deletion, and Prader Willi syndromes (Gillberg and Coleman 2000).

Passage of the Individuals with Disabilities Education Act (IDEA) is often credited with expanding educational opportunities for children with special needs, especially children who reside in areas of the United States with lower access to care (Losen and Orfield 2002). But the distribution of resources has perpetuated inequalities by race and class and has also led to an imbalance in autism diagnoses across diverse communities. Autism-related services can sometimes cost twice as much as those for other classifications. In some public schools, autism has increased as a primary diagnosis for children who reside in states in which these costly services are provided. Fiscal incentives and disincentives play an important role in the number of school diagnoses of autism: the more diagnoses, the more money the school receives (Sigafos et al. 2010). In Texas and California, for example, the provision of financial support for children with autism spectrum disorder (ASD) led to significant increases in special education classifications and autism in particular (Cullen 2003). On the flip side, autism rates fell when those resources were removed (Kwak 2010). Parents fighting for autism-related services often find themselves in a legal quagmire, depending on the availability of support in their districts. Those who can afford it seek legal support for special education litigation. This also contributes to the profitable legal business in autism, as the rate of autism-related suits is disproportionate to enrollment of students with autism in special education programs in the United States (Zirkel 2011).

From classroom aides to speech and language pathologists, child psychiatrists, and vocational trainers, an increasing number of workers now rely on autism for their income and professional identity. In 2013, 20% of the pediatric caseload of private speech and language pathology practitioners was with patients with a diagnosis of autism, and the percentage of those receiving services within schools is probably even higher (ASHA 2012; Brook 2013). Child psychiatrists also perform a crucial function since some school systems require a diagnosis from a board-certified child psychiatrist before agreeing to deliver autism services. There are currently 8,500 board-certified psychiatrists in the United States, and no state in the United States meets the standard (one child psychiatrist per 2,127 children) suggested by the American Academy for Child and Adolescent Psychiatry. If one is lucky enough to get an appointment with a child psychiatrist, the fees can be as high as $600 per hour.

Medical costs for autism interventions involve not only direct expenses incurred from conventional care but also complementary and alternative therapies, many of which are not reimbursable by insurance. These include chelation, hyperbaric oxygen chambers, nutritional therapies, and other treatments based on unproven ideas, such as the hypothesis that autism is caused by chronic bacterial or viral infections, yeast infections, or mercury poisoning (Fitzpatrick 2008). Menus of “biomedical” treatment plans can be found throughout the internet and sometimes include daily regimens of items such as horsetail grass, Ora-Placenta, gold salts, grapeseed extract, fenugreek, milk thistle, and a range of amino acids (Fitzpatrick 2008). Additional costs include hippotherapy, communication devices, and countless trademarked therapies (e.g., SCERTS, Son-Rise, Floortime, etc.). Thirty-one percent of children with ASD use some sort of non-school-based service such as academic tutors, applied behavioral analysis, legal aid, and school observation services and consultants (Lavelle et al. 2014). Buescher et al. (2014) estimate that for the United Kingdom, the average lifetime cost of care for a person with autism is $1.4 million; Leigh and Du (2015) estimate that by the year 2025 the total national cost in the United States for caring for people with autism will exceed $461 billion per year.

Recognizing the potential for the increase in diagnoses of autism to bring financial revenue, universities now offer on campus and online graduate degrees in education or psychology with certification in clinical treatments of autism. There are new PhD programs on autism, programs focusing on autism and play therapy and social skills, and master’s degrees in applied behavior analysis, most of which justify their existence as a necessary response to the increased prevalence of autism. Moreover, the nonprofit sector for autism continues to grow, especially in terms of awareness promotion, the area of philanthropic activity designed specifically to increase the visibility of the symptoms of autism and available services. In 2013, according to tax returns filed with the IRS and available through a GuideStar search, the wealthiest 100 nonprofits devoted...
to autism were worth close to $1 billion in assets and income (e.g., Autism Speaks, the Anderson Center for Autism, and Eden Autism Services). All these developments bespeak the challenges and struggles that parents face as they seek to find services and social supports that will enable their diagnosed children to be educated and launched into the neurotypical world.

**Autism Goes to Work**

One of the current professional goals of interventions for people with autism is “independent living,” a term first coined in the 1960s by disability rights activists in the United States, launching a “philosophy and a movement of people with disabilities who work for self-determination, equal opportunities and self-respect” (www.independentliving.org). The goal is also for people with disabilities to “show the solutions we want, be in charge of our lives, think and speak for ourselves” (www.independentliving.org). The language of the Independent Living Movement influenced the United Nations Convention on the Rights of Persons with Disabilities, which states that its goal is “to enable persons with disabilities to live independently.”

The Independent Living Movement, motivated by a foundational commitment to self-determination, continues to animate disability activism worldwide; yet at times its language has been co-opted and reduced under late capitalism as a hallmark of successful neoliberal existence, a gloss on economic self-sufficiency. This appropriation of “independent living” both embraces and contradicts the original and ongoing meaning of the Independent Living Movement. On the one hand, few would argue against expanding opportunities for meaningful work, a sense of purpose, and integration into community life for all people with disabilities. The more they are able to gain access to the same kinds of practices open to people without disabilities, the easier it will be to reduce stigma. On the other hand, taken too far in certain contexts, this expectation might suggest that a meaningful life is impossible for someone who is not economically productive or able to live on their own, a far cry from the intentions of the activists who catalyzed the Independent Living Movement over a half century ago. Disability activist and scholar Sunaura Taylor offers a cogent critique in her landmark 2004 essay “The Right Not to Work: Power and Disability.” She writes:

The fact is that impairment reveals our interdependence and threatens our belief in our own autonomy. And this is where we return to work: the ultimate sign of an individual’s independence. For many disabled people employment is unattainable. We often simply make inefficient workers, and inefficient is the antithesis of what a good worker should be. For this reason, we are discriminated against by employers. We require what may be pricey adaptations and priceless understanding. Western culture has a very limited idea of what being useful to society is. . . . Disabled people have to find meaning in other aspects of their lives and this meaning is threatening to our culture’s value system. . . . The same rule that often excludes the impaired from the traditional workplace also exploits the able-bodied who have no other choice but to participate. The right not to work is an ideal worthy of the impaired and able-bodied alike. (Taylor 2004)

Similar critiques of the commodification of autism serve as cautionary tales about how categories can be taken up under capitalism in ways that challenge the more inclusive imaginary proposed by activist scholars such as Taylor. For example, Anne McGuire writes of the “autism industrial complex,” a phrase she uses to characterize the complex infrastructure for autism, and to criticize the capitalist valuation of the person (McGuire 2013, 2016). The vital economic role of autism is evident in websites like the Autism Speaks Marketplace or Autismsthings.com, where autism is branded and commodified and emblazoned on T-shirts, coffee mugs, and other objects. A handful of movie and Broadway theaters are now marketing directly to autistic people and their families, advertising their occasional subsidized “autism-friendly,” “sensory-friendly” performances; for example, the use of strobe lights and pyrotechnics is limited, and quiet spaces with “fidget toys” are provided. Such shows offer a rare welcome for those on the spectrum and their families and allies, accommodating a wide range of autistic behaviors like stimming and vocalizing, with actors prepared for lively if unruly audience participation (Ginsburg and Rapp 2015; Silberman 2015:472).

As Ian Hacking and others have so lucidly described, once a diagnosis takes hold and serves as the hub around which so much wealth, so many people, and activities coalesce, it takes on a life of its own as an authentic, naturalized classification (Hacking 2000). This category, in turn, provides an incentive for manufacturing people with the diagnosis of autism whose presence and needs support this financial infrastructure. The autistic person becomes increasingly defined in the terms of capital. McGuire notes:

The Starbucks cup, World Autism Awareness Day and the sheer breadth of the “autism industrial complex” all gesture
towards the cultural fact that, under neoliberal rule, social and/or economic investment in the untimely autistic child is not just an investment in the realization of the “future-citizen-worker” but in the potential for its realization. In one unbroken—and clearly very lucrative—move, our market-driven times, at once, produce and regulate, create and constrain conducts that are beyond the norm. (2016:124)

British autism researcher Bonnie Evans (2017a, 2017b) offers a new twist on autism diagnosis in the context of capitalism in the United Kingdom. She suggests that the government promoted autism diagnoses not just to facilitate service delivery but because these diagnoses provided a way to justify the absence of certain kinds of individuals from the workforce as governments were dismantling social welfare programs—that is, the state could argue that autism, and not government policies, was to blame for much of the unemployment in England. She draws on Nikolas Rose’s characterization of neoliberalism as involving the shifting focus of government action from society to individuals (Rose 1998). Autism, Evans says, “grew up as a kind of resistance to a neoliberal agenda, a tool for sheltering certain people” who might otherwise fall through the cracks (2017a).

A more persuasive argument for the increased popularity of autism, however, is that at least some autistic individuals now fit better with our economy and society than ever before. Advocates, especially parents, may have motivated the delivery of government-funded services, but far from separating and sheltering autistic people from the economy, the services have in many cases served to integrate people with autism and other disabilities into it, the goal of many activists. In places where autistic people used to be hidden away, like India, Korea, and South Africa, people with autistic children are now publicly insisting on their rights to be full citizens. Increasingly, autism is understood less in terms of lack and more as distinctiveness or eccentricity, if not talent and genius.

In large part the result of the writings of autistic individuals, many of them activists (see, e.g., the works of Temple Grandin and Donna Williams), scholars are chipping away at the assumptions of deficit by identifying rationality, coherence, logic, creativity, and metaphor where these were assumed to be absent (Costa and Grinker 2018; Draaisma 2009; Savarese 2018). Following Biklen (2005), Hacking (2009), and others (see Osteen 2008), Costa and Grinker (2018), for example, draw on phenomenology and philosophy of mind in an analysis of first-person accounts of autism by Sean Barron (Barron and Barron 2002), Lucy Blackburn (Blackman 2001), Carly Fleischmann (Fleischmann 2012), Naoki Higashida (Higashida 2013), Tito Mukhopadhyay (Mukhopadhyay 2011), Stephen Shore (Shore 2003), and Daniel Tammet (Tammet 2006) to challenge long-standing assumptions about the nature of autistic cognitive impairment. In psychology and allied disciplines, researchers are detailing new kinds of sociality (Frith 1989; Happé, Briskman, and Frith 2001; Hobson 2014). By listening to the voices of people with autism—Temple Grandin, Ari Ne’eman, Lydia X. Z. Brown, Deej Savarese, and Amanda/Mel Baggs, to name just a few leaders in the neurodiversity movement—researchers are seeking to find a balance between the depersonalized knowledge constructed by science and individual claims for knowledge that had been previously silenced or dismissed as anecdotes. As Jenell Johnson writes (2011), the person with a mental illness used to be almost completely without voice or volition. And if the person spoke or wrote—memoir, fiction, and poetry—what she said was often valued only as evidence of the illness, as when doctors analyze the writings of a patient with schizophrenia, looking only for examples of irrationality and disorder. “To be disabled mentally,” disability scholar Catherine Prendergast notes, “is to be disabled rhetorically,” not because one inherently lacks the ability due to the disease but because it has been taken away by society (Prendergast 2001:45). It is as if when you have a disability you can no longer mean what you say.” Clearly, times have changed.

Technologies have made new forms of sociality possible for many who in the past may have been isolated; verbal and nonverbal individuals can now use technology to build and maintain meaningful relationships and even new social identities. Beyond social media and online chat groups are new kinds of employment that require extraordinary memory for details about narrow topics and the ability to detect visual and mathematical patterns. Such skills are highly advantageous for computer programming, software development, and other areas of basic science. For this reason, Temple Grandin once described NASA as the largest sheltered workshop in the country. This same argument has led some to wonder if autistic people are responsible for more than we ever imagined. As one journalist wrote, paraphrasing an earlier comment by Grandin, “For all we know, the first tools on earth might have been developed by a loner sitting at the back of the cave, chipping at thousands of rocks to find the one that made the sharpest spear, while the neurotypicals chattered away in the fireplace” (Silberman 2001:5). In addition, in response to the tireless efforts of families and self-advocates, employers and schools now offer varied environments for disabled workers, including the neurodiverse, most of them created in response to parent and autistic self-advocacy efforts. These include sensory-friendly environments, telecommuting, and autism-friendly performances.
of theater and films. Nonetheless, people on the spectrum are imagined to be consumers of a booming industry of “geek culture” such as memorabilia and literature related to Star Trek, Dr. Who, Star Wars, computer or hand-drawn animation (anime), and activities like Comicon and Cosplay. Of course, this comes with a risk of stereotyping. It is important to remember the now widely circulated sobriquet: “If you’ve met one person with autism, you’ve met one person with autism” (interview with Shore [Lime Connect 2019]).

In April 2017, 50 large corporations such as JP Morgan, Ford Motor Company, Ernst and Young, and numerous high-tech businesses met in Silicon Valley to talk about ways to hire more adults with autism. A German software company, SAP, hosted the event and talked about how over the past 5 years it had hired 128 people on the autism spectrum. The initiatives were launched not only at the request of employees who have family members with autism but by those who have other disabilities, for example, executives such as Jim Sinocchi at JP Morgan Chase, who is a wheelchair user, and Jenny Lay-Flurrie at Microsoft, who is deaf. Both JP Morgan Chase and Microsoft have programs to hire autistic workers, and some smaller companies are following suit. The executives I interviewed following the meeting insist this new openness to inclusion and support of neurodiversity is not a rejection of the capitalist sink-or-swim ideology. Nor do they see their role as a replacement for government services or interventions. Simply put, they are competing for labor.

Michael Fieldhouse, an executive at DXS, a cybersecurity offshoot of Hewlett-Packard, told me, “I’ve talked to colleagues at places like Marks and Spencer, the food company in England, mining executives from BHK in Canada looking for people with good visualization skills, and the leaders at Freddie Mac, and we all agreed that the demand and supply equations were out of whack in some talent pools, especially those we needed at DXC.” James Mahoney, who directs the Autism at Work Program at JP Morgan Chase, insists the initiative was not born of sentiments like compassion and passion. “We never said, ‘Let’s do the right thing and be charitable.’” For Mahoney, fighting stigma certainly has nothing to do with pity, which is simply stigma clothed as compassion. “We never said we had jobs for people on the autism spectrum. We said, ‘We want talented people and maybe there is a group of talented people we’re not hiring.’” For both Fieldhouse and Mahoney, the “normalization” of autism in the economy is a response to the labor market. Inspired by the Danish company Specialisterne, which was founded specifically in order to hire autistic software engineers, Mahoney created a separate autism recruiting track that focuses more on job skills so that people with social skills deficits do not get eliminated prematurely in the interview process. As Mahoney put it, “An interviewer might write that the applicant was socially awkward, made poor eye contact, and gave long and rambling answers, and then end the interview without ever discovering that the person is an incredible Java coder.”

The majority of the workforce at Rising Tide, a car wash company in Miami cleaning approximately 160,000 cars a year, is autistic. My daughter has found a job she loves caring for laboratory animals in research settings. At both Rising Tide and in the laboratory where my daughter works, the highly repetitive tasks are well suited to many autistic persons’ skills and enjoyment. Autism can become an exemplar of how work and productivity can decrease social exclusion and increase social interactions, but only if we can reconfigure our expectations about what constitutes a valuable life under capitalism.

Conclusion

As the case of autism suggests, stigma decreases when a condition affects us all, when we all exist on a spectrum, with more or less of a certain set of features. With autism, as with many medical diagnoses—like hypertension and obesity—the boundary lines are drawn more by culture than by nature. A spectrum simultaneously presents an opportunity for people to negotiate their subjectivities more freely and to challenge the diagnostic stability and chronicity that so often characterizes stigma. The spectrum is also an invitation. It asks us to join the rest of the world on a continuum of suffering. It asks us to say, along with neurodiversity advocates, that both normality and abnormality are fictional lands no one actually inhabits. This was Freud’s great hope: that by showing that we are all neurotic we might understand that we are all afflicted in some way. To his credit, Goffman attempted to do this when he said that the so-called normal have little more than a shaky advantage since everyone has some form of difference to be protected from social approbation. This new condition of normality may be the one Andrew Solomon describes in his book Far From the Tree: it is difference, not homogeneity, that unites us. While writing about schizophrenia, autism, deafness, and dwarfism, among other conditions, Solomon realized something important about himself—that as a gay man with a history of serious depression and suicidality, he is more normal than abnormal. “The exceptional is ubiquitous,” he writes. “To be entirely typical is the rare and lonely state” (Solomon 2013:4). Solomon’s perspective may help people to become more empathic and may motivate broader participation in conversations about mental health and disability rights. For example, in autism research, scientists have shown that mild symptoms of autism are common in the general population and that family members of a child with autism often exhibit isolated and subtle autistic traits. With these insights in mind, where might stigma begin and end?


15. Interviews with Michael Fieldhouse (May 8, 2019) and James Mahoney (September 28, 2018).
Conventional wisdom holds that stigma is universal—humans evolved the capacity to stigmatize as a way to protect themselves from dangerous individuals. Yet I argue that we are not hard-wired to exclude people who are atypical. There is nothing natural about any particular kind of shame, alienation, and discrimination. These are attitudes we have to learn within our communities. If stigma is ahistorical, it not only is stripped of its cultural history but becomes resistant to change. If stigma is universal and ineluctable, then it becomes a fact as objective as air and water, and then the questions of variability across the globe and in history lose meaning. Imagine if we used the word “stigma” less often, or if the word did not exist. Perhaps we could then confront the specific ways a society brands and excludes those who do not conform and understand that those processes are inseparable from our culture, history, and the possibilities twenty-first-century capitalism offers. Culture put stigma and mental illness together, so we can surely take them apart.

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References Cited


Activism, Anthropology, and Disability Studies in Times of Austerity
In Collaboration with Sini Diallo

Pamela Block

How can we practice an “anthropology of disability” that is in respectful alliance with the disabled people and disability groups we study? What does critical theory making look like within the politics of such collaborative practice? What valued expertise do anthropologists offer and what do anthropologists gain? In an age of austerity and precarity in academia and in general, disabled people and disability groups struggle for survival while secure funding for grants and programs supporting graduate students and emerging scholars is increasingly precarious. In what interdependent spaces is it possible to imagine disabled activists and scholars working together for survival into an uncertain future? These questions stand at the heart of this collaborative auto-ethnographic essay.

This article offers an auto-ethnographic account of intersecting relationships between disability activism and disability studies in neoliberal academia in times of austerity. I am writing about experiences of precarity that sometimes involve death or near-death experiences especially for people with disabilities, intertwining in various ways with experiences of privilege. My use of the term “privilege” builds on the work of disability and critical race theorists Nirmala Erevelles and Andrea Minear (Erevelles 2011; Erevelles and Minear 2010). I examine intersections of disability, race, ethnicity, gender, and social status within structures of academic privilege and precarity. I consider the advantages, benefits, opportunities, and protections that are offered to some but not to others, often on the basis of these identity categories. Since privilege can be experienced as a lack (e.g., not experiencing harassment and discrimination, rudeness and barriers), those who have it often do not recognize it. To some, because it feels so natural, the loss of privilege can feel like oppression. Privilege can sometimes, but not always, mean the difference between life and death.

Here I share stories of three people: Nick, Sini, and me, examining our networks of care, collaboration, and activism straddling two sides of my university campus: the east campus houses the medical and health schools’ programs and the west campus is home to most of the undergraduate programs and a diversity of arts and sciences departments.

My research “occupies” disability by engaging disabled people from a particularly vulnerable category of citizenship: adults, or join, yet programs may come and go at the whim of the financial or strategic priorities of people in power. As noted above, along with these precarities are certain privileges that may flow along lines of gender, race, social status, tenure, or other employment security, economic security (via employment or benefits), the presence or absence of less tangible social power (such as the ability to publicly shame those in power), and the presence or absence of an interdependent community that supports and tries to protect you. Precarity and privilege dance together—sometimes one takes the lead and sometimes the other.

1. This work is in part a collaboration, with Pamela Block writing in the first person and commentary written by her colleague, whose name has been changed to Sini Diallo.

2. My grounding in anthropological disability studies is influenced by and descended from multiple sources: the groundbreaking volumes edited by Ingstad and Whyte (1995, 2007) as well as Field and Fox (2007) and Ginsburg and Rapp (2013). The collection Occupying Disability: Critical Approaches to Community, Justice, and Decolonizing Disability (Block et al. 2016) raises questions regarding who has the authority to “occupy” expertise in disability experience in the fields of anthropology, occupational therapy, disability studies, and disability activism. My article builds on these works as well as my experience at the intersection of cultural anthropology and disability studies in applied health fields contexts (Block 2004, 2007, 2017; Block, Skeels, and Keys 2006; Block et al. 2005, 2010; Pollard and Block 2017).

3. There are actually several different forms of precarity as discussed by Povinelli (2016), Povinelli, Coleman, and Yusoff (2017), Price (2018), Stewart (2012), and in the examples below. There is the precarity of body, where a person’s body is at risk of death due to things like pressure sores and infection. There is the precarity of spirit when a person’s body-mind is under extreme stress due to loss, fear of loss, and hostile workplace or living conditions and environments. There is the precarity of economic status due to unemployment, impending unemployment, or the very real fear of losing your job or benefits. There is the precarity of social status, feeling the loss of a social role as an artist, scholar, or academic along with job or program such that the person feels devalued. Finally, there is the precarity of programmatic status, where people may or may not be at risk but the programs they care about have been suspended or are at risk for suspension (Price 2018).

4. My experiences are with one east campus school and one west campus college, but I choose to specify neither their names nor the names of most programs and individuals I discuss here.
particularly young adults, requiring constant technological intervention and 24-hour skilled nursing. Who occupies disability? Certainly, disabled people do, and yet there are other categories of scholars and clinicians who claim disability expertise that sometimes supersedes or overshadows the authority of disabled people themselves. Such expertise is monetized through health or academic systems, “occupying disability” in ways that I seek to problematize. Those who claim disability expertise have power and resources that can potentially be of benefit to disabled people and groups; their inaccessibility can also be life threatening. Life-sustaining technologies such as mechanical ventilators have enabled increasing numbers of people to survive for longer periods of time; however, policies and practices that provide meaningful life options for this expanding group are sorely lacking (Block et al. 2016; Crockett 2012; Dwyer, Nielsen, and Brinchmann 2011). Indeed, policies for people with disabilities in the United States are increasingly imperiled, with growing threats to benefits and social entitlements supporting health and housing; these can be matters of life or death to many disabled people across diverse diagnoses, categories, and conditions. Disability activist movements such as ADAPT and Little Lobbyists sprang into action in 2017,5 highlighting the negative consequences of several versions of current Republican health reform bills. Neoliberal discourse too often assigns individuals responsibilities for their own health limitations (Block and Friedner 2017). Additionally, public health response in times of crisis emphasizes saving the largest numbers of people as quickly and affordably as possible. This practice, articulated during recent hurricanes, does not favor individuals with complex medical conditions, as the case of Nick Dupree makes clear.

Nick’s Crusade: Life Transitions, Privilege, and Precarity

In 2001, at the age of 19, writer and artist Nick Dupree started a social movement called Nick’s Crusade that received national attention (Dupree 2017; Wynn Newhouse Awards6). His efforts focused on changing policy to allow people like him—with an extremely rare disorder requiring 24-hour skilled nursing and complex medical technologies—to stay at home in Alabama once they turned 21, when pediatric services and policies end and adult policies (with far less funding attached) kick in. In Alabama, where Nick lived, vent-users and others require continual technological and nursing support were taken from their homes at age 21 and sent to nursing homes out of state. The difficult “crisis in transition” he and his peers faced as they grew older—aging out of the pediatric social services and funding—is shared by all young people residing in or receiving services from children’s hospitals or health systems. Technology can keep these children alive—more are living into adulthood than ever before—but is bare survival enough?

In 2003, Nick was successful in getting the policy changed for himself and others (including his younger brother) when Alabama was mandated to fix the problem; the result was a Medicaid waiver program that allowed them the necessary support to stay at home. Nick wrote on his blog:

Independence from institutional models of care remains so important, socially, spiritually, medically, in every area. Though it can be extremely difficult maintaining in-home care day-to-day, staying healthy and in the community is pivotal. I continue advocating for those of us, who, like me, have complex and intensive needs, to be allowed the in-home support necessary to stay out of high-risk hospital settings. People misunderstand . . . I was talking survival, and they were talking rights, independence, more abstract concepts.

Community is survival. The greater the medical needs, the greater the necessity to hold fast to kith and kin, to have a circle of support protecting and looking out for you. (Dupree 2017)

Nick was never afraid to take chances. In August 2008, he moved to New York to be with his partner; this intimate relationship lasted many years. He first had to establish 12 months of residency in New York State, so he went directly from the airport to a residential hospital where he lived for a year. After this mandatory year, friends and allies helped Nick and his partner set up the supports that allowed them to live together in the community. They used a transition waiver program, based on the Olmstead Act that mandates the least restrictive environments for disabled citizens (Schubel 2018). This was not easy to accomplish, but Nick’s experience shows us what is possible through networks of activism and support. In 2016, Nick described his experience and philosophy:

In the 18 months or so following my “victory” I tended to ditch my nurses, or take a gap between nurses, and pile into the family van with Spring Hill friends and go to a movie or concert or just hang out on campus. In retrospect this was super dangerous, given ventilator technology’s reliance on flimsy plastic tubes that tend to blow themselves off, though I did try to educate friends on the tubes and emergency bagging protocol. I got lucky and didn’t die, though the first time I went out without a nurse, the tube came off of the humidifier and Sarah Jane, the 18-year-old freshman, and Frankie the unlucky neighborhood guy with a mullet put it back on. Growing up on a ventilator means isolation. You must try to become a man (or woman) while many milestones of psychosocial development are delayed or blocked by the unusual levels of medical supervision required to maintain survival on a ventilator. Knowing that many of the milestones and rites of passage of young-adulthood are largely off-limits to you, would you give up on extraordinary efforts to interact with peers? If not, how far would you go for opportunities for human contact? Sometimes breaking the isolation is more important than

avoiding risk. Despite the rule-bending involved and an acute awareness that the bulk of college life would be out of reach, I judged opportunities to connect with others as worth a lot of risk. Human connection is what makes life worth living, and without it, it’s difficult to justify continuing the daily battle that is living with mechanical ventilation. (Dupree 2016: 227)

It is important to note the privilege in Nick’s narrative. Nick was an educated, charismatic, and articulate white male. Similarly, the media representations of ADAPT and Little Lobbyist actions largely feature white people, even though the issues that concern them have particular relevance across intersectional and regional lines. Additionally, Nick had the ability to move from Alabama to New York; many people are unable to make this kind of move. Education, the ability and opportunity to advocate, and access to good health care vary from state to state and can tip the balance between life and death no matter where you live. People have options or at least pathways to survival in New York that are unavailable in states like Alabama or Texas, where personal support is limited to a maximum of 6 hours per day. New York offers a maximum of 24 hours per day via the Community Choice Integration Act that allows “money to follow the person” so that they can receive services at home. Yet entitlements in New York State vary by diagnostic categories: those with complex medical conditions accompanied by intellectual disability have access to residential and vocational supports unavailable to Nick and others like him.

These disparities extend beyond the United States, as access to complex health technologies is a privilege that many in the Global South will never have. Individuals like Nick may be vulnerable in relation to many other groups in the United States. However, those with complex medical problems, such as Nick, may be seen as elite and privileged in their access to education, resources, and social supports as well as their public visibility.

What lessons can we learn from the experiences of people like Nick as they face transitions when policies and services shift from pediatric to adult, or as adult relationships transform and lead to life changes? In the US cultural imaginary, turning 22 and legally becoming an adult is depicted as a time of increased freedoms and responsibilities. However, for young adults with complex medical conditions, it may mean moving directly from a children’s hospital to a geriatric nursing home. Individuals in such circumstances requiring high levels of support are commonly forced to live in places not of their choosing.

In the past, children like Nick rarely lived into adulthood; Nick was one of the earliest examples of unplanned survival. Advances in medical technologies and care systems have extended life for an increasing number of people. Yet the policy mechanisms that would allow for more than pure survival are not in place. Without the material and social structures of support, such youth are in a holding pattern, surviving but not thriving, with little opportunity to do more than exist. There is no doubt that with the proper supports in place, many could be living in the community, going to school or participating in work or day programs, engaged in meaningful pursuits. While New York is far better than many, perhaps even most, other states, Nick’s case shows that it still falls far short. This is an issue that deserves correction by policy makers on the state and federal level.

In short, those with complex medical needs transitioning from childhood to adulthood constitute a hidden population, often kept at home or in hospitals. It is not easy for them to access the community safely. Many attend segregated schools, sometimes within a hospital. Some scholars argue that this is an issue of involuntary incarceration; nursing homes and prisons all serve similar roles for disabled people, who often shuttle among them (Ben-Moshe, Chapman, and Carey 2014). Such policy failure is based on an inability to imagine a future where these children can survive into adulthood and live independently with support.

The precarity of their situation can become life threatening in emergency circumstances (Lapon 2012). Super Storm Sandy in New York City in October 2012 provided a particularly harrowing example of the vulnerability of people with complex disabilities. Nick’s apartment was without power for over a week (Evans 2012). Bypassing both federal and charity-based emergency management organizations’ insistence that he should be hospitalized (the hospital in question was later evacuated due to flooding), Nick was able to stay in his home. He accomplished this with the help of a group of friends who worked with him and his partner to ensure they received the care and support they needed when regularly scheduled nursing staff were unable to travel to them. They carried Nick’s ventilator machine batteries up and down the 10-story building to the fire station across the street where they could be recharged every two hours to ensure that Nick was able to continue breathing. Eventually, friends launched a fundraising campaign/road trip in order to buy the supplies needed for longer-lasting batteries (cobbled together from various parts including a car battery, and delivered to them) so that he needed to recharge only twice a day (Evans 2012).

I reached out to Nick and other vent-users to organize some educational and artistic programming about their emergency planning issues. We formed the VENTure Think Tank—designed to push for policy and technology innovation. Our first eVENT in September 2014 featured keynote speaker Marci Roth, then the director of the Office of Disability Integration and Coordination at FEMA (Federal Emergency Management Agency). Nick’s art was showcased at this event; though communication problems kept Nick from directly participating via phone or Skype, his partner was present and gave a speech on his behalf (Ospina 2014). My colleague, the well-known disability activist Brooke Ellison, also a vent-user, wrote up policy recommendations for the Moreland Commission, established to identify

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better strategies for emergency responders in future disasters (Block, Ellison, and Squillace 2016; Ellison 2013; Ellison and Block 2014).

Taking Chances for a “Life Worth Living”

In May 2016, Nick left his domestic partnership and sought other housing. Since it was not immediately available, he was first in the hospital and then in a series of nursing homes. In multiple email and chat conversations, he explained his vision to me: a residence for a community of young vent-users with different diagnoses and intellectual abilities living together, supporting each other and being supported by well-paid skilled caregivers. He saw his role in this imagined community as a scholar and teacher, offering art lessons as well as all kinds of learning, writing, and creating for his housemates and a larger community of vent-users who could come to the residence for day services.

Because Nick did not have an intellectual disability, he was barred from housing provided to this group, even though he had a housing voucher and would have been happy to live in a group home that supported such a population. Unfortunately, he gained a “frequent flyer” reputation from bouncing between the hospital, where they respected his vent settings but where he was susceptible to infections, and the nursing homes where they used inappropriate settings for his mechanical ventilation so he was not getting enough oxygen, which almost killed him. He was also susceptible to infection there. This made attempts to find community housing impossible as he was seen as at high risk of being unable to live in the community due to his mounting health needs, and service providers were less willing to work with him. If someone like Nick goes back and forth from nursing home to hospital too often, the insurance company determines that the person needs emergency room–level care, and they will most likely lose their right to community-based housing. The “why” of how you wound up there does not matter; the simple frequency is seen as justification enough to deny housing.

By January 2017, cycles of infection and pneumonia weakened Nick’s body. He had pressure sores for the first time in his life and was in constant pain. Policies regarding ventilator settings (volume in relation to his height) meant that he lost his ability to speak, was not given an accessible call bell, and required a lawyer’s assistance before the hospital gave him assistive technology with eye-tracking capability.

Activist and friend Julie Maury and I planned for Nick’s move to a nursing home in Long Island where he could be closer to a supportive network. But by February 2017, he was in the ICU waiting for a custom-made part that would make his trach tube changes safer; unfortunately, it was lost in the mail. These tubes connect Nick’s body to the ventilator and allow him to breathe. To replace them requires a medical procedure. While in the ICU he caught several more infections and developed a stage 4 pressure sore. Infections led to sepsis, weakening his heart. There was a crisis during a trach change; the crucial part never arrived and Nick coded. He was resuscitated but not fully conscious again after that. He died on February 18, right before his thirty-fifth birthday. By February 19 we were planning his funeral.

Nick fought his entire life to stay away from hospitals, nursing homes, and related residential institutions, first in Alabama and then in New York. Eventually, when his domestic partnership ended in 2016, he succumbed to a bombardment of infections acquired in hospitals and nursing homes. Prior to his decision to leave his partnership and their home, Nick had been in stable health. If there had been safer residential options available, financed, and with appropriate support for his unique medical needs, he would likely have survived. However, there were no options available to him other than staying in a domestic partnership he no longer desired or living in nursing homes that put his health in danger. His death was preventable.

At each of the pivotal moments of Nick’s life, he knew his life was in danger. Simply going out with friends without skilled nursing help was a life risk. Moving to New York, knowing he would be living in a hospital for an undetermined length of time (this being something he had fought against so stridently back in Alabama), was a gamble he was willing to take. The move from the apartment in Manhattan to a hospital was a grave risk, but one he was willing to take to secure the future that he was hoping for. Unfortunately, this last time he did not accomplish his goal. We are left with his dreams and his vision and memories of his friendship, camaraderie, and scholarly collaboration.

As a tribute to Nick’s spirit, Julie and I started working with St. Mary’s Children’s Hospital in Queens, New York, in the spring of 2017, hoping to bring their vision and Nick’s together for a better future for vent-users. St. Mary’s serves an ethnically, regionally, and religiously diverse group of families, offering a vision of community living for young vent-users and a house for those aging out of the pediatric hospital system, as well as a hospital ward specifically for young adults. This would be the group home for vent-users that Nick envisioned. We saw St. Mary’s as a site for collaborative research focused on the lives of those with medically complex conditions and a place where activism, friendship, and scholarship could intermingle.

Our goal has been to design informational workshops and leadership/advocacy training programs for the disabled youth and their families, for health services staff, and disability support services. I also have been consulting with the New York City and Suffolk County Emergency Management and collaborating with FEMA’s Office of Disability Integration and Coordination to support a local core disability advisory group to ensure that vent-users and those with other disability experiences have a say in their emergency planning. We are gathering a group of technology specialists to help St. Mary’s build a “smart” house for the eight youth who will be moving into the new home. We want technologies that ensure a secure energy supply, to provide access to eHealth so that routine (but mandatory) medical appointments can be safely accomplished without unnecessary transport, to ensure expert consultation...
regarding the home’s complex medical equipment, and to allow families to communicate easily with their loved ones. Most importantly, technology can be used by the youth to access the world—for creativity, education, and fun, just as Nick wanted. Julie and I are working together with research assistants to gather stories of these young people.

Disability in a Time of Academic Precarity: The Case of Sini

In March 2017, less than 2 months after Nick’s death, I learned that the doctoral program housing the Disability Studies concentration would be suspended. Power was clearly shifting. The doctoral students were told there would be no funding for them after May 2017, throwing them into a panic; international students were especially affected, given the Trump travel bans. Students organized and got their funding back, but several untenured faculty were told their contracts would not be renewed. This is exemplary of the ongoing austerity actions occurring university-wide as other program closure announcements and faculty “non-renewals” followed. Indeed, such measures have been increasingly common across the country at public and sometimes private institutions. While fighting for the future of disability studies on our east campus, I accepted an interim appointment on west campus to chair three humanities departments that had been unwillingly grouped together, subject to nonrenewals of faculty, lecturer, and adjunct lines and the suspension of a doctoral program. I hoped I could help forge a livable future for all concerned, but I was naïve.

