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Disability

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Disability is a form of difference that is created when the social participation of someone with an impairment is 'dis-abled' by normative expectations and material conditions. This entry reviews some of the key contributions anthropologists have made to studying