

Disability Worlds

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Annu. Rev. Anthropol. 2013. 42:53–68

First published online as a Review in Advance on
July 24, 2013

The *Annual Review of Anthropology* is online at
anthro.annualreviews.org

This article's doi:
10.1146/annurev-anthro-092412-155502

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Keywords

disability studies, impairment, embodiment, reflexivity

Abstract

Disability is a profoundly relational category, shaped by social conditions that exclude full participation in society. What counts as an impairment in different sociocultural settings is highly variable. Recently, new approaches by disability scholars and activists show that disability is not simply lodged in the body, but created by the social and material conditions that “dis-able” the full participation of those considered atypical. Historically, anthropological studies of disability were often intellectually segregated, considered the province of those in medical and applied anthropology. We show the growing incorporation of disability in the discipline on its own terms by bringing in the social, activist, reflexive, experiential, narrative, and phenomenological dimensions of living with particular impairments. We imagine a broad future for critical anthropological studies of disability and argue that as a universal aspect of human life this topic should be foundational to the field.

INTRODUCTION: DISABILITY AS A FOUNDATIONAL CATEGORY

Disability is a profoundly relational category, always already created as a distinction from cultural ideas of normality, shaped by social conditions that exclude full participation in society of those considered atypical (Canguilhem 1991, Kasnitz & Shuttleworth 2001, Shuttleworth & Kasnitz 2004). What counts as an impairment in different sociocultural settings is highly variable. In the past 20 years, the growth of both a worldwide disability rights movement (Shapiro 1993, Charlton 1998) and the academic field of disability studies has inspired new approaches (Linton 1998, Devlieger et al. 2003, Addlakha et al. 2009, Davis 2013). The idea of disability as a stigma has come under critical scrutiny by disability scholars and activists alike, especially by those in the Anglo-American traditions who developed “the social model of disability” (Shakespeare 1998). This paradigm insists that disability is not simply lodged in the body, but created by the social and material conditions that “dis-able” the full participation of a variety of minds and bodies. Disability is thus recognized as the result of negative interactions between a person with an impairment and his or her social environment. For example, ramps dramatically change the inclusion of wheelchair users in public life, an aspect of universal design that is fundamental to a fully democratic built environment (Russell 2002, Crews & Zavotka 2006; cf. Friedner & Osborne 2013). The social model involves a foundational critique of medicalization and its hegemony in defining and categorizing nonnormative subjects. Nonetheless, the relation between embodied limitations and social discrimination remains complex and enduring (Kasnitz & Shuttleworth 2001). Hence, we choose to use “disability” and “impairment” somewhat interchangeably.

Until recently, the study of disability by anthropologists was, with a few exceptions, intellectually segregated, often considered the province of those in medical and applied anthropology (Armstrong & Fitzgerald 1996; Kasnitz 2008; Rapp & Ginsburg 2011b, 2012). Additionally, Shuttleworth & Kasnitz point out in their 2004 review essay, “Despite this increased attention to the topic and theory of disability in anthropology, the anthropology of impairment-disability still suffers from terminological confusion, theoretical oversimplification, and a radical relativist bias that is adverse to critical approaches” (Shuttleworth & Kasnitz 2004, p. 153). In addressing literature of the past decade, we show in this review article the growing incorporation of disability in the discipline on its own terms. Notably, the turn to the corporeal at the end of the twentieth century has had a salutary effect (Csordas 2002), bringing in the social, experiential, narrative, and phenomenological dimensions of living with particular impairments (Frank 2000). Furthermore, in the past decade, anthropologists interested in activism have found the study of disability in multiple locations to be an exciting arena of fundamental social change (Holzer et al. 2001, Addlakha et al. 2009). They join disability scholars across disciplines who have worked to expand the theoretical frameworks beyond the social model, without abandoning the connection to activist concerns (Groce 2001, Shakespeare 2005, Blume & Hiddinga 2010).