In my new role as chair I learned that the contract of one of the instructors, Sini Diallo, was not renewed. Sini writes about his experience from his own perspective:

Black, male, African, migrant, disabled, scholar, and lecturer: here is the ecosystem of my personal identity and my identity politics. This is the broth that soaks up my lived experiences and conscientização. This is who I am. I claim the world and occupy spaces qua black, qua African, qua resident alien, qua unmarried male, qua mobility impaired, qua scholar, qua lecturer at an American higher education institution. Occupying space from at times one and at other times from a combination of the multiple aforementioned identity worldviews has its privileges, precarities, and hopes. At my arrival as a disabled faculty of color, I was bestowed privileges and opportunities. Accommodations were made, for example, to provide me with a wheelchair-accessible office and classrooms and preferred teaching schedules. I was also recruited (Pam, following Joseph and Hirshfield [2013], would say invisibly taxed) to serve on committees and task forces charged with the advancement of transformative diversity, disability learning, and disabled work experience. I thus contributed to the President’s Advisory Committee on the Americans with Disabilities Act.

I also found myself facing precariousness within my home department relative to junior faculty mentoring and development as well as relative to the ethos of the department. My home department was a ghastly cliqued, old white male top-heavy place with a highly recalcitrant three-tiered system that vested in senior faculty (the old white males) the teaching of seminars at extremely sought-after time periods and days. Junior faculty (three women and one disabled person of color) had the responsibilities for most department-level and institution-level committee services. Lecturers/adjuncts (all women) were given teaching of service courses on a 5-day weekly schedule. Nearly no mentoring initiative existed. I ended up finding a mentor (really a person to talk to) in a department other than my home department.

Sini had been a tenure-track faculty member who was badly mentored: instead of being supported and accommodated for his disability and illness issues, someone convinced him to step down to the instructor track, given his resulting slow rate of scholarly production. Thus, instead of potentially being a protected tenured professor, he was therefore vulnerable to nonrenewal in the cutbacks of 2017.

A wheelchair user of color, Sini had recently almost died of a pressure sore and related secondary conditions. He lived alone and had no family nearby. In November 2017, worried friends and colleagues convinced him to go to the hospital, saving his life. After immediate emergency surgery and strong antibiotics, he was stable. However, given how long it takes for pressure sores to heal, his colleagues worked together to cover his classes since he was not physically ready to return to work. When the hospital was ready to release him to a rehab center, we helped him find a general practitioner, a physiatrist, and a wheelchair dealer, as well as a local independent living center for assistance with benefits and transportation, etc. Other friends ensured his bills were paid and his home clean and ready with proper assistive equipment for his return. It was hard to find a rehab willing to take him because many were afraid he was being “dumped” on them and might never go home.

Eventually, Sini regained strength; arrangements were made by the faculty social worker, his colleagues, and his clinical professionals for him to return home in March 2018. Ironically, because he was doing so well, he risked having his insurance cut off before the equipment he needed was in place at his home.

The messages that his life was over were overwhelming. He is a green card holder from Burkina Faso; what does that mean for his unemployment, his visa status, his eligibility for benefits, his future in his chosen home? What does it mean for his sense of self as a scholar and teacher? I became involved in the consideration of all these issues, although I was not successful in securing a long-term contract for him. In Sini’s words:

Early into my journey as assistant professor, I lived a number of medical challenges which significantly threw off course my progress toward tenure. At the times, I was aware of rumors about and representations of the institutional environment that were less than praiseworthy as to the recruitment, the promotion, and the retention of students and faculty of
color and the disabled (particularly disabled people of color). Conversations about my tenure process within my department and the dean’s office led to the advice that I switch from a tenure-track appointment to a term appointment. I was a major actor in my department as a program advisor and a key contributor to the university’s foreign language teacher education program. No one foresaw days when my skills and talents would not be needed. Then came times of uncertainty: budgetary constraints, program contraction initiatives. My contract was not renewed beyond the academic year 2017–2018. Coincidently, this was another time of medical challenge for me. I saw myself descending into the precariat: insecure employment and income, lack of occupational identity, unaffordability of healthcare expenses, etc. To date, my contractual situation remains unsolved. I have temporarily been renewed for fall semester 2018 and again in spring semester 2019 and fall 2019, one semester at a time, and at a lower salary. Nothing is yet known about spring 2020 and beyond.

Sini’s contract is now renewed semester by semester and with a hefty pay cut. We also do not know what recent and proposed laws will do to the social and health benefits he might be relying on in the near future. Despite the rhetoric of support for a disability-inclusive campus, the university’s actions have had a disabling effect on Sini’s academic life and career. Notwithstanding this difficult situation, he still had a certain kind of privilege—the privilege of first-class medical care, full-time academic employment, at least for now, and a network of supportive colleagues—along with the privilege of a green card and health insurance, providing continued benefits available even in the worst possible circumstance, should Sini’s employment contract not be renewed.

Theorizing Disability in a Neoliberal Era

The conditions of the lives of these two men—one a white man from Alabama on a ventilator, one a wheelchair user of color from Burkina Faso—are unfortunately exemplary of theories addressing the intersections of disability, health, precarity, surveillance, and incarceration (Ben-Moshe, Chapman, and Carey 2014; Berlant 2007; Puar 2015, 2017; Shildrick 2015). These authors also underscore the importance of theories of care, interdependence, and counter-narratives when we think about the racial, gendered, and ethnic aspects of care that these men have received, largely from women whose efforts are partially or fully obscured (Kitay 1999; Nishida 2016; Stewart 2012). These include Julie, Nick’s former partner, and the many women and men who provided different types of care for Nick during his life, while he was dying, and after he died. Sini’s support network included many women, including clinicians, friends, and colleagues, working directly and indirectly to smooth the bureaucratic and structural disturbances caused by his near-death experience and the ensuing required bureaucratic documentation and environmental transformations. Papers and exams needed to be graded, rent had to be paid, timesheets filled out and approved, new equipment ordered, and accommodations made to his condo. Much of this labor is undertaken invisibly and mostly by women volunteers.

Disability and Precarity in Academia

Those of us who are not in the deadly danger experienced by Nick and Sini can nonetheless be threatened by both blunt and subtle harms produced in academic systems. The neoliberal duality of austerity and hyperproductivity in academia can be disabling, as Akemi Nishida points out (2016). It can make us sick, provoking anxiety, exhaustion, and feelings of hopelessness and worthlessness. Systems of gendered, racialized, and ethnic bullying and harassment coexist with formal discourse celebrating diversity on campus. Would I take the risk of publicly shaming powerful administrators if it would help to get Sini reappointed and students properly supported, and insisting that the university administration adhere to ethical and legal requirements for the treatment of disabled people on campus?

In March 2018, Sini finally came home from the rehabilitation facility. He had been experiencing increasingly erratic quality of care at the skilled nursing facility, noting that a fellow patient had been dropped from a Hoyer lift and subsequently died. Some days, Sini reported that he did not get out of bed until after 1:00 p.m. because of staffing shortages. Flu and viruses swept through the facility in mini-epidemics. Though some of his friends thought he should stay in the facility and believed he was safer there than at home, it was pretty clear to Sini that home was far safer. In Sini’s words:

Early into my journey as assistant professor, I lived a number of medical challenges that significantly threw off course my progress toward tenure. At the times, I was aware of rumors about and representations of the institutional environment that were less than praiseworthy as to the recruitment, the promotion, and the retention of students and faculty of color and the disabled (particularly disabled people of color). Conversations about my tenure process within my department and the dean’s office led to the advice that I switch from a tenure-track appointment to a term appointment. I was a major actor in my department as a program advisor and a key contributor to SBU’s foreign language teacher education program. No one foresaw days when my skills and talents would not be needed. Then came times of uncertainty: budgetary constraints, program contraction initiatives. My contract was not renewed beyond the academic year 2017–2018. Coincidently, this was another time of medical challenge for me. I saw myself descending into the precariat: insecure employment and income, lack of occupational identity, unaffordability of healthcare expenses, etc. To date, my contractual situation remains unsolved. I have temporarily been renewed for fall semester 2018 and again in spring semester 2019 at a lower salary. Nothing is known about fall semester 2019 and beyond.

Sini was able to return to work in August 2018. His employment contract is now renewed semester by semester and with a hefty pay cut. Thus, he lives in continued precarity and income
disability studies certificate. The justifications for this decision were inadequate and needed to be addressed if the university is truly to be supportive for diverse groups of students and faculty that it claims to be. The university with a focus on building diversity claims to "love" disabled people, much in the same sense discussed by Michele Friedner (2020) regarding how nondisabled people in corporations professed loving the disabled employees. Such anonymous love (Stevenson 2014) is useful for corporate, governmental, hospital, or academic institutions but of no practical use for actually disabled people. Similarly, the borders and boundaries between campus units, much like those out in the world, are imaginary, yet they frame our programs, our scholarship, and our lives. In what interdependent spaces is it possible to imagine disabled activists and scholars working together for survival into an uncertain future?

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References Cited


Concluding Thoughts

My life was transformed through my relationships with Nick, Sini, and the undergraduate student group the Peer Mental Health Alliance. I have documented these cases as exemplars of how disability, precarity, and privilege in academia and activism are entwined. Their different narratives, of body-minds, social, economic, employment, and programmatic status illustrate the multitude of precarities of occupation, policies, and institutions faced by people with disabilities.

In 2019, many close friends have left the university due to program closures, nonrenewals, and refusal to remain in a hostile workplace environment. Over 30 people are going or gone from my campus home, an enormous demographic shift for such a small school that barely topped 100 faculty before the mass suspensions that began in 2017. I know of several other disabled faculty members and instructors (aside from Sini) who have left, been nonrenewed, or otherwise were forced out of the university. Now I am leaving myself. I am left to wonder, applying the ideas of Arseli Dokumaci (2017, 2020) about the significant constraints that exist in academia, in activism, and in the places where these overlap and also the affordances that exist and that we can create for each. Whatever affordances exist are not sufficient; the constraints are significant and need to be addressed if this university is truly to be the supportive home for diverse groups of students and faculty that it claims to be. The university with a focus on building diversity claims to "love" disabled people, much in the same sense discussed by Michele Friedner (2020) regarding how nondisabled people in corporations professed loving the disabled employees. Such anonymous love (Stevenson 2014) is useful for corporate, governmental, hospital, or academic institutions but of no practical use for actually disabled people. Similarly, the borders and boundaries between campus units, much like those out in the world, are imaginary, yet they frame our programs, our scholarship, and our lives. In what interdependent spaces is it possible to imagine disabled activists and scholars working together for survival into an uncertain future?
Block, Activism, Anthropology, Disability Studies, Austerity


Prosthetic Debts
Economies of War Disability in Neoliberal Turkey

Salih Can Açiksöz

Following the neoliberal restructuration of the Turkish welfare and banking systems in the 2000s, many veterans of Turkey’s Kurdish war faced debt enforcement due to failed payments for prosthetic limbs. Veterans responded to debt collection by turning their own bodies into spectacles of debt and sacrifice by publicly removing and showcasing their debt-ridden prostheses. The media interest in these prosthetic spectacles further amplified the visceral threat of dismemberment evoked by veterans’ embodied performances. The public debates surrounding “prosthetic repossession” cases extended well beyond veteran welfare issues, inscribing all sorts of social and political anxieties on the amputee veteran body, such as anxieties around the incommensurability between the value regimes of nationalism and neoliberalism or around the Syrian refugees. Providing a window into larger questions about the interconnections between disability, gender, nationalism, and neoliberal capitalism, prosthetic repossession cases show us how debt and disability coproduce each other at the nexus of consumer debt and nationalist welfare in Turkey. By homing in on the prosthetic re-membering and dismembering of veteran bodies in a rapidly changing health milieu, we see how the political economy of violence and the violence of political economy become complicit in the production of debt, dismemberment, and prosthetic rehabilitation.

“He left us nothing but debt,” responded Serhat, an amputee veteran in his late thirties, to my question about his deceased father. “My whole life was spent paying debt.” His words were more than mere metaphor. After his father’s death, Serhat had dropped out of high school to work to offer financial help to his family in debt and then gone into military service to pay his “debt to the homeland,” as compulsory military service is popularly called in Turkey. After losing his right leg below the knee in a mine blast, he lost his manual job and piled up a large amount of social and financial debt during the many years he spent trying to recover his health. Thanks to the prosthetic, financial, and employment benefits that the state had recently introduced for soldiers disabled in clashes with Kurdish guerrillas, he was literally and figuratively back on his feet when we met. He could walk without pain, had just paid off the debt on his car, and was paying the interest-free mortgage that the state provided exclusively to disabled veterans of the Kurdish conflict. “I paid all the debts I owed,” he murmured as he revealed his prosthetic leg, asking, “Who will pay the debt owed to me for this?”

Coming from an amputee veteran of the counterinsurgency war that the Turkish state has waged against the Kurdistan Workers’ Party (PKK) guerrillas since 1984, Serhat’s narrative reflects the ways in which different forms of debt structure war veterans’ disability worlds and life-history narratives. Most of the disabled veterans that I got to know during my fieldwork in Turkey between 2005 and 2008, including Serhat, had been conscripted and injured during the height of the clashes in the mid-1990s, when the country was grappling with a debt crisis, and its health and welfare systems were crumbling under the pressures of a ruthless neoliberalization program overseen by the International Monetary Fund (IMF). Although they had accumulated disability-related debts as a result of health expenses and the loss of wage income, in their life-history narratives, these veterans often expressed a political sentiment that they were owed unpaid debts by the state. The economic fact of indebtedness, combined with the idea that the state has defaulted on the politico-moral, financial, and biopolitical debts of war disability, guides the welfare and political activism of Serhat and other disabled veterans in twenty-first-century Turkey.

The theme of debt suffuses disabled veterans’ mediated representations in contemporary Turkey, where veterans frequently call attention to, refashion, and contest the debt relations woven into their lives through embodied political performances that rely on the nationalist politics and visual technologies of spectacle. Prosthesis, the historical icon of postwar state projects to recuperate productive and hetero-reproductive male bodies,

1. I borrow the concept of “disability worlds” from Ginsburg and Rapp (2013).

2. I use “spectacle” loosely to denote something that is presented to be seen and to be looked at, often in an objectifying way. Spectacle implies an audience and emphasizes the primacy of the gaze and the image in the mediation of power relations. For works that engage the concept of spectacle in the field of disability studies, see Garland-Thomson (1996, 2009).
has emerged both as the privileged symbol and the very material medium of such performances. In various contexts of protest, ranging from mass demonstrations to individual statements, veterans have publicly doffed their prosthetic limbs for the mediated gaze of the national community, imagined as a spectator. I examine in detail elsewhere (2019) the different forms that such "prosthetic spectacles" take. The particular prosthetic spectacle in question here concerns veterans’ removal of their prosthetic limbs in protest of the debt enforcement proceedings against them.

Following the neoliberal restructuring of the Turkish welfare and banking systems in the 2000s, many veterans faced debt enforcement either because they did not pay their prosthesis bills or because they did not repay the bank loans that they used to pay for their prostheses. Veterans responded to the threat of debt collection by deploying the political idiom of sacrifice, which signified veterans’ lost limbs as sacrifices for the Turkish nation-state. Turning their own bodies into spectacles, they recorded their grievances without wearing their prostheses and posted their grievances on social media, deliberately attended official commemorations with journalists present and absent their prosthetic limbs, and showcased their debt-ridden prostheses for the media during press interviews.

The media interest in these self-spectacles fueled the birth of a new genre of prosthetic spectacle: "prosthesis repossession." The media represented any prosthesis-related debt enforcement as a repossession order on the prosthesis itself, amplifying the visceral threat of dismemberment evoked by the veterans’ bodily performances. As mediated human-interest stories concerning the threat of the repossession of disabled veterans’ prosthetic limbs proliferated, prosthesis became the material epicenter of the public debates around the moral, political, biopolitical, and financial debts enveloping veterans’ disability worlds. Such public debates extended well beyond veteran welfare issues, inscribing all sorts of social and political anxieties on the amputee veteran body, such as anxieties around the incommensurability between the value regimes of nationalism and neoliberalism or around the Syrian refugees.

Prosthesis repossession cases provide a window into larger questions about the interconnections between disability and debt, neoliberal capitalism, militarism, nationalism, and political violence. In their recent attempts to think beyond the identitarian and rights-based models that are hegemonic within the white, middle-class, Euro-American disability worlds, feminist-, queer-, and crip-theory-informed scholars have critically engaged the quandaries of identity and inclusion under neoliberalism (Friedner 2015, 2017; Fritsch 2013; Markotić and McRuer 2012; McRuer 2006; Mitchell 2015; Puar 2017). Dovetailing with these emergent interests in political economy and violence in the field of disability studies, this article presents an ethnographically grounded analysis of the ways in which the political economy of violence and the violence of political economy become complicit in the production of debt, dismemberment, and prosthetic rehabilitation. Thinking prosthesis repossession through the gendered notions of debt and sacrifice, this article shows how nationalist cultural politics, neoliberal biopolitics, and the political economy of war disability feed into each other in gendered and classed ways as they form and constrain the prosthetic abilities and debilities of veterans in a rapidly changing health and welfare milieu.

Debt and Disability

Debt and disability intersect with and coproduce each other in multiple ways. Despite the dearth of cross-cultural and historical research looking at the interactions between financial debt and disability (Grech 2015), we know that people with disabilities end up having more debts (Elwan 1999). There is a strong association between acquiring impairment and acquiring debt, especially because many people have to leave paid employment for a reason directly related to their impairment (Kober 2005). Families with a child with a disability are also more indebted than the general population (Harrison and Wooley 2004) because of the temporal and financial demands of care (Houle and Berger 2017), which have often devolved onto families and individuals in neoliberal times due to the slashing of welfare systems.

If disability produces financial debt by hindering access to adequate nutrition, shelter, and health services, debt produces disability in return. Debt cycles can, and in the neoliberal era frequently do, devastate a country’s financial system, which can in turn be used by international organizations and creditors to abolish welfare benefits and health services, leading to mass poverty, precarity, debility, and disability (McRuer 2010). Poor and homeless people have more disabilities than the rest of the population (Hansen, Bourgois, and Drucker 2014). Research demonstrates the mental health aspects of debt’s significant public health impact. In the United Kingdom, around half of the people in the general population with debt have a

3. For the history of postwar prosthetics in different contexts, see Bernstein (2015); Neumann (2010); and Serlin (2004, 2006).

4. This article draws on research and analysis from my book Sacrificial Limbs (2019), esp. chap. 6.
Debt to the Homeland and Other National Debts

Since the 1990s, the indebtedness of the state is frequently represented through reproductive futurism in the Turkish media: each child is born with such and such amount of debt. Within the logic of this platitude, each Turkish citizen comes into this world as an already indebted financial being. Such imagination of an equally shared national debt also operates in the context of military service, which is popularly called vatan borcu (debt to the homeland). Although the constitution defines military service as “the right and duty of every Turk,” debt to homeland is a classed, abled, gendered, and sexualized debt, as are all debts. It is a debt that an able-bodied man owes to the state for his heteropatriarchal privileges as a gendered and sexualized citizen and social subject. Military service is compulsory only for able-bodied men and excludes men with officially recognized disabilities, women, and openly gay and transgender men. At this juncture of the regimes of compulsory able-bodiedness and compulsory heterosexuality (McRuer 2006), compulsory military service operates as a financializable political transaction through which male citizens pay either through military labor or by monetary means for their initiation into hegemonic heteromasculinity and the national community.

The notion of debt is not metaphorical here; the debt embedded in military service is quantified and financialized through the routinized practice of paid military exemption. In 2011, I had to pay the state US$7,000 to get away with completing 3 weeks of basic military training and buying off my remaining time. In 2014, 203,824 people applied for the paid military exemption amid the intense competition among banks to give loans that would pay for exemption applications. My interlocutors tended to resent the state’s policy of raising financial resources through the practice of paid exemption and always showed an acute awareness of the financial character and “political etiologies” of their disabilities. They articulated an implicit class critique against the privileged exempts, of which I am one, in their life-history narratives.

5. I borrow the term “reproductive futurity” from Edelman (2004), who uses it to define the cultural logics by which the social good is expressed through heterosexual biological futurity.

6. In her work on organ transplantation in Egypt, Sherine Handly (2012) uses the term “political etiology” to conceptualize the process whereby patients actively link their bodily symptoms to their larger political critiques of the state’s unequal distribution of resources and risks.
The state takes harsh measures for debt enforcement. In practical terms, being a draft evader means facing the suspension of basic citizenship and social rights. Because evaders are taken into custody and forcibly recruited upon being caught, they have to avoid everyday encounters with state institutions, meaning that they cannot renew ID cards, get married, travel outside of the country, open bank accounts, or even vote. Debt enforcement is also implemented at a societal level; potential employers and prospective in-laws often require that a young man complete his military service to become eligible for work and marriage (Sinclair-Webb 2000). In newspaper job ads, for example, employers typically seek employees who have completed their military service, and job seekers have to write down their military service status in job application forms. Families rarely favor marriage before the prospective husband completes military service and hence simultaneously cleans his debt to the homeland and brings himself out of harm’s way. In this context, military service operates as a masculine rite of passage that seals an ableist and hetero-patriarchal contract between the state and the male citizenry: by paying the financial(izable) political debt of military service, young male citizens become full-fledged masculine citizens/workers/consumers who are eligible for marriage and employment.

No matter how strong the moral and judicial mechanisms of enforcement are, with any debt there is always an imminent possibility of default (Graeber 2011). The record number of conscription evaders (recently reported as around 627,000) and the increasing number and political visibility of conscientious objectors testify to this central insight of the anthropology of debt. Yet there is another social complication with debt that has not attracted as much attention: What happens when a debtor clears off his debt (in this case, the debt to the homeland), but the transaction fails to deliver its promise (in this case, the gendered promise of sovereign masculinity)? What distinct kinds of debts accrue through war disability?

My disabled veteran interlocutors’ experiences of military service ended up being markedly different from the hegemonic “becoming a man through military service” narrative. Most of my respondents hailed from the urban poor and working class and were conscripted during the 1990s, when the economy was undergoing neoliberal structural adjustment programs. During that period, state indebtedness increased alarmingly, reaching 150% of Gross National Product (GNP) by 2001. With Turkey’s entire tax revenue required to service the debt, successive governments found themselves squeezed for funds and had recourse to new loans, especially from the infamous IMF (Keyder 2004). State protections against the ravages of neoliberal market forces were crushed under the weight of debt; welfare and health services were left to deteriorate under IMF prescriptions (Keyder 2004). It was within this context that most of my interlocutors were wounded and hospitalized and experienced the first years of their injuries and lives with disabilities. It was also against this backdrop that these veterans found themselves in the proliferating neoliberal “zones of social abandonment” (Biehl 2013), such as the social security hospitals where destitute patients were taken hostage by hospital administration for the nonpayment of user fees.

In these zones of abandonment that materialized at the intersection of ableism, class inequality, bureaucratic indifference, and gender normativity, my interlocutors were not left to die but were made to live a life characterized by stigma and exclusion from public citizenship, heteronormative masculinity, and wage labor. Their post-injury lives were often characterized by the loss of breadwinner status in the discriminatory labor market, difficulties in getting married, and dependence on their natal families for financial support and daily care. In sum, they were disenfranchised, infantilized, and expelled from the institutions and performative practices of hegemonic masculinity. Moreover, they had to face the strong stigma of disability and live in an ableist cultural climate in which people called them “half-men” or even “half-dead.”

All these experiences are squarely situated within the cultural politics and biopolitics of disability in Turkey. Historically, the country’s welfare regime has not offered disabled citizens much, constituting them as subjects of familial care and charity (Yılmaz 2011). Notwithstanding the recent attempts at governmentality under the rule of the Islamist authoritarian Justice and Development Party within the context of Turkey’s European Union (EU) harmonization process, accessibility remains acutely limited in terms of urban infrastructure, transportation, and jobs. Finally, the strong socioeconomic and cultural stigma associated with disability, condensed in the figure of the disabled street beggar, persists despite the emergence of increasingly vocal and visible disability rights movements and national(ist) disability awareness campaigns that construct disability as “feel good diversity” (Friedner 2017). A nationwide research project reports the stunning finding that, in Turkey, the word “impaired” (sakat) is most commonly associated with the word “needy” (muhtaç). Still another recent finding suggests that 70% of Turkish people without disabilities do not want a neighbor with an orthopedic disability. In this milieu, my interlocutors honed their resentment toward the state, which had failed to conform to the terms of the heteropatriarchal contract, despite the fact that disabled veterans paid—or, in fact, overpaid—their debt to the homeland.

The abjection of disabled veterans from the gendered moral and political economies tethered to compulsory military service started to change as the disabled veteran body became a sacrificial figure. From the mid-1990s onward, disabled veterans were increasingly hailed in nationalist public culture as tragic heroes who self-sacrificed for the survival of the Turkish nation-state. These sacrificial discourses and

7. For the changing sociopolitical landscape of disability in Turkey, see Açıksoz (2015); Bezmex (2013); Bezmex and Bulut (2016); Bezmex and Yardımcı (2010); Erven (2012); and Yılmaz (2011).

8. For works that describe the 1990s nationalist public culture in Turkey, see Navaro-Yashin (2002) and Özyürek (2006).
Imagery was anchored to the honorific military title of gazi (in Arabic, ghazi), which can roughly be translated as "veteran" or "disabled veteran." However, none of those secularized words carries the historical weight and political charge of the term gazi, which was incorporated into secular Turkish nationalism in the early twentieth century with considerable Islamic historical baggage. In contemporary Turkish nationalism in the early twentieth century with considerable nationalist discourse, gazis are lionized as consecrated warriors, witnesses, and worldly representatives of martyrs, who are often eulogized as attaining the highest spiritual rank after prophets. With the deployment of such potent religious idioms, the disabled veteran body was placed deeply within a militarist economy of sacrifice.

The increasing currency of sacrificial discourses and imageries has rewritten the terms of the debt relationship between the state and disabled veterans. It is now the state that is said to owe a debt to my interlocutors. At the official commemorations I attended during my fieldwork and in their public remarks, political leaders underlined constantly the nation-state's appreciation, gratitude, and indebtedness for the sacrifices of disabled veterans, who were owed "a debt of honor" (namus borcu, şeref borcu) or "a debt of gratitude" (vefa borcu) for the independence, survival, and "indivisible unity" of the state and the nation. This sacrificial debt was not conceived in abstract terms; rather, it mirrored the gendered logic of the debt to homeland, which was supposed to (but failed to) initiate young conscrits into the world of hegemonic masculinity upon its payment. In order to pay the debt back, various bureaucratic, medical, and welfare institutions were expected to take drastic steps to fix thisgendered crisis by ameliorating the disabled veterans' lives.

The gendered logic of sacrificial debt is clearly reflected in the material and symbolic rights and entitlements that the state has bestowed exclusively on disabled veterans of the Kurdish conflict, leaving aside the "duty disabled" (vazife malûlü), conscripts who were disabled in incidents unrelated to the armed conflict. These entitlements include free, high-quality prostheses that, at least in discourse if not in practice, "meet the highest standards in the world," in addition to job placement, interest-free housing credit, firearm licenses, and even state-sponsored assisted conception (Açıksoz 2015). The lurking gendered agenda of recovering the masculinity of disabled veterans is obvious here. Prosthetic limbs restore normative body image and, if only partially, mobility. Interest-free housing credits are aimed at making disabled veterans homeowners, thereby increasing their eligibility for marriage. Note that the Turkish word for getting married, evlenmek, is derived from the root ev (house) and literally means "getting a house." The job placement policy seeks to restore their breadwinner status, whereas firearm licenses provide them with the masculinizing capacity for violence that they are thought to have lost by becoming disabled. In sum, through the gendered logic of debt, disabled veterans are reinterpellated and recuperated as productive and reproductive male bodies through technoscientific and socioeconomic interventions operating at the most corporeal and intimate levels.

Political and moral debts imagined in terms of sacrifice render the debtor always "100 percent in debt" (MacLeish 2013; see also Wool 2015). "We can never pay our debt to our gazis" has been the rhetorical device underlining efforts to remasculinize disabled veterans through governmentalizing measures. The rights and entitlements introduced by the state have not come close to clearing the state’s sacrificial debts to veterans because sacrificial debt, with its nonsecular temporality and register of value, has no possibility of full payment and certainly no possibility of overpayment. In a message released to commemorate Gazis’ Day in 2017, President Erdoğan succinctly expressed this point: “The designations of the şehit (martyr) and gazi (veteran) are so venerable that they are incommensurable with any material value or this-worldly distinction.” In evoking sacrificial debt, there is always an excess that exceeds material benefits and resists attempts at financialization. It is this excess—the spectral power of loss signified as sacrifice, an unreturnable debt—that disabled veterans and the larger nationalist public would mobilize in prosthesis repossession spectacles.

Prosthesis Possession and Repossession in a Neoliberal Era

In the 2010s, national newspaper headlines and TV news stories were crowded with captions such as “Property repossession order for disabled vet’s prosthetic leg,” “Repossession order for disabled vet’s leg,” “ Shameless repossession order,” or “Disabled veterans in the grip of repossession.” Evoking dismemberment of disabled veterans through the forced removal of their prosthetic limbs, these prosthesis repossession stories conjured a morally charged spectacle of debt in which the audience as spectator was made to feel moral outrage at the financially motivated violation of the sanctified disabled veteran body.

Prosthesis repossession stories resonated with a longstanding cultural critique of neoliberal economic policies in Turkey. Forcible repossession of property has been vividly portrayed in Turkish cinema as the metonym of the gendered predicaments of neoliberalization. Some of the most famous Turkish films of the late 1970s and 1980s, when Turkey went through structural adjustment programs, involve indebted male protagonists who have their properties repossessed. Working multiple jobs but still unable to make ends meet, buying on credit, and indebted to the neighborhood’s shop owners for basic staples, these protagonists are symptomatic figures of the

9. For the historical baggage of the gazi title, see Açıksoz (2012, 2019).

loss of breadwinner masculinity in a neoliberalizing economic milieu. The melodramatic scenes of protagonists’ furniture being carried out of their houses under the reproachful gaze and remarks of their wives and in-laws are the epitome of their protagonists’ failed heteromasculinity. Cinematic images of repo men forcefully entering a house and seizing private and often feminized property, such as kitchen appliances, allude to the penetration and violation of the mahrem (the domestic intimate sphere in Islamicate contexts) space of the home by the masculine state and market forces through debt enforcement mechanisms, further emasculating and shaming the protagonist.11 This sentimentalist cultural repertoire informed news stories about prosthesis repossessions and disabled veterans’ mediatized voices.

The sentimentalist tone of prosthesis repossession stories was complemented and augmented by their sensationalism. These stories were sensationalist in the sense that they portrayed any debt proceeding tied to prosthesis debt as the re-possession of the prosthesis itself (protezine haciz geldi), evoking dismemberment of disabled veterans through the forced removal of their prosthetic limbs. In my inquiries within disabled veteran circles, I have not been able to verify a single case in which that happened. Yet despite their sensationalism, such shockers also represented actual shifts in the material conditions of prosthesis ownership: the entry of a new generation of prosthetic technologies into the marketplace, the increasing availability of consumer credit, and changes in the country’s social security system. With these shifts, an increasing number of disabled veterans faced debt enforcement proceedings due to nonpayment of their prosthesis bills or of the bank loans they had taken out to pay for their prostheses.

During my fieldwork between 2005 and 2008, most of my disabled veteran acquaintances used prosthetic limbs manufactured by the Turkish Armed Forces’ Rehabilitation and Care Center, the flagship Walter Reed–like military medical center exclusively designed for the care of disabled veterans of the Kurdish conflict. The kinds of prostheses that were made in the rehab center were lifelike plastic or silicone artificial limbs with custom-made and prosthetist-fitted sockets that had no myoelectric or microprocessor control mechanisms. With the increasing availability of more advanced and considerably more expensive prosthetic limbs through the private market in the late 2000s, many disabled veterans started to resort to commercial prosthetics providers for the replacement of their worn-out prosthetic limbs when their useful lifetime (5 years by law) was over. However, that came with an extra financial cost. At the rehab center, disabled veterans were not charged for prostheses; but for prosthetic devices bought through the private market, veterans had first to pay out of pocket and then make a claim for reimbursement. Because paying out of pocket required large sums of payment beyond veterans’ financial means, privately sold prosthetic limbs forced disabled veterans into debt.

The transformation of the prosthetics industry coincided with the changes in debt patterns among disabled veterans and more broadly in Turkey. At the time of my fieldwork, it was still very common among disabled veterans’ informal circles to pool money for things like weddings and new cars. But it was also clear that such cooperative financial practices, previously the economic backbone of disabled veterans’ collectivities, were increasingly undermined by the growing availability of consumer credit. This economic shift reflected the overall financial transformation of banking and household economies and the emergence of new indebtedness mechanisms after the 2001 financial crisis. In this period, marked by IMF-led structural reforms in the banking sector, the demand for consumer credit increased and banks pursued aggressive marketing and advertising strategies to encourage the use of consumer credit across social classes (Karacimen 2014). The result was a rapid increase in consumer loan and credit card use, making Turkey the largest market of bank card carriers in Europe.12 The total amount of consumer loans and credit card debt increased sharply from 1.8% of the gross domestic product in 2002 to 18.7% in 2012. The prosthesis repossession stories I share here were enmeshed in this debt-financed consumption pattern.

Coupled with these shifts in the prosthetics industry and the credit sector, the restructuring of the Turkish welfare system prepared the ground for the emergence of prosthesis repossession stories.13 The new welfare system introduced all sorts of new quantification, financialization, and audit technologies often associated with neoliberal reforms, to prevent welfare fraud that was said to be rampant.14 For example, a mediatized medical fraud scandal uncovered by a police operation called, importantly, Operation Prosthesis revealed a network of doctors responsible for US$100 million of financial damage to the social security system through fraudulent charges.15 In 2013,

11. Derived from the Arabic root l-r-m, the Turkish word mahrem “literally refers to intimacy, domesticity, secrecy, women’s space, what is forbidden to a foreigner’s gaze; it also means a man’s family” (Gole 1996:7).


13. For the restructuration of the Turkish welfare system, see Bozkurt (2013); Buğra and Keyder (2006); Eder (2010); Yılmaz (2017); and Yörükk (2012). These works demonstrate that, rather than being a straightforward example of the neoliberal retreat of the state, the restructured Turkish welfare system is a unique amalgam of neoliberalism mixed with political patronage, populism, and containment strategies, which together have led to the expansion of state welfare spending.

14. For audit cultures, see Joseph (2014); Kipnis (2008); and Strathern (2000).

following similar stories of fraud that implicated disabled veterans’ prostheses, the Social Security Institution (Sosyal Güvenlik Kurumu, hereafter SGK) established a set of regulations called Health Care Implementation Communiqués that listed prices and determined upper payment limits for each medical device sold on the market. Any payment above the upper limit was not ratified by inspectors or approved by auditors. This neoliberal bureaucratization would lead to the bureaucratic impasses underlying the prosthesis repossession cases.