Our review brings together reflexive and ethnographic accounts drawn from the analytic space where anthropological and disability studies have started to converge. Many anthropologists working on disability-related topics have been motivated not only by these new perspectives, but also by their own encounters with disabling conditions—whether through their own bodies or those of kith and kin—an existential position that brings a sense of urgency to much of this work (Rapp & Ginsburg 2001). Increasingly, researchers are focusing on social, political, and narrative strategies that address the experience of disability within the production, reproduction, and transformation of broader forms of social inequality. Our goal is to map recent writing on the experience of disability in relation to kinship, community, and religion, as well as the commercial, scientific, medical, and media worlds that everywhere shape both intimate domains and public spheres. We stress the contribution of our discipline’s distinctive ability to study lived experience via ethnographic methods

and to imagine a broad future for critical anthropological studies of disability. Unlike the categories of race and gender from which one can only enter or exit very rarely and with enormous and conscious effort—"passing" or "transgendering," for example—disability has a distinctive quality: It is a category anyone might enter through aging or in a heartbeat, challenging lifelong presumptions of stable identities and normativity. Of course, some will be more vulnerable than others owing to poverty, war, disaster, and the vagaries of health and health care, but no social category is exempt from disabling experiences, however they are defined (Block et al. 2001, Boyce & Weera 2001, Fjord & Manderson 2009, Eide & Ingstad 2011, MacMakin 2011). Despite the universality of the experience of disability, the approaches taken by scholars working out of different national contexts often vary not only by cultural norms but also in terms of policy, educational practices, forms of research funding, and social movements (Varenne & McDermott 1998, Holzer et al. 2001, Ville & Ravaut 2007, Addlakha et al. 2009, Blume & Hiddinga 2010, Teruyama 2011, Addlakha 2013).

Given the centrality of diversity to our epistemology, why has the subject of disability not been a key topic for our discipline? Indeed, this is the first *Annual Review of Anthropology* piece to address disability as a general concern, although in the past decade, the topic has had a significant presence in excellent reviews addressing particular forms of disablement: autism, sensory impairment, bodily enhancement, and Deaf communities (Senghas & Monaghan 2002, Hogle 2005, Keating & Hadder 2010, Solomon 2010a). Anthropology is well known for its capacious and ever-expanding framework for understanding "human nature" (Rapp & Ginsburg 2010). The potential significance of disability is emerging across the subfields (Hubert 2010). For example, discoveries of burials of individuals who survived for years with disabilities have opened up work on the "bioarchaeology of care," showing the relevance of this category across time (Tilley & Oxenham 2011). We have also learned from studies of early and latter-day eugenics and histories of institutionalization that the label of disability has been used to dehumanize populations across the globe (Groce & Marks 2000, Longmore & Umansky 2001, Landsman 2004, Comfort 2012). Such wide-ranging findings invite anthropological research on how disability is framed through the social organization of daily life, understandings of personhood, and governmentality. Surely this form of difference is a universal aspect of human life. We argue that this insight is so foundational yet so often neglected that anthropologists should be encouraged to integrate disability into virtually every topic they study and teach. Although the discipline has been a latecomer to this growing field, anthropology has landmarks that established what we might contribute to this emerging area of study.

THE EMERGENCE OF DISABILITY IN ANTHROPOLOGY: A GENEALOGY OF THE PRESENT

Pioneers in the field, mostly working in North America, set a high bar for later scholarship. The 1967 publication of Robert Edgerton's monograph was foundational both for its insights and for its attention to a historical paradigm shift in the place of disability in American public life. The title of his book, *The Cloak of Competence* (Edgerton 1967), highlights the strategies deployed by those who learned how to "pass" when the local impact of an international movement for the closing of asylums repatriated them to "their" home communities after long-term institutionalization. Others followed Edgerton's inspiration in taking up research with cognitively impaired adults. In the 1990s, Angrosino published his vivid accounts based on a decade of fieldwork with adults with intellectual disabilities living at Opportunity House. His work demonstrated the value of life histories and a collaborative research approach; using the narrative device of short stories, he renders a rich and complex portrait of a community whose humanity is often overlooked (Angrosino 1994, 1997). His ethnography foreshadowed Nakamura's engaged research at Bethel

House with a community of people with psychiatric disabilities in rural Japan, portrayed in both her documentary film as well as her writing (Nakamura 2009, 2010, 2013).

Other early ethnographies focused on the phenomenology of embodied difference in a less-than-accommodating world. Groce, Becker, Gwaltney, and Deshen were particularly attentive to different communicative practices entailed in impaired hearing (Becker 1980, Groce 1985) and sight (Gwaltney 1970, Deshen 1992), with a focus on management tactics as well as the creation of communities, whether inclusive or exclusionary of difference. The pioneering medical anthropologist Joan Ablon authored several key studies on the social consequences of genetic differences. Her important books on short-statured people and 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 most recently *Brittle Bones, Stout Hearts and Minds* (Ablon 2010). As Shuttleworth & 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” (Shuttleworth & Kasnitz 2004).

Many of the works cited above were initially conceived as broad cultural projects, offering a critique of medicalization, which the ethnographers and their subjects jointly articulated. 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 discipline took shape under the auspices of the Society for Medical Anthropology in the 1980s (Kasnitz & 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 disease and disorders (Manderson 2011, Inhorn & Wentzell 2012). For example, disability and chronic illness in broad sociocultural context inform Rouse’s work on sickle-cell anemia in the lives of young African Americans (Rouse 2004, 2009). Some authors also place themselves in their ethnographies as Americans participating in the stereotypes, services, and social movements that framed the lives of their subjects. Frank addresses the importance of intermittent surgeries in the life of Diane DeVries, a woman born without arms and legs, in her book on DeVries’ life, *Venus on Wheels*; she also reflexively explores the long-term psychodynamics of their relationship as fieldwork blurs into friendship and Frank (2000) helps with personal care.

Research and writing on disability in anthropology have also been especially enriched by another time-honored ethnographic strategy: autoethnography. Some anthropologists, when confronted with their own chronic disabling conditions, use an autoethnographic lens to offer powerful insights into their own experience, illuminating the broader terrain they inhabit. The classic case is Murphy’s (2001) influential book, *The Body Silent*, a gripping narrative of his struggle with a spinal tumor that eventually resulted in his quadriplegia. His analysis showed how American cultural norms that valorize independence serve to dis-able identity, status, and social relations, revealing the cultural and existential dynamics of marginalization. Firsthand experiences with chronic pain are another form of embodied access that generate important insights. Jackson’s (2000) *Camp Pain* and Greenhalgh’s (2001) *Under the Medical Gaze: Facts and Fictions of Chronic Pain* both reveal the moral burden placed on those with hard-to-define disabling conditions. Similarly, 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.

Reflexivity has been central to the exploration of what it means to do fieldwork that incorporates the experience of the ethnographer with disability, whatever the focus of their research. Colligan analyzes the epistemological value of her own embodied difference as a feature of fieldwork with Karaite Jews in Israel, given her occasional physical dependence on community members for help. Rather than see her disability as a form of “privileged access,” she suggests that every ethnographer consider how “their own bodies potentially enrich anthropological insight and experience” (Colligan 1994, p. 9). Myerhoff’s (1985) extraordinary film, *In Her Own Time*, shows how fieldwork while seeking a cure for her cancer in fact opened research possibilities with her Orthodox Jewish subjects that would never have otherwise emerged. Other first-person accounts address the experience of disability when it is not visibly apparent. Three anthropologists with diverse learning disabilities (LD) use their own life histories of living with “brain difference” and its attendant stigmas, arguing that this experience made them more sensitive to “the kinds of intuition and other such skills that are adaptive in nonwriting nor reading focused cultures” that are central to anthropology (Raphael et al. 2001, p. 159).

A reflexive perspective also deepens the insights that anthropologists bring as parents to their fieldwork and analysis. Landsman’s experience as a mother of a child with cerebral palsy informs *Reconstructing Motherhood and Disability in the Age of “Perfect” Babies*, a longitudinal study of how mothers of newly diagnosed disabled children come to revise the concept of “normal,” a journey she herself had to undertake (Landsman 2009). Haldane & Crawford (2010) offer insights into the slippery nature of labels: Their daughter, diagnosed with autism in the United States, was incorporated into village life in the mountains of Morocco during fieldwork as simply a child with unusual attributes.