During my fieldwork, I heard rare instances of prosthesis fraud. One of my interlocutors, Ramazan, for example, made a deal with a prosthesis company and traded his 5-year prosthesis replacement right for cash that he used to pay his mortgage, another novel technology of debt introduced in the 2000s. The company apparently issued a fake prosthesis bill and charged it to the state and then split the profit with Ramazan, who kept on using his worn-out prosthesis at the expense of being taunted by other disabled veterans, who said things like “you walk like a harlot” because of his uncomfortable gait and walking problems. After the introduction of the aforementioned neoliberal bureaucratic technologies, such shady deals probably became harder to make. Nevertheless, regulations like Health Care Implementation Communiqués also led to many problems and much confusion in practice. The defined upper payment limits rarely reflected actual market prices, and as the lists were constantly changing, my disabled veteran acquaintances were never sure which prosthesis was included in the communiqués and which was not. Thus, after buying prosthetic limbs from private companies through loans or certificates of indebtedness, many disabled veterans faced unpaid debt and thus prosthesis repossession initiated by the manufacturers, providers, banks, or the Social Security Institution.

Heroes in Debt

Not all disabled veterans were equally influenced by the neoliberal transmutations of the welfare system and the prosthesis industry. The differential political valuation of disabled veteran bodies within a tiered military welfare system rendered some bodies more vulnerable to indebtedness and prosthesis repossession than others. Most of the amputee ex-conscripts who faced prosthesis repossession by state institutions due to the nonpayment of their prosthesis debts were the duty-disabled, soldiers injured in non-combat-related incidents. As mentioned previously, ex-conscripts with disabilities who were officially classified as “duty-disabled” did not have access to the rights enjoyed by the gazi, apparently including the right to use the most technologically advanced prostheses. Their repossession cases were activated by the auditors of the Ministry of Labor and Social Security, who concluded in their reports that government reimbursement payouts were unwarranted in their cases because they lacked the official status as gazi. Following each audit, the Social Security Institution initiated a debt enforcement proceeding against the ex-conscript in question, often adding on interest charges and attorney fees. These ex-conscripts often went to the media to complain about unfair treatment, bureaucratic indifference, financial setups of the state’s welfare laws and institutions, and the violation of the gendered military contract between the state and its male citizenry.

The coverage of prosthesis repossession stirred up a certain amount of popular reaction on social media and even led to the foundation of a parliamentary commission to probe disabled veterans’ prosthesis debts. One repossession case caught the media’s attention when the victim iterated the form of the prosthetic protest against the financial practices around prosthesis debt by attending an official commemoration at a martyr’s cemetery without donning his prosthetic leg. As a form of protest, he had turned his body into a spectacle of debt by refusing to wear his prosthesis, thereby embodying the threat of dispossession imminent in prosthesis repossession. This action touched a nationalist nerve.

Yet it was only in 2014, when Bülent Köcağlan, who was a gazi and hence a proper sacrificial hero, became the victim of a repossession order that there was strident public outcry about the relationship of (political) sacrifice to (financialized) debt, a relationship made evident by the political and financial limits of prosthetic recovery. This veteran’s intricate debt story lasted for over a year, gaining extensive coverage in the media as it unfolded through multiple shifts of blame and responsibility. These shifts involved numerous institutions and politicians, including the prime minister, which led to multiple press statements from the General Staff and the Social Security Institution and to a parliamentary inquiry directed at the Ministry of Defense.16

The news stories about Köcağlan all detailed how he had lost his leg, framing him as a sacrificial hero. According to these media narratives, “Gazi Bülent lost his left leg in a terror attack in Hakkâri, Çukurca in 1996, during which his sixteen brothers-in-arms were martyred.”17 “Miraculously surviving” the attack, he had an above-the-knee amputation and a long rehabilitation in multiple military hospitals. In the end, he received a prosthetic leg, began working as a state employee, got married, and started a family. In photographic images that accompanied coverage of his indebtedness and the repossession of his prosthesis, he posed with his three children and with his three old prosthetic legs, thus displaying an eerie correspondence between prostheses and fatherhood. By portraying his prosthetic limb as constitutive of the productive and reproductive masculine world he inhabited, these narratives constructed prosthesis repossession as the unmaking of his gendered lifeworld—and by extension the entire gendered governmental edifice built to remasculinize disabled veterans.

16. Although parliamentary questioning is not a major mechanism of parliamentary control of the executive in Turkey, it is a principal means of collecting information.

Kocaoglu’s debt story reportedly began when he decided to use his legal right to replace his prosthesis with a more technologically advanced model through market channels. Like many of my interlocutors who wanted to buy outside of the rehab center and start using their new prosthetic limbs before the completion of payments, he made a murky financial deal with the prosthetics company, allegedly via an under-the-counter advance payment, a common practice that left room for fraudulent transactions, which led to back and forth accusations when the arrangement soured. To make an advance payment for his prosthetic limb worth TL 135,000 (back then US$65,000), he took a TL 50,000 loan from the bank and agreed to pay the rest upon receiving reimbursement from the SGK. Yet despite a 7-months-long wait, the SGK did not process the payment. Unable to repay his bank loan and facing multiple repossessions of his prosthesis, appliances, and furniture initiated by the bank and the prosthetics company, Kocaoglu first tried institutional appeals and then resorted to social media by uploading a clip from his son’s smartphone in which he voiced his grievances.19

The clip became a social media phenomenon right around a time when the government was under intense criticism for failed peace negotiations with the PKK, a period in which a sense of sacrificial crisis pervaded Turkish society. The media immediately picked up the story and journalists flooded Kocaoglu’s apartment. In one of the more widely circulated news stories, the Hürriyet TV camera follows Kocaoglu as he walks with a limp, his medal of honor pinned to his chest.19 The scene goes like this: he sits on his living room sofa with a jaded expression, wearing his new prosthetic leg with two different models of prosthetic legs lined up next to him. He shakes some papers, which turn out to be petitions that he has submitted to different institutions, seeking help. He voices his grievances about how he has been treated by the addresses of his petitions: “They say, ‘Submitted for necessary action.’ This is the only response I got from them. I wrote to the prime minister, still no response. Maybe he hasn’t seen it. I don’t want to accuse him wrongly. Only one of the ministers has responded to my appeal and referred my case to the governor. That’s it!” The audience is given a sense of bureaucratic indifference but no clue that institutions like the Prime Minister’s Communications Center have no bearing on his problem in terms of their bureaucratic functions and responsibilities.

During my fieldwork, I collected a pile of similar petitions and institutional responses that my interlocutors shared with me. Like those of Kocaoglu, most of these petitions were addressed not to the bureaucratic institutions in charge of the issue under petition but to randomly chosen influential politicians, statesmen, or state offices in the hopes that the performative power of their appeal might be enough to suck the potential influencer into their bureaucratic drama, thereby rendering their target morally and politically accountable. These papers constituted intimate bureaucratic archives in the disabled veterans’ homes, chronicling their vexed relationship with state institutions and state fantasies.20 Compiled and read by my respondents as archives of bureaucratic disinterest and political betrayal, these petitions produced and incited a strong affect.21 My interlocutors especially loved to read aloud the very last sentences of the institutions’ responses to their appeals—“Your request cannot be processed at our institution. Submitted for necessary action”—which they followed up with a mouthful of curses. Their angry responses to these documents were provoked by the sense of bureaucratic obliviousness to the bodily loss and suffering they had experienced. The neoliberal regime of so-called accountability functioned not only as a form of violence and slow death but also as a betrayal of their sacrifices. Their own regime of accountability, on the other hand, was very different, predicated as it was on the nationalist logic of unredeemable sacrifice.

The televised news story about Kocaoglu similarly draws from the idea that moral and political accountability engendered by sacrificial loss cannot be overridden by financial and bureaucratic modes of accountability and governance. In the Hürriyet TV scene, right after he shows the audience the petitions, Kocaoglu explicitly contrasts the immobility and deferred action represented by the documents with the mobility and enhanced embodied capacities enabled by his new prosthetic leg.22 The new prosthesis, he says, enables him to walk on uneven surfaces and especially down slopes. Then, he violently manifests the very immobility that bureaucratic inaction creates for his life by taking off his prosthetic leg. “If the state did not pay, I would walk like this,” he says, holding the artificial leg in his hand while hopping around the sitting room on his real one. “I would make do! But was I like this when I went to do my military service?” Then, he points at his son peeping through the door and adds, “When I went to military service I was fit as a fiddle, just like him.” In other media interviews, he continues to emphasize the sacrificial dimension of his bodily loss: “I took a loan to pay for the prosthesis, trusting that I would be reimbursed. But I’ve made a mistake by trusting the state. Now, my hearth and home are about to fall to pieces.

18. Buğat Kocaoglu, “VID 20141002 155102,” YouTube video, October 2, 2014. https://www.youtube.com/watch?v=m5H2IJKLs14 (accessed December 12, 2018 [in Turkish]). In the Turkey of the 2010s, cellular phones became another technology of debt when bank loans for mobile phones became widespread and use of mobile minutes reached the highest rate in Europe.


20. The phrase “state fantasies” refers to psychic attachments to the state as a site of desire and fear. For the elaboration of the concept of state fantasy, see Arezaga (2000) and Navaro-Yashin (2002).

21. In making this argument, I am informed by Navaro-Yashin’s (2012) work, which analyzes bureaucratic documents as affectively charged material objects.

22. For the theorization of the link between bureaucracy and deferral, see Secor (2007).
Who is responsible for that? If I had known that I would not be reimbursed I would rather jump on one leg and not buy this prosthesis. This is unfair! I was a sapling when recruited. Not like this! They should find a solution to our problem.”

Disabled veterans’ public performances of destitution, although rare and strongly reproached by other veterans, are often very efficient in eliciting results. An ex-conscript ineligible to receive gazi benefits despite getting injured in the Kurdish region told me that after many fruitless appeals he decided to organize a protest in the middle of the government district of the capital city of Ankara with a placard that read, “I am gazi and I am jobless.” He was taken into custody by military police in less than half an hour but managed to reap some benefits after the event with the help of the commander of the military unit where he was detained.

Kocaoğlan’s appeals similarly received a response in no time. Precisely 1 day after the first news piece, various offices of the Social Security Institution began issuing contradictory statements one after another. The local office swiftly passed the buck to the central social security office and the Ministry of Health by placing the blame for delay in payment on the new financial accounting practices of the neoliberal audit culture. Its statement argued that the delay was caused by a pileup of files in the central office after new regulations came into effect that required auditors to review all prosthesis bills above the upper payment limits for financial wrongdoing before approval. The following day, it was the central office’s turn to issue a press statement and argue that the delay was actually caused by the fact that the prosthesis could not be found on the list of medical supplies eligible for social security coverage. After detailing the back and forth correspondence between different branches of the Social Security Institution, the statement reassured its readers that “the units responsible for processing this transaction have been informed and our institution thereby demonstrates the sensitivity necessary for the speedy resolution of the victimization of Gazi Bülent Kocaoğlan.” The Office of General Staff also joined in the chorus of press statements so as to quell the public uproar, explaining the measures the military had undertaken to resolve veterans’ problems with prosthesis payments.

Yet despite all these reassuring press statements, the debt story only became more labyrinthine when the SGK finally reimbursed the upper payment limit (TL 98,000), a sum significantly lower than what Kocaoğlan owed the company (TL 135,000). In the first round of media coverage of the prosthesis repossession, Kocaoğlan was exclusively portrayed as a hero who had been victimized by bureaucratic indifference and incompetence. The story then began to take strange twists and turns when the owner of the prosthetics company that had initiated the debt enforcement proceeding also went to the media to contest the veteran’s debt story. Asserting that the company never received the advance payment allegedly paid through the bank loan, he rebutted the veteran’s media statements by saying that Kocaoğlan actually had not paid a penny for the prosthesis he was using at the time of his public complaint, implying that he also misused the money reimbursed by the Social Security Institution. Maintaining that Kocaoğlan had deceived the public by appealing to the sensitivity around disabled veterans, he announced that he would file a lawsuit against the veteran.

Although Kocaoğlan was quick to refute these claims, the alternative version of the debt story cast doubts on his victimhood. As his case burgeoned into a scandal viewed through the lens of nationalist representational politics, the media stopped following the story. The very idea that a disabled veteran’s complaint could be disingenuous could not be assimilated into nationalist discourses on prosthesis repossession. The government’s official response to a parliamentary inquiry into Kocaoğlan’s case by the main opposition party also tacitly verified the prosthetics company’s version of the story while still acknowledging the general problems of prosthesis payments: “The veteran had renewed his prosthesis six times between 1997 and 2014, had already received the upper-limit payment, and lacked receipts proving his alleged advance payment.”

More strikingly, the official governmental response argued that there was no debt enforcement or repossession proceeding against the veteran from the bank, the prosthetics company, or the SGK. As a result, Kocaoğlan’s case was dropped and disappeared from parliamentary politics and the governmental bureaucratic sphere altogether.

Despite media and bureaucratic indifference, Kocaoğlan’s debt story has taken on a life of its own as a trope of oppositional nationalist populism. In the ultranationalist media, which sharply opposed the AKP government and its peace attempts with the PKK, the reposessed prosthesis came to symbolize the deep and pervasive politico-moral crisis that had bankrupted the nation. In one such news story, a disabled veteran challenged President Erdoğan by asking if his palace, the highly controversial luxury presidential palace built at the behest of Erdoğan, was constructed with the money he had denied for veterans’ prostheses. More importantly, Kocaoğlan’s case was circulated as a populist class critique with explicitly racist undertones and became the hashtag banner of the anti-Syrian refugee campaign, #Suriyelleriistemiyoruz (#wedontwantSyrians). In social media posts, images of disabled veterans with reposessed prostheses were frequently

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juxtaposed with an imagined carefree Syrian refugee, whose in vitro fertilization and cosmetic surgery expenses were falsely rumored to be paid for by the state. A particularly provocative tweet read, “250,000 bicycles for Syrians, but not a single prosthetic leg for a veteran”—a response to a rumored government campaign to distribute free bicycles to refugees. Contrasting the imaginary leisurely mobility of Syrian refugees with the immobility of the financially dismembered disabled veteran, this last tweet epitomized how prosthetic repossession cases have been mobilized for a diverse set of nationalist political agendas through the language of sacrifice and betrayal. The tweet also demonstrated how the “needy” Syrian refugee, very much like the figure of the disabled street beggar, had become a cultural figure set in juxtaposition over and against the disabled veteran, in an effort to call attention to the state’s betrayal of those who had sacrificed themselves in service of it.

Sacrificial Limbs and Prosthetic Debts

Prosthesis constitutes one of the main material/symbolic loci of the uneven distribution of bodily capacities and debilities by state and market forces. This distribution takes place along the axis of sacrificial debt in war-torn Turkey. Those ex-conscripts who are folded into the economy of sacrifice by virtue of fighting Kurdish guerillas and being recognized as gázis are deemed worthy of being prosthetically capacitated; whereas those who are excluded from the economy of sacrifice, such as the duty-disabled, are denied financial support for advanced prosthetic devices. Here, financial debt plays a dual and somewhat contradictory role: on the one hand, it enables veteran bodies through the purchase of technologically advanced prosthetic limbs that enhance mobility, while on the other hand, it threatens to debilitate and even re-dismember veterans through repossession. Ultimately, Turkish veterans’ prosthetic abilities and disabilities are fashioned through the ways in which different terms of debt (fail to) get translated into each other at the tension-ridden nexus of nationalist and neoliberal debt economies.

Prosthesis repossession cases are nationalist spectacles within which these debt relations are animated and contested through the mediated images of veterans’ dismembered bodies. They represent, in amplified form, the gendered cult of sacrifice around the disabled veteran body by construing the moral debts of war disability as incommensurable with the financial debts that accrue within a neoliberalized welfare system. In these spectacles, the legitimacy of financial debt is interrogated through the notion of the unpayable debt of self-sacrifice. Specifically, financial debt is represented as a secondary form of violence that shatters the prosthetic recovery process through which lifeworlds, unmade by a primary scene of violence, are remade with great difficulty.

These spectacles illustrate the contours of the contemporary biopolitics of war disability in Turkey as refracted through the gendered politico-moral economy of nationalism, neoliberal debt economies, and the new audit culture. In the nationalist politico-moral economy, the sacrificed body of the disabled veteran is deemed a creditor, rendering the state, as the beneficiary of sacrifice, a debtor. Yet such nationalist logic has been incompatible with the reigning consumer debt economy and neoliberal audit culture of a restructured welfare regime in which acquiring a cutting-edge prosthesis requires a significant amount of finance. Despite all the gendered political value inscribed on their bodies and prosthetic recoveries, many disabled veterans still face repossession for failed payments for prosthetic limbs. Supported by the wider nationalist public, disabled veterans have resisted this financialization by mobilizing the notion of sacrificial limb debt. In their attempts to overrule the neoliberal logic of financial indebtedness, disabled veterans have invoked the burden of their health expenses from within a separate sphere of exchange, one requiring protection from the intrusion of market forces. In the mediatized stories about repossession cases, all these tensions between the rival but interlocking value systems of nationalist sacrifice and neoliberal finance play out in the form of the spectacle. Highlighting the need for disability studies to engage seriously with questions of violence and political economy, prosthesis repossession spectacles remind us that the historical experience of disability produced by war is always mediated through debts, which operate within differential value and exchange regimes traversing the gendered formations of symbolic, structural, and political violence.

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References Cited


26. For the making, unmaking, and remaking of lifeworlds, see Das et al. (2001) and Scarry (1985).
Torture without Torturers
Violence and Racialization in Black Chicago

Laurence Ralph

What happens when trauma becomes a political frame for recognizing anti-black racism and police violence? I grapple with this question by illustrating the ways that survivors of police torture must present themselves as a part of a disability category. More broadly, this article demonstrates that, as opposed to being a category of difference unto itself, the idea of police torture in Chicago has been transformed through legal precedent, activism, and the resulting legislation to emerge, as it has in its latest rendition, as a medical condition. I argue that the role of trauma in producing such categories of disability is not unidirectional. Since racialized debilitation always already informs societal institutions before any contemporary incidence of state violence occurs, these concessions reify a “racial caste system” by putting the onus on the traumatized to gain state recognition. If they do not, then they have no one to blame but themselves. In sum, I show that the problem with trauma as a legal category is that it justifies inequality for black victims of police violence because these concessions betray a tacit assumption that they are debilitated by virtue of their racialized status before they can gain relief through the law.

November 2, 1983—The officer with the pump shotgun played Russian Roulette by showing me the shotgun shell, then turning his back to me saying, “Listen Nigger!” And all I could see was his back and not the shotgun or the shell. And I heard two clicks of the shotgun as if he was loading it. Then he turned to face me, forcing the barrel into my mouth saying, “Nigger! Are you going to tell us where A.D. is?” I honestly didn’t know A.D.’s whereabouts, and I tried to indicate this fact by trying to speak with a shotgun barrel in my mouth, when Grunhard said, “Oh, you know nigger.” Then the other officer said, “Shoot this nigger’s head off.” And I heard the shotgun click. This scene was repeated three times. On the third time, when I heard the shotgun click in my mouth, I actually felt the hair on the back of my head stand straight up. It felt as if the back of my head was being blown off. (Cannon affidavit)

The above excerpt is from Darrell Cannon’s 1985 affidavit. Two years before, Chicago police officers had tortured Cannon to elicit a confession that served as the linchpin that convicted him of murder. Cannon served close to 24 years in prison before he was exonerated and released. I am interested in Cannon’s case because he was one of the 125 African American “suspects” who, between 1972 and 1991, were tortured at Chicago’s Area 2 police precinct under the supervision of former police Commander Jon Burge. Although there is certainly evidence of more incidents of torture before and after these years, the number of victims and the dates identified correspond to Burge-related cases of torture. This is why, when I refer to the number of torture survivors here, I use the estimate of approximately 125, which is conservative since it refers only to documented and proven cases. I focus on these particular torture survivors because it is members of this group that initially petitioned the City of Chicago for reparations.¹

In the spring of 2014, Cannon’s case was included among a group of survivors of police torture who sued the city. The survivors’ case for reparations included a number of demands, such as a public apology from the city and a monument to be built in honor of the torture survivors. The survivors also filed for a monetary settlement to finance the Chicago Police Torture Reparations Commission and additional funding to pay for free tuition at the City Colleges, job training and placement for the survivors and their families, and health care. On May 6, 2015, the Chicago City Council agreed to many of these demands, including providing a collective settlement of $5.5 million to the survivors of police torture. The Reparations Ordinance also entailed the creation of a counseling center where torture survivors and victims of police violence could be treated for trauma. That request was realized in late May 2017, when the Chicago Torture Justice Center opened its doors. The Chicago Public Health Department provided most of the center’s funding and resources. As a result, police torture became managed by the city as a form of trauma. As I will show, the result of this new

¹ After Cannon’s torture in 1983, he gave a statement implicating himself in the murder. Later he sued the City on the grounds that he had been tortured into confessing, and he filed a motion to suppress his confession. The discussion of torture in this article is from an affidavit in Cannon’s motion to suppress hearing when he describes being tortured. Transcript of Affidavit of Defendant Darrell Cannon, People v. Cannon, No. 83-11830 (Cir. Ct. Cook County June 8, 1985); hereafter Cannon affidavit.

Laurence Ralph is Professor in the Department of Anthropology of Princeton University (124 Aaron Burr Hall, Princeton, New Jersey 08544, USA [lralph@princeton.edu]). This paper was submitted 11 XI 18, accepted 17 VII 19, and electronically published 26 IX 19.

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management scheme is that the actual act of torture is subsumed by an abstract notion of “trauma” and further muddled with the question of wrongful conviction, resulting in a situation in which the burden of proof becomes elevated for torture survivors, obscuring the constitutional tenet that torture in and of itself is wrong.

While certain previous settlements did acknowledge that a person was tortured, that acknowledgment always hinged on whether or not someone had committed a crime. In order to win a judgment, a person not only had to prove that they had been tortured but also that they were innocent of the crime that they had confessed to. By contrast, the 57 black men who were awarded reparations from the city of Chicago were never exonerated of the crimes for which they were convicted. Put differently, they were able to claim the status of torture survivors while not contesting their guilt. Consequently, all of these men—the ones who could prove their innocence as well as the ones who could not—were compensated for their torture, not for time they had wrongfully spent in jail. In this sense, the Reparations Ordinance separated the legal notion of guilt from the issue of torture. This is what made the ordinance unique: it was a concession on the part of the City of Chicago that torture was wrong, no matter what—wrong regardless of whether the suspect was innocent or guilty. That concession was unprecedented. Still, it is important to note that by limiting the number of torture survivors to 57 Burge-related cases, the city government has enforced the idea that torture is a problem of the past.

The Emergence of Trauma as a Disability Category

Here, I am interested in the present-day implications of this history; in particular, I examine the ways African American torture survivors must prove themselves adequately disabled to receive the benefits of reparations. I regard this invocation of trauma as a kind of “disability argument,” forcefully made by historian Douglas Baynton, who demonstrates that disability has been called on frequently “to clarify and define who deserves, and who was deservedly excluded from, citizenship” (2001:33). As he notes, disability arguments were prominent in the justification of slavery. “The most common disability argument for slavery was simply that African Americans lacked sufficient intelligence to participate or compete on an equal basis in society with white Americans” (37). Extending Baynton’s insights into the Chicago police torture case, I examine how torture survivors navigate reparations through a language and legislation of trauma that, by legal necessity, highlights their debilitation.

The literature on injury and disability commonly notes that, in the mid 1800s to early 1900s, as industrial accidents proliferated and more laborers were physically injured, disability congealed as a legal category as workers attempted (often unsuccessfully) to sue for compensation (Jain 2006:11; Samuels 2014). As a result, increasing numbers of disabled men and women fell into poverty and street begging (Braddock and Parish 2001:11, 35). This shift, according to Samuels (2014:2), “challenged ideologies of self-reliance.” Citizens lamented the fact that a worker might be disabled on the job, transforming a breadwinner into an “indolent pauper” in the blink of an eye, says Garland-Thomson (2017 [1997]:48).

More recent disability categories have also come into being through social movements. The Americans with Disabilities Act (ADA, 1990) is often cited as the preeminent example of how people who recognized themselves as unduly injured and excluded at the hands of the state, have made powerful claims for the growing recognition and inclusion of people with disabilities into society (Scheid 2005). Following the passage of the ADA, Longmore and Umansky (2001) show how individuals with disabilities must navigate social and governmental classifications to obtain resources necessary for daily existence. But the category of “disability” begins to break down when one considers the various kinds of identities and injuries contained within it (Davis 1995:xv). Building on this work, I ask, What are the limitations and possibilities associated with the fact that, now, the category of “torture survivor” in Chicago entails a medicalized notion of trauma linked to disability?

In this article, I adhere to the call for scholars to pay attention to how a person acquires a disability identity, noting here the significance of “traumatically induced impairment” (Berger 2014:164). Police torture is explicitly seen as a trauma with “chronic impacts” that “unfold over time,” which take the form of panic attacks, depression, and flashbacks. The trauma invoked here relies on a notion of impairment that is characteristic of the medical model of disability, which individualizes pain. Yet, I argue that the medicalization of torture entails “disability arguments” that are more appropriately framed within a “political/relational” model of disability (Kafer 2013:6). This is because the traumatizing effects of torture exist within a political terrain in which many more people have been traumatized by the police than those who have now been recognized as legitimately having the right not to be injured (Jain 2006:2). These claims are also political in the sense that arguments that one has been injured are often accompanied by the government’s attempt to evade responsibility for producing traumatic injury (7).

What happens when trauma becomes a political frame for recognizing anti-black racism and police violence? And what, for that matter, is the relationship between the traumatic effects of disability as recognized by the state and disability as an identity category? This article grapples with these questions by illustrating the ways that survivors of police torture must present themselves as a part of a disability category. This category, that of the “torture survivor,” has expanded beyond its legal and political domains in recent years, such that the management of survivors of police torture has shifted from the criminal justice system to health care services. As a result, the medicalization of this social issue has become a form of depoliticization (Kafer 2013:10). This is because a major effect of the Reparations
Ordinance is to locate and assist only those deserving of aid, and once aid is granted, the problem of police torture is presumed to be solved. The effect of this depoliticization, in other words, is that it allows the public to imagine a future in which police torture no longer exists without ever having to address the material conditions that led African Americans in Chicago to become systematically targeted for torture in the first place.

The Chicago case and redress won by torture survivors sheds light on the legacy of racism and violence in the United States, and yet, these concessions have created a paradox. While reparations in Chicago are delivered in the name of police torture, now seen as a historic injustice, no police officer has been indicted for torture (let alone tried or convicted of the crime). In this, Chicago’s city government has created a world in which the tortured exists, but torturers do not. I argue that this social phenomenon of torture without torturers must be understood in a context in which torture survivors are treated as trauma victims.

To this end, I begin by describing the different legal tactics that have historically worked to erase the perpetration of torture. I explore, in other words, what it has taken for people like Darrell Cannon to be recognized by his city as a torture survivor. I follow Cannon’s case from the details of his arrest and torture to his afterlife as a torture survivor and outreach specialist for the Chicago Justice Torture Center, discussed below. This trajectory demonstrates that, as opposed to being a category of disability always already informs societal institutions beyond its legal jurisdiction not only to recognize someone who had been wrongly accused or convicted of a crime but also to include someone who has been wrongly injured but may be guilty of said crime. In short, I show that the problem with trauma as a legal category is that it justifies inequality for black victims of police violence because these concessions betray a tacit assumption that they are debilitated by virtue of their racialized status before they can gain relief through the law.

More broadly, I argue that the role of trauma in producing such categories of disability is not unidirectional. Since racialized debilitation always already informs societal institutions before any contemporary incidence of state violence occurs, these concessions reify a “racial caste system” by putting the onus on the traumatized to gain state recognition for their wounds. If they do not, then they have no one to blame but themselves. The Reparations Ordinance has been an important and necessary milestone in Chicago for addressing the legacy of police violence. Nevertheless, it is also important to note that this legislative win provides resources without ever holding anyone accountable. This is why a growing number of Chicagoans are calling for the abolishment of the police, because as long as the police exist, they will never be held accountable, and therefore no justice can ever really be achieved.

The Category of “Torture Survivor”

“Becoming disabled,” says Garland-Thomson (1997), is a fluid process that depends on a given social context. Indeed, disability scholars have long contemplated what it means to inhabit a nonnormative body (Salamon 2010), how particular modes of embodiment become associated with the human (Chen 2012), and how common conceptions of the citizen and consumer can shift when people contest normative conceptions of embodiment in which “atypical bodies and minds” are assumed to be somehow “deviant, dysfunctional, and pathological” (Kafer 2013:5). When it comes to disability, ideas of normacy and deviations from them take particular shape within the public domain of health. The concessions won around a given health challenge make it acceptable for people to unapologetically call themselves disabled. Thus, many disabilities, rooted in rights-based activism, have become legible through market-driven awareness campaigns and institutional recognition. Such is now the case with the category of torture survivor in Chicago.

The category of torture survivor exists within a “capacitating frame” that recognizes some injuries at the expense of others (Puar 2017). This further cements the phenomenon of unaccountability because those victimized by the police have to pursue legal recourse to prove that they have been injured, while those who enacted torture are, by and large, not legally pursued. For example, to be eligible for reparations under the ordinance, a person had to be subjected to police violence within a particular time period (between 1972 and 1991) at a particular police precinct (Area 2), which was commanded by a particular man (Jon Burge). Everyone else who might have likewise been subjected to police violence outside of these parameters is not legally a torture survivor and is thus ineligible for the benefits that the ordinance provides.

In this scheme, “capacity” indexes the requirements for someone to reap the benefits of the Reparations Ordinance. For the purposes of the ordinance, only certain people can make a viable claim to inhabiting the position of torture survivor. Thus, the category of torture survivor “becomes a privileged category by virtue of state recognition” (Puar 2017:xvi). This section

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2. This article forms part of my larger research that examines the history of police torture in Chicago. Based on participant observation, focus groups, and structured interviews with 100 Chicago residents, including 17 victims of police torture, I show how the case for reparations expanded conventional ways of thinking about police torture survivors and how they should be compensated for their injuries. Here I explore the enduring link between disability, race, and criminality.

3. As I will explain later, I am thinking here of racial fantasies rooted in disability arguments, such as Hoffman’s black extinction hypothesis (1896), which attributes lower life expectancy to genetic weakness of blacks rather than structural violence.
illuminates the material conditions that have allowed torture survivors to gain such recognition.

With rare exceptions, known torture survivors are men. Overwhelming evidence suggests that police systematically targeted black men, making this the story not just of police brutality but also—as is often the case in police excessive use of force—of gendered institutional racism. The targeting of black men, specifically, for police torture, is illuminated in the material conditions that have allowed torture survivors to seek legal recourse. The legal legibility of the category “torture survivor” has been dependent on relationships and contingencies that have shifted over time. Cannon’s 1985 affidavit grounds this analysis. The intimate details of Cannon’s torture demonstrate his relationship to the wider torture scandal and how his fate as a torture survivor relied on the fragile contingencies through which lawyers, activists, and everyday Chicagoans developed the capacity to successfully demand that the city reckon with the issue of police torture. This point is evidenced in the following description in which Cannon discusses how Chicago police officers hang him by his arms before torturing him.

Cannon writes:

The two officers on each side of me were trying to lift up my body to a third officer, who was standing on the back bumper of the police car. Once the other two officers had lifted me up within reach of the third officer, they let me go, and the detective standing on the bumper would lift my body off the ground by holding my handcuffed arms behind my back. This would cause my arms to swing up backwards, creating unbearable pain. But that torture didn’t work too well because of the light rain. (The bumper was very wet, and the officer kept slipping off of the car. Then came the Cattle Prod.) This electric Cattle Prod is about ten inches in length, and about an inch and a half in width. The first time I saw this Cattle Prod was on the morning of Nov. 2, 1983. It was in the possession of Detective Burns. This Cattle Prod wasn’t made for torturing humans with. It’s for making stubborn cows or hogs move along when they might not want to. And it is a common fact that a cow or hog’s skin is far tougher than a human being’s.4

Through Cannon’s descriptions we witness how the police reinforce a racial hierarchy (cf. Smith 2016) in which Cannon is made to feel less than human. We see this as he is placed in a lower position from the officer, and made to linger in this lower position (indicative of his place in the social order [cf. Fassin 2013 (2011)]). When that technique fails, the officers treat him as they would an animal by shocking him with a cattle prod. In this way, through brutal violence, they are trying to force him to accept his dehumanized state. Although Cannon himself mentions the word “torture” twice in this excerpt, one cannot take for granted that what happened to him would be considered torture by law. These techniques of coercion come to be identified as torture, as opposed to mere brutality, in relation to techniques in other cases that were already associated with torture—most importantly the Andrew Wilson case.

Andrew Wilson was the first person to sue Jon Burge and the City of Chicago, claiming that he had been tortured. The first civil trial, in 1984, resulted in a hung jury. The second took place in the summer of 1989. Wilson’s testimony hinged on his description of a torture device called the Black Box, a cube-shaped box with a handle attached to it, like an antique music box. A generator inside the box produced an electric current. Electrical wires extended from the generator to alligator clamps. When the handle was cranked, electricity passed through the clamps and into the body.

“He put it on my fingers,” Wilson said that day in court in 1989. “One [of the clamps] on one finger and one on the other finger. And then he kept cranking it and cranking it, and I was hollering and screaming. I was calling for help. My teeth was grinding. Flickering in my head. Pain . . . .”

This last word, “pain,” was a fading whisper. Wilson’s voice grew softer as he spoke. He paused for a short while, and after reflecting on the horrifying memory of his torture, Wilson returned to his testimony.

“It hurts,” Wilson continued. “But it stays in your head, okay? It stays in your head and it grinds your teeth . . . it grinds, constantly grinds, constantly. The pain just stays in your head. And your teeth constantly grinds, and grinds, and grinds, and grinds and grinds.”

Seven years after he was tortured, Andrew Wilson was still unable to recount what had happened at Area 2 without choking up. When describing the Black Box, Wilson grew so upset that he wanted to leave the courtroom. The judge declared a short recess to grant him relief. Once the court proceedings resumed, Wilson came close to breaking down again. John Conroy (2000), a reporter who wrote about Wilson’s testimony that day, said that his lawyer urged him to “take a minute to compose himself.”

“It’s just like this light here like when it flickers, it flickers,” he said, before reminding the jury again of how the current from the Black Box made him grind his teeth. “All my bottom teeth was loose behind that. These four or five . . . and I tried to get the doctor to pull them. He said he wouldn’t pull them because they would tighten back up.”