Attention to narrative is ubiquitous in recent scholarship on disability, notably in the analytical work of Couser (2009) on the growing disability memoir phenomenon. Shuman (2011) examines the politics of recognition and “empathic unsettlement” in stories told by parents of children with disabilities—including her own child—using a phenomenological analytical approach (p. 160). In a rich body of work on the place of narrative in healing beyond the constraints of the medical, Mattingly & Garro and colleagues (2000) show how clinical cases involving disability take on dramatic plots that reorient subjects to the task of constructing new futures. In her most recent book, Mattingly (2010) interprets “the paradox of hope” in narratives of impoverished African American families with children diagnosed with chronic medical conditions (Mattingly 1998, 2010). In *Racialized Bodies, Disabling Worlds*, Dossa (2009) shows us how disabled Canadian Muslim immigrant women claim their humanity in a deeply storied fashion. Geurts (2009) calls attention to the significance of upright posture and balance as a cultural value in the stories of Ghanaian disability activists, whereas Le Clair uses Canadian swimmers’ tales to show their transformation from disabled athletes to Paralympians, paralleling the increasing inclusion of disability into the public culture of sport (Le Clair 2011a,b; Limoochi & Le Clair 2011). In our own work with parents of children with cognitive differences, we reflect on our own and our subjects’ efforts to “rewrite cultural scripts” to encompass the unanticipated experience of disability in the family (Rapp & Ginsburg 2001). We have discussed this new narrative genre as a counterdiscursive “unnatural history” through which families construct a meaningful understanding of life with a difference that, we argue, collectively becomes constitutive of an emergent disability counterpublic, what we discuss below as a “new kinship imaginary” (Rapp & Ginsburg 2011a).

CAN THE CATEGORY OF DISABILITY TRAVEL?

Research on disability in parts of the world where medical technologies are less readily available demonstrates that the very category of disability has quite different configurations in diverse

cultural and economic settings. In the Global South, where an estimated 80% of people with disabilities reside, cross-cultural work in anthropology and disability studies shows that what counts as a disability in different cultural settings cannot be taken for granted (Devlieger et al. 2003, Addlakha et al. 2009). Ingstad & Whyte's landmark coedited volume, *Disability and Culture*, early on highlighted non-Western social circumstances to understand how people with impairments survive and are integrated into or segregated from local social worlds. As Africanists, Ingstad & Whyte point out the complexity of the very category of disability when working in cross-cultural settings: "In many cultures, one cannot be 'disabled' for the simple reason that 'disability' as a recognized category does not exist. There are blind people, lame people, and 'slow' people, but 'the disabled' as a general term does not translate easily into many languages" (Ingstad & Whyte 1995, p. 7). The essays in their trailblazing collection range across topics such as cosmology, personhood, and social contexts and disabilities as diverse as blindness, epilepsy, deafness, and mobility impairments. In the introduction, the editors point out the danger of imposing a Western individualizing model onto the heterogeneity of cultural worlds. At the same time, they caution against cultural essentialism: While they characterize societies as on a continuum that ranges from individualistic to sociocentric, they are quick to point out that either framework might be called into play as individuals negotiate kinship and opportunity structures (pp. 11, 36). Such research makes clear that the presence or absence of disability in familial life is constructed by broader notions of kinship as well as radically different epistemologies, whether positive or negative (Das & Addlakha 2001, Kohrman 2005). For example, a condition such as epilepsy may be seen as a divine gift or a rare genetic condition understood as an ancestral curse (Whyte 1995, Fadiman 1998, Biehl 2005). Family members with disabilities may be hidden and silenced, integrated as laborers, or encouraged to migrate from villages to cities in search of education, work, or services (Sachs 1995, Eide & Ingstad 2011, Phillips 2011).