After Wilson testified, Flint Taylor, in his closing arguments, reminded the jury that the case was not about the murder of two policemen (the crime for which Wilson was accused). Nor was it about the quality of Andrew Wilson’s character. Instead, the trial was premised on an ethical question: Had Andrew Wilson been beaten, tortured, and deprived of his constitutional rights after his arrest? Taylor argued that the city had done nothing to investigate Wilson’s allegations of torture. “Just because a policeman thinks Andrew Wilson deserves the electric

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5. Testimony here is from Wilson v. City of Chicago (N.D. Ill. 1989). Portions of this testimony are also recounted in Conroy (2000:69).
chair,” Taylor said, “doesn’t mean he can start the process.” Taylor, though, could not present the actual Black Box to the jury as evidence since Burge was rumored to have destroyed the device. Even so, Wilson was able to connect his description of the box to marks the torture device left on his body. The device produced tiny loops on the top of Wilson’s ears. Wilson’s right ear bore a zipper-like scar. Wilson testified that these marks came from the clamps connected to the box, and that when he ripped them off with his shoulders, those clamps had left scars. He also testified that because the police officers were frustrated by his constant squirming, they handcuffed him to two rings on the wall of the interrogation room. While Wilson’s body was stretched out he was facing a radiator located against the wall between the rings. The radiator, positioned just inches from his chest, burned Wilson’s flesh. His skin blistered and began to blacken. Like the loop marks on his ears, the marks on his chest were indicative of the methods of torture Wilson described. Given this evidence, the second verdict, issued on August 8, 1989, acknowledged that Wilson’s constitutional rights had been violated, and that Chicago police officers at Area 2 precinct had a policy of systematically abusing criminal suspects. When viewed in light of the Wilson case, one can see precisely how relational Cannon’s torture is, and how this relationality operates as a capacitating frame that allows brutality and abuse to be legible as torture. In the 1980s, when Wilson’s case first came to trial, the mobilization of “torture” as a juridical category was hardly thinkable. Wilson’s lawyers tried calling, as a witness, a doctor who had experience treating victims of torture in Eastern European war zones. The judge in the case refused to let the jury hear his testimony because he (the judge) was skeptical that there was an established field of expertise in which medical professionals could identify the signs of torture. The point here is that, in terms of the rule of law, torture was not determined by examining the quality of violent acts in and of themselves. Through a long process (that I describe below), Cannon’s case was eventually connected to Wilson’s by virtue of the precedent the Wilson judgment had set. The electric cattle prod, for example, draws a parallel with the black box, especially when one considers that the officers who elicited Cannon’s confession were from the same precinct and had been trained by the same man: Jon Burge. Crucially, Cannon’s torture occurred 6 years before the verdict in the Wilson case. Therefore, it cannot be reasonably argued that his affidavit had been influenced by the substantial exposure that the Wilson case yielded. It is important to note, as well, that if the violence enacted upon Cannon had occurred in another city, by another group of police officers, it might not have been seen as torture. Here the similitude of the two cases not only demonstrates the difficulty of even having torture recognized but also serves to erase the torturers themselves. The material techniques and instruments, such as the black box and the cattle prod, shift the focus within the legal discourse to nonhuman actors. Torture is recognized as such precisely because of the way these instruments burn, blister, and scar the skin. Each scar is scrutinized and presented as “evidence” that a person has been tortured and is deserving of recognition.

Yet the capacity for police abuse to be classified as police torture is not merely a result of dedicated liberal rights-bearing subjects professing those rights. Historical contingencies (Sahlin 2013) brought the legal category of torture into being. Based on the findings in the second Wilson trial, Amnesty International connected the abuse in Chicago to the episodes of torture taking place in other countries. In January 1991, Amnesty issued a report asking for a full-scale inquiry into the torture allegations at Area 2, lending its prestige as an international human rights organization to charges of police torture in Chicago. Seeing an opportunity to seize momentum, Wilson’s lawyers held a press conference and released Amnesty International’s report. During the press conference, a representative from Amnesty International declared:

People of color, particularly in Chicago, they understand automatically, situations like South Africa and Guatemala because here in Chicago you walk the streets with terror. You don’t have any concept of the police as a service—to serve and protect. Instead your view of the police is a view that they are getting ready to whoop on you the minute that they encounter you.”

This quote highlights the material conditions that allowed police violence to be understood as torture in Chicago. Over the decades, torture has become legible through an ongoing process by which international organizations (like Amnesty International, Human Rights Watch, and later the United Nations) have referenced the Burge cases. This, in turn, has allowed political groups and lawyers to mobilize torture claims locally, arguing that what happened at Area 2 was not merely abuse but torture as defined by international law. It is important to note that activists and allies believed that the US government would be mobilized to act on behalf of torture survivors because its global image would be tarnished if they did not. As anthropologists like Johanna Crane (2013) have shown in other contexts, the US government is so ill equipped or unmotivated to address domestic human rights violations against black populations that it must rely on the international frame.

More specifically, during the 1990s, when international human rights agencies were drawing attention to the perils of apartheid in Africa and the horrors of dictatorships in Latin America, the issue of torture provided a discourse about the abuses of corrupt governance. Through the Burge cases, Amnesty International drew Chicago into this orbit. A number of factors allowed for the mobilization of torture as a political claim in this


7. For coverage of this press conference, see Peter Kuttner, Cyndi Moran, and Eric Scholl, The End of the Nightstick, July 5, 1994. This documentary film can be accessed here: https://www.pbs.org/pov/watch/theendofthenightstick/.
context. Burge’s military career was a significant factor. Once Wilson’s lawyers did their research, they found that, in all likelihood, the black box originally served as a portable telephone for military personnel in the field. Jon Burge would have been familiar with these field telephones from his time in the army (Conroy 2000). Because Burge would never answer questions about it, we do not know for certain if the black box was in fact a military-grade field telephone or a new kind of hybrid torture machine. However, Wilson’s lawyers believed that it was exported from the jungles of Vietnam, where Burge had possibly dabbled in torturing suspected members of the Vietcong, skills he later dusted off for the streets of Chicago. (This theory was made more convincing by the fact that police officers in Burge’s unit later testified in civil suits that Burge would brag about giving criminal suspects the “Vietnamese treatment.”)

The understanding of police violence in Chicago as torture has also held sway, in large measure, because of the sheer number of cases that have inundated the city’s court system. After two civil trials, Andrew Wilson, the first person to sue the city, won his suit in 1996. By the time Wilson died in 2007, over 100 torture victims had been discovered, and the City of Chicago had paid out approximately $43 million defending police officers against torture claims. Lest readers think the word convicted by confessions allegedly coerced through torture seems hyperbolic, today the amount exceeds $130 million. Additionally, the city has paid out another $22 million in pensions for police officers implicated in torturing criminal suspects. A significant portion of this money ($15 million) was spent defending Jon Burge. The city has spent an additional $85 million in legal settlements to compensate Burge’s wrongfully convicted torture victims.

A number of these cases were filed in a post-9/11 world that brought renewed attention to torture because of the war on terror. Just as they had done in the 1990s, in the early 2000s lawyers and activist groups in Chicago would leverage this renewed attention as a way to draw parallels between international torture regimes that the US government had acknowledged and condemned and the Chicago cases. Additionally, scandals like Abu Ghraib forced Obama to condemn Bush-era enhanced interrogation techniques, which provided another opportunity for comparison.

The efforts to incorporate torture into the lexicon of police violence in Chicago has been so effective that in 2009, the state government created the Illinois Torture Inquiry and Relief Commission (TIRC) to investigate torture claims related to Jon Burge. In 2016, the TIRC expanded its jurisdiction beyond claims of Burge-related torture to anyone in Chicago convicted by confessions allegedly coerced through torture. In just a year, the new law quintupled the commission’s caseload. So far, 400 cases are pending investigation. But the commission only has the resources to investigate 16 per year. At this rate, “the Commission would need more than 23 years to make it through the cases currently before them,” writes Duaa Eldeib of the Chicago Tribune.

The current pending cases do not take into account the three to five torture claims the commission receives each week. Though its findings have the power to grant convicted persons a new trial, exoneration is no guarantee. Still, every year the City of Chicago uses taxpayer money to settle cases as the tally of torture survivors grows.

The next section discusses the experience of torture, examining how contemporary understandings of this juridical category are now being expanded to include dimensions of trauma. While it is tempting to think of trauma as the natural outgrowth of police torture, the phenomenon of police torture in Chicago did not gain status as a disability category until the 2015 reparation rulings and its provision to provide counseling to torture survivors. Below, I explore how the category of torture survivor becomes medicalized, maintaining its legitimacy in the eyes of the law. Ultimately, I show that the problem with this approach to trauma is that it does not account for the fact that people of color are always already debilitated by virtue of their (naturalized) racialized status.

**Torture and Racialization**

When they pulled the trigger, I thought I really got my head shot off that morning. (Darrell Cannon)

I have heard Darrell Cannon repeat that sentence at public forums on police torture many times over the years. Much as trauma victims are called upon to reiterate and re-perform their trauma over and over again (Allen 2013; Fassin and Rechtman 2009; James 2010; Ticktin 2011), Cannon is constantly called upon to perform his suffering. Each time he says those words, Cannon pauses, his body visibly shakes and he cries. These pauses have varied from 23 seconds to several minutes. The last time I saw Cannon was in the summer of 2016 at a press conference for the opening of the Chicago Torture Justice Center. The center is located on the south side of the city, in the Englewood Neighborhood Health Clinic. Cannon stood at a podium, surrounded by other torture survivors and center staff. Local news stations’ microphones were tilted upward to capture his voice. I watched with a small crowd gathered behind the photographers, video camera operators, and reporters, who waited to ask questions after everyone had spoken.


Christine Haley, the executive director of the center, began the press conference by informing everyone that this building had materialized as a result of the Reparations Ordinance. She went on to explain the center’s mission: “The Chicago Justice Torture Center provides group therapy and healing to any Chicaconan impacted by police violence. We will link residents to additional community supports such as primary care, job placement, and education services.” Shortly after Haley, Darrell Cannon spoke: “The place that we’re in today stems from a lot of blood, sweat, and tears—not only of survivors, but for their family members as well. No one should have to go through hell in order to bring about a measure of justice,” he said, wiping away tears. “Forgive me for being emotional, but I stay mad. I’m not hurting,” he insisted. “But I stay mad.”

After Cannon, Julie Morita, the Chicago Public Health Commissioner, took the podium, subtly framing Cannon’s emotions and anger in terms of structural inequality: “We at the health department understand that trauma is an issue impacting our communities, and we know that people who face trauma have disproportionate amounts of disease and poor health. . . . In order for us to improve the health within our communities, we really have to address this trauma.” After the press conference, I began scouring the internet for coverage of the Chicago Torture Center’s opening. One broadcast in particular was striking. On Chicago Tonight, Cannon went into even more detail about the long-term impact of his torture, explaining that he lost “everybody” that was close to him while he was incarcerated. His mother, father, and son all passed away, Cannon said, before describing the roots of his anger once again: “I get mad. I get emotional. And then I get so mad that I’m emotional. That is the trauma we torture survivors endure, every day, every night.”

Alongside Cannon, executive director Haley was interviewed on Chicago Tonight, explaining the “active symptoms” that one might experience after having been tortured by the police: anxiety, nightmares, not being able to sleep through the night, flashbacks. “We want to be that space where we can provide some respite, provide some support, so that folks can get better,” she said. Haley imagines the center to be a space where people are free to talk about anything. Once torture survivors feel comfortable, she and her staff hope to do “trauma-focus work,” she says, including narrative therapy and cognitive behavioral therapy. Cannon, himself, serves as an outreach specialist for the center.

The opening of a center for police torture survivors demonstrates how the disproportionate exposure to state-sanctioned violence produces traumas that the center seeks to manage and heal. Its location within an existing health clinic in the low-income African American neighborhood of Englewood is significant. Englewood has a long history of dealing with crime and violence. The city is thus targeting members of a population that they imagine are likely to be the current and future victims of police torture, while recognizing that these residents are disproportionately exposed to a host of social maladies—that is, school closures, mass incarceration, high unemployment, and high rates of illness and disease. Although a neighborhood health clinic already exists to address the medical needs of this constituency, as Christine Haley notes, this particular center will address the problem of police violence, and it is only able to do so because of the reparations judgment.

By positioning the center within a health clinic, a medical framework literally subsumes the problem of police torture, thereby transforming the category of “torture survivor” from someone whose constitutional rights have been violated to someone who must learn to manage the traumatic effects of disabling violence. This is not to say that the center only proposes medical solutions to the myriad social problems that torture survivors face. They offer additional services, such as job placement and educational advice. Still, one cannot overlook the fact that the largest funder of the center is the Chicago Public Health Department. Julie Morita, the Public Health Commissioner, not only correlates police torture with trauma but she also links this kind of trauma to disease and poor health outcomes. She draws upon her professional identity as a “neutral” and “apolitical” medical authority even though she is speaking in the context of politicized violence (cf. Hamdy and Bayoumi 2016:224). Notice that torture was successfully introduced as a specifically political category through the interventions of international organizations, yet this political claim is muted through and by individual clinical practice that seeks to relocate the event of torture within the treatment program of each subject (Fassin and Rechtman 2009:84). In so doing, the main practitioners at the center, its leadership, and its funders characterize police torture as a public health issue, not merely as a matter of injustice. For many of the torture survivors in Chicago, this is a new framework.

In his Chicago Tonight interview, Cannon himself says that he had not received any counseling regarding his torture until a few weeks before the center opened. Whereas he had come to understand his torture as a violation of his constitutional and human rights, now it was also something that a trained health professional could identify and diagnose. Thus, in Cannon’s second act as a torture survivor, he is becoming someone who can expect to manage chronic anxiety, nightmares, flashbacks, and anger for the rest of his life. He is also now a professional “outreach specialist,” presumably learning the necessary techniques to help others cope with the medical consequences of their disability. In this process, the medicalization of torture is produced through the social context of state governance. And this medicalization of police torture is also racialized.

Thus far I have discussed how marginalized groups are disproportionately subject to disabling violence; indeed, theories of governance can help us to comprehend how legal and medical categories come into being. Yet, such theories do not inherently account for the racial histories that underpin the social processes they describe. Contrast this with scholars who have studied the relationships among debility, disability, and race, examining how social processes are informed through and

by racialization (Berlant 1998; James and Wu 2006; Selden 2000). According to Samuels (2014:3), such processes seek to definitively identify bodies, to place them in categories delineated by race, and then to validate that placement through a verifiable, biological mark of identity. She elaborates, noting that processes of racialization ‘operate on the level of the ‘obvious,’ the ‘commonsense,’ yet simultaneously claim that only the expert can fully discern their meanings . . . They merge imagination and the real through desire, a desire that manifests in material effects on actual people’s bodies and lives’ (3).

When it comes to the process of racialization that informs the notion of black criminality, in particular, the signifying feature is the black skin that operates as an “embodiment of true physical difference.” As Samuel notes, such distinctions no longer confine themselves to the biological realm but penetrate cultural and social practices. It is instructive to understand how racialization informs policing; these processes operate on the level of the “obvious.” Practices associated with police torture, in particular, merge the imagination of black threat with the desire to tame it, thereby demonstrating the police officer’s heroism in saving society from the fantasy of black predatory violence. The black male sexual predator, in the white imagination, is assumed to be debilitated. He is subhuman and animal-like in the sense that he is assumed to lack the capacity to tame his cardinal desire (James 2013:128).

We can see this dehumanization clearly in the last paragraph of Cannon’s affidavit where he elaborates on the techniques of torture used on him:

The officer with the electric Cattle Prod was sticking it to my penis and testicles while my pants and shorts were pulled down around my ankles. And he kept his feet on top of mine so I wouldn’t be able to kick my legs up as I was being shocked. And from time to time officer Byrne would stick the electric Cattle Prod in my mouth to stop me from yelling so loud. And indeed I did stop yelling for a minute. And as they kept this up, Grunhard was over my head saying, “Nigger, why are you being so difficult. Just fill in the missing blanks for us and we’ll stop this right now.” And as soon as I said, “I don’t know,” I was hit with more electric shocks around my penis and testicles. After what seemed like hours of torturing me, I was ready to say my mother did it because I just couldn’t take any more shocks.

In this disturbing example, we learn that the way that Cannon is tortured proves significant. The techniques of torture that are deemed appropriate for black criminal suspects like him coincide with the way that black men have historically been portrayed in American society—particularly as sexual predators. Here the police inhabit the position of experts who “have a scientific way of interrogation” and can therefore identify a predatory criminal.

In US cultural history, the mythology of black criminality has often been premised on the idea that black men were a threat to white women. As many scholars have noted, D. W. Griffith’s 1915 film Birth of a Nation was a major cultural event (Rhodes 1993; Singh 2004; Williams 2001). The film, praised for its artistry and political commentary, advanced representations of black male criminals as the primary threat to society in the aftermath of the Civil War. Based on a popular novel, The Clansman, its cinematic makeover is now thought to be responsible for the rebirth of the Ku Klux Klan and the thousands of lynchings its members and other vigilantes enacted between Reconstruction and World War II (Mitchell 2011).

Consider the historic case of Chicago teenager Emmett Till. In 1955, Till was lynched while visiting his family in Mississippi, after a white woman claimed that Till had whistled at her. The vigilantes who hunted, tortured, and then killed Till were all exonerated. Recently, Till’s accuser, Carolyn Bryant, now an elderly woman, admitted that she had lied about her encounter with Till.11 If we think of Emmett Till (perhaps the most famous Chicago torture victim of all time) as someone who had been targeted based on being interpolated as a racialized subject, we can understand the significance of Chicago police officers electrocuting Cannon’s genitals. This form of torture serves to tame and punish Cannon for his imagined hyperbolized sexual prowess, marking him as a black predator from the perspective of his tormentors. In this sense, police torture operates through a mythology of black predatory violence that existed long before the designation of “torture survivor” was legally realized. Thus, these processes of racialization are haunted by the specter of debility. The empowerment of the category “torture survivor” is produced through the maintenance of longstanding racialized debilitation and the disposability of blacks on a disproportionate scale.

Conclusion: Deciphering the Flesh

Processes of racialization are central to the relationship between state-sanctioned violence, debility, and disability. Here, however, a crisis of interpretation arises that forces us to ask how we can accurately identify these processes and/or decipher them. While a forensic scientist accounts for a theory of the crime by examining the marks left on the corpse’s body, we can account for racialization by deciphering “hieroglyphics of the flesh,” those hidden messages that obscure social inequality (Spillers 1987:67). Put differently, the blackened and burnt flesh that the cattle prod inscribed on Cannon’s skin is not merely evidence of police torture. These hieroglyphics are intended to mark him as animal-like, subhuman, a deprived social being who has been historically targeted in order to protect white property and privilege.12 When he is electrocuted, the police

reproduce the social hierarchy in which he is deprived of personhood. His confession and eventual confinement serve to justify his torture. Racialization exists prior to the institutions that enact structural violence on people who, as a result of slavery and colonialism, we now refer to as black.

Thus, a major implication that stems from the concerns of this article is this: when it comes to the category of torture survivors under the Reparations Ordinance, the danger of disability rights discourse is that it seeks capacitation for some, while accepting the debilitation of others (Livingston 2012; Puar 2017). Worse yet, it operates in accordance to an ableist rationale, which posits that if a group’s injuries were dire enough, they would gain governmental recognition. The problem with this formulation is that by putting the onus on the debilitated to gain state recognition for their wounds, they have no one to blame but themselves if they cannot accomplish this task. In this way, the notion of accountability is shifted from the institutions that facilitate state violence to those who are debilitated by said violence.

My analysis is aimed at understanding why reparations in Chicago—that is, the city government’s attempt to repair the relationship between itself and its constituency—take their current form. Beyond the gains of “torture survivor” as a disability category, what are the structural solutions to the issue of police torture that address the problem of policing itself? Most of the reparations the city has awarded torture survivors are aimed at helping them help themselves. Yet, since no police officer has ever been convicted of torture, it can be said that no police torturers have ever existed in the eyes of the law. Such a world, bereft of accountability, remains dangerous for populations subject to debilitating violence. Meanwhile, popular policing philosophies and techniques, such as the Broken Windows approach, are often paired with metrics of officer performance, resulting in actual or implied quotas that drive increasing stop-and-frisk encounters, escalating misdemeanors into arrests and violent, even deadly, encounters with citizens. Likewise, current policing trends in Chicago are about targeting high-crime areas through quantitative metrics that attempt to predict where crimes will take place using algorithmic databases that categorize information on criminal suspects’ bodily identifiers (i.e., tattoos, bullet wounds, and birthmarks).

In contrast, I suggest it would be more worthwhile for the police to understand the processes of racialization through which their institution has been forged and to which it is still inextricably bound. This is especially dire since Chicago’s police department currently relies on quantitative data based on its own biometric fantasies of “pre-crime” prediction.13 These have had their own long histories in disability discrimination long before fingerprinting, when inmates skulls were measured upon booking (Samuels 2014:4). In short, human biometrics in the United States are deeply entwined with the white supremacist project of eugenics. Indeed, the notion of black criminality is rooted in the foundational disability argument that black people are innately inferior, justifying their categorization as property.

In the decades since abolition, lynching, convict leasing, police brutality, police torture, and police and vigilante killings, as well as mass incarceration, have perpetuated this logic of debility, always relying on the projection of black criminality and black subhumanity as justification. Such enduring rationalizations for social inequality are why, for many activists in Chicago, it is not enough to merely acknowledge the dialectic between debility and disability that continues to reinforce itself through policing. From their perspective, we cannot reform the police as an institution. They call for its abolition. From its ruins, they propose new models and practices of community safety and justice with the potential to break a debility-producing racialized cycle perpetuated by the “disability arguments” that justify torture without torturers.

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References Cited


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People as Affordances
Building Disability Worlds through Care Intimacy

Arseli Dokumaci

This article builds on the critical disability theory of affordances that I have been developing through ethnographic inquiries and the notion of “microactivist affordances,” by which I mean micro and everyday acts of world building with which disabled people literally make up, and at the same time make up for, whatever affordance fails to readily materialize in their environments. Drawing from fieldwork in Turkey and Quebec with people who have chronic pain and mobility-related disabilities, I explore how microactivist affordances emerge, not through the complementarity of a single perceiver and the world but through the complementarity of multiple perceivers and the world, within the particular material conditions of living with disability. Taking into account the sociality of my interlocutors’ microactivist affordances and their, after Ginsburg and Rapp, “disability worlds,” I propose the notion of “people as affordances” as a way to describe how people can enable the emergence of, or directly become, affordances for one another, especially where no other affordances exist. I then explore the various forms that “people as affordances” may take and that allow people to create access by their own means, and the socialities within which that access creation may—or may fail to—materialize. Finally, I suggest that “people as affordances” can provide new ways of understanding care that I, after Mia Mingus’s work, conceptualize as “care intimacy.”

I meet Ahmet at his workplace, a public library in a municipality center that offers educational activities, arts and crafts courses, and other services for people with disabilities. The center is located in a poor, densely populated neighborhood of Istanbul where, Ahmet says, over 4,000 people with disabilities live. We walk toward his home, which he shares with his sister and brother (fig. 1). Ahmet is disabled and has been living with rheumatoid arthritis (RA), a chronic inflammatory disease affecting the joints. I ask him how it started.1

Ahmet: [Translated from Turkish.] When I was six, in my feet and then my wrists. . . . I couldn’t stand on my feet. I was holding onto the walls. At first, they thought I was playing around, I mean, when it started in my feet. But I couldn’t walk. I mean, I could walk but I was tired right away, and then I asked my dad to carry me—and then my dad thought, this kid is just playing around. You know sometimes kids are like that. They don’t want to walk. So my dad thought that’s what I was doing. Then gradually my feet started to swell. Then my back and neck [pausing and trying to remember] . . . I remember a time—in the ’90s—we were going to the city. . . . Whenever the car and the wheels shook [mimicking shaking], I was dying from the pain. . . . I mean, I could move my head but it was so painful, you know, when the car was bumping along the road.

Arseli: Like the vibrations in a minibus (dolmuş, a common method of intercity travel in Turkey)?

Ahmet: Of course. Imagine, even with those minimal movements, I was in immense pain.

When Ahmet was about 10 years old, he was hospitalized for a time.

Ahmet: The disease, of course, progressed a bit during that period. You know, like when I was going to primary school, I walked by holding onto things, like walls. [His eyes gaze into the distance as he recalls the past.] That was it. I was holding onto things.

Arseli: Did you have any support while you were going to primary school?

Ahmet: [Smiling.] Well, I could walk, but only by hanging on to things.

Arseli: Were you able to attend classes?

Ahmet: Of course. But my dad helped me. He carried me in his arms. Because it was a village road, and the school was a bit far, about one and a half country bus stops (durak) away. They call it a footpath (patika), but it was a rough country road. Because it was rough, my dad would carry me to school in his arms and then

1. Names of participants have been anonymized. Translations from interviews in Turkish are my own. Unless otherwise noted, all other interviews were conducted in English.
go back. At the end of the day, he would come back to pick me up.

Arseli: Every single day, your dad carried you?

Ahmet: [Smiling emotionally:] Sure, he did—almost until middle school.

During his middle school years, Ahmet had to take a five-year break due to illness. He tells me, “My dad, of course, told me to get an education (oku). So I went back to school. In the meantime, he started to work somewhere else. My father’s an imam, a hodja (hoca). I went back to school. And again, my father brought me back and forth to school in his arms.” Such was Ahmet and his father’s journey.

I now move on to another journey. Over the past 10 years, I have been on an intellectual journey developing what I call a “critical disability theory of affordances.” Like any other critical disability (or what some prefer to call “crip”) theory, my theory of affordances is a work in progress that can always be bent, queered, and—as I shall do in the following—taken in unanticipated directions. This article builds on “microactivist affordances”—a term I use to describe micro (and often ephemeral) acts of world building, with which disabled people literally “make up,” and at the same time “make up for,” whatever affordance fails to readily materialize in their environments (Dokumaci 2017). Ahmet, for instance, leaves his shirts partly buttoned and takes them off as though they were pullovers, minimizing the need for buttoning. But his father also becomes an affordance for him, especially when no affordance exists that would enable him to access education. So might a father, living in a resource-deprived Syrian refugee camp in Turkey, invent a prosthesis from tuna cans, allowing his disabled daughter to move around the dusty campgrounds. These stories provoke the question: What if the making of micro-activist affordances is not, and has never been, one person’s individual affair? This is the question I explore in what follows.

Anthropologists of disability have already shown us how disability can enable the imagining of new forms of kinship (Rapp and Ginsburg 2011), how it could be occupied with new meanings (Block et al. 2016), and how the category of disability, as well as of independence and individualism, do not necessarily travel to non-Western cultures (Ingstad and Whyte 2007; Livingston 2006). Taking this literature as my starting point, I explore the sociality of affordance creation within the historical, material, and politico-economic specificities of “becoming disabled” (Erevelles 2011). Drawing on ethnographic stories of people with invisible disabilities, I discuss how people may enable, facilitate, or interfere with and disable the emergences of affordances for one another. To capture this sociality, I propose “people as affordances” as a subcategory of micro-activist affordances and as a new way of conceptualizing “care.”

I begin with an introduction to a critical theory of affordances, followed by ethnographic accounts demonstrating the different forms that “people as affordances” may take (or fail to take). I end with a reflection on what the notion of “people as affordances” could offer to an anthropology of disability.


3. I am of course not the only one to spot the need to talk about the sociality of affordances. Gibson himself writes about how “behavior affords behavior” (1979:135) and how children are socialized only when they begin to perceive the affordances of things for others with whom they share a niche (141). And with his notion of “canonical affordances,” Alan Costall calls for “socializing affordances” (Costall 1995, 1997). Giving the example of a chair, which, he argues, does not just happen to afford sitting but is “meant to” afford sitting in a sociocultural context that names, maintains, and sustains it as such, he calls attention to the canonical meanings of things. Similarly, Schmidt writes about how social properties of the environment also factor into affordances, not just, say, an object’s graspability. For instance, he discusses the “gift properties” of a mug given as a present and “ownership properties” of goods in a market (Schmidt 2007). Other post-Gibsonian commentators also note an “extraindividual” context (Heft 2013:165), a certain “normativity” (Rietveld and Kiverstein 2014:330) that shapes affordances and into which humans are enculturated. In a study informed by science and technology studies, Bloomfield and his colleagues show how the affordances of technological objects are not a pre-given effect of the relation between the user and the object but are “collective accomplishments” of various actors and their assemblages (Bloomfield, Latham, and Vurdubakis 2010:419–420). Most notably, Tim Ingold, with his notions of “enkillment,” “taskscape,” and dwelling approach, provides an anthropological context for affordances (Ingold 2000). My discussions build on this literature and expand it further by bringing into focus the sociality of microactivist affordances within what Nimra Erevelles (2011) would call historical-material transnational contexts.
Ethnographic Context

From 2009 to 2010 I undertook a visual ethnography in different parts of Istanbul (Turkey) and Quebec (Canada), working with people who have invisible disabilities related to rheumatoid arthritis. I visited participants in their homes, filming them as they undertook a series of daily tasks (such as cooking and dressing), and interviewed them about how they live with chronic illness and disability. I myself live with invisible disabilities related to rheumatoid arthritis, and all participants knew of this prior to our meetings, which eased the sharing of experiences and ingenious affordance improvisations. My own journey of living with chronic illness and disability for the last 20 years, in five countries, has provided the experiential groundwork for my proposal for a critical disability theory of affordances. Each location, each encounter, and each life cycle change has been an opportunity to flesh out the theory and rethink what microactivist affordances are or can be: how they are, and why.

A Critical Disability Theory of Affordances

The original theory of affordances comes from ecological psychology, proposed by James Gibson (1979) to describe how action and perception are shaped through the complementarity of organism–environment relations. Affordances are what an organism can do with its environment—its surfaces and its substances—depending on how their properties come to correlate with those of its own. “To be graspable,” for instance, “an object must have opposite surfaces separated by a distance less than the span of the hand” (Gibson 1979:133). Affordances are “invariant combinations of properties of things . . . taken with reference to a species or an individual . . . and [its] needs (biological and social) as well as to its action systems and its anatomy” (Gibson 1982:410). They reside neither in the environment nor in the body but in the inherent coupling of the two (see Stoffregen 2003). This means that a flat, rigid, horizontal surface may be “walk-on-able,” “crawl-over-able,” or “wheel-on-able,” depending on the organism in question (its scale, age, needs, skills, emotions, etc.), and the conditions of their encounter. Affordances are relational, situated, and emergent—but they are also simultaneously objective, invariant, and “always there to be perceived,” independently of whether they actually are perceived or not (Gibson 1979:139). In short, affordances are “equally a fact of the environment and a fact of behavior” (129).

I first engaged the theory of affordances during fieldwork for my doctoral research and questioned it in relation to what Ginsburg and Rapp (2013) call the “disability worlds” that I encountered. My research in Istanbul and Quebec at that time (2009–2010) explored how people with disabilities related to rheumatoid arthritis (RA) went about their everyday lives and tasks. Because RA affects joints, and because joints mean movement, one’s everyday life turns into a stage for “cho-reographing the dance of avoiding pain”—a dance that is done solo at times and with another, or others, at other times. This particularity of RA–related disabilities (which I knew firsthand) first led me to question the theory of affordances. What possible affordance could there be when life was lived in constant pain from joint inflammation? But then I also asked, If to be disabled is to “realize that . . . the world is not [your] dance floor,” as Vivian Sobchack puts it (2005, 62), what if disabled people imagined new floors to be danced on? What would these disabled reimaginations of the world do to the theory of affordances? I pushed this critical interrogation further during fieldwork in Montreal, where I collaborated with three differently disabled individuals, exploring their practices at home and following their daily mobilities through public places over the course of a year (2013–2014).

This incessant questioning, disrupting, and troubling—or “cripping” (Sandahl 2003)—of the original theory of affordances led me to develop a critical disability theory of affordances. In order to approach this theory, we must first ask what disability is in terms of affordances.

Whether as barrier, chronic illness or pain, or debilitation or lack of access to resources due to structural inequalities, disability, I propose, can be defined ecologically as a shrinking of the environment and its available affordances (Dokumaci 2019). But this shrinkage can also incite invention and improvisation that make the same environment afford otherwise and “slantwise” (Ahmed 2006:65), leading to microactivist affordances. In more empirical terms, a twist-off cap, for instance, does not complement a body with inflamed fingers in pain, or “deformed” fingers, or a body without arms. The cap is a materialized form of “ignorance” (Scarry 1985:288) of corporeal variations and vulnerabilities. But when my interlocutors bite a cap off or put the deformities of their hands to creative use, squeezing and twisting the cap, they bend its rigid materiality toward new possibilities of action. The everyday lives of disabled people may be full of such microactivist affordances. Frida Kahlo, for instance, designed blouses without fastenings and wore exuberantly colorful dresses of a length that allowed her to move easily, making her disability less noticeable.

5. Sara Ahmed uses the notion “slantwise” in reference to Maurice Merleau-Ponty’s phenomenology, where he describes the effect of seeing a room “not straight” but obliquely and as “ queer” (Merleau-Ponty 2002:289 cited in Ahmed 2006:65). Relating to the world slantwise, according to Ahmed, is a generative moment of disorientation to the right angles and right order of things.

6. In 2018, the Victoria and Albert Museum in London held an exhibition of Kahlo’s personal artifacts and clothing, aptly titled Frida Kahlo: Making Her Self Up. The exhibition demonstrates how Kahlo was a master affordance maker. The details of her microactivist affordance creations can, e.g., be traced in the following description in a New York Times review of the exhibit: “The boxy huipil blouses were made without fastenings, and could
So while the external world can be hostile to bodily particularities and oblivious to the experience of pain (Scarry 1985: 288) and illness, the affordances that an environment fails to provide in the form of built objects, places, and socially recognized gestures, disabled people may invent in and through the everyday improvisations and DIY inventions that I call microactivist affordances. These are mundane, ephemeral, and often unrecognized, parts of a process of “worlding” (Ginsburg and Rapp 2017:5–6) that allows disabled people to “create and dwell in inhabitable worlds” (Friedner and Cohen 2015). They let disabled people occupy niches “that are yet to be occupied” (Gibson 1979:128), when existing niches fail them persistently and pervasively (Dokumaci 2017:404). In short, microactivist affordances, in the way I define it, bring “accessible futures” into life in the ephemeral, ordinariness, and ongoingsness of day-to-day activity.

Thus whereas Gibson’s original theory focuses on affordances as a way to capture “the mutuality of the organism and the environment in a way no existing term does” (1979:127), my theory of affordances focuses instead on what happens when that mutuality cannot be readily found within the given order of things. My theory is not so much concerned with the entirety of action possibilities the environment offers to the organism as it is with those possibilities that its existing niches fail to afford, and what follows from that failure. Microactivist affordances catalyze the radical potentials of performance, improvisation, and creativity, allowing us to politicize and historicize affordances. They are activist because within their making the environment emerges not as static materiality but as “a total movement of becoming” in which “our actions do not transform the world, they are part and parcel of the world’s transforming itself” (Ingold 2000:200).

But what if microactivist affordances emerge not just from the reciprocity of organism and environment, as Gibson presumed (1979), but also from the reciprocities of multiple organisms and the environment within the particular historical-material circumstances of their encounter?

“People as Affordances”: Making Up Access by One’s Own Means

Let us return to Ahmet, who grew up in a small Turkish village in the early 1990s. To access hospital care he had to travel to the city, and there were few pharmacies in the region. His parents could only get medication for Ahmet when they drove into the city, and those medications only worked if taken regularly; otherwise the disease could suddenly flare up. And it did flare up. Ahmet’s primary school was far from his home, with neither a proper road nor a transportation system between them.

Connecting the two was a rough country road (a patika—literally, “a path to be walked upon”). Ahmet’s feet were inflamed and swollen. He could not walk without support.

All things considered, there was no way for Ahmet to get to school on his own. While many people with disabilities, in many situations, can “make do” by putting their bodies and surrounding materials in hitherto unthought of combinations (see Dokumaci 2013, 2017)—that is, creating microactivist affordances—there was no way for Ahmet to negotiate the footpath, to make it afford him otherwise or slantwise. Its uneven surface (cluttered with pebbles and weeds) and lack of railing was hostile to his disabled body in pain. Unless, of course, another body came in between, as did Ahmet’s father’s, who lent his arms to be carried within, and his feet to be walked with, becoming the affordance of what would have, in ideal circumstances, been a wheelchair, an adapted public transportation system, or a smooth-surfaced road.

Affordances, according to Gibson, are environmental properties “taken with reference to the observer . . . If a terrestrial surface is nearly horizontal . . . nearly flat . . . and sufficiently extended (relative to the size of the animal) and if its substance is rigid (relative to the weight of the animal), then the surface affords support” (1979:143). But this was obviously not the case with the footpath for Ahmet—the physical properties of the cluttered path in reference to his body were a “barrier” to an affordance. So what made school nevertheless attend-able for him? How did an un-walk-able path become walk-able?