A decade later, Ingstad & Whyte (2007) published their second edited volume, *Disability in Local and Global Worlds*. These case studies document how the international spread of the disability rights movement, from the late twentieth century forward, has improved the lives of people with disabilities and their social inclusion, although unevenly. The editors expanded their framework from their first book to include topics such as social movements, eugenics, citizenship, state policy, and human rights. Such themes characterize the work emerging on disability in the twenty-first century, not only in anthropology but also in disability studies in general, which increasingly offers historical perspectives, such as Livingston's analysis of an "African history of disability." She focuses on relations of intergenerational care as more elders survive while their middle-aged children are increasingly disabled from chronic illnesses such as HIV/AIDS and other "new" diseases. These changes deeply disrupt cultural norms and gendered kinship expectations of caretaking (Livingston 2003, 2005, 2006).

History and social movements also inform Kohrman's (2005) *Bodies of Difference: Experience of Disability and Institutional Advocacy in the Making of Modern China*. Through the history of the China Disabled Person's Federation, founded by Communist leader Deng Xiaoping's disabled son Deng Pufang, Kohrman narrates the emergence of disability as an acknowledged, socially productive, and masculinist category in late-twentieth-century China. His analysis shows how the embrace of disability as a statistical object of scrutiny and policy has enabled China's recognition on the world stage—particularly in the United Nations—as part of a community of modern nation-states. Like Kohrman, Phillips (2011), in her book *Disability and Mobile Citizenship in Postsocialist Ukraine*, analyzes how contemporary state policies are shadowed by legacies of the prior socialist era. Her compelling and deeply engaged ethnographic study of people with spinal cord injuries shows how they managed during the upheavals of post-Soviet reforms in the neoliberalizing era of the twenty-first century. She uses the central metaphor of "mobile citizenship" to underscore how

people with mobility impairments find creative strategies to claim citizens' rights to education, the workplace, politics, and an inclusive social/familial life, not to mention navigating buildings without elevators. Her subjects' activism takes shape in many arenas, including competitive sports for disabled athletes, an activity long valorized by the state while also enabling transnational support and recognition (Phillips 2011). These approaches bring rich resources to a disability studies that aspires to a more global presence.

A SENSE OF DIFFERENCE

The complexity of what counts as disability in different cultural milieus is perhaps most evident in analyses of deaf communities; some reject the label of disability, while embracing the idea of Deaf culture as comparable to the status of other minorities. This twenty-first-century view rests on a history of struggle against widespread discrimination (Lane et al. 1996, Lane 1999). Not only are these debates, like many questions raised around disability categories, significant in and of themselves; they also are epistemologically challenging to anthropology's theoretical engagement with the question of culture. Taking an agnostic position, we choose to include ethnographic perspectives on deafness in this review as a robust subcategory of disability. We embrace the view of writer and d/Deaf activist Mark Drolsbaugh (2008), who in his memoir notes, "Deafness is a disability that is so unique, its very nature causes a culture to emerge from it. Participation in this culture is voluntary." Groce's innovative early study of the d/Deaf community on Martha's Vineyard demonstrates just this kind of emergence, showing how the social definition of normality can be transformed by the robust presence of d/Deaf culture. In an insular community where dense networks of intermarriage transmitted hereditary deafness with regularity, the hearing population learned sign language as a regularized feature of local public culture (Groce 1985).

Historically, as Senghas & Monaghan noted in their review on sign language, "deaf people have been marked as different and treated problematically by their hearing societies" (p. 69). Response to that segregation has produced a remarkable panoply of sign languages, which at times also leads to both involuntary and voluntary cultural segregation (Monaghan et al. 2003). The question of how to understand the experience of being deaf without imposing ethnocentric ideas has been a source of contention; Ladd (2003) has proposed the term "deafhood" as a neutral locution. Recently, some contemporary activists and scholars have noted that many deaf people do not want to be labeled as impaired but rather as constituting a minoritized Deaf culture (Fjord 1996, Hauland 2007, Blume & Hiddinga 2010, Hiddinga & Crasborn 2011). Friedner refuses this binary. Using science studies and Foucauldian frameworks, instead, she analyzes Deaf community formation in terms of biopower, a perspective that encompasses both the productivity of an activist identity and the discriminatory ramifications of bearing a categorical label (Friedner 2010).

What constitutes Deaf politics varies widely across contexts, often depending on the status of minoritized identities in different national settings, historically changing circumstances, technologies, and notions of the sensorium. For example, in her work in Japan, Nakamura's deaf subjects prefer to be identified as a linguistic minority due to the negative stigma associated with ethnic minorities (Nakamura 2006, p. 8). She gives us a historical sense of what it means to be deaf in Japan over three generations, placed in the context of the rise of deaf activism and recent "language wars" that have emerged around Japanese signing (Nakamura 2006). It is not only the status of deafness as a culture or a disability that is contested; other issues associated with deafness have frequently catalyzed heated arguments. Blume—a hearing father of two deaf sons—reflexively chronicles his own family's experiences as participants in the passionate debates surrounding cochlear implants, which he follows across four countries, demonstrating how the context of state policy can profoundly affect the acceptance or rejection of this technology (Blume 2009). Friedner also reminds

us of the significance of national contexts in shaping different forms of “deafhood.” She shows how at a recent international d/Deaf empowerment camp in Bangalore, India, American Deaf activists championed a universal Deaf culture while deaf Indian elite students were uninterested in participating in such an inclusive social formation (Friedner 2008) that some think of as deaf utopias (Kusters 2010). Friedner & Helmreich (2012) have recently mined the epistemological possibilities that alternative modes of embodiment can provide. They bring sound studies and Deaf studies into a bracing conversation that stretches the boundaries of the auditory, suggesting it might include phenomena such as vibrations. Additionally, the authors reposition phonocentric models of speech, arguing for attention to the diversity of what they call “sensory socialities” (Friedner & Helmreich 2012).

Exploration of alternative socialities has emerged in another growing field of inquiry for anthropologists addressing disability: autism (Solomon 2010a). This work challenges longstanding views of people with autism as lacking in basic human capacities for social interaction and empathy; instead, researchers offer “evidence of the limitless potential and neurodiversity of the human mind” (p. 241). The upsurge in autism awareness in the United States (and elsewhere) is mirrored in the emergence of a number of lively recent studies. Writing as a father of a daughter diagnosed with autism, Grinker (2007), in his influential and persuasive book, *Unstrange Minds*, weaves together a reflexive approach, with ethnographic comparison of this condition in other locations, notably India, South Korea, and South Africa. Silverman (2008, 2011) investigates collaborations and conflicts among activist families and scientists. She and others shed light on what underlies the popular suspicion of vaccines as causing the so-called autism epidemic (Grinker 2010, Kaufman 2010). The contributors to a special issue of *Ethos* on “Rethinking Autism” underscore the epistemological shift in understanding the range of humanity when the “diversity of minds” (Solomon & Bagatell 2010) represented by autism and other forms of cognitive difference is taken seriously (Nussbaum 2001; see also Grinker 2010). The editors’ commitment to the inclusion of diverse minds is underscored by the article by Prince (2010), a primatologist who writes compellingly from her perspective as a person who identifies as autistic to “illuminate not the disability of autism, but the reward of the struggle and the gifts that are part of a different way of being,” including her role as “mother to a son who would himself be diagnosed as autistic in a different context” (p. 57). Ochs & Solomon (2010), in their long-term interdisciplinary investigations of US children on the autism spectrum, their families, and their schools, propose the idea of “autistic sociality” as part of a range of human possibilities for the fundamental practice of “social coordination with others.” The central contribution of their rich, diachronic research is a studied appreciation of the autistic child’s capacities and creativity, not only their limitations (Ochs et al. 2004), including the expansion of “autistic sociality” to include service dogs and other animals (Solomon 2010b).

FEMINIST CRITIQUES, LIFE COURSE PERSPECTIVES, AND THE NEW OLD AGE

The longstanding and recent work in feminist disability studies usefully complicates these philosophical and empirical challenges (Wendell 1996, Rousso 2013). Fine & Asch’s (1981) early critique focuses on the exclusion of women with disabilities who are “beyond pedestals”: They hold jobs at lower rates, marry less and often find motherhood unobtainable. In their classic works, philosophers Kittay, Fineman, and Nussbaum highlight the centrality of difference and dependency not only to disability but as endemic to the human condition. Yet, “love’s labors” that enable survival and integration of children and adults with significant disabilities are rarely recognized or theorized, let alone adequately remunerated among the many mothers and others who perform the caretaking work (Fineman 2005; Kittay 1999; Nussbaum 2001, 2006; Hall 2011). Caretakers