The answer is Ahmet’s father. In the absence of a wheelchair, accessible roads, or public transport, Ahmet’s father became his affordance. This is what I mean by “people as affordances”—that people can enable the emergence of, or directly become, affordances for one another, especially when the affordances that their coming-together might create do not and could not otherwise exist within the niche they share.

“People as affordances” is therefore an important subset of microactivist affordances, bringing into focus the sociality involved in their making, through improvised relationalities between the world and one’s own body as well as between multiple bodies. If the affordance of support comes about in Ahmet’s story, it is not because only his physical and subjective properties are fundamental in reference to his environment, but because they also relate with his father’s properties, which in turn relate with their environment. The affordance of a walk-on-able surface for a child who cannot walk cannot be understood separately from the arms and hands and legs and feet and devotion, love, and care of a father who strongly believes in the value of education and who walks with and for his child.

The concept of “people as affordances” foregrounds another crucial dimension of microactivist affordances: the material conditions that shape their making. We cannot understand how the footpath becomes walk-on-able for Ahmet apart from the relationship between him and his father, nor apart from their specific living conditions. Rural 1990s Turkey lacked basic infrastructure and services (well-tended roads, hospitals, schools,
It is a story of affordances is a product of the macro as much as the micro. 

When people become affordances for one another, and create port for the disabled child and his family fail to materialize. And home within a locality where basic infrastructure and support for the disabled child and his family fail to materialize. When people become affordances for one another, and create access by their own means, we cannot understand this in isolation either from the structural conditions that necessitate their making (in Ahmet’s case, the lack of basic provisions in rural Turkey during the 1990s) or from the love, devotion, and care (between Ahmet and his father). In brief, “people as affordances” is a product of the macro as much as the micro. It is a story of “becoming disabled” (Erevelles 2011).

“People as Affordances”: Pain “Leaks”

In 2009 I visited Valerie and her husband at their country cottage in Eastern Canada. They live in a stone-built house—the house of their dreams—amid vast open lands, far from neighbors. They have a farm, and Valerie has a huge vegetable garden where she spent most of her time when she was still mobile. Her husband, Patrick, has installed an irrigation pipe so that Valerie can water the garden by just opening the tap without having to manipulate the hose, which is now difficult for her given her painful joints (fig. 2). When I met her, Valerie had been living with RA and its related disabilities for only a few years. The flare-ups, health complications, and pain, including during our interview, are difficult for her. I ask Patrick how the illness has affected their life as a couple.

Well, it started showing up very shortly after we were together. So, it’s not like we have, you know, 10 years before and 10 years after. Um, but yeah, I can see that she is in pain and I think we have just developed a way of, you know for some things, just doing stuff, day-to-day life . . . I don’t think about it very much anymore . . . Um, but there are times when it’s not always easy to understand and you know, sometimes . . . I mean . . . Sometimes. It’s not always easy, [turning to Valerie] but I think we manage.

I ask Patrick whether he could give some examples of the routine he mentioned and whether they do anything differently now than before the onset of Valerie’s illness.

Valerie: Let’s say we are at a place outside and people come with a, I don’t know, a water bottle. Brand-new water bottle. You always crack the seal and then you give it to me.

Patrick: Yeah. . . . Just trying to pay attention. Yeah, like when you put the cap back on something like we were saying before, not to put it, not to tighten it, right?

Valerie: Always, always, always. Or open a pop can, you know the little lid. [Mimicking opening a can.] You always do it.

Patrick: Yeah, it’s true.

Valerie: I don’t think you notice it anymore.

Patrick: Yeah, no.

7. In this regard, the notion of “people as affordances” is in conversation with AbdouMaliq Simone’s notion of “people as infrastructures,” with which he traces how “limited resources can be put to work in many possible ways” by urban residents of the inner city of Johannesburg, where institutions and infrastructures fail and immiseration prevails (2004:426).

8. It might be tempting to consider “people as affordances” as a form of Deleuzian “becoming,” as discussed by Margit Shildrick within her emphasis on “global intercorporeality” and corporeal interdependence within the network of globalization (2009:154–155). I would, however, along with Erevelles, express “cautious optimism” about this temptation (2011:53). When Ahmet’s father becomes an affordance, we are asked by Erevelles to, as she does in her own work, give a transnational, material historical account of “becoming disabled” (26), not just a celebratory account of transgressions.

Figure 2. Using the affordance of a piping extension built by her husband, Patrick, Valerie is able to tend to her garden without needing to manipulate a hose with her painful joints. (Photo by A. Dokumaci.)
Elaine Scarry suggests that pain is the most aversive form of human sentience, resisting any form of expression (1985). There are no words, tools, or objects in the world outside of us to correspond to this unique bodily state (Dokumaci 2013:109). But this very resistance to expression makes pain, as Scarry brilliantly shows, a generative source for pushing the limits of its representation. When the environment becomes most inhospitable, the very “counterfactual wish” that pain was gone allows us to imagine, make up, and inhabit a world of artifacts that embodies and expresses that wish, “redistributing” and “diminishing” pain (Scarry 1985:291). This is how the story of “the most contracted of spaces,” that is, pain, becomes the story of “the most expansive territory” of human sentence and expression: “the making and unmaking of the world” (22–23).

Allyson Patsavas also explores the relation between pain and its communication, in what she terms a “cripistemology of pain” (2014). Drawing on her own life, she writes: “My experience of living with pain leaks onto those around me in a way that cannot be contained by the boundary of my body or experience” (214). Following Margrit Schildrick’s idea of “leaky bodies,” she proposes “a queercrip understanding of pain,” where pain “flows through, across, and between always-already connected bodies” (213).

To be clear, Patsavas herself does not align her work on pain with Scarry’s. In fact, she positions her queercrip reading in opposition to Scarry’s work on pain, which she considers to be focused on pain’s unshareable and disruptive ontology. However, I disagree with Patsavas in the sense that Scarry discusses the unshareable and nonrepresentable ontology of pain, not to invoke an impossibility but precisely to foreground how this resistance allows us to push the limits of its representation further through the act of “making.” In this sense, I see more connections than contrasts between the two readings of pain and a shared emphasis on its shareability.

Both Scarry’s and Patsavas’s ideas, for example, are found in Valerie’s and Patrick’s accounts of living with Valerie’s pain. Pain does indeed leak. It brings “counterfactual revisions” (Scarry 1985:22) of an existing world, as in the piping extension that Patrick built for Valerie, the microactivist affordance replacing a heavy hose. But there is something more in Valerie’s and Patrick’s accounts. Building on Scarry and Patsavas’s arguments, I suggest that not only can pain leak or become expressive against all odds, but its leaking can also allow the ones across whose lives it flows to become affordances for one another, “as if” they were themselves already in pain.

Thus, for instance, Patrick participates “as if” anticipating the pain in Valerie’s swollen fingers as his own, and he obviates it by becoming her affordance, cracking the seal on a water bottle before handing it to her. Just as with Ahmet’s case and the walk-on-ability of his road, we cannot understand the twist-off-ability of the cap separately from the properties of a cap in relation to Valerie’s swollen fingers—and the pain she feels as Patrick relates to it. The microactivist affordance with which Valerie and Patrick imagine an otherwise world—one in which Valerie’s pain is alleviated (though not eliminated)—comes into being not just through the complementarity of a single perceiver and the world but through the complementarity of multiple perceivers and the world. Again, this complementarity cannot be thought of independently of the environment—transnational context where profit-driven capitalist markets continue to drown us, perhaps not in liquid but certainly in bottles, cans, and lids. Just as Ahmet’s father enacts the affordance that could have otherwise been provided by an accessible road, a transport system, and a wheelchair, in letting Valerie’s pain leak to him, Patrick performs the affordance that would, in a more accessible world, be arthritis friendly caps, or in an ideal world, a publicly accessible drinking water system that would have rendered both bottles and caps redundant.10

In another telling moment, when I ask Valerie to pick up a bag from the floor as she normally would—part of the study that I ask all of my ethnographic interlocutors to do if they can—she points at it and says:

I would ask Patrick to give it to me. That’s what I would do . . . Everything that’s on the ground, I don’t go and pick it up. I ask Patrick to pick it up for me or to put it on the table or even, I don’t know [pausing] put the dishes in the dishwasher [she hits one hand on the other and makes a facial gesture, indicating the impossibility of the task for her]—I leave it on the counter and he puts it in.

“The temporality of the taskscape,” Ingold writes, “is social” (2000:196). If microactivist affordances emerge in all the shared routines of Valerie and Patrick counted above, they emerge, I argue, not because of the momentary encounter between a single organism and its environment but because of the temporality of “choreographies” emerging between more than one body and their shared environment. The choreography of “people as affordances” is thus not only a temporalized but also a “socialized” event.

Care Intimacy

In these accounts of a shared everyday, Valerie’s experience of living with pain and Patrick’s experience of living with Valerie’s pain “bleed and leak onto one another,” making it impossible to talk exclusively of “one’s” pain (Patsavas 2014:215). The vital

9. Here I refer to the “as if” situation of the ontology of pain, and its counterfactual wishes, that is central to Scarry’s readings (1985:22).

10. For human-centered design and how it may be critically approached from an anthropological lens, see Hartblay, Hankins, and Caldwell (2018). “As anthropologist Peter Redfield (2012) has observed,” they write, “when Western design firms tackle problems of the global South through what they term ‘elegant’ or ‘simple’ design strategies, they tend to focus on solutions rather than the fully elaborated social and cultural worlds.” Though the authors are here referring to the global South, design solutions such as arthritis friendly bottles can be thought of in a similar way.
affordances of their common environment begin to carry the traces of their shared pain. Things lie on the ground, groceries and used dishes wait on the counter, until “people as affordances” comes about. A similar pattern emerges within the “disability world” that my life-partner, François, and I share. Sometimes, I imagine my pain flowing through the pores of my skin like my sweat, touching François and those around me in invisible yet visceral ways. I know this because, when I wake up, I find two slices of bread and a full kettle on the counter that François has sliced and filled with his limbs that do not experience pain so as to prevent an experience of pain from my use of my morning-stiff limbs. This is another instance of “people as affordances.” If the bread becomes edible to me, this is not because I have come up with an ingenious affordance of slicing the loaf but because François has it sliced on my/our stiff hand’s behalf. The rest of our kitchen, our household and its physical organization, too, bear the blueprint of our shared pain and of “people as affordances.” Heavy pans and plates lie either on lower shelves or on the countertop, saving me the pain of reaching. Couch cushions are turned upside down and pillows are placed at odd angles to create a sit-on-able surface with least pain. This queer furniture (Ahmed 2006:167) and the overall “disoriented” layout of our living space makes the “counterfactual wish” (Scarry 1985:292) of diminishing—not eliminating—Arseli’s pain factual. So does the “inhabitable world” that Patrick and Valerie create through their choreographies of “people as affordances.” The seals of bottles are always already cracked before they reach Valerie. A full grocery bag stays on a lowered counter until Patrick gets home to empty it (fig. 3). Dishes lie on the counter for Patrick to put in the dishwasher. Valerie, Patrick, and the objects in between may not share the same time and space of an action, and yet they come together to invent an affordance to reduce Valerie’s pain.

Drawing from these accounts, I would argue that “people as affordances” exhibits itself as a most fluid form of what Mia Mingus calls “access intimacy,” that is, the “elusive, hard to describe feeling when someone else ‘gets’ your access needs” without them being made explicit (2011). And it is precisely in the elusiveness and ephemerality of its occurrences that “people as affordances” provides new ways of understanding care. Following Mingus, I propose the notion “care intimacy” as a way to describe how the need for care can be articulated, responded to, and engaged with through intimate and unspoken means as people provide or become affordances in and of themselves.

Nonperformance as Affordance: Loving Nonetheless

Sevim and Guven, a married couple whom I interview at their home in Istanbul, reflect on how illness and disability affect their relations with their children and grandchildren.

Sevim:  [Translated from Turkish.] [Proudly pointing at a photo.] This is my granddaughter, that’s our daughter. When she [Sevim’s granddaughter] started walking—let’s say we are going to a park or something. Poor kid, she tugs my hand [mimicking her hand being pulled], and I go, “Ow, ouch!” [mimicking expression of pain]. I say, “Don’t do that!” She got scared and let my hand go. But then she got used to

Figure 3. Valerie sets down her groceries on a low kitchen shelf for Patrick to put away. (Photo by A. Dokumaci.)
it. She started asking, “Which one of your hands was it, Grandma? Should I hold this one, or the other one?” I mean the kid is . . .

**Guven:** I mean, it [illness] does not just affect the person who’s sick. It affects the people around her.

**Sevim [interjecting]:** Like I say to her, “Ouch! Don’t pull me, my dear.”

**Arseli:** How does it affect the people around her, for example?

**Guven:** Look, here you go. Even if her granddaughter is young . . .

**Sevim [speaking at the same time]:** I mean, it does hurt of course . . .

**Guven:** . . . subconsciously at least . . .

**Sevim:** . . . then she asks, “Which one hurt, Grandma?”

**Guven:** . . . she thinks it could hurt her grandma if she holds her hand.

**Sevim:** But what can the kid do? From the moment she opened her eyes, that’s how she saw me. Even then I couldn’t hold her in my arms.

Back in Canada, Melanie, her husband, and I sit at their dining table as François helps me. Melanie is in her mid-40s and has been living with disability and a chronic illness similar to RA for the last 15 years. Perhaps because I am the ethnographer, and I have a similar illness to hers and am there with my partner, or perhaps because she simply wants to talk about it, Melanie reflects on the difficulties of engaging in sexual activity when living with a highly disabling illness:

**Melanie [mother tongue French, speaking in English]:** And it affects too . . . our sex life! I was so much tired. So much pain. [Mimicking a hand touching her arm.] “Don’t!” You can’t touch me. Do this [extending her arm and touching me very gently and then screaming], “Argh! [mimicking pain] No [recoiling in pain] touch, don’t touch me! I have pain, you know.” So it affects this part too. Because it’s important to know that we want to but we can’t. It’s not because I don’t love you, it’s not because I don’t feel like. I can’t . . . I am tired.

**Arseli:** It hurts.

**Melanie:** It hurts! It hurts a lot and I am tired and after that it’s “argh” double pain you know [mimicking aching, with her tongue out]. It’s “Argh! Argh! Argh!” [Each “argh” is preceded by one of her arms touches the other. She lets go of her hands.] It’s important in this way too. It may not be easy for him because we were so young. At the age of 30, you know, you want it, eh! It’s good. But, um [making a face so as to signal What can I do?] “I’m sorry!”

Thus far, my discussion of “people as affordances” has focused on how affordances are collectively brought into being as one person dwells in another’s experience of disability, including chronic illness and pain. But what of situations where the non-performance of an (expected) action becomes an affordance in and of itself? Philosophers of action note that not-doing or negative actions can be as important as positive ones, and in some cases withdrawals or intentional omissions may as well become acts of resistance (Kärki 2018:365). In what follows I want to briefly consider how mutual avoidance can become a microactivist affordance in its own right and how it can bring a “new kinship imaginary” into being (Rapp and Ginsburg 2011). But first I must ask, What affordance is being mutually given up here?

As Gibson notes, “the richest and most elaborate affordances of the environment are provided by . . . other people” (1979:135). Our bodies, materially speaking, are substances with surfaces whose layouts change as we move, do things, and make gestures. These changes emit perceptual information about us, what we are, what we ask, demand, promise, encourage, and so forth. “What the male affords the female is reciprocal to what the female affords the male; what the infant affords the mother is reciprocal to what the mother affords the infant,” and so on, giving rise to “mutual affor-dances” (135). If we follow this logic, we must assume that in Sevim’s and Melanie’s stories, mutual affordances are simply being given up, as sexual activity is not engaged in and a hand is not held. But Rapp and Ginsburg’s notion of new kinship imaginaries leads me to ask, Is it really thus? Must it be?

Perhaps not. In their longtime work on the experiences of families with disabled children in the United States, Ginsburg and Rapp trace how families, in the face of such experiences “find themselves recognizing and reorganizing tacit norms about familial relations” (2017:2). Living lives where “the temporalities and expectations of conventional kinship narratives” such as “college, job, marriage, children” will not necessarily materialize, families begin to rewrite the normative social and cultural scripts of the middle-class American nuclear family (Rapp and Ginsburg 2011:385, 400). “From household budgets to school careers to sibling relations to models of humanity,” these families remake everything “in ways that take into account life with a difference,” opening up meaningful spaces for what normative expectations preclude (383). This is how they begin to bring into being new kinship imaginaries.
mean the absence of “mutual affordance,” within a new kinship imaginary. Rather, it may only mean that the mutual affordance does not materialize according to traditional normative expectations that presume that a grandchild’s hands should automatically be held by his/her grandparent and that couples should make love. But mutual affordances are not like other affordances: when they fail to actualize in expected ways, they elicit a response from the person in need of affordance, such as acceptance, refusal, indifference, or encouragement (none of which one may expect from a water bottle, e.g., that one may open or not be able to open). The mutual forgoing of an action can be a microactivist affordance in itself—one that brings into being a new kinship imaginary, not because an otherwise unimaginable action possibility is cocreated but because an already established and socialized action possibility is not undertaken.

Thus “Please don’t” and “Don’t touch me” are the terms of the (non)engagement of a grandmother and her grandchild, or of a couple. A mutual affordance emerges not because the action in question is performed but because it is mutually let go of. Here, people become affordances for each other, not by way of enabling the emergence of, or directly undertaking, an affordance, but by way of agreeing to let go of an affordance that could have been of benefit to themselves. It is the non-performance of a traditionally mutual affordance that becomes an affordance in and of itself, as Sevim’s grandchild enacts by asking “Which one [of your hands] hurts, grandma?” Not touching, not holding, not caressing, and loving nonetheless.

When “People as Affordances” Fails to Materialize

Let me be clear that my point is not that people at all times and under all circumstances become affordances for one another. In proposing the notion of “people as affordances,” I describe how people may enable the emergence of, or may become, affordances for one another, especially in circumstances where there are no readily available affordances or convenient tools, objects, and infrastructures to respond to their pain, ill health, and bodily particularities. But this surely is not a general rule. In fact, as I show below, “people as affordances” may fail to materialize for a variety of reasons.

A grandchild may, over time, learn to ask which one of her grandmother’s hands was in pain and not hold it. In another story, one’s own child may fail to perceive or may misperceive” (Gibson 1979:135) the call for an affordance. Jacques, who is in his 60s, reflects on his first years of living with a debilitating and disabling illness:

I was the only one working; my wife was taking care of the kids. The kids! . . . our children were born in ‘68, ‘70, and ‘74. So . . . if you go back to 1982, when it all started, the oldest one was 14, right? And the youngest one was 8. So, at 14, when you cannot do something, and you ask your son, “Could you cut the grass for me please, I cannot do it?” or “Can you clean the snow with a snow blower? I cannot do it.” What he thinks is, “Ah, here is another way that dad has found to get me to work!” Right? He doesn’t realize that you have arthritis and you cannot do things like this.

Second, pain may leak. But not always. This is what Patrick’s careful, self-critical reflection, “There are times when it’s not always easy to understand,” reminds us of. Third, pain may fail to reach and “contaminate” the other because the person in pain may deliberately contain it.

Valerie: I am still in that emotional phase where I don’t know how I’m supposed to be. I don’t know if I’m supposed to, like you said, am I supposed to push myself beyond what I feel I am capable to do to show that I do an effort? Or I should use something to help me. And I get very angry also. So, I do a lot of things out of rage. Angry, you know. If I get really angry, I can pick up the bag.

Arseli: I can understand that.

Valerie: I don’t have to tell anybody that I have a hard time. I get really angry and I pick up the bag, you know. So, nobody has to listen to me saying [in a tone that mimics seeking pity], “Can you help me do this?”

Whether pain becomes permeable between bodies depends on a host of social and cultural contingencies. Valerie might prefer the physical pain of picking up the bag to the emotional pain of “having to” ask for help—an example of how valued and “fetishized” (Livingston 2006:121) independence and autonomy are in North America. This ideal becomes a barrier to seeking help from others; removing it requires long and arduous work. “She is getting better,” Patrick says, but he adds, “It’s a very slow process. For years, she didn’t have anybody helping her.”

Learning to let others become affordances for oneself can indeed be a slow and laborious process—one that may reveal itself only in retrospect. Julie, now an elderly grandmother, has spent almost 30 years of her adult life with disability related to RA, and it brought turmoil (drame in French) when she fell ill because she had three children. She was not able to do daily chores, cooked as little as possible, and got help from her mom and sister. At a certain point, her children stayed at her mother-in-law’s because she was hospitalized for a month.

“My life changed completely,” she says. When I ask her how her children responded to seeing their mother ill, she replied in a moving, regretful tone:

11. Disability activists, advocates, and scholars have already called attention to the creative possibilities and pleasures to emerge from sexualities of disabled embodiments (see Erevelles 2011:89; Shildrick 2009:128; Wendell 1989:120). What I want to add is that, at times, not engaging in sexual activity, no matter how involuntarily it is done, can open up new ways of imagining sexual relations as well.
[In English.] Well, you know, something happened and today, I’m so sorry for that. But, I wasn’t able to accept the sickness. I wasn’t able. . . . So, I was trying all the time to do . . . more than that I can do. And the kids tell me today, we knew that you were suffering but I didn’t want them to see me suffering. So, I was hiding myself and umh . . . I was not coping a lot with the sickness. No. . . . But now today, I, I tell to myself, it would have been the best solution to say, “Mom is sick and um, we have to care, er, about her” and explain them and say but the. . . . For many years, there was a lie in the family situation.

In addition to all other situations exemplified above, “people as affordances” may also fail, or be slow, to materialize because at times, “we all need care simultaneously” (Piepzna-Samarasinha 2018:65). But just because I am chronically ill and don’t have the energy/strength to lift you onto the toilet,” Piepzna-Samarasinha adds, “doesn’t mean that I am a bad ally” (65). It means that the care intimacy that “people as affordances” entails can still be in place even in the absence of its actualization.

Habitus of Ableism: People as Barriers to Affordances

In the previous section, I have discussed situations in which “people as affordances” does not come to pass. Sometimes pain does not leak. People may not have the active tentacles to sense and respond to another’s impairment. Sometimes, in living up to the ideals of independence, in hiding their pain and impairments, and in what I call “overpassing” as able-bodied, disabled people may themselves be the biggest barriers to others becoming affordances for them. “Compulsory able-bodiedness” (McRuer 2006) can make disabled people their own worst enemy, precluding the possibility of imagining new forms of kinship, relating, and dwelling with others.

I end with a story that occurs in many guises in disabled people’s day-to-day lives. It is the polar opposite of Ahmet’s story that opens this article. A page from my own notes:

16 March 2018, sometime before noon. Hammersmith bus station. Surprisingly, a warm sunny spring day in London. I am coming back from Tucson where the Wenner-Gren’s “Disability Worlds” workshop (which led to the writing of this paper) has taken place. Having flown over ten hours, I am sleep-deprived and exhausted, and stiff with pain. By experience, I know very well that people with buggies tend to take up the space in the bus where I could potentially put my luggage. Not wishing to engage in a needless fight for space (which I am doomed to lose since what I am carrying is not a cute baby and my body does not at all look deserving of priority space), I decide to wait for the bus standing up, forming the first point of a queue. As painful as that standing/waiting is, it helps me get a place to sit, just beside the doors in the middle, where I also manage to squeeze in my luggage. Exhausted, I sink in the seat. The usual suspects on a weekday bus during working hours are students, tourists, elderly people, parents with their babies and kids—and on occasion, people with disabilities. Not wanting to miss this rare, glorious weather, people fill up the double-decker. At one point, a woman with a buggy comes in and takes up the first half of the priority area for travelers with wheelchairs. From her casual chat with a friend seated with her kid a few rows away, and their glittery bags, I gather they are on their way to a birthday. A few stops later, a man with a buggy comes in and takes up the other half of the priority area, which a sign indicates should be emptied if needed by a person in a wheelchair (fig. 4). A few stops later, among the crowd of bipeds trying to push their way onto the bus, I see an old man, with weakened arms, trying to make his way through the crowd with his manual wheelchair. He approaches the middle door. Catching a glimpse of the impending “nightmare,” the woman with the buggy tells her friend, “Oh shit, now we have to move.” Which they never do. The middle door opens, and a grave silence sinks in. The two people with buggies look helplessly at each other, wondering who would be kind enough to go out so one of them could stay in. They exchange a few gestures, make a few moves, and mumble some words—just enough to make them look courteous, but not so much as to actually move and give the space to the man in the wheelchair to whom it rightfully belongs. Perfect balance. Just enough civility.

Figure 4. On a London bus, prominent signs denote designated spaces for wheelchair users, with buggies permitted if wheelchair users do not require the space. (Photo by A. Dokumaci.)
but not too much generosity. The bystander effect—the fact that they are not alone in their shared ignorance—makes it easier for them to literally hold their ground, and to occupy someone else’s affordance. In the meantime, bipeds continue to get onto the bus with the privilege others do not have. After a while, the woman and man with buggies give up even their fake civility posing. Now they completely ignore the old man as if he did not exist. No PA announcement is made. The bus driver does nothing. Neither do other commuters. Standing up on a crowded bus, on a hot day, they just want the bus to move on. They ignore the ignorance going on. The person in a wheelchair is a problem everyone wants out of their way. Boiling up inside, I stand up and say, “He needs to come in, he should come in!” as I look with fearful eyes at the woman and man taking up all the space. To show that they are civilized enough to be disturbed by my cry, they do just a few more “just enough . . . but not too much” moves. Everyone on the bus preserves their complicit silence. The old man has waited long and patiently for a gesture of recognition that never came. He waves his hand, and shouts in his weak voice, “It is okay, driver. It is okay.” He pushes his wheelchair back and wheels back to the bus stop where he was previously waiting, and will continue to wait, for who knows how long.

After the door closes, the woman with a buggy shouts to her friend with a big grin, “Oh thank you nice man in the wheelchair!” Happy that the hindrance is now out of their way, they continue to talk about their birthday party and other mundane stuff. After literally two stops, the man with a buggy gets off the bus—a distance that he may as well have walked on that rare, beautiful London day.

“The fear of pain,” Siebers writes, “is often the beginning of oppression. But pain can also be the beginning of compassion” (2010:190). This polarity of two extremes also lies at the heart of Scarry’s important work The Body in Pain (1985). While pain, at one extreme, can be inflicted to unmake the made world (as in war and torture), it can in other circumstances (as in the making of artifacts), be redistributed and alleviated in ways that transform the external world into a more compassionate place. Siebers and Scarry write specifically about pain, but we can replace the word “pain” with “disability” to better capture the tensions that shape “people as affordances.”

In one disability world, where no proper roads, transportation systems, adapted devices, or even basic services exist, a father carries his disabled son to school, day after day, year after year, becoming his affordance and creating “access by his own means” where no other exists. In another disability world, where there is a highly accessible public transportation system, with a wheelchair priority area designated by signs, and with rules and regulations to keep it as such, people ignorantly, aggressively, and collectively take up the only affordance that a disabled person might have. People as affordances, and people as barriers to affordances, constitute the poles of the sociality of affordance making and unmaking, in and between which all other stories fall.

In this article, I introduced the notion of “people as affordances” as a way to describe how the coming together of the environment and more than one perceiver can bring into being affordances where none exist. It also opens new ways of thinking about care, which I have articulated as “care intimacy.” “People as affordances” thus helps us to see how disability worlds are made (or denied) in intimate microactivist practices of daily life, an area that anthropology of disability is well equipped to explore.

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References Cited


12. Transport for London’s guide for drivers (2017) states that “if customers are still unwilling to move from the priority area,” then bus drivers “should make a PA announcement to emphasise customers are required to make space for the wheelchair user or play the second iBus message: Customers are required to make space for a wheelchair user. The bus will wait while this happens” (https://www.whatdotheyknow.com/request/436894/response/1063795/attachment/63275?OFL%20Wheelchair%20buggy%20ruling%20staff%20leaflet%204%20with%20cookie%20PRINT%20A6%20ROLL%20OLD.pdf;cookie_passsthrough = 1). In fact, the release of this new guide came after a passenger in a wheelchair, Doug Paulley, won a Supreme Court case after he was denied access to a FirstGroup bus in 2012, when the bus failed to make space for him and a mother with a buggy refused to move (see http://www.transportforall.org.uk/about/news/new-leaflet-and-bus-drivers-forums-further-steps-from-tfl-on-wheelchair-priority).
The Ability of Place
Digital Topographies of the Virtual Human on Ethnographia Island

Tom Boellstorff

In this article I explore the relationship between digital place and disability through an ethnographic study of disability experience in the virtual world Second Life. I discuss how forms of landscape and interface shape disability experience, how building relates to “being-in-world” in digital place, and how proximity and collaboration relate to disability embodiment in a virtual context. “Participant building” on a virtual island created for this research, “Ethnographia,” complements participant observation and other methods to investigate these questions of digital place. Through these lines of analysis, I develop a notion of “digital topography” to illuminate the implications of digital place for disability and human experience more generally. This allows for differentiating digital places from digital media and thus forging conceptual frameworks that reflect how the internet is not a unitary entity. It also allows for considering digital emplacement as related to, but distinct from, digital embodiment. This helps draw attention to questions of digital placemaking alongside the better-known phenomena of avatars. Avatars are important, but it is crucial to highlight the virtual geographies without which the emplacement of those avatars would be impossible. These materials speak to broad questions regarding embodiment, ability, the digital, and the real.

Prologue: Around Ethnographia Island

Let’s fly together around Ethnographia Island a bit, shall we? We can fly because this island exists only in Second Life, a virtual world. We can do it together because no matter where you and I are in the physical world, if logged on, we’re copresent here. Let’s start at my office. I like its curvy walls and high ceilings, its views of the island and the digital ocean lapping up on its shores. I built it myself. That lovely modern chair by my desk (fig. 1)? Far beyond my ability, I bought it from a home furnishings designer.

Here, next to my building, Jeanie has a crystal ballroom, complete with dance floor and sofas upstairs for relaxing. True to its name, crystals are scattered about. Jeanie, who is blind, enjoys their soft tinkling sounds. Next door, Megan has built a gigantic picnic bench. Silhouettes of adults speak gibberish as they tower over a girl sitting on the ground (fig. 2). We feel small and overlooked— a taste of what Megan, who is deaf, felt on family outings as a child. A little past Megan’s build, Paula’s structure rises 30 virtual meters into the sky; I stand on its roof, silhouetted by the setting sun. The building is composed of stacked squares, with a glass room in the center of each square. The walls of the room on the ground floor are opaque; inside there’s a chair for your avatar to sit in blackness. As you move up, floor by floor, the walls of each room are more transparent, until on the roof, a chair sits in the open, with unobstructed views across the island.

More than 30 people have parcels of land on Ethnographia Island: so many other stories. But explaining Paula’s building must wait; I just got a message that Jeanie is Djing at a club on another island, and we want to go dance away to her tunes.

Disability, Mediation, Place

In exploring the ethnographic materials from which this prologue draws, I employ an analysis informed by the critique of “inspiration porn,” the tokenistic use of disability experience to comfort able-bodied persons and thereby shore up ableism (Rousso 2013). Given this critique it is understandable that some researchers are “uncomfortable with scholarly insistence that people with disabilities teach us something” (Kulick and Rydström 2015:16). But a complementary danger is isolating disability experience, as if it offers nothing beyond disability itself.

My path out of this impasse of inspiration versus isolation builds on a time-tested anthropological truism: particular ways of life speak to general questions of human being. In its classic mode, this meant studying “among a community of perhaps four or five hundred people” (Rivers 1913:7; see Redfield 1955) while addressing enduring topics like religion or kinship. At first glance Ethnographia Island might resemble these little communities of classic ethnography, and the impression is not entirely mistaken. The internet may make possible “mass” communication and “big” data, but much online sociality is constituted of smaller groupings. Those groupings, networked and translocal, differ from the classic communities of ethnographic inquiry—but they share features, too, not least because those earlier communities were networked and translocal in their own right.

In this article I move outward from a specific online community to address broad questions related to digital place. The conceit is not that disabled persons are poster children for virtual worlds.1 The point is rather that the experiences and

1. I use the term “disabled persons” rather than “people with disabilities.” Both phrases are commonly employed and neither is perfect, but I
insights of my interlocutors have wide implications, reflecting how disability “is a category anyone might enter through aging or in a heartbeat, challenging lifelong presumptions of stable identities and normativity” (Ginsburg and Rapp 2013:55).

Questions of digital embodiment have long fascinated scholars of the online (e.g., Damer 1998; Hillis 1999). While I share this interest, this article originates in the realization that embodiment always involves emplacement: “Just as we are always with a body, so, being bodily, we are always within a place as well” (Casey 1997:214). What are the implications of digital places for embodiment?

Given the centrality of “place” to this article, before proceeding further I need to distinguish it from “media.” The distinction is complex and contested, not least because places and media coexist and overlap. At the most fundamental level, however, media link places (harking to the etymology of “media” in the Greek preposition metaxú [between] [Kittler 2009:26]), but are not necessarily places themselves. A newspaper is media, but a newspaper cannot be termed a place without stretching the meaning of place to the point that hardly any phenomenon would fall outside it. It is absolutely true that from Facebook and Twitter through the global ecosystem of web pages and email, a key form of the digital has been mediation—communication between places that are distant from each other. The very word “internet” denotes this, and it harks back to the first generation of technologies named with the Greek prefix of distance, télé: television, telephone, telegram, telegraph. Traditionally the implied distance was miles apart, even halfway around the world. You would not telephone someone sitting beside you, nor listen to someone playing piano on the radio if the piano was in your home. But proximal mediation is now a powerful phenomenon. We need theories for Bluetooth socialities, for the mediation of the nearby.

But while “media” is polysemous, it is not all-encompassing. At the risk of pointing out the obvious, not everything in the physical world is media. “Offline” and “media” are not synonyms. However, “online” and “media” are not synonyms either. Since the 1970s—and arguably, a century before that—digital places have existed alongside digital media. Some digital places, which include virtual worlds, are comparatively open-ended: for instance, Minecraft or Second Life. Others are structured more as games: for instance, World of Warcraft or Fortnite. Regardless, as emphasized by Richard Bartle (cocreator in 1978 of MUD, the first publicly accessible virtual world) digital places “are not games. Even the ones written to be games aren’t games. People can play games in them, sure, and they can be set up to that end, but this merely makes them venues. The Pasadena Rose Bowl is a stadium, not a game” (2004:475; emphasis in the original). Paraphrasing Bartle: digital places are not media. Even the ones written to be media are not media. In the burgeoning literatures on digital culture, work on media tends to overshadow work on places: from communications and media studies find person-first language less effective because it “suggests that the [disability] can be separated from the person” (Sinclair 2013 [1999]:1; see also Broderick and Ne’eman 2008; Titchkosky 2001). As Sinclair notes, “characteristics that are recognized as central to a person’s identity are appropriately stated as adjectives, and may even be used as nouns” (1). We do not normally speak of “people with gayness,” “people with athleticism,” or “people with femaleness”; we speak of gay men, athletes, women, and so on.

2. Telephone conversations, which date to the 1870s, can be seen as taking place in “the place between the phones” (Sterling 1992:xi; emphasis in the original).
perspectives, digital places often seem narrow and unimportant. This can lead to digital places being analyzed as if they were digital media, with confusing results.

In saying all this I do not mean to detract one iota from the rich body of media studies scholarship, which is vital for the study of digital places (not least because many digital places have media inside them, or about them). I am simply saying that digital media and digital places cannot be conflated. For disability, the consequences of digital media understandably involve mediation, particularly with regard to mobility and access (e.g., Chib and Jiang 2014; see Ginsburg 2012). If you cannot drive in a place with limited public transportation, going online can offer important possibilities for information, advocacy, and support. If you have a caregiver, going online can offer opportunities for independent socialization (Anderberg and Jönsson 2005).

But how does disability intersect with digital place? If four people leave their physical homes to meet in the physical home of a fifth person, that fifth locale does not “mediate” their interactions in the same way that a shared newspaper subscription would. So how do online places shape disability experience, in ways distinct from mediation? How does this speak to cultural questions of place in the most fundamental sense? Such questions motivate this article. To investigate them, I first clarify my field site and approach. The main body of my argument then moves through three sections that explore themes of landscape, interface, building, proximity, and collaboration. These themes respond to digital embodiment not in terms of appearance but engaged relationships to digital place, recalling cultural geography’s attention to “the articulation of social relations which necessarily have a spatial form in their interactions with one another” (Massey 1994:120). Such work now includes “theoretical and empirical exploration of the digital as a particular geographical domain with its own logics and structures” (Ash, Kitchin, and Leszczynski 2016:8). By the penultimate section of this article I will advance a notion of digital topography in response to the digital as a geographical domain of disability experience and in the conclusion use this notion to rethink prosthetic metaphors regarding relationships between ability and technology.

Sites and Methods
This article is based on a collaborative, multiyear study of disability and virtual worlds. For this article I draw exclusively on data gathered from Second Life, owned and managed by the company Linden Lab. I got to know disability communities in this virtual world by building on 14 years of prior research (e.g., Boellstorff 2015, 2019), with key data collection taking place between 2013 and 2018. During this period, Second Life was an open-ended virtual world with about 600,000 active residents. You could access Second Life from any computer with an internet connection by downloading free software known as a viewer. An official viewer was available on the Linden Lab website. Several “third-party” viewers existed as well, usually produced by volunteers; the most popular such viewer was Firestorm. Another, Radegast, had fewer features but was popular.

3. For the sake of variety, in this article I treat “digital,” “online,” and “virtual” as rough synonyms.

4. My collaborator, Donna Z. Davis, and I received support from the National Science Foundation, Cultural Anthropology and Science, Technology, and Society Programs (grants 1459219 and 1459374).
with some disabled persons (particularly those with visual impairments) because it allowed one to render one’s virtual environment as text that could be magnified or spoken through a screen reading program. Viewers are thus interfaces, analogous to browsers like Chrome, Firefox, or Safari, distinct from the servers that contained the virtual world itself.

Second Life avatars are highly customizable—not just clothing and jewelry, but any gender or race, a few inches to a hundred feet tall or more, an animal or object, even a ball of light. Moreover, avatars can be changed at will, and it was common during the time of this research to have multiple avatars with distinct identities, like having two email accounts. Because of this, determining the precise population of Second Life was difficult. Most Second Life residents lived physically in the United States and Europe, but some lived in South America, Asia, and Australia. More than half of my interlocutors were female, a pattern common in open-ended virtual worlds (Pearce, Blackburn, and Symborski 2015:15).

The world of Second Life is composed of areas of virtual land (called simulators or “sims”) 256 × 256 virtual meters in size. At the time of writing, 24,020 of these sims constituted Second Life; 6,806 of them made up a series of continents, and the remainder were islands composed of one or more sims. Second Life’s economy is based on land. Accounts (and thus avatars) are free, but to build one had to own land (for a monthly fee), rent land, or be part of a group that owned land. Objects (including items worn on avatar bodies like clothing and jewelry) could be given away or sold for Linden Dollars, an “inworld” currency exchangeable with US dollars. Second Life is thus predicated on user-generated content, a common online economic model (e.g., Facebook, Instagram, YouTube; Ondrejka 2004).

During my research I met several interlocutors in the physical world, but they are not privileged in this analysis. The disabilities of my interlocutors reflected the diversity of disability more generally and included visual and auditory impairment, limb loss, autism, post-traumatic stress disorder, epilepsy, cerebral palsy, multiple sclerosis, and the effects of cancer, Parkinson’s disease, strokes, and other illnesses. Of course, many of the conditions in question were not considered “disabilities” in any straightforward sense; instead, they were considered diverse forms of ability that manifest as disability in ablest social contexts.

My methodology, building from earlier work (see Boellstorff et al. 2012), involved regular participant observation with my interlocutors in various Second Life locales. These included personal places like homes and places specifically for the disability community (places that often act to create forms of online disability community). It also included a range of places where my interlocutors socialized with other Second Life residents who were not disabled or whose disability status was not known—beaches, shopping malls, dance clubs, book discussion groups, role-playing regions with medieval forests or postapocalyptic deserts, you name it. I conducted 42 in-depth interviews as of the time of writing, with many additional shorter interviews; these were drawn from about 50 individuals with whom I was deeply engaged for this study (and a larger group of about 150 encountered during participant observation). My coresearcher and I also held 75 focus group meetings.

For 3 years of the research, grant support allowed my coresearcher and me to purchase two sims that we joined to create Ethnographia Island (fig. 3). Thirty disabled persons received parcels of virtual land on which they could build anything that expressed their experience of disability and virtual worlds. These 30 persons were chosen on a first come, first served basis. Their disability status was based on self-identification as disabled.7 A few parcels on Ethnographia Island were also set aside for collaborative building projects. John Law, in his call to “remake social science . . . [to] catch some of the realities we are currently missing” (2004:2), concluded “the argument is no longer that methods discover and depict realities. Instead, it is that they participate in the enactment of those realities” (5). In this case the research design included a field site—Ethnographia Island—that literally came into existence in the research context.8

6. Ethnographia Island’s name comes from the office I created and named Ethnographia when beginning Second Life research in 2003. There have been other projects in Second Life providing temporary land to disabled artists (e.g., https://uwainsl.blogspot.com/2013/09/the-freedom-project-initiative-by -uwa.html). Many disability groups in Second Life (e.g., Virtual Ability and Dreams) have owned land and used that land for socializing, for support meetings, for individual residences, and even for building competitions. This meant that many disabled persons who participated in Ethnographia Island were already familiar with the idea of disability groups having places in Second Life.

7. One reason for this is that not all disabilities are officially recognized, and such official definitions vary globally. My coresearcher and I met some of these disabled persons in the physical world, and some of them were also active in disability communities in Second Life, but we did not ask for medical records or any other official proof of disability status. Ethnography always involves an element of trust in this regard. Most ethnographers of disability in the physical world do not ask for proof of disability status either, and, e.g., in my earlier research on gay and lesbian Indonesians, I never asked interlocutors to somehow prove their same-sex desires and practices (Boellstorff 2005).

8. Some might see a similarity between Ethnographia Island and the Modernity Project at Vicos, where a group of anthropologists from Cornell University took ownership of a hacienda in Peru between 1951 and 1962 as an applied social science experiment (Stein 2003). Projects like this, however, are not analogous. Ethnographia Island allowed for specific forms of data to be collected but did not exist for the entire period of fieldwork. Many participants did not have parcels on the island; those who did were already active elsewhere in Second Life. For no one was Ethnographia Island the sole or even primary site of inworld sociability. A better parallel would be participatory visual and digital methods (Gubrium and Harper 2013).

5. See http://www.gridsurvey.com/ (the quoted numbers are from March 31, 2019).
Landscapes and Interfaces

Violet, an Ethnographia Island resident, invited me to sit with her in a quiet meadow:

Violet: I’m struggling with something, to the point of an anxiety attack.

Tom: Oh gosh, what’s wrong?

Violet: Remember how we’re supposed to restrict sounds to our parcel? It’s Saul and Lydia’s builds. There’s a visual side to the sounds thing.

Tom: Are their builds blocking your view?

Violet: Not blocking, it’s like they’re screaming. Maybe they could put a screen around them? It’s my PTSD [post-traumatic stress disorder], my disability.

Tom: Let’s think about this together.

Violet: I know they don’t mean it.

Issues of sound had arisen on the island before. As noted in the prologue, Jeanie used auditory effects in her ballroom. I once placed a lighthouse adjacent to the ballroom without realizing the interference its ambient sounds produced (unlike a physical lighthouse, the sounds could be simply turned off). I first misunderstood Violet’s concern as analogous—blocking a view—but the issue was actually the negative impact of bright colors and flashing lights. Other residents shared the concerns, which were familiar to inworld disability communities with regard to, for instance, PTSD and epilepsy.

This virtual-world problem, and its eventual solution, links up to anthropological scholarship addressing “worlds” of disability experience and sociality (Ginsburg and Rapp 2013), including interfacing objects like wheelchairs, motorcycles, doorways, and ramps (Kohrman 1999; Phillips 2010). This scholarship reflects anthropological understandings of place as “inhabited and appropriated through the attribution of personal and group meanings, feelings, sensory perceptions and understandings” (Low 2017:32). One form of ableism involves unequal access to, and participation in, such inhabitation and appropriation of place (Titchkosky 2011); interfacing objects are one response to that inequality. This is one reason why “a focus on disability makes it easier to understand that embodiment and social location are one and the same” (Siebers 2013:283). Social location can now take the form of virtual social location: What are the implications for embodiment?

This issue of visually triggering objects relates to topics of building and proximity addressed later in this article. Here I use it to launch an exploration of interface, turning to something that might seem unrelated, even trivial: “third-party” viewers. I noted in the previous section that many disabled persons preferred Radegast to the more popular and full-featured Firestorm viewer. Now consider this conversation between myself and two avatars, Ruby and Diamond, who in the physical world are one visually impaired person, Molly:

Diamond: See, Ruby is my main avatar, and I used to move her from Radegast into Firestorm when I wanted her to do something like dance with a
partner [because dancing is difficult in Radegast]. And then, one day I tried that and my avatar became a cloud. And nobody could figure out why.

Molly eventually learned that viewer incompatibilities were damaging Ruby to the point that:

**Diamond:** If I wanted to be able to speak, I’d have to create another avatar that would live in Radegast. Only in Radegast. Ever. And that Ruby could never set foot in Radegast. Ever. Because then she couldn’t come back. So I created my voice, I created Diamond.

Molly’s challenge might seem unrelated to Violet’s. Yet despite obvious differences between visual triggers and visual impairment, both involve interfaces between the physical and the digital. The literature on people having multiple avatars often emphasizes role-playing, but for Molly multiple embodiments responded to the affordances of interface. Ruby and Diamond would, for instance, go shopping together in Second Life, with Molly accessing Diamond (for speaking) through Radegast and Ruby (for making purchases) through Firestorm. Yet this took a surprising turn:

**Diamond:** At first, manipulating Diamond was like playing with paper dolls. Diamond’s job was to talk for Ruby. And then something happened. And I’m going to sound really silly, and I don’t apologize for it, you’ll just have to believe it. She became her own person. Diamond kind of took on her own personality. So I kind of think of her somewhere between a staff member, a maid, and a baby sister for Ruby.

Despite these unexpected consequences of her work-around, Molly saw her solution as suboptimal. This is why she participated in a set of focus groups together with the volunteer programmers behind the Firestorm viewer, who were passionately interested in access. Molly’s struggles with speech and text were not unique: the most desired feature from the more than 40 participants in the focus groups was better voice-to-text and text-to-voice functions (to benefit those with auditory and visual impairments, limited hand movement, or fewer than two hands). Another desired feature—responding directly to the issues that had appeared on Ethnographia Island and elsewhere—was the option to hide bright flashing colors and lights. Other suggestions related to the landscape. For instance, Radegast could translate a virtual landscape into text, but only as a list of objects. As one person noted, “This list does not tell you in which direction the object is located. It is just a vague list.” Furthermore, if creators did not properly title their objects, visually impaired people could not identify them: a screen reader would simply say “object.” These concerns about interface reflect broader imbrications of interface and digital place in everyday disability experience. One virtual morning, Hazel invited me to sit with her on a wooden deck looking out over the unending Second Life ocean, next to a harmless volcano whose churning lava never escaped the cauldron high above our heads. Like many autistic persons, Hazel preferred text chat: no tone of voice or facial expressions, and one could edit a statement before sharing it. Hazel once said these benefits were the “same with email,” and I responded: what is distinct about digital places? She had once told me that she liked to have clear lines of sight in her physical home (doors kept open, no stacking of taller objects in front of shorter ones, etc.). Could a digital place like Second Life work in the same manner—in a way that, say, email or Facebook could not?

**Hazel:** Yes indeed, what a wonderful area of thought. This spot here is an example of my “line of sight” need. I can see all around, and nothing can creep up, hidden by buildings, etc. In that way, my Second Life interface is very “safe” for me.

**Tom:** Right.

**Hazel:** And I always use the chat window . . . Encapsulated in its own box, with a black background. Not distracting. Boxes and boundaries—very important to me.

Hazel here describes a dynamic I encountered with a range of interlocutors: since digital place can only be accessed through interfaces, they embody, in a sense, digital selfhood. We might consider Hazel’s use of chat windows, or Molly’s inworld existence as Ruby and Diamond, in terms of “interface embodiment.” In fact, right after mentioning chat windows, Hazel added that some of her disabled friends in Second Life were also communicating using Discord, a web-based chat platform. I noted that both Second Life and Discord employed text chat, so why did Second Life hold particular value?

**Hazel:** I must say I am not as comfortable with Discord as I am with chatting in Second Life. Discord is not a “place” so the geography is lost . . . . There is no view, no perspective . . . . If I cannot see safely, I start to feel panicky . . . . So “safety sight” works both for the text and the space—I need to see the text to think and speak. And I need to have my line of sight to breathe and feel safe.

Hazel’s words regarding disability, safety, and “line of sight” reminded me of Paula’s build on Ethnographia Island, mentioned in the introduction—a tower with walls becoming more transparent on higher floors. Paula explained it as follows:

**Paula:** A series of four floors. I have used the floors to represent my feeling and how I have seen the world for many years. Floor 1: A completely black room from the inside. A place where I mostly feel
safe and calm. Floor 2: A room where I can see those on the other side of the wall. The place where I spend most of my time. I very rarely interact with people, but I can if I wish to. Floor 3: A room where I am able to see and interact with those on the other side of the wall. The place “I can live in,” but it is not always comfortable for me. Floor 4: A room where there is little to no wall between me and others in the world. I have not come to this place in either my physical life or my Second Life. Now just what does this have to do with my living in Second Life? Well my Second Life is much the same as my physical life. The same four floors are always there, but in Second Life I feel more free to venture out of my dark room and explore, talk, and do things!

Hazel did not know about Paula’s structure, so I showed it to her:

_Hazel:_ Really interesting build. I have the feeling that it is all about control. What I can control and what I can’t. Even my issue with voice and text has that element. See your thoughts and build on what you see. . . . you can’t do that with voice.

Hazel’s use of lines of sight and Paula’s build both recall notions of “landscape,” a way of seeing dominant in the Western tradition and which is important to the experience of digital place more generally (Boellstorff 2015; see Cosgrove 1998; Cray 1990, 1999; Friedberg 2006; Healy 1997; Hillis 1999). Indeed, the problem with which I opened this section—builds with bright colors and flashing colors—is a problem of landscape as well. Since Paula’s build is close to Violet’s, we might as well return to this issue. Ethnographia Island residents, working in close virtual quarters, helped come up with several solutions. We moved some builds hundreds of meters in the virtual air. We also built a curtain 60 virtual meters tall, which screened off some parcels. Saul and Lydia moved their builds “behind the curtain”; they could no longer be seen unless visited intentionally.

How might we consider this curtain a digitally material “interface”? And what questions might this discussion raise beyond digital disability? What are our interfaces in the physical world: the “viewers” that perpetuate ableist constructions of place and those that disabled persons use to reconfigure and challenge those ableist lifeworlds?

**Building and Being-Inworld**

The discussion thus far already reveals how Second Life is not just a place: it is a place that is built. In virtual worlds predicated on user-generated content, many residents build at least occasionally; arranging and modifying the creations of others (e.g., when furnishing a home) is often considered a kind of building. What does this tell us about placemaking, embodiment, and ability?

Let us join some Ethnographia Island residents on a tour of what Phoebe termed her “Build Biography.” After leaving a successful career due to disability, Phoebe discovered Second Life, which “made all the difference in the world.” She wanted to show how:

_Phoebe:_ Second Life helped me to construct a new, “many-faceted identity” which now includes being an artist, a builder, a business owner, a teacher, and a philanthropist. I decided to . . . tell my story using a kind of gallery or museum type exhibit . . . I’ve also written out note cards (60 in all) that tell the fuller story behind what is being shown on each sign. The note cards also make the installation accessible to anyone who uses a screen reader, or language translator.

This first area described how she became a builder: “I found building to be like a meditative process for me. I could lose myself in it, getting into something like a ‘flow state’.” The next area showed how she started making sculpture and seeing herself as an artist. She then led us to a third area, the “Black Tunnel”:

_Phoebe:_ This part represents a period from 2011 to 2014 . . . It became very difficult for me to leave the security of my home in the physical world. I felt like I had invisible glass walls around me. A very strange sensation. And in Second Life, I quit all of my public activities, slashed my friends list, stopped building even, and kept almost totally to myself.

_Paula:_ [Nods.] I understand that.

_Phoebe:_ Yeah, Paula, quite a bit like the rooms in your build, come to think of it.

_Paula:_ [Nods.]

Phoebe then brought us to “a demonstration that I’ve created, of something that I was experiencing a lot during that time”:

_Phoebe:_ There’s a teleporter (the blue sphere here), which goes up to an Emotional Flashbacks Demonstration, which is on a platform in the sky. I built it here to give people an idea of what it’s like when a person who has PTSD from chronic trauma (versus a one-time event) has flashbacks.

We tried the demonstration, placed in the sky to account for the concerns with visually triggering objects discussed earlier. It featured an invisible trapdoor causing one’s avatar to
fall without warning to a room below. As we moved through the demonstration, Phoebe said:

Phoebe: I love this so much about Second Life, that it has this "immersive experience" aspect. As we all know, it's not just "show" and "tell." like the 2-D internet, it is also "be" and "do." What we have here isn't mere information delivery. What we have are experiences. Put another way, "There is a 'here' here."

I can think of no clearer explanation of how digital places and digital media are distinct. Phoebe closed her tour by stating, "Second Life has given me a way to feel once again like I am a contributing member of society. It has helped me reconstitute my sense of identity, in the wake of becoming disabled . . . The purpose of my build here is to tell my whole story about that."

I could devote this article to Phoebe’s “Build Biography,” or other Ethnographia Island builds just as fascinating. But even this brief tour highlights implications of digital place for theories of physical-world placemaking (Lefebvre 1991), theories to which anthropologists have long contributed. For instance, in her classic ethnography The Fame of Gawa, Nancy Munn noted, “The point of departure for this study is the notion of a lived world that is not only the arena of action, but is actually constructed by action and the more complex cultural practices of which any given type of action is a part” (Munn 1986:8). Munn’s pivotal “notion of a lived world” originated in the phenomenological philosophy of Husserl, where what orients experience is not the body as “a thing in objective space, but as a system of possible actions, a virtual body with its phenomenal ‘place’ defined by its task and situation. My body is wherever there is something to be done” (Merleau-Ponty 1962:250; see Habermas 1987). Husserl himself distinguished between the physical body (Körper) and the living body (Leib), identifying the “living body” as “the only one which is actually given [to me as such] in perception” (Husserl 1970 [1954]:107). Avatars are digital “living bodies,” defined through actions and situated tasks. Perception and experience through avatars challenge notions of embodiment predicated on kinesthetic experience, as well as arguably ableist configurations of sensation (Serres 2008).

A novel method of what I term “participant building” on Ethnographia Island complemented participant observation, providing opportunities to articulate relationships between digital living bodies and digital lived worlds. An example: next to Phoebe’s “Build Biography,” Claire’s parcel had a series of objects, including a tire swing that was not quite connected to the tree above it. Leading other island residents on a tour, she noted she had only entered Second Life 3 months before getting the parcel. She described how building the tire swing helped her understand that a moving object often should not be attached to a stationary one:

Claire: It was an experiment for me . . . I needed to understand animation in Second Life . . . I needed to understand how things fit together when they weren’t logical to me. Because to me, the swing had to be attached to the tree, and it’s not attached to anything because if it is, the pivot [animation] doesn’t work . . . I literally couldn’t wrap my mind around it.

Next to the tire swing was a tall building crowned by two large books that formed a house:

Claire: The bookcases of my mind . . . the reality is that when I was little, I couldn’t communicate well with others . . . so I retreated to books. Books were my life and soul, my food, my blood, my air; they were my everything.

Claire had chronicled a physical-world history of disability, but also a virtual-world history of learning to build. And the experience of building had helped her socialize offline: “because of this I’ve moved into restarting things in my physical life. So this is a huge thing.”

This interplay between digital body and digital place recalls Heidegger’s phenomenological understanding of “dwelling” as central to what it means “to be a human being” (2001 [1971]:145). Dwelling for Heidegger was a form of action—he noted that the Old German and Old English word buan meant “to build” and “to dwell.” It is thus intrinsic to being-in-the-world (1962), a notion I have reframed as “being-in-world” now that virtual worlds make more than one world possible (Boellstorff 2011). Construing being-in-world as “building-in-world” allows for considering how ableism is manifest in a phenomenology of placemaking: “Any body that is excluded from making a contribution to the construction of the social world cannot find a home in it” (Paterson and Hughes 1999:604; see Petrick 2015; Saerberg 2015; Salamon 2007). This reflects how in the physical world, disability exclusion takes forms of “misfit,” how “the particularities of embodiment interact with the environment in its broadest sense . . . a particular aspect of world-making” (Garland-Thomson 2011:591). Digital misfit should be avoidable in virtual worlds, given the possibilities of different interfaces and reworked relationships to materiality, but because ableism is a cultural logic continually expressed as technological barriers, ability-diverse digital cultures are neither automatic nor inevitable.

Proximity, Collaboration, Digital Topography

While leading us on the tour discussed above, Claire paused to say, “I have learned from each builder that I’ve seen here. Each one of you, I have walked your plots. Trust me, you may not have seen me, you may have not been around when I did it, but I did it.”
From the ethnographic materials above, we see many cases of disabled persons engaged in social relations with others through digital place and placemaking, even when the others were not online at the time. For instance, Claire noted how when she walked those plots of other disabled builders and learned from them, they were often “not around when she did it.” Furthermore, the specifics of her digital embodiment were not pivotal: her learning did not depend on looking like a young woman, an old man, or a fuzzy rabbit.

This demonstrates a broader and often-overlooked aspect of digital place: when persons move through a digital landscape, their embodied status creates emplaced social relations distinct from avatar appearance or copresence. One’s avatar embodiment would not directly affect the experience of Paula’s tower: the experience comes from moving through its levels and experiencing the interplay of visibility, height, and security. Someone could move through Phoebe’s “build biography,” experiencing the installations and reading the note cards without Phoebe being online. For these social relations, appearance is not fundamental: they are mediated by the fact of embodiment in digital place as such. Such social relations of place recall the ontological notion of “media” as mode of transmission: “In the middle” of absence and presence, farness and nearness, being and soul, there exists no nothing any more, but a mediatic relation” (Kittler 2009:26). An important area for further research is to consider how these mediatic relations of digital place are similar and different to, say, reading someone’s Facebook page when they are not online.

It is to highlight this aspect of digital place that I have not described or included images of my interlocutors’ avatars. This is not to downplay the importance of specific avatar embodiments, or of verbal and nonverbal avatar communication (Tanenbaum, El-Nasr, and Nixon 2014). Rather, my focus in this article is on how disability experience elucidates a lesser-discussed aspect of digital embodiment: presence in digital lifeworlds. Unlike digital media, which entail connection across distance, digital places thus foreground questions of proximity: they allow for copresence (not just communication) even in cases where the persons in question are physically distant.

In thinking through the emplacement of self in landscapes of digital place, I find it useful to develop a notion of digital topography.9 Geography references geo, the physical world, but topography references any *topos* (place). Whereas, say, all websites are “equidistant,” digital places exist on a topography where some things are closer or farther. The concern over visually triggering objects discussed earlier reflects this. (Compare: an article on cnn.com with visually triggering images does not impinge on nbc.com.) The fact that Ethnographia Island was composed of nearly adjacent parcels foregrounded these issues of proximity—as a problem or a resource, as in Claire’s statement about exploration, or when Paula and Phoebe realized their builds responded to similar life challenges. Of course, proximity was relevant across Second Life: for instance, disability groups using virtual land for activities involving copresence (a disco) or not (a water slide on the beach). Any disabled person in Second Life moved across landscapes of digital place, many not designed with disability in mind.

Although Claire’s statement indicates that embodiment in digital place need not involve copresence, she did deliver it while leading a tour. We are often with others in digital places, and that copresence can involve highly valued forms of collaboration (Boellstorff 2019). In Second Life (as in the physical world), this could take place with other disabled residents, able-bodied residents, or those who did not reveal their disability status. The range of possible activities was also wide: a support group, playing games, relaxing by a virtual campfire. It could also include placemaking. For example, Phoebe offered to help Jeanie create her build. Jeanie’s transcript of their conversation included the following:

| Phoebe: | Hey, Jeanie! What are you wanting to make? |
| Jeanie: | I want to make a ballroom, if you can make it out of crystal pieces. |
| Phoebe: | Wow, crystal ballroom! I think I can help with a crystal ballroom. Can you build at all? |
| Jeanie: | No, I can’t with Radegast, and it’s very visual. I can’t see, in RL. |
| Phoebe: | Yes, I didn’t know what’s possible though. I just wasn’t sure if there are any kind of descriptive assistive devices. |
| Jeanie: | I’m not sure if there are any. |
| Phoebe: | You can tell me whatever layout you picture in your mind, and whatever look. Have you ever been sighted? May I ask that? |
| Jeanie: | No, I’ve been blind all of my life. |
| Phoebe: | How do you imagine a ballroom to be? I would love to know an exact description of what you have in your mind, if you would like to do that. |

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9. A notion of cultural topography has been used by intelligence analysts; I do not draw on this work (e.g., Johnson and Berrett 2011). The only anthropological use of “cultural topography” of which I am aware is Ferguson’s analysis of wealth in Lesotho (1992).
Phoebe: Do you have a sense of colors for these things?

Jeanie: No, I don’t.

Phoebe: Warm versus cool “feel.” Blue and green are “cool,” red and orange are “warm.”

Jeanie: Ah. I would like the ballroom to be red.

Collaboration could also involve larger groups, and Ethnographia Island provided opportunities to explore this through participant building. Since Second Life’s founding, residents have held a birthday celebration with the support of Linden Lab, which provided temporary islands for builds created by individuals and communities. During the first year of Ethnographia Island the Second Life birthday celebration’s theme was “the shared adventure.” A subset of Ethnographia Island residents decided to build an exhibit, and we set aside a plot of land on the island to prepare it. The design, with colors inspired by Vincent van Gogh’s *The Starry Night*, featured a meandering pathway between square blocks (figs. 4, 5). A text written by residents explained:

What is Ethnographia Island?

There are a number of parcels on the island where capability-diverse people like you and me are spending time expressing themselves. Many are making statements directly related to disability and how it affects our lives. Some are giving a direct line to their perspective—of themselves and of their worlds (physical and virtual). Some are interactive. Some are static. Some are playful. Some are serious. All of them are full of heart. All of them take you to a place of exploration.

Each resident had an installation with an image of their build; when clicked, the image provided an explanatory note card. Claire’s note card stated: “A newcomer to Second Life, Claire has used her studio parcel to learn how to build, code, have fun, and express being capability diverse . . . Second Life, in particular Ethnographia Island, provides a means of expression—both creative and mundane. No matter how you perceive yourself, whether that’s ‘capability diverse’ or ‘able-bodied’. . . That makes you and I similar.”

A few days before the birthday celebration was to begin, residents moved the exhibit to the assigned location: they were pleased this was directly southeast of the celebration’s “Welcome Area.” Northeast lay an exhibit about Bhutan; north and east, installations of photographs taken inworld. Southwest was a collaborative build by a well-known residential community. Visitors could move through the landscape to find our exhibit, and walking through it, encounter a series of reflections on disability and digital place. To consider, as Claire put it, capability-diverse possibilities for creativity and expression.

A Prosthetic Conclusion

This analysis of disability and digital place has focused on landscape, interface, building, proximity, and collaboration. I came to these topics from ethnographic engagements, but they are in no way limited to this field site, to virtual worlds, even to

Figure 4. The birthday celebration build.
disability. Recalling my desire to avoid isolating disability experience, I conclude by turning to something associated with both disability and the digital: the prosthetic metaphor. The prosthetic metaphor has served as a key trope for conceptualizing the relationship between technology and the human (Bateson 1972); a version of the metaphor that has emerged in recent decades is the cyborg (Balsamo 1996; Haraway 1991). However, the prosthetic metaphor is “insufficient to analyze...the questions of body-technology boundaries” (Jain 1999:47) when based on an ableism that “turns on the problem of the ‘wholeness’ of the body and thus cannot but invoke the questions of whose bodies are whole and how this wholeness is culturally determined and recognized” (47).

Some uses of the prosthetic metaphor do presume a teleology of fusion—technology augmenting flawed flesh to make it whole. This teleology of wholeness or fusion resonates with the idea that dualisms of any kind are bad: Cartesian impositions dividing up a world of blurring and flow. With regard to disability studies (and in medical anthropology more broadly; see, e.g., Schepers-Hughes and Lock 1987), the dominant approach has been to critique the distinction between body and mind as an artificial or misleading imposition that misses the myriad ways that body and mind are mutually informing, or even a single domain. This line of social constructionist critique continues to the present with, for instance, insightful uses of the concept “bodymind” to “insist[1] on the inextricability of mind and body” (Schalk 2018:5; see Price 2015).

In questioning the prosthetic metaphor, I am building on a line of analysis in disability studies that challenges the social constructionist idea that the body/mind dualism is an imposition. This line of analysis explores how body and mind are in some ways distinct, and how this is important to the understanding, experience, and politics of disability.

Disability scholars have begun to insist that strong constructionism either fails to account for the difficult physical realities faced by people with disabilities or presents their body in ways that are conventional, conformist, and unrecognizable to them. These include the habits of privileging performativity over corporeality, favoring pleasure to pain, and describing social success in terms of intellectual achievement, bodily adaptability, and active political participation. The disabled body seems difficult for the theory of social construction to absorb: disability is at once its best example and a significant counterexample. (Siebers 2001:740)

In this regard it is striking that my disabled interlocutors often emphasized that they were not their bodies. As one Ethnographia Island resident put it:

I used to be “mind over matter,” push push push, but now unfortunately when the mind’s the thing that’s the matter, you have limits, and it’s knowing your limits and accepting your limits in terms of accepting your new self. Because I will never be the self I used to be. . . It’s hard to slow your mind down to the same, to be where your body is, actually I don’t want to slow my mind down to be where my body is.10

10. This quotation is taken from Davis and Boellstorff (2016:2105); see that article for additional ethnographic examples and discussion regarding disability and the mind/body dualism.
Indeed, the ethnographic materials presented in this article show how digital embodiment in digital place permits forms of sociality and subjectivity that realize a sense of separation between mind and body. My interlocutors were clearly aware that just as the body can impinge on the mind (e.g., chronic pain, exhaustion), the physical world can impinge on digital place. This could include bodily limitations (e.g., hands that shook due to Parkinson’s disease, so that voice chat was preferable to typing). It could include limitations of one’s computer or internet connection, reflecting how many disabled persons live on limited incomes due to unemployment and meager-to-absent state support. It could include issues of interface. But all this was possible precisely because the online/offline binarism did not “blur” (see Veerapen 2011). Online and offline are distinct, but as with any other binarism, this does not imply the absence of a relation. The distinction makes relation possible.

Overall, this analysis suggests future pathways for research, three of which I briefly mention here. First, I have only touched on precisely how disabled persons build in Second Life. This includes interface tools that allow creating objects inworld and also outside programs like Maya or Blender that more advanced builders use to create “mesh” objects (which were added to Second Life in 2013).11 Medicalized discussions of disability often focus on “activities of daily living” like bathing and eating. How might the ability of “disabled” persons to build in virtual worlds contribute to expanding notions of daily activities in the digital age?

The relation of gender to disability and digital place is another rich domain for continuing research, which can build on the scholarship on gender, design, and disability more generally.12 Building and placemaking have typically been androcentric categories, and associations of women with the “domestic” have long been of interest to feminist anthropologists (Rosaldo 1974).

As noted earlier, women outnumber men in socially oriented virtual worlds; they predominated on Ethnographia Island, and I have focused on women’s accounts. How does digital place relate to female agency when what is at issue is not avatar appearance but building as a social practice?

The relationship between “virtual worlds” and “virtual reality” is a third area where including disability in the discussion from the outset is of the utmost importance. Confusion between virtual worlds and virtual reality is rampant, leading designers, users, and critics to speak past each other. As should be abundantly clear, “virtual worlds” are places online. “Virtual reality” refers to three-dimensional sensory immersion, usually with goggles for vision, headphones for sound, and tracking technology that allows for kinetic movement within a virtual space. But while virtual worlds and virtual reality share the word “virtual,” they are distinct. Virtual worlds are typically experienced with a regular computer screen and can even be composed solely of text. On the other hand, virtual reality technology can be used with a flight simulator on a computer not connected to the internet.

Virtual worlds are about digital place, while virtual reality is about interface, which as we have seen can constitute a site of ableism. Virtual reality technology can represent a delightful way to experience virtual worlds. However, this benefit is thus far limited by assumptions about “sensory immersion” that discount persons who cannot see or walk around a room, or whose tremors make them unable to wear a headset. The conflation of virtual reality and virtual worlds is ableist. If future virtual worlds are predicated on the idea that you must be able to, for instance, see and hear, then persons with visual and auditory impairments will be excluded from those virtual worlds.

The study of disability and digital place, including the method of participant building, has much to offer the study of digital disability more broadly. Research thus far has focused on digital media (e.g., Goggin and Newell 2002; Hansen 2006). Some scholarship in this area has already begun addressing digital places (e.g., Ellis and Kent 2011). Joining that growing body of scholarship to the literature on digital media can, for instance, contribute to debates over the social construction of disability (e.g., Beckett and Campbell 2015; Shakespeare 2013): How do places versus media “construct” ability diversity in everyday practice?

Finally, further work on disability’s intersection with digital place holds great promise for anthropology. Embodiment has been important since the beginnings of the discipline (Csordas 1988; Mauss 1973), but this work has explored embodiment in the physical world. Linking this scholarship with interdisciplinary research on avatar embodiment (e.g., Mazalek et al. 2011) can expand our ethnographic understanding of “situated embodiment” (Lock 2017:11) as distinct from, but intertwined with, questions of avatar appearance.

It is time to teleport away from Ethnographia Island, illuminated by a setting virtual sun and hosted by servers in the physical world. By the time you read this article the island may have disappeared; indeed, this whole virtual world will someday end. But virtual worlds are here to stay as places of culture; their inhabitants will include those excluded by ableist discourse from the “normal.” Lifeworlds of digital disability speak back to this exclusion, suggesting new possibilities for the virtual human.

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11. Objects in Second Life are composed of “primitives” (known as “prims”). For instance, a table might be composed of five prims: a square prim for the tabletop and four tall rectangular prims for the legs. However, if this table was composed in Maya or Blender and imported into Second Life as a “mesh” object, it would use only one prim. This means that the table would load into the world more quickly. Additionally, land in Second Life has a “prim count” limit regarding how many objects that parcel of land can contain. A mesh object counts less toward that prim limit, allowing for more objects in a place.