both act as citizens (and sometimes, activists) and enable the civic participation of others who would otherwise often be excluded from public life (Cushing & Lewis 2002, Cushing 2010, Rapp & Ginsburg 2011a). These ideas inform Bumiller's (2008) study of what she calls "quirky citizens": autistic neurodiversity activists and their online organizing. She suggests that feminists and disability activists should be actual and epistemological allies in the struggle for more democratic inclusion of diverse forms of personhood in America. Bumiller also highlights the work of "gender and sexual outlaws" in both movements: Many online autism self-advocates refuse conventional notions of their sexualization, as do feminists and their allies (Bumiller 2008). The question of sexual expression among people with disabilities was long overshadowed by a denial or repression of their desires and fear of their reproduction, contained by segregation and eugenic sterilization. Recently, both activist projects and critical, historical, and empirical studies are opening up this important area of sexuality and disability for scrutiny (Block 2000, O'Toole & Doe 2002, Desjardins 2012, McRuer & Mollow 2012, Shuttleworth 2012).

Disability's relevance to the range of human experience across the life cycle is particularly salient for anthropologists as we attend to what counts as normative or atypical at different key moments over a life course, from birth to death (Priestley 2001). For example, both Iwakuma and Breitenbach demonstrate that people with lifelong disabilities often transition with relative ease to the changed pacing of old age when compared with their typical peers (Breitenbach 2001, Iwakuma 2001). Lock's comparative work in North America and Japan on aging, brain death, and most recently Alzheimer's disease offers a cultural critique of assumptions about life, death, and living with disability (Lock 1993, 2002; Lock et al. 2006). Similarly, Cohen's (1998) book, *No Aging in India*, situates and contrasts South Asian and American assumptions about cultural understandings of senility, as does the edited collection *Thinking About Dementia* (Leibing & Cohen 2006).

Attention to disability over the life cycle extends not only to "the new old age," to borrow the title of a *New York Times* blog, but also to the earliest stages of life in a postgenomic age. New medical technologies have resurrected old questions about the status and stratification of disability in family formation. Since the 1970s, a burgeoning popular and scholarly literature has responded to the escalating array of genetic tests increasingly being used for "quality control" of anomalies present in both parents and fetuses (Parens & Asch 2000). The range of tests available for potentially disabling conditions is increasing geometrically, but the fund of social knowledge accompanying such decision making is limited. Pregnant women and their partners become "moral pioneers" (Rapp 2000) when confronted with the dilemma of making a decision about the presence of disability at the earliest stages of life; few have an adequate understanding of what it might be like to live with the particular disability diagnosed in their fetus (Franklin & Roberts 2006; Rapp & Ginsburg 2007, 2012).

Although there are eugenic echoes in these practices, the choice regarding who is admitted to the human community is officially placed on the shoulders of women and their families, assisted by emergent Foucauldian pastoral professions such as genetic counseling (Roberts 2009, Samerski 2009). At the same time, the spread of disability consciousness has given greater support to couples with disabilities that choose to create families of their own (Finger 1999, O'Toole & Doe 2002). Additionally, medical technologies in the developed world have increasingly provided life-saving possibilities for compromised infants, those with spinal cord injuries, wounded soldiers, the frail elderly, and other disabled family members who might not otherwise have lived. Their survival brings new challenges to families whose narratives are necessarily reframed by the fact of disability (Becker 1980, Layne 1996, Cohen 1998, Livingston 2005, Leibing & Cohen 2006, MacMakin 2011).