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References Cited


The Skilling Journey
Disability, Technology, and Sociality in Postconflict Northern Uganda

Herbert Muyinda

In Uganda, people affected by war-related impairments may engage in “skilling” as a way of dealing with the disability problem. The aim is often to acquire skills that can enable them to adapt to their new conditions. As we look closely at the process, two questions arise: How are the skills passed on to persons with disabilities (PWDs) translated into daily life experiences? How do these processes (re)shape the “world-making” of PWDs in such settings? In this paper, I examine skilling as a translation process—the interface between the sociotechnological innovations (skills) developed to deal with disability and the socioeconomic shifts due to violent conflict, and how such interface influences the making of disability worlds. I analyze the global-local (dis)connections and their influence on the skilling journey of PWDs. Through ethnographic vignettes in war-torn Gulu District in Uganda, I illustrate how skilling processes and PWDs’ translation of technologies are influenced by changing socialities in the diverse domains of interaction: the individual and the collective, the formal and the informal, and the physical and the technological. I observe that skill is socially constructed: it is linked to people’s lives not only through bodily (dy)sfunctions alone but also through social connectivity—sociality.

A single mother of five, Akello returned to Awach village after 11 years of internally displaced persons (IDP) camp life. An antipersonnel land mine survivor and amputee, Akello moves with a prosthesis on her right leg and with the support of an elbow crutch. Akello suffered the land mine blast during the more than 2 decades (1986 until 2006) of protracted war between the Lord’s Resistance Army and Government of Uganda forces in Northern Uganda. The war was characterized by violence in the form of gunshots, bomb blasts, and stampedes that led to an increased number of people with disabilities (Spittal and Muyinda 2000). The conflict ravaged the region, resulting in the displacement of over 1.8 million people (90% of the region’s population; Office of the Prime Minister 2004). With most of the population confined to IDP camps for over a decade, the economic activities in the region collapsed, leading to widespread poverty and food shortages. In addition, physical infrastructure and social services were destroyed, and the social and economic fabric of society was grossly weakened (Fabiani et al. 2005; Liebling-Kalifani et al. 2008). This crisis has had a direct and continuing impact on the lives of people with disabilities.

Before the impairment, Akello was a professional dancer, a skill she lost due to the land mine injury. I was a professional dancer, and you know with dancing you need to look capable, and attractive . . . . you need to do it perfectly well for people to enjoy, but this is not possible with one leg. . . . I tried to do it with a prosthesis—with one leg—but the whole thing was very different, and people did not think what I was doing was dancing dwola anymore, so I had to stop. For sure I am no longer a dancer. Part of my work was to teach dwola (Acholi traditional royal dance) in schools, but I can no longer do that. Now with one leg, with no house, no land, . . . I am just starting all over again, trying to catch up with life . . . . many of us [disabled people] are just trying to catch up.1

In the IDP camp, Akello sold charcoal and fish for a living. After shifting back to Awach, things changed; she could hardly continue with her businesses since she could scarcely get buyers. She survives on support extended to her by her sister in Gulu town, in addition to a small income from a mobile money business she has started, discussed below. The several times I met Akello, she was trying to acquire skills to deal with the rapidly changing situation, while interacting with different people including PWDs in the nearby communities to start working together. As she explains:

I and Emajong are pursuing a baking course to acquire alternative skills. We [together with people who are not disabled] have also formed a mobile money stall and credit saving scheme. In fact, I plan to borrow funds to start up my bakery from our credit scheme. Also, we have formed the disability self-help group (dul me konye ki pi jo matye ki goro) here in Awach to support each other, particularly in terms of acquisition and utilization of mobility devices.

Emajong lives with double impairment—amputated in both lower limbs and blind in both eyes. He moves in a wheelchair with the support of a neighbor who helps to push him around in exchange for cultivable land, since Emajong can no longer cultivate it by himself. In the IDP camp, Emajong was supported by a volunteer from Associazione Volontari per il Servizio

1. All interviews in this study were done in the local language (Luo) through a translator and independently back translated by a Luo speaker. Particularly in the cases of Akello and Emajong, I did the follow-up interviews in English because both Akello and Emajong are English speakers.

Herbert Muyinda is Senior Lecturer in the Child Health and Development Centre of the College of Health Sciences at Makerere University (Upper Mulago, PO Box 6717, Kampala, Uganda [muyindaherbert@hotmail.com]). This paper was submitted 11 XI 18, accepted 9 VII 19, and electronically published 24 X 19.
Internazionale (AVSI, an Italian NGO), who left when the camps were closed. In the absence of functional government social welfare institutions and services, Akello and Emajong depended on others for their daily life, making the quality of relationships in the various domains of interaction critical. From camp life, to resettlement back in the villages, to day-to-day survival, to commuting in search of alternative skills, Emajong was being supported by others; all these relationships are not static.

**Approach**

I begin this article with the two life stories of Akello and Emajong, not only to show how violent conflict situations can disrupt affected people’s lives, as they have to discover how to adapt to their new conditions within rapidly changing domains of sociality. Their stories illuminate the focus of this article—skilling as a translation process. This phrase captures a sense of the disability world produced at the interface of the sociotechnological innovations (skills) developed to deal with disability and the socioeconomic shifts due to violent conflict. The resilient response as illustrated by Akello and Emajong engaging in alternative activities initiated by the PWDs themselves represents a quasi-(in)formal reaction, forming new socialities as well as skilling practices articulated in this paper. These cases illustrate the continuum of change in the social relations of PWDs as they navigate many domains: the individual and the collective, the formal and the informal, and the physical and the technological.

As the influence of technology becomes stronger, the forms of interaction change and the social relations and skills—the desired product—become (un)stable. This is because, I argue, skill is linked to people’s lives not only through bodily (dys-)functions alone but also through social connectivity and interaction, making skill a function of sociality. With both deliberate and unintended sociotechnical (dis)connections that emerge during the process of acquiring them, skills can be looked at as every PWD’s necessity-in-the-making that has to keep developing, and in the process, it reshapes sociality and the disability worlds of the PWDs.

As a term, “skill” has many facets; it is often understood in terms of activity, work, occupation, and employment. It is also sometimes equated to capability attributes like knowledge, expertise, and experience. These are all different and in some instances overlapping, and they relate to particular disabilities in different ways (Block et al. 2016). Conceptually in this article, I have considered skill to be associated with virtues like “competence,” “ability,” and the application of different forms of technology. As a form of embodiment, skill presents itself as an imaginative process regarding what the body may perform or produce; it is therefore a social construct. To NGOs and other agencies, skill is often understood as the ability to apply knowledge in its current design and to perform to one’s own and others’ benefit. It is therefore about the ability to deliver expected outcomes: competence in using the skill.

Among PWDs, skilling as an activity is usually framed within the struggle to transform an impaired body toward visible and tangible outcomes that ideally can be socially recognized. Particularly in postconflict settings, such as those in Uganda following the civil war between the Lord’s Resistance Army and the Government of Uganda (Allen 2006; Finnstrom 2005) as described below, skilling and acquisition of skill are conceived as aspects of adaptation to the new conditions, mitigating the effects of the conflict, and addressing issues of marginalization and inequity. Thus, the entire life of the disabled person in such settings is (re)constructed within the socioeconomic and technical attribute of “possessing a skill.” It is a rigorous sociotechnical process through which practices have to be recognized as either progressive or retrogressive. Thus, “skilling” on its own as a process and bodily application, or skill as an intended product, shapes the (re)construction of disability, the quality of relationships (sociality) involved, and the worlds that PWDs inhabit.

Theorists who write about skills state that ideas, including those embodied in skills, have to undergo a translation process for their utility value to be realized in a “new” context (De Laet and Mol 2000; Flitsch 2008). Green (2011) refers to skill as a personal quality with three key features: productivity, expandability (training and development), and being social (meaning that skills are socially determined), pointing out that each of these attributes needs to be translated if they are to be meaningful. In his work on traveling models, Richard Rottenburg argues that for an idea (skill) or a technology to be useful and meaningful in a particular context, it has to undergo the process of translation—where an idea is changed in order to make sense and be useful in that given context (Rottenburg 2012:483). In Northern Uganda, the multiple dimensions and (re)presentation of skills highlight challenges in their translation—as they are often developed in the Western world and applied to low-income settings—to fit the local needs of PWDs. Several questions then arise: How are the skills passed on to PWDs translated into daily life experiences? What facilitates or frustrates these adaptation processes? How do they (re)create or shape the “world-making” of PWDs in war-affected settings during their time in IDP camps and when they leave the them to settle back to their original villages?

Here, I analyze the global-local sociotechnological (dis)connections and their influence on what I call the “skilling journey” of PWDs. My focus is on the shifting of socialities, from formal to informal, from physical to technological, and from collective to individual or vice versa, and how these changes influence acquisition and application of skills by PWDs. Analyzing the development of skills among PWDs in postconflict Northern Uganda during 8 months of fieldwork, I illustrate how disability and sociality intersect, and how this intersection shapes

2. The term “sociality” has been used to refer to various forms of social interaction and organization (Bamford 1998; Monaghan 1995). Anderson (2002:19) observes that the term “sociality” has been taken up by
the translation of skill for PWDs in a postconflict setting. I show that disability informs skill, and at the same time skill informs disability, and this happens through a translation process shaped by local sociality.

In an attempt to address disability problems, particularly in war-affected areas, intervention agencies—both government and nongovernment—initiate activities to (re)build capacities of the persons with disabilities (PWDs) by passing on (new) skills: the body and its “ability to perform” certain roles and/or to apply technologies becomes central. For example, while training amputees, the visually impaired, and polio survivors in Gulu, a town in Northern Uganda, in electronics repair, leathering amputees, the visually impaired, and polio survivors in electronics repair, leather work, pottery, metal work, carpentry, crafts making, repair of assistive mobility devices, and management of rotating credit, the instructor grouped her participants into those who could learn new skills—the “active disabled”—and those who could “hardly learn” any new skills—the “disabled disabled,” the two categories used by agencies working in Northern Uganda. Akello was categorized as “active disabled,” while Emajong was categorized as “disabled disabled.” These socioeconomic and technical dynamics highlight two different but overlapping perspectives: the global and the local. The two perspectives not only reveal differences in the significance attached to the sociotechnological innovations and skills offered to PWDs, a transfer between global and local actors; they also highlight the political, socioeconomic, and technical (dis)connections associated with disability intervention elucidated in this section.

NGOs and government agencies focus on skills because they are widely regarded as a core objective for policy interventions both locally and globally. These international agencies, NGOs, and government policies often intend to build capacity to address all the needs of PWDs in different situations. Likewise, interventions and policy issues have both national and international agendas (Ingstad 2007:2). In the aftermath of major periods of violence, as in the case of Northern Uganda (and elsewhere), appropriate skills can be useful in ensuring that the structural inequalities before the war are not reinforced and that equitable support is enhanced. There is recognition that lack of skill can hinder attempts toward reintegration of PWDs back to their communities. Additionally, the ideal of “equal rights for disabled people” compels local authorities to fulfill national and international policies aimed at enhancing opportunities for people with disabilities (Ingstad 2007:2; UNHCR 2007). Skilling is therefore seen as a national and international responsibility and is characterized by formal/institutional deliverables that operate within stated parameters and standards. These globalized guidelines inform standards; however, they tend to create new sociotechnical (dis)connections between the body (disability), skill, and the social relations involved, sometimes to the extent that whatever does not satisfy their set parameters may not be considered as skill. Consequently, the local needs of PWDs are often overlooked by planners and program implementers.

In Northern Uganda, although PWDs benefited from the training skills in different ways, the effects of displacement and separation of families and communities were largely ignored. The sociopolitical and historical processes responsible for the life conditions of PWDs were often not part of the policy formulations that were being implemented. The NGOs, government, and international agencies that decided, defined, and delivered the effects of such decisions on individuals had predefined objectives and “standard” guidelines under which the intended interventions occurred. These shaped the sociality for PWDs in such a way that some of the targeted people were excluded.

In the IDP camps, PWDs received full skills-training packages, many of which they could not use after resettlement. The skills passed on seemed to address particular challenges that were not those considered crucial by PWDs: planners and program implementers never seemed to have envisaged the effect of people leaving the camps to go back to their former villages. Despite the differences between camp and village settings, participants were trained in the same content and following the same schedules as those used in the IDP camps. People in the villages, for example, were being trained in computer skills, secretarial services, electronic repair, etc., skills that were rarely relevant for rural settings. Thus, reintegration into their communities was a challenge. Instead, rural PWDs needed training in modern agriculture, food preservation and storage, and crafts making and the marketing of such products appropriate for rural conditions. Moreover, the lack of electricity affected practical learning, including use of computers, metal working, and communication infrastructure. In the absence of a functional public transport system, participants had to move long distances to training venues. Despite the challenges, PWDs were expected to adhere to the skills passed on to them according to the set standards regardless of the realities in their local settings.

While academics and policy makers had embraced the social model in advocating and planning for PWDs (Ingstad and Whyte 1995; Shuttleworth and Kasnitz 2005), in practice there was a tendency for the focus on disability to shift from the collective to the individual. While disabled people in Northern Uganda depended on others for their daily life, skills were passed on to individual PWDs, leaving out those in their network who might be instrumental in assisting them in their application. Family members and/or the community were not included in skills development programs, despite the fact that skills-training agencies knew the importance of family support for PWDs. Bamford (1998:6) argues that a person is not viewed as the proprietor of an individualized entity but is seen as a “composite”—the sum total of those social relationships in which he/she participates. Following Bamford’s observation, ideally, activities like skills training should be delivered through
local and traditional institutions such as the family, religion, and the elders. But in Northern Uganda, most skills-training agencies targeted PWDs as individuals. While in most of the Western world, the use of technology is meant to create or enhance independent living of PWDs (Ingstad and Whyte 1995; Livingston 2005; Shakespeare 2006), in much of Africa technology creates dependencies, making the quality of relationships critical, especially given inadequate or complete lack of skills development. In fact, in all cases, the skills-training agencies in Northern Uganda delivered their interventions with the assumption that the families and the communities would support the targeted PWDs. This was not necessarily the case; family and community support was not always forthcoming, affecting the application of their skills.

This trend of individualizing disability was also evident in formal institutions, as particular skills were linked to certain impairments. The stereotype holds that “normal” work for a disabled person is being a cobbler, a tailor, shopkeeper, crafts maker, telephone operator, etc., activities that can keep a PWD in one place, minimizing the need to move. Importantly, I underscore that disabled people can potentially do anything, though in some cases differently. However, when such stereotyping reaches institutional levels, it impacts the planning and effective implementation of the disability skills programs. The skills-training agencies in Northern Uganda expected the skills and technologies to be adhered to immediately. There was noticeable pressure on PWDs to “accept” and adapt the interventions. As one gunshot survivor explained: “After training, all of us are mobilized into groups by the training agencies even when we want to work alone, especially where the groups would not work due to the long distances between us, or lack of common interests.” At the same time, there were some excesses; PWDs were targeted by more than one intervention agency addressing the same problems. As the gunshot survivor added: “Sometimes each organization comes up with different programs to impart the same skill, others train us in skills we already obtained from another agency and even have a certificate. But to keep a good relationship you may need in future, you just cooperate with all of them.” In other words, PWDs were compelled to observe technological adherence, which presented itself as political since it was largely serving other agendas rather than the needs of the PWDs. This is not to say that the activities recommended by the intervention agencies were “bad” occupations; however, they risk stereotyping when planning skills development for PWDs.

Furthermore, planners and program implementers perceived disability as a homogeneous condition and PWDs as people with “similar” problems and needs (Ingstad 1995; Merkin and Smith 1995; Office of the Prime Minister 2004). This led to application of uniform approaches to diverse disability problems, rendering it difficult to focus on particular skills that would benefit different categories of PWDs, making some of the skills passed on look irrelevant. Such lumping together of the different types and extent of disabilities not only ignored bodily physical differences but it also ignored the changes within domains and forms of sociality, an issue discussed below. More critically, even disabled people’s organizations at both grassroots and national levels tended to downplay or were unaware of the diversity that existed among PWDs. Thus, the skills obtained by most PWDs were hardly connected to the resettlement conditions.

Intervention agencies, particularly in low-income settings, are never neutral. Some get entangled with the practices and politics of the areas in which they operate (Finnstrøm 2005:112; Ingstad 1995). Others set their objectives according to funding sources and their own agendas (Chibwana and Mohan 2001). In many African countries, for example, care of PWDs traditionally has been embraced by faith-based organizations, and Uganda is no exception (AVSI 2004; Hartley 2003; Anderson, Sewankambo, and Vandergrift 2004). Elsewhere, intervention programs have been put in place to fulfill political interests (Bruun 1995; Silla 1998; Van den Bergh 1995). In Northern Uganda, some agencies were interested in specific conditions and targeted particular groups like former rebels as well as government soldiers, leaving out those with other disabilities. Some were interested in offering specific services like credit facilities, literacy courses, and counseling, while others focused on particular groups: women, children, the formerly abducted, and so on. Many concentrated on people in particular locations like markets, military barracks, displacement camps, and slums. This range of projects by the various intervention agencies was not accidental; it represented sociopolitical steps toward predefined agendas and targeted different people, in different places, and at different times. These often inflexible agendas knowingly or unknowingly create different socialities that keep changing, affecting the translation of skills by PWDs.

Some skills-training agencies were perceived to be fulfilling their own sociopolitical agendas rather than a life-changing initiative for PWDs. These agencies neglected to examine the impact of their activities on the target populations, focusing instead on the (pre)defined “guidelines,” “methods,” and ultimate “indicators” of achieving their objectives. They failed to reflect on their assumptions, roles, and effects of their activities or on the life conditions of PWDs, nor did they take into account the changing socioeconomic and political conditions.

The construction of disability as a war phenomenon led to the exclusion of those whose disabilities were due to causes that were different from those targeted by most skills-training programs. Particularly in the rural areas, few had gone through the formal institutional processes. Polio survivors and the visually impaired were categorized as “disabled disabled,” and as such, were not targeted for skills training. Several agencies in war-affected areas insisted on making their decisions regarding the kind of skills to pass on to PWDs based on available “reliable” data, usually in terms of severity of impairment, perceived appropriateness of skill, and the associated technology. The presence or lack of “reliable” data becomes a measure that reconstructs disability and (re)defines the sociality of PWDs. In Northern Uganda, the focus on “reliable” data, for instance, envisioned people with war-related disabilities, mainly those
who had a history of being in contact with formal institutions that could issue documents about their conditions. Most of those injured during the war went through hospitals and rehabilitation centers and had “valid” documents needed for the “evidence-base of their interventions.” This left out PWDs whose impairments were due to other causes.

The emphasis on valid documents also left out many women; the few that were reached often received training in inappropriate skills. This is because most of them did not participate in combat activities like men did. Also, apart from the land mine survivors, most women had disabilities due to causes other than the war and therefore lacked the valid documents and did not “qualify” for skills training. Most disabled women were not connected to formal institutions since they spent most of their time at home, while men were mobile and had contacts with formal disability organizations and other sociopolitical and economic groups. This low or complete lack of mobilization affected the skills training, and as a result the agencies reported that less than 30% of women, particularly in rural areas, turned up for the training programs (AVSI 2004).

The need for accurate data is often based on the prejudiced assumption that all problems people have in Ugandan postconflict settings are due to the war. Yet, it is evident that many of the cited problems in postconflict settings are also due to other factors found even in areas where there is no war (Finnstrom 2005). Although there is need for accurate data to plan for proper resettlement and skills training, in war-affected areas like Northern Uganda, sound social, health, and demographic data are often missing; use of personal accounts, demands, and dynamics of communities to address real-life situations is sometimes inevitable. Moreover, during such fluid situations like that of resettlement, people’s needs often become clear even without “reliable” or “scientific” data, and it is usually easy to reach consensus on what should be done. Unfortunately, international, national, and local organizations rarely acknowledge the challenges to aid provision in order to develop meaningful approaches to understanding and addressing them. As one study points out (Ghobarah, Huth, and Russet 2004), if this acknowledgement does not occur, it may hinder the capacity of programmatic responses to deliver appropriate skills consistent with realities on the ground.

Skilling and Unstable Domains of Sociality

Before the war, the Acholi people traditionally lived in family-based households surrounded by homes of patrilateral relatives who supported their disabled kin (Girling 1960). Relatives assisted their disabled members by offering direction for the visually impaired, carrying or pushing wheelchairs for those with mobility problems, providing shelter and protection against any dangers, and more (Atkinson 1999). This process also supported the skills learning of many PWDs involved in activities such as pottery, carpentry, music instruments, and other hand crafting of stools and baskets. They depended on their relatives to gather raw materials and to sell their products. Kin-based sociality is the means through which the conditions of disabled persons are understood and accepted and legitimate social positions are (re)created and acted upon.

However, as the local population moved into displacement camps, the impact on PWDs was compounded by disruption of family networks and weakening of the Acholi cultural principles. The problem became more apparent during the resettlement process, forcing changes in the different domains of interaction that made access to and utilization of skill by PWDs challenging.

In August 2006, when the Cessation of Hostilities Agreement between the warring parties was signed, IDP camps were officially closed and people were required to return to their home villages (Government of Uganda 2007; Roberts et al. 2009). After 20 years of conflict, a semblance of peace began appearing in Northern Uganda, and the lifting of restrictions on the population’s movement was one of the first major steps toward the implementation of the peace agreement; then efforts were made to begin allowing civilians to return to their ancestral homes. As the region transitioned from emergency and post-emergency scenarios into resettlement processes, there were rapid socioeconomic changes. The government of Uganda issued an official Peace, Recovery and Development Plan 2007–2010 (PRDP) that outlined four strategic objectives: (1) the consolidation of state authority; (2) rebuilding and empowering communities; (3) revitalizing the economy; and (4) peace building and reconciliation (Office of the Prime Minister 2012). To implement the PRDP, the Ugandan political authorities immediately demanded that the emergency organizations reorient their services to infrastructural development since the war was over. Both the international and local organizations that had provided the backbone of much of disability support began pulling out. The few service providers that remained were either scaling down or reorienting their activities, a situation that was made more complex by uncertain kinship support. The rather drastic withdrawal of services was done without possible alternatives; PWDs did not have a chance to prepare for such drastic changes. The removal of the emergency services outpaced their replacement by government programs (UNHCR 2007), a plan that was hindered by a lack of adequate funding.

Northern Uganda is traditionally a patrilineal society, and most resources—both material and social—were controlled and primarily devoted to satisfying men’s needs. This was still the case, even when, over time, women assumed many responsibilities that were previously identified with men. On top of being the main producers of food and caretakers of their families, women were also active in income-generating activities. This was especially important given that most disabled women in Northern Uganda were single mothers (Muyinda 2013). Like Akello, most were rejected by their spouses and other family members; this hampered family support for them and their skilling process. Traditionally among the Acholi, the man’s family could provide assistance to a woman if the husband was dead, but such support would be difficult for
the man’s family to deliver if the husband was still alive because he would accuse any other man trying to help his rejected “wife” of having sexual contact or interests in her. So the brothers and other male relatives of a man would not provide assistance to such a woman for fear of accusations of sexual trespass. Thus, the rejected disabled women would face challenges regarding housing, cultivation, and other activities associated with moving back to villages because relatives would not openly help them when their husbands had abandoned them. Without family and institutional support, the disabled women would have to be multiskilled so that they could handle their various needs.

Further, the effect of the changes within the domain of sociality was evident in the skilling of former fighters. These were impaired government soldiers and the former Lord’s Resistance Army fighters who had lost one or more of their limbs and eyes. The disabled government soldiers were trained in various skills and were given a package for resettlement to start a new civilian life after retiring from the army. For the former rebel fighters, the government set up reception centers specifically for their rehabilitation. The former fighters received technical skills training in carpentry, shoemaking and repairs, electronic repairs, financial management, and use of assistive (mobility) devices and were given farm instruments and seeds. With such skills, the former fighters considered their abilities in performing their roles to be superior and expected to be treated with high regard and respect by their communities. As one former rebel fighter amputee related to me: “As a professional [soldier] I feel I can do so many things and can work with anyone. We were trained to follow systems and to be professional [soldier] I feel I can do so many things and can work

The former fighters underwent was hardly relevant to their reintegration into their communities. This was partly because much of the skills training in military rehabilitation institutions and reception centers for the former rebels emphasized technical skills—mainly tailoring, carpentry, agriculture, and metal works—and so little attention was placed on social and behavioral life skills. The material training neglected the reintegration skills the former fighters needed to help them fit into the civilian communities. The military skilling institutions were faced with bureaucratic and hierarchical challenges. There was confusion as to whose decisions to follow—those of the army officers or the technical skills trainers. In most cases, the skills trainers were of lower rank than the army leaders. As a result, the latter did not respect the decisions of the technical trainers. When they tried to settle back in their villages, most of the former fighters were rejected since they continued to live a military-like life in civilian settings. The former fighters continued to communicate by giving orders; they expected to be given free food, services, and other necessities of life as in the military; and some of them were violent. With such behavior, many of the disabled former fighters were not perceived as “real” disabled people; they were seen more as people who had caused deaths and instability in the area, rather than as persons with disabilities needing sympathy. Their war-related identities overshadowed their physical impairments and functional limitations. Yet, to fit in their new settings, they needed to interact with others. The former fighters needed to unlearn some of the militaristic practices and approaches to life and at the same time adopt civilian approaches.

The few former fighters who had been accepted in society had translated their military and other skills learned in the rehabilitation centers into locally applicable services to their communities. Some of them started adult learning sessions in the community, bicycle repair, carpentry—skills applicable to meet local needs and integration into the “new” domains of sociality.

New Socialities

In Uganda, people affected by recent war-related impairments may engage in a number of unpredictable attempts to adapt to their new situations and integrate these novel experiences into their lives as individuals and members of collective groups. The impaired person can stop or alter ways of doing particular things due to changes in the body; someone may no longer be able to stand for long, move across long distances, use one or both hands, or be able to read or write due to loss of sight. These experiences are defined by intersections of disability, lack, loss, and/or underutilization of resources, both material and nonmaterial.

As a way of dealing with the above challenges, new forms of sociality emerged. PWDs in Northern Uganda initiated what they called “shared knowledge” work groups in their villages. These were meetings of two or three PWDs with either varying or similar skills gained from the diverse training agencies, forming a platform of people working together on a particular activity. There were four such platforms in Gulu that developed, based on geographical proximity and different activities. One of the groups (two men, one woman) established a mobile phone charging project. Most of the rural areas in Northern Uganda had no electricity, yet many people used mobile phones. These PWDs initiated a phone charging center in their community using a solar panel and a multipurpose cable to charge phones in the community, from which they got an income. Another “shared knowledge group” of two men started an electronic repair shop, and another two women living nearby started a hair salon. These projects were based on the skills PWDs shared, including those acquired from skills-training sessions. This new quasi-formal sociality facilitated application of shared skills, learning from each other, and ways of supporting one another to deal with their resettlement challenges.

The long distances and use of cell phone technology in addition created more technosocial communities, (re)shaping the skilling processes. This sociality replaced the institutionalized forms where members were officially registered and had memberships and offices, followed a particular time schedule, and
had regular meetings to review their progress and follow up on their members. The following quote gives a sense of the vibrant entrepreneurialism that such small initiatives inaugurated.

I and Jessica (another skills trainee with disabilities) are operating a mobile money stall in the trading center. We also formed a rotating credit group, and we advance money to members and they pay back with a small interest using a mobile money system. Our main customers are Boda-boda (bicycle and motorcycle taxi) people, the shopkeepers, and other members of the community. Our connection as group members, and follow-up of our customers, is by mobile phone contacts, and that is how we are managing. Otherwise it would be very difficult for us to carry out such businesses because people live up to 20–30 kilometers apart.

Another form of technosociality was based on the need to share skills in the use and maintenance of assistive mobility devices. PWDs formed disability self-help groups (dal me konye ki pi jo matye ki goro) to support each other, especially in terms of acquisition and utilization of assistive physical mobility devices. People were given artificial limbs, white canes, wheel chairs, and tricycles, etc. without being trained on how to use them, especially in their local settings. This led to frequent breakdown of the devices. It was always a challenge to use mobility assistive devices in the narrow and bushy foot paths, narrow corridors, tight doorways and verandas, and staircases without ramps. Women in particular did not know how to pedal tricycles, push a wheelchair, or to use other assistive devises within their local settings. Many used their wheelchair only when there was someone to help push them. Those with prostheses had to use them on uneven ground, requiring a considerable amount of training. As a result, many people looked at the mobility devices as more disabling, and so hardly used them. It was common to find prostheses hanging in people’s houses, to be used only on special occasions, for instance, when one needed to look smart. Some PWDs resorted to using local sticks for canes or crawled on the ground.

The person in charge of the orthopedic workshop, who was part of the task force, attributed the failure to use the devices to inadequate or incomplete lack of training, explaining:

Depending on the nature of the impairment, training in the use of a device may take several weeks, which is difficult for people coming from distant places. People now can hardly get more than two days of training because they come from very far. A person comes for one day, tries on the device for a few minutes, and travels back home. Some even send friends and relatives to pick up the devices for them; such people do not even get the slightest opportunity to get the skills and the counseling they may need to use the devices.

The skills transfer in the camps was free to PWDs since the emergency intervention agencies paid for it. But after resettlement they had to pay for it themselves, in addition to transport costs, since the skills training was no longer taking place within their villages. They also had to bear accommodation and feeding expenses if they were to stay for more than a day, on top of paying for the training. The person in charge further explained that “when people were still in the camps, they would come to the workshop for training up to even four weeks. But because of the long distances now (since they come from the villages) this is no longer possible because they have nowhere to stay in Gulu town and do not have enough money to sustain themselves.”

The support of AVSI and other NGOs for PWDs to stay in a hostel and receive physiotherapy and learn skills in using mobility devices is no longer there. In the NGO-supported hostel, the clients used to be supported with meals, accommodation, and sometimes transport for those who were required to report back for review, but all the support stopped when the IDPs closed. The relocation of PWDs to the villages also made it difficult for orthopedists and physiotherapists to provide follow-up support due to long travel distances in settings without effective (public) or program transport.

The challenges in the use of mobility devices brought PWDs together in an attempt to solve their physical mobility challenges through self-help groups and shared knowledge clubs, where PWDs started training themselves in different skills. In Northern Uganda, the ability to use mobility devices was taken for granted. PWDs themselves created task forces to facilitate the retraining of their members to use their mobility devices in the new settings. These groups of two to three PWDs tasked themselves with the responsibility of identifying the physical mobility needs and obstacles of their members in their villages, working to link those who needed support to different intervention agencies. Akello’s (Awach) village was linked to Gulu Hospital Orthopedic Workshop outreach services, which helped them acquire and (re)train PWDs on the use of the mobility devices.

It is a truism that because disabled people are usually poor and dispersed, they have limited advocacy and means to press for their needs to be addressed; sometimes there is lack of knowledge on what to do in a practical sense. This places PWDs in a position that makes them accept any form of intervention targeted at them, with a hope that it may be beneficial in one way or the other, even when the ultimate outcomes are not known. As in the cases of Akello and Emajong, PWDs in Northern Uganda redefined their reality—including skill and sociality—to deal with their challenges. With the disruption of social and kinship contacts due to displacement and long distances between homesteads, coupled with complete lack of or poor public transport systems, physical and social contact among PWDs has been reduced. Technology is (re)defining sociality, increasing connectivity of PWDs through mobile phones rather than physical contacts.

Perspectives

This work builds on the wider discussion regarding how skill is socially constructed and embodied, both as a physical and as
a technological phenomenon. This paper illustrates how skill-
ning processes and disabled people’s translation of skill are
largely influenced by embodiment and changing socialities—
particular dynamics between individuals and others, in specific
domains of interaction that are existentially dynamic. Such
processes are manifest not only among individuals but also in
the functioning of the structural skilling processes of (formal)
institutions, (informal) families and kinship networks, com-
munities, and local and international organizations where skills
were learned and applied. Violent conflicts create crises and
instability, causing dis-
ability and at the same time constituting the local circum-
stances in which disabled people live as they manage their lives
(Anderson, Sewankambo, and Vandergrift 2004:27; Muyinda
2013). At the same time, government policy and institutional
and societal responses have been important to changing the
life conditions of disabled people (Bruun 1995; French 1994).
Bruun (1995), for example, describes how the Nicaraguan gov-
ernment’s policy transformed the status and identity of disabled
soldiers from that of beggars to heroes. Similarly, in Mali, Silla
(1998) shows how government intervention programs changed
the manner in which leprosy generated stigma. In the United
States and Europe, where disabled people have comprehensive
legal rights and strong social support institutions, much of the
effort is about equality and dignity (Barnes, Oliver, and Barton
2002; Ingstad 2007; Stiker 1999). In much of Africa, however,
institutionalized rights for the disabled either do not exist or are
rarely enforced (Van den Bergh 1995) and in some instances
serve divergent agendas.

In Uganda the disability movement has been quite effective
in achieving certain levels of “equal rights for disabled people.”
There are considerable policy achievements by way of effective
representation for disabled people at various levels of decision
making and increased public awareness of the special needs of
people with disabilities (Ndeezi 2004:3). However, matching
particular disabilities to appropriate skill training still needs
deliberate attention, particularly in war-affected and under-
erved areas. In low-income settings, such interventions are
designed and implemented with a taken-for-granted assump-
tion that they are appropriate for PWDs, ignoring how local
disabled actors mobilize their potential to improve their own
lives. The overlap and in some instances the polarization of the
local and global perspectives help us to critique the taken-
for-granted truism that local social support networks comple-
ment interventions based on Western models. Structural anal-
yses highlight the technical weaknesses in such interventions
but fail to acknowledge the dynamics that create new socialities
and the accompanying challenges that may stifle effective par-
ticipation of PWDs. When life is so fundamentally based on
social relations, any changes in the social networks or any other
spaces of interaction can have considerable implications. Dur-
ing and after the war in Northern Uganda, social interactions,
especially for PWDs, were mainly shaped and experienced in
three domains of interaction: the informal—the family (kin-
ship) and the local community; the formal—the intervention

Conclusion
The translation and utility of a particular skill is not only
about the interface of the impaired body and the technology
alone; the socioeconomic and technical processes that the body
and the technology undergo to attain such value are also im-
portant. Skill is constantly transforming due to changes in tech-
ology and sociality, and at the same time, changes in sociality
rotate around the constantly evolving meanings of skill. Thus,
one’s sociality represents the guide, the guard, and the measure
of one’s technical and technological performance. In debating
aspects of disability and skill, therefore, there is need to dif-
ferentiate technological challenges from the processual socio-
political dynamics involved. Finally, the creative local efforts
and agency of PWDs themselves as they organize entrepreneurial
self-help projects, as shown in the ethnographic vignettes in this
article, are too often ignored in standardizing NGO projects.
Yet, I argue, their insights and transformative actions are essen-
tial to successful “skilling journeys” in postconflict Uganda.

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References Cited


Blackwell.


Chibwana, Bridget, and Prasad Mohan. 2001. The role of information, education and communication in the Malawi Social Action Fund. Social Innovation Notes

Chipungu, B., and S. Chibwana. 2001. The role of information, education and communication in the Malawi Social Action Fund. Social Innovation Notes

Monitoring programme in Northern Uganda.


In the Long Run
Ugandans Living with Disability

Susan Reynolds Whyte

Uganda has progressive legislation in place to support the rights of people with disabilities, and it has received donor support over the years for special education and community-based rehabilitation programs. Yet while political mobilization and interventions that aim to minimize disabling conditions have been important, they are not necessarily seen as a means to achieving rights and self-sufficiency. Using examples of families I have known for decades, I show how disability interventions and institutions affect their lives in the long run. James Ferguson’s approach to relations of dependence is useful in understanding how people in eastern Uganda perceive the possibilities in disability projects. I contrast global health time as instantiated in such projects with lifetimes of people and families with disabilities. Humanitarian and development projects sometimes feed into life projects such as education, housing, livelihood, and making families. But their impact is often not so great in the long run of lifetimes intertwined with lives of intimate others.

“The man must be punished! She’s a schoolgirl, a child of the government! He must cover all the expenses for her and the baby at the hospital and after they come home. And he must pay for her to go to boarding school. Her parents will have to care for her child—they have to sacrifice so Penina can go back to school.” The three people who had just come across from Penina’s home to ours wore grave expressions that morning in 2004. They were members of the Community-Based Rehabilitation (CBR) steering committee on tour visiting people with disabilities in their subcounty in eastern Uganda. Penina had just delivered her first child by caesarean section at the regional hospital. Seven years had passed since she had undergone a contracture release operation and rehabilitation for the effects of polio that had kept her on hands and knees. At the age of 12 she had stood more or less erect for the first time and painfully learned to swing herself forward on crutches. Both becoming upright and bearing a child were major events in the life of Penina and her family—vital conjunctures as Johnson-Hanks (2002) terms those moments in life when possible horizons open and different futures are at stake. The three CBR volunteers with their severe mien, facilitated by a Norwegian-funded project, touched her life briefly then, as did other interventions before and later. But the time and relationships of her life were of a different scale and nature than those of the programs implemented by government and donors in the name of human rights and global health.

In this article, I consider the temporalities and relationships that shape the lives and possibilities of people with disabilities in eastern Uganda. I argue that relations with passing disability projects are seen largely as opportunities for benefits that might be useful in life projects. The sporadic involvement with disability activities contrasts with the durable interaction in relations of interdependence with kin. What Ferguson (2015) calls “distributional labor”—the efforts to position oneself as a beneficiary—is a kind of work that must be understood in terms of people’s broader concerns. Many studies take humanitarian and development interventions, not least global health programs, as points of departure, thus adopting their time frames and their focus on disruption and transformation. I wish instead to consider the long run of lifetimes and their conjunctures and continuities.

Scholars working on chronic health conditions in the Global South have dealt with time in diverse ways. The work of Julie Livingston (2005) concerns “historical time” as she traces transformations in the political economy of Botswana and how they have changed the nature and management of debility (a term she uses to include frailties of old age and chronic illness). She touches as well on what might be called “care time,” the daily rhythm of intimate care and the everyday intermittent exchange of concern and recognition in reciprocal social life. With the increase in biomedically managed chronic illness, some scholars (Ferzacca 2010; and S. R. Whyte’s comment titled “Three Temporalities in AIDS Treatment” in Benton, Sanga-moorthy, and Kalofonos [2017]:470–471) use the term “vital time” for the regular punctuation of experience by testing, medication, monitoring, and return appointments. Perhaps those attempts to discipline long-term illness could better be called “treatment time”—a form of temporality more and more relevant in Uganda where thousands of “clients” report regularly to clinics for HIV, diabetes, hypertension, and epilepsy. But my errand here is with two other kinds of temporality, which I will refer to as “global health time” and “lifetime.” I will explore how Ugandan disability policy and projects (one configuration of global health time) intersect with the
life courses and life chances of people with certain kinds of bodily difference. I do this on the background of a particular methodological temporality: my intermittent engagement with some families over many years.

A Local World

Much research on disability in the Global South takes place in urban or semi-urban situations. Often disability institutions, organizations, activities, and programs are points of entrance. In contrast, this study is from a thoroughly rural area and describes families I knew that happened to have a member marked by some form of disability. The study finds people where they live and try to grasp their own perspectives on their lives and, where relevant, the interventions meant to change them. It does not pretend to offer a full picture of life with disability or of the policies and projects that are being implemented in Uganda. It describes one disability world inhabited by people in particular positions. Or perhaps more accurately, it describes one local world inhabited by some people with disabilities in families and neighborhoods.

Rural eastern Uganda largely escaped the depredations of Idi Amin and the subsequent era of “regimes” as well as the violence of war that northern Uganda underwent for 20 years. But neither has it enjoyed the economic growth that has boosted parts of western and central Uganda. Livelihoods are tenuous, based on a combination of subsistence farming and small-scale business, with few in wage employment. Families are large, reflecting national demographic patterns. The total fertility rate is falling slowly, down to 5.8 live births per woman in the 2014 census; however, many of today’s adults grew up in families with even larger sibling sets. This is a world where people move through their life courses with many relatives and never enough money, circumstances that are fundamental for those living with disability.

The state is present in the form of schools, health facilities, roads, and administrative structures. The hierarchy of local councils (LCs) from village to district ensures that government communication reaches neighborhoods and that there is a functioning system of representation. Members of LCs are elected, and in the decentralized system of government, they have some financial and other authority. In important ways, however, this is a para-state (Geissler 2015) in that donors and NGOs fund many of the services that a more robust state would offer. Often they do this through state institutions, so it is not clear to citizens what the state itself is actually doing for them. Sometimes it seems that government institutions orchestrate rather than shoulder the provision of services. This is clearly the case for AIDS treatment and prevention and, as we shall see, for many disability programs.

My husband Michael and I first lived in what is now Butaleja (formerly Tororo) district from 1969 to 1971 and have since kept in touch with families we knew then, through regular return visits after 1989. We built a house together with one family and have in many ways taken on the obligations that people with good jobs have toward relatives and neighbors—in a kind of participant observation that is sometimes uncomfortable and often revealing of the workings of patronage. Among other forms of assistance, we have paid school fees at a deaf boarding school, facilitated rehabilitation efforts for Penina, bought assistive devices, and contributed to building a house for a friend who is blind. Over the years, we have ourselves made some of the kinds of intervention that I am interested in here.

Returning to Butaleja for 3 weeks in late 2017, I visited five people with disabilities whose families and stories I had known for years, in order to get an update (M. Whyte 2013) on their situations and to try to make sense of how their lives related to Uganda’s progressive disability policy. I recorded interviews with them and went back into old notes to reexamine what I had written about them in years gone by. Penina and Helen both lived with the sequelae of polio; while Helen had one sound leg, Penina needed calipers on both legs and could not stand without them. Mulongo and Veria were blind, Mulongo from birth and Veria from young adulthood. Jassi lost her hearing as a small child after a “fever of the brain” that could have been meningitis. They range in age from 20 years (Jassi) to 65 (Helen). These are people with “conventional” disabilities who do not require the intimate daily care needed by some of the debilitated old people in the neighborhood, nor are their minds different in the worrying ways that preoccupy some families. They are people whose bodily differences are likely to fit with the sorts of interventions most widespread in the Ugandan disability landscape.

Give a Man a Fish . . . or at Least Something

James Ferguson (2015) argues for a rethinking of African societies—recognizing the centrality of dependence without necessarily vilifying it. Dependence and redistribution have long characterized African social relations. They have taken new forms in the eras of labor migration, humanitarian relief, and development aid, and they are ever more prominent in

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1. A methodological point of departure always gives one or another kind of selection bias. In earlier studies, colleagues and I made contacts through programs for people with chronic conditions, as in our study of living with HIV (S. R. Whyte 2014), thus excluding sick people who were not in treatment. Herbert Muyinda and I worked with a group of people engaged in a specific activity when we did research on disabled people in the cross-border trade (Whyte and Muyinda 2007), focusing on a cohort of enterprising men. A recent study on deaf identities in Uganda (Mugere et al. 2015) contacted respondents through national and district associations of deaf persons and conducted all interviews in Ugandan Sign Language (USL), thereby excluding those who were not members of deaf organizations and never had the chance to learn USL.

2. For a discussion of dependency as a feature of Ganda social life, see Scherz (2017).
current times when salaried jobs are scarce and other livelihood possibilities undeniable. Ferguson revisits the old adage, arguing that teaching a man to fish is a vain endeavor if he has no fishing rod and the fish are insufficient. He considers giving fish instead, in the form of cash transfers. He suggests that redistribution is already a principle of social life and that people are widely engaged in distributive labor, that is, declaring dependence or trying to position themselves as dependents or beneficiaries. Distributive labor is not the work of distributing but of managing to be distributed to.

Committed and articulate disability activists play a significant role in Uganda. Their advocacy and networking with international activists are largely responsible for the legislative record of which Uganda is justly proud. I fully acknowledge the work they have done in struggling for rights and projects for disabled people. However, the notion of distributive labor is useful for understanding another part of the picture. For many rural, less educated people living in poverty, projects and even representation are not only about rights and recognition. They are highly significant for what they can provide in concrete material terms. They are the objects of distributive labor, and relations to them should be understood, at least partly, in those terms. Nikolas Rose (2007:51) famously wrote that in contemporary liberal democracies (of the Global North), biology is not destiny but opportunity. For people with certain kinds of bodily difference in rural Uganda, biology is also an opportunity—to engage in distributive labor. They hope to get at least something when they are called for meetings or visited at home.

Uganda is rightfully renowned for its progressive policies on disability. Just as the National Resistance Movement (NRM) was a leader in promoting gender rights and taking up the struggle against AIDS, so too it adopted legislation in the 1990s that aimed to include people with disability, particularly in the arenas of education and political representation (Abimanyi-Ochom and Mannan 2014). Notably, the 1997 Local Government Act earmarked two seats for people with disabilities, a man and a woman, on every local council, from village to parish to subcounty to district. (In Parliament, five seats are reserved, of which one must be held by a woman.) The implementation of these laws gives Uganda a higher proportion of elected representatives with a disability than almost any other country in the world. The disability representatives on the lower-level local councils are often the point of contact for donors and disabled people’s organizations. They maintain lists of the people with disabilities in their villages.

Uganda was a “donor darling” for 2 decades after the access to power in 1986 of Yoweri Museveni and the NRM. Bilateral and multilateral development aid has been supplemented by aid from national and international NGOs. Bilateral assistance is often funneled through NGOs, whether international or homegrown. Community-based organizations form in the hope of attracting funds for projects. Particularly in the area of health, this has led to projectification of services and interventions—most striking in activities concerning HIV (Meinert and Whyte 2014). Initiatives are implemented in donor-funded project cycles, often linked to enduring government or other institutions, but with a limited time span. Among these was the CBR program that facilitated those three visitors to Penina’s home in 2004.

The Norwegian Association of the Disabled began providing support to CBR in Uganda in 1991, and from 2002 to 2005 it identified Tororo as a model district to benefit from resources for a range of activities including sensitization, assessment, referral, training, provision of assistive devices, and support to disabled people’s organizations (Claussen, Kandyomunda, and Jareg 2005). Many, probably most, people with disabilities in the district did not know which organization was funding these activities, nor how long the funding would last. What they did understand was that some individuals had connections to sources of funding and it was important to know those persons. Such connected people commonly gave the message that they should join groups in order to benefit from projects.

“Groupism” characterizes very many development efforts in Uganda. In earlier times, organizing for common betterment was a grassroots initiative. From the 1980s, groups were often formed as a kind of “astro-turf” in response to external funds and programs. They were inspired from the top down rather than the bottom up, even if they were supposed to be grounded in local communities. For people with disabilities, the importance of joining a group became evident after 1987, when NUDIPU (the National Union of Disabled Persons of Uganda) was formed as an umbrella organization. Under it were district groups and organizations for women and for different types of disability. Helen, who represented disabled people on the subcounty council for 15 years, put it succinctly: “You make a group; without a group you won’t get something.” Groups appeared with names like Obuleme sibugwisa lyuba (Disability doesn’t wait for the sun to go down, e.g., disability can affect you today); Muleme, twoyambe (Disabled person, let’s help one another); Kola baje (What I do, they laugh [alluding to proverbs about how those who laugh at the disabled might become disabled themselves]).

The distributive labor of groupism involves individuals in a series of activities. They cultivate relationships through which they might hear about upcoming opportunities. If they receive an invitation to a meeting, they try to respond, which might involve mobilizing money for transport. Indeed, joining a group often requires a membership fee, and the costs of transport and membership fees limit the ability of many to position themselves for benefits.

3. I take this term from the work of Herbert Muyinda, who heard it from disabled people in Gulu District. They complained that “groups do not help solve some of their personal problems as individuals” (Muyinda 2008:186).

4. Lunyole, the language spoken in Butaleja District, contains many proverbs about disability suggesting that disability can happen to anyone, anytime.
In the Subjunctive Mood

People orient toward projects and groups in a subjunctive mode of hope and doubt. Veria told me in 2002 that NUDIPU had called disabled people to a meeting 8 months earlier to fill out forms that would be sent to Kampala. They were to list their problems on the paper. “Now we are waiting for results,” she said, “but they haven’t come back.” People spoke positively of having their names written on a list—one that might make them and their needs legible to those with resources. Being acknowledged gave them expectations. There were sufficient examples of rewards that people kept on hoping and encouraging others. Mulongo, who served on the LC3 (subcounty level) and was therefore well-connected, joined many groups. As he said, “You just go on trying one group and another—maybe something good will come from one of them.” Or, as Helen said, also in the subjunctive mood, “We hear there is money [for disability groups] at the district, but we don’t know if it’s a lie. Our group meets on the 26th of every month and we make a contribution of 500 or 1,000 shillings so that we can make a constitution [a prerequisite for district recognition].” But the other side of this distributive labor was doubt, suspicion, and pessimism. Often enough, nothing came of it. “They just wrote our names. That’s all.”

Even those groups that were active for a period almost inevitably declined and folded. In retrospect, people looked back with disappointment at groups for which they had held high expectations. Penina told how excited she was about a group with disappointment at groups for which they had held high expectations. There were sufficiently examples of rewards that people kept on hoping and encouraging others. Mulongo, who served on the LC3 (subcounty level) and was therefore well-connected, joined many groups. As he said, “You just go on trying one group and another—maybe something good will come from one of them.” Or, as Helen said, also in the subjunctive mood, “We hear there is money [for disability groups] at the district, but we don’t know if it’s a lie. Our group meets on the 26th of every month and we make a contribution of 500 or 1,000 shillings so that we can make a constitution [a prerequisite for district recognition].” But the other side of this distributive labor was doubt, suspicion, and pessimism. Often enough, nothing came of it. “They just wrote our names. That’s all.”

Groupism is a breeding ground for suspicion about corruption, especially in a country like Uganda where corruption is a fact of life. Those who did not receive something from their group mistrusted its leaders or those at a higher level who were supposed to distribute resources. As Helen said of the CBR project in Tororo District: “The project is helping but they are slow. They don’t give things out. Maybe they keep things for themselves at the district.” At the time, she held a disability seat on the subcounty council and knew that people suspected her when benefits were not forthcoming. The chairman of Obuleme si wa Mulala (Disability is not of One Person) group said that other members were annoyed with him because they think he ate the money. “I have no heart of rejoining and the group has collapsed.”

Leaders were suspected not only of “eating the money” but also of favoritism. “I hear that World Vision helps people with disabilities, but only people they know. I heard some got houses, I tried to talk to them, but they have never helped. They help those who already have something.” Indeed, favoritism is unavoidable when much depends on personal connections. William, a lineage father of Penina, who had connections to disability organizations at the national level, told her with satisfaction that he got her name at the top of the list to receive a wheelchair. Currently, word is that there is money at subcounty level for disability groups that are well organized and propose feasible projects. In one neighborhood, people had formed a group, filled out papers, and obtained a license at 20,000 shillings. They failed to get anything and noted that Mulongo, who represents disabled people on the district council, favored his own group, which was given cows.

People were engaged in distributive labor when they attended meetings or joined groups where they could position themselves to receive material benefits. When they spoke of the meetings, they frequently mentioned how those in charge were able to distribute things such as transport allowances or snacks. Members of local councils might receive an attendance allowance for meetings, and both LCs and NGOs often gave transport allowances, which always exceeded the actual cost of getting to the meeting. In 2002 (when Tororo was a model district with funding from Norway), Veria told about the formation of a group for blind people. “The first meeting was ok, they gave us biscuits, soda and transport. The second meeting we got nothing but 2,000 [0.55 USD] for transport. Then they wanted us to go to Tororo for a meeting and they would refund transport but I didn’t have money to go.” Expectations of material resources were so strong that people were up in arms when they were not forthcoming. Helen recounted a meeting called by World Vision in 2013.

They invited all people with disabilities in the district but did not give us transport. When I reached the district headquarters, I wondered that there were so many people with disabilities! The World Vision organizers told us there was no food for us, even though we had left home early [implying without eating]. They had cooked only for the children and people fought for that little food. We said, “If you don’t give us food and transport, we won’t leave this place.” Finally they provided vehicles going to different parts of the district. From that time, even if they call for meetings, I have never gone. When I used to go for subcounty council meetings, they gave breakfast, lunch, and transport.

Seldom did anyone mention what actually happened at the meetings. Veria was an exception. She said that they were taught to form groups, to visit one another, to work at farming, to attend funerals and mix with people, not to worry, and to eat well. Then they selected officers. Neither she nor others talked of the rights of disabled people. Helen, the spokesperson for disabled on the subcounty council for 15 years, always asserted that disabled people were suffering and needed help. I never heard her speak the discourse of disability rights.
In Ferguson’s view, distributive labor is oriented toward the cultivation of relationships of dependence. Ideally, they should be durable, not simply one-off distributions of some or another resource. This may help to illuminate a pattern that many have noticed: when people are given something, they expect more. They are imagining, hoping for, a more lasting relationship. In 1997, Veria reported that two men came to her home, gave her a white stick, taught her how to use it, to cook safely, and do other domestic chores. When I spoke to her recently she remembered her disappointment. After the training, a man from Kampala, a European, assessed what she had learned, and she passed. She requested some capital to start a business and the European said that the trainer, a local man, would come with help. But she never heard from him again. Did he take the help meant for her?

Hopes for durability also seemed present in Penina’s remarks about a wheelchair she was given during the time of the model district. It was not a hand-crank tricycle, like her first one that got stolen; she had to turn the wheels, which she found too difficult on the uneven ground far from any tarred road. It stood unused, and I asked her why she did not sell it, since she was in desperate need of money. She replied that some others who had received such wheelchairs had indeed sold them. “But I fear to sell it because it was given to me and they might find out. Besides, if something good comes, I might not get it.”

When I brought Penina and Helen to the orthopedic workshop 50 kilometers away because their calipers had fallen into disrepair, the technician sighed. “It’s so typical that people don’t maintain their devices. If someone gets a free wheelchair and the tire gets a puncture, they wait for the donor to fix it. I’ve decided not to give free things.” It is a familiar (though not inevitable) pattern that an object given often seems to represent a relationship that the recipient hopes will continue in the form of more help. One person who was given a bicycle from the Norwegian project so he could make home visits complained that the project did not repair the bike for him—“Not even a single spoke!” Helen protested that she was given too little for attending meetings. At the same time, as a mobilizer for the Norwegian project, she criticized people’s attitudes. The project was supplying free appliances for people with mobility problems, but the recipients had to get to the orthopedic workshop on their own. “You know these African people. If you have given them something, they say I lack transport. I am fed up with some of them!”

Like the orthopedic technician, and even Helen herself, local people in positions of authority at times construe examples of distributive labor as illustrative of ingratitude, fecklessness, and lack of initiative . . . even of a beggar mentality. I am suggesting that we can also see them as hopes for a relation of more dependence—not “declarations of dependence” in Ferguson’s words, but tentative moves, keeping an eye for opportunities in the spirit of the oft-heard remark “You never know.” When global health time takes the form of treatment time, as it has done in the programs for antiretroviral therapy, there is a continuing, regular relationship between client and patron. The temporality of disability programs and projects is of a very different nature. After the Year and the Decade of the Disabled, global health and rights were instantiated in a major UN Convention on the Rights of Persons with Disabilities. The recent legal history of disability in Uganda has been punctuated by the passage of various statutes and acts. Yet, on the ground, donor-funded projects continue to run their cycles, and groups form and dissolve, making it difficult for poor rural people to maintain durable relationships of dependence on the basis of their disabilities.

In emphasizing people’s hopes for material benefits from disability interventions, I do not want to dismiss the importance of rights and recognition, which are central in the intentions of new laws, policy, and projects. Certainly, people appreciate being recognized, as is evident in the significance attributed to getting one’s name on a list. But they feel that recognition should be materialized in relationships with patrons and concrete benefits.

Life Projects: Education, Livelihoods, and Houses

More enduring, and far more significant, are the everyday relationships of kinship that are both dependent and interdependent. Resources of all kinds come through these relationships, and once in a while, the resources from disability projects can also be deployed to feed into them. In turning now to lifetimes, I move beyond Ferguson’s paradigm in order to ask what people do with the benefits of distributive labor. This requires considerations of lifetimes, intertwined as they are, and the long-term hopes and expectations that family members have for one another.

Rapp and Ginsburg (2011) wrote of how disability in a family promotes new, or alternative, kinship imaginaries, using data from their interviews with New York parents who reimagined what life might be for their disabled children and themselves, when it was not possible to enact the cultural script of success. In eastern Uganda as well, there are general ideals for individual and family futures: children should go to school, gain a livelihood that helps support themselves and others, get a house of their own, marry, have children, and care for their parents and other relatives. They should live, and not die before their parents do. Yet very many children, and not only those with disabilities, do not follow this trajectory. Alternative kinship imaginaries and reshaping of family relations have been ongoing since the 1980s with the population explosion and land shortages, the AIDS epidemic, the decline of formal marriage, the cost of (even allegedly free) schooling, the lack of wage jobs for educated youth, and the decline of reliable cash crops. Rural families living in poverty already face many challenges and misfortunes. The presence of a disabled member requires reimagining and readjusting, but it is not as unique and unexpected a problem as it seems to be for the New Yorkers whom Rapp and Ginsburg describe.
The concept of kinship imaginaries is more productive if we are more general about the imaginary and more specific about the disability. All of the life projects I describe have in common that they open horizons by creating new social connections and consolidating existing ones. Such connections build the family as well as the individual—bringing schoolmates (“old girls and old boys”), in-laws, trading partners, children, grandchildren, and, perhaps even fellow persons with disabilities met through a group or a project. It is basically the expansion of sociality that is at the heart of the kinship imaginary in societies where people are wealth. Thus, an impairment that inhibits social interaction is particularly disabling. As I suggested in an earlier study (S. R. Whyte 1999), disabilities affecting communication, especially those associated with aggressive behavior, are the most challenging for a family precisely because they restrict that extension of positive sociality that kin groups imagine. When government policy encouraged children with mental disabilities to attend local schools, their parents were supportive. Although the children never learned to read or write, they acquired social skills from interacting with teachers and other pupils (Jacobsen 2000). Among those I write of here, only Jassi, who could not hear or speak, had impaired communication. Yet, she was alert, even extra attuned, to other people and their expectations of her.

Parents want education for their children. Since 1997 when Uganda introduced Universal Primary Education, schooling is nominally free for the first 7 years, and all children are supposed to attend. Yet even primary school requires sacrifices for most families in the form of school uniforms, books, and myriad extra fees. For the parents of children with disabilities, especially the blind and deaf who need specialized boarding schools that are not free, the obstacles can be tremendous. What educational opportunities do they have and what difference does schooling make in the long run of a lifetime?

Penina started school in 1997 after her operation and participation in rehabilitation training, cranking her way along the path on the tricycle we got for her. She was 12 when she started first grade, but there were many her age in the class because that was the year that Universal Primary Education was introduced. Children whose parents had not been able to afford to send them began school for the first time. They were the “children of the government” since, it was said, the government and not their parents paid for their education. The authorities announced that priority should be given to girls and disabled children, so Penina was exemplary as a child of the government. The three CBR volunteers who visited her in 2004 also treated her as exemplary in that they identified her as the object of defilement. Since 1990, sexual intercourse with a girl under 18 is a capital crime no matter if she consented or not. In practice, cases of defilement are mostly claimed if a schoolgirl falls pregnant, and they are often settled without police intervention, with the girl’s father putting pressure on the man and his family to pay him (Parikh 2012). Penina’s father confided to me at the time that she was actually 19, “but that’s our secret.” He claimed she was younger so that he could extract money from the father of her child—a vain endeavor as it turned out because his family was as poor as hers, and he was in prison for stealing a bicycle.

Having been expelled for pregnancy, Penina did not want to return to her former school where she had been in her last year, P7. In any case, the journey to school had proved too difficult and she had been staying with an aunt who lived closer. I offered to pay for her to attend a nearby boarding school so that she could finish her Primary Leaving Examination, but in the end, she declined. There were various reasons: she would have to repeat a grade, she could not do all the chores required of boarders, she had started to experience epileptic seizures. But I think the most important reason was that she had a child and was older than the other pupils. It is hard to say what difference schooling made in Penina’s life. When I had a long talk with her in 2017 and asked her what had been the best time of her life, she said it was when she was in P7. “I was fat and beautiful. You gave me money and I had nice clothes and looked smart at school—even the headmaster wanted to con [court, flirt with, or seduce] me.” Now, at age 30, she says she is faded and always poor.

Present policy in Uganda is that disabled pupils should be integrated in regular government schools. But this is not a satisfactory solution for children who need to learn sign language or braille. For some children with mobility impairments, it is difficult even to get to school. The burden is on their families. Some, like Helen and Mulongo, had parents who managed to educate them through primary school. For others, like Penina and Jassi, their parents cultivated a donor-patron who made it possible. For many, primary schooling is out of reach. The chairman of the local council in our village spoke sharply about the inequitable education concerns of the CBR model district project, which had called local leaders and secondary school prefects to a workshop. They had talked about the need to support disabled children in secondary school. “Tell me,” he said, “who are the parents who worry about sending their children to secondary school? They are the ones who had enough to send them to primary. Why help those who already have? What about all those families who cannot even get their disabled children through primary school?” I would add, what about the disabled parents who are trying to send their children to school, as were Penina and Veria? Schooling is a life project for parents, and one of the reasons they engaged in productive and distributive labor was to obtain resources that might support that project.

Livelihoods are dominant concerns for everyone in rural eastern Uganda, but especially for those living with disabilities that limit their activities in some way. None of the few people I am considering here were able to use their schooling or training to earn money, with the possible exception of Mulongo, who was taught music at a school for the blind and earned money as a musician for some years. Like others, they were trying to subsidize from agriculture and small-scale business.
Unlike others, they also lived with the hope and doubt that their biology might be an opportunity. Through the right kind of distributive labor, they might be able to benefit from a project or a place on a local council that paid allowances. Only for Jassi was this irrelevant since she seems never to have been touched by disability projects or groups. She farmed with her parents and hired out her labor to others in order to earn some cash.

There were (and are) some attempts to help people in ways that would continue to generate livelihoods, but none of these was more than a temporary supplement to the livelihood dependence and interdependence they shared with their families. A few groups were given livestock to distribute to their members. A few groups scattered. It was the CBR project from Norway. That was 2006. They used to come but I don’t hear of them anymore.” All this time, Mulongo was part of his father’s household, eating the food his stepmother produced and cooked. Veria was given a pregnant goat when called for a meeting by NUDIPU, and later she bought two more from the allowances she was given for attending meetings in connection with the CBR project. In the classic local move, she let her goats reproduce and traded them for a cow. This was a help to her family, but she still depended on them for her basic livelihood. As her first husband fell into drunkenness, serious illness, and death, her sons took over more and more of the farm work. One was expelled from school because he so often skipped in order to weed millet.

With a bit of capital I provided, Penina had a little business trading tomatoes and small dried fish for a time. But as so often happens, she used the profits on pressing family needs and was unable to maintain her stock. Still, fulfilling those needs allowed a more active reciprocity within her household. After her father died, she continued living with her mother and siblings, farming with them by leaning on one crutch and wielding the hoe with her other arm. It is a large household, whose only sources of cash are the occasional earnings of her brother and the day labor of family members including Penina, who hire themselves out to work in others’ gardens. When I saw her in November 2017, she was happily going off to help harvest the groundnuts of her married sister in another village. No doubt she brought some home to share with the rest of the family.

A key life project is to acquire and maintain a serviceable house. Back in 2003, Mulongo had asked me to talk to organizations like Lions and Rotary in nearby towns to see if they would give roofing materials for a blind man. “When you are blind and sleep in a grass-thatched house, it can leak [implying that you cannot inspect the state of the thatch]. That’s the biggest problem I have—I need ten iron sheets.” Years later he got lucky. He was chosen as NRM district vice-chairman for disabled people. This position in the structure of the ruling party paid him an allowance for the term of 5 years, money that he used to build a proper house with a tight roof. “A house is better than money,” he remarked. For Helen too, it was the money she got for sitting on the subcounty council as representative for disabled women that allowed her to build a house. Fortunately, her 15 years as councillor included the time of the CBR project, so she also received some allowances for her work with that. She was tired of living in the same house with her husband and his other younger wife. Veria benefited from iron sheets to roof her house as well, in a direct distribution to disabled people from the CBR project. These much-appreciated resources came as cash or building materials that could be used directly in life projects. They were more like cash transfers than teaching a man to fish. Long after the project or the term on a council or committee came to an end, those who were able to build a house enjoyed that life project together with their families.

For the people I know, it was not vocational training or group business projects that contributed to their livelihoods. Cash from allowances, or material gifts in the form of iron sheets for a roof, or an animal (if it survived) were more durable resources that could be brought into the enduring relations with families. It was those relations, within and across generations, that sustained them and with whom they shared livelihoods, precarious as they often were.

Life Projects: Making Families

The great life project for people in Uganda, perhaps everywhere, is making families. That people with disabilities should pursue this project is a given. I have never heard anyone suggest that they should not have children. Whether they also manage to marry or find a lasting partner is another matter. Most people said that in principle, anyone who was hardworking could marry. Once I asked whether a deaf woman unable to speak would find a partner; my friend laughed and said, “Of course! You know men and women!” implying that they will always pair up. That said, marriage was not straightforward. While those who have attended institutions for the deaf and the blind might acquire a partner there (Sentumbwe 1995), rural disabled people do not necessarily find disabled mates. Jassi left her boarding school for the deaf when she was still young and attended the local government school. She fell pregnant when she was 18; her parents said she was raped and they knew who did it but have been unable to get his family to provide any support. Jassi cares well for her little daughter; her mother notes that the only problem is that she cannot hear when the child cries. But her parents and six siblings are her ears. Her mother would like Jassi to marry if she could find a good man.

Finding a good man has totally eluded Penina. She too claimed that her first child was begotten by rape after she repulsed the advances of the man who did it. She knew the man, and her mother, father’s brothers, and I went to his home to

5. An interesting further development is the pattern of “sero-sorting,” where HIV-positive people form partnerships with others of the same sero-status (Whitty, Siu, and Kyaddondo 2014:140). This pattern emerged when antiretroviral therapy became widely available and HIV became a chronic rather than fatal condition.
demand that his family support her and the baby. (Her mother specifically did not want her husband to come because in case they extracted any money, he might use it for drinking.) Penina herself and her family disregarded the biological father as a potential husband; he was a thief and idler (muyeyi). He and his family recognized her son but did nothing to help him. She loved the father of her second child, and that boy is now staying in his home. But they never married; Penina said the man’s father forbade it because as the firstborn, his son should not marry a disabled woman as his first wife. Now Penina wants to bring that son back because his father’s family does not care well for him. As for the third child, a girl, the father is also irresponsible. He gave his daughter a name, and nothing more. Penina sounded sad as she reflected on the fathers of her children. “I’ve always wanted to marry, but the fathers of my children are helpless. They promise, but they can’t take me home. They are not ready for serious commitment. And I’m afraid that in their home I might not be able to do all the housework like going for water. They can’t be patient with my situation.”

After her last birth, Penina decided to stop “because God had given me three children by different fathers who did not support me.” Another reason for agreeing to a tubal ligation might well be that she had to deliver by caesarian section and in Uganda, doctors are loathe to do “Caesars” more than three times. No disability program assisted Penina in these life projects. As we saw, the CBR volunteers only came to scold. Help came from her brother, who was poor enough himself. Penina explained: “For the first child, he sold a calf and paid the hospital expenses of 190,000 shillings [52.25 USD]. For the second birth, he sold his bicycle and our mother’s goat and paid 140,000 [38.50 USD]. For the third one, he rented out his land and paid 130,000 [35.75 USD]. He said that since I helped you to bring the children into the world, I will not pay for their books or school fees.” But Penina’s brother has certainly supported her and the children. The household counts about a dozen, including their mother (now a widow), his own wife and children, and another unmarried sister with a child.

Recently Penina went to marry (cohabit). It was her first time to live as a wife in a man’s home. He worked for a security company and she hoped for some relief from the constant poverty of her own family. It only lasted 2 months, however; he sent her away when she finally told him that she could not have more children. Formal marriage is declining all over the country, and cohabitation is the most common form of partnership. But cohabitation is often unstable, with many women leaving their partners’ homes and returning to live with their natal families. So Penina’s situation is not at all uncommon.

Married or not, women with disabilities have children and, in time, grandchildren. It seems to have escaped the notice of disability policy makers, advocates, and project implementers that children constitute the most sustainable mobility assistance poor people with disabilities ever have. Penina does not use her standard wheelchair but sits on the baggage carrier of a bicycle pedaled by her 13-year-old son. Veria said at one point that she would ask for meetings to be held on Saturdays, when her children were not in school and could bring her by bicycle. The image of a blind man being led by a child has been materialized in a statue outside of the World Health Organization building in Geneva. It is still relevant despite the fact that children are supposed to be in school. For years, Veria counted on her eldest daughter to take her places. When that girl married (at a very young age), her brother took over. Now a granddaughter stays with Veria, and she keeps the girl home from school if she has an important journey. Mulongo has three sticks for feeling his way: a local wooden one for the village, a metal white one for going to the trading center, where he holds it out to show cars that he cannot see, and a smart folding white stick for trips to Jinja and Kampala. Still, adept as he is at finding his way, he occasionally has to borrow a child.

Visiting his home, I saw how two of the boys in his extended family gently and deftly steered him in the right direction when he stood up, one smoothly passing him on to the other. At the age of 55, he finally married, and he and his wife had a new baby when I visited. In a few years his own child will extend his competence in the same way. Alternative kinship imaginaries are not only about how parents adjust to the children’s disability, but also how children and grandchildren’s lives are affected by the disabilities of their senior relatives.

Of course, children are not only helpful in practical matters. They are company, they bring life to the home, they are concerned about their parents. They care, but they are also a source of worry for poor mothers with disabilities, like Veria and Penina, who have struggled through the years to send their children to school, to clothe them, and to feed them properly. Parents with disabled daughters like Jassi and Penina are angry that men have used them without taking responsibility for their pregnancies. But they do not regret that their daughters have children of their own. Children are about generations and the intertwining of lifetimes that are a primary mode of experiencing the passage of time. Here we really are in the long run, a mode of temporality that touches only intermittently on that of projects and donors.

Conclusion
Disability policy and interventions, as experienced on the ground in rural eastern Uganda, run on time that is sporadic and limited. Although the local councils are part of an enduring structure, the councillors for disability sit only for set terms. Interventions are either one-off events or they end when the project cycle ends. Yet people try through distributive labor to position themselves in order to receive benefits, and they hope that the relationships will hold long enough that more material benefits will come through. In this they know they may be disappointed, but in the spirit of subjunctivity, they keep possibilities open.

Lifetimes have a much longer temporal arc, and they involve growth and change, as people move through life courses that are intimately linked with those of others. It is not only that
relations of kinship and neighborliness sustain people—disabled or not. They grow them socially. Gaining partners, in-laws, children, and grandchildren changes them as persons. In this process, interventions or holding a disability seat in a political structure can make a difference. But that difference comes about through the way disability interventions play into life projects of schooling, livelihood, and making families.

Penina’s life was changed by surgery, training, and assistive devices. She had no further relation with the NGOs that helped her then; the Cheshire rehabilitation home and the project for disabled children in the next county closed down long ago. But her family embraced her ever more firmly. She told me that she thought her mother loved her more when she did not have to crawl anymore. She could go to school and look smart. Staying with her aunt near the school, she met the man who forced himself upon her and caused the pregnancy that so alarmed the CBR volunteers. They demanded that she go back to school (and I agreed), but her life took a different direction at that conjuncture. For a time, she worked with a disability group and earned a small income that allowed her to buy daily necessities for her children and family. But looking back, that was just a short phase in a life that has been difficult and yet somehow viable thanks to her family. The Norwegian wheelchair is parked in a hut and her son carries her on a bicycle.

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