We have proposed the term new kinship imaginary as a way to underscore that families not only are flesh-and-blood collaborations; they also engage in acts of cultural imagination to encompass the fact of disability as part of a family narrative, whether exclusive or inclusive (Rapp & Ginsburg 2001, 2011a). Family members may feel compelled to rewrite preexisting cultural scripts that relied

on seemingly stable notions of kinship that no longer seem relevant. In the process of incorporating or rejecting disability, they often find themselves transforming the arrangements they themselves may have previously taken for granted. When disabled family members are embraced, despite prejudicial landscapes, they and their intimate supporters often become “accidental activists” (Rapp & Ginsburg 2011a) as a result (Panitch 2007, Silverman 2011). In turn, kinship imaginaries require continual reinvention, from the rearrangement of caretaking responsibilities in the household to the production of family narratives embracing rather than excluding the fact of disability, stories that increasingly are making their way into popular culture. This sort of public storytelling has appeared in media of all sorts, ranging from personal memoirs and television shows to activist documentary projects and to scholarly works that offer compelling perspectives on the “new normal” established by living life with a difference (Bérubé 1996, Linton 2005, Trachtman 2008, Habib 2009, Solomon 2012).

ENABLING MEDIA WORLDS

Recent scholarship shows how media of all sorts are deeply implicated in the creation of a more inclusive sense of citizenship for nonnormative social actors (Coleman 2010, Ginsburg 2012). Garland-Thomson’s (2009) term “visual activism” describes how people with disabilities and their allies are increasingly using the visual arts to position themselves in the public eye, saying “look at me” rather than “don’t stare.” Snyder & Mitchell (2008) suggest that disability film festivals enable people to vicariously experience disability worlds in ways that resist the conventions of exclusion, both on screen and off screen, by providing captioning and audio description for film texts as well as space for wheelchairs and other accommodations in viewing spaces. In his ethnography of the virtual world of Second Life, Boellstorff shows how people with disabilities can expand their social networks and gain an enhanced sense of agency. He writes, “Virtual worlds can be sites of grieving [bullying/harassing] and inequality, but they can also produce new ways of living, including a kind of empathy that recalls the ethnographic project itself” (Boellstorff 2008, p. 249), a point reinforced by both Gold and Miller (Gold 2008, Miller 2011). Boellstorff also draws attention to how the design of digital media can be disabling, from standardized keyboards to small fonts to flash effects that induce seizures in those with epilepsy. Issues of digital design concern more than political economy or tweaking technology; they reflect the politics of recognition and the need to extend access to include the full range of people who constitute the body politic without requiring typical others to interpret for them (Goggin & Newell 2003, 2007; Ellis & Kent 2010).

CONCLUSION: DISABILITY WORLDS

We chose “Disability Worlds” as the title of this review article for multiple reasons. Inspired by the local and worldwide disability rights movements, we are increasingly convinced of the global importance of bringing disability perspectives to every domain of human life, recognizing the commonalities as well as differences among them, as we have tried to demonstrate throughout. We argue that the lens of disability enriches and expands anthropological work whether one studies activism and human rights, language acquisition or burial practices, kinship or the sensorium. Over the past two decades, we have certainly found this to be the case in our own work as scholars, parents, advocates, and teachers. Our students’ responses to encountering anthropological work on disability strengthen our conviction that this form of difference can and should be essential to the discipline. In class evaluations, students asked why work on disability is not being taught more widely as a fundamental feature of global diversity, whether in introductory or graduate courses. Clearly, the significance of disability is not lost on this emergent generation coming into

anthropology, perhaps because they grew up in a world in which disability is a fact of life at home and in the public sphere. They recognize that disability, as a feature of their own experiences, is a category that demands anthropological attention as an essential form of human nature. We concur.

DISCLOSURE STATEMENT

The authors are not aware of any affiliations, memberships, funding, or financial holdings that might be perceived as affecting the objectivity of this review.

ACKNOWLEDGMENTS

We thank the *ARA* Editorial Committee for inviting us to write this review and Fred Myers for reading a first draft. We are grateful to Alison Cool for her excellent research assistance and Bambi Schieffelin for her collegial recommendations of literature. Over the years, we have been fortunate to be in conversation with many disability scholars and activists, including Rachel Adams, Adrienne Asch, Lawrence Carter-Long, Lennard Davis, Gelya Frank, Richard Grinker, Devva Kasnitz, Simi Linton, Harilyn Rousso, and the members of the NYU Council for the Study of Disability, along with many others. Last but not least, we owe our children Samantha and Teo a debt of gratitude for giving us our passports to disability worlds we might otherwise never have encountered.

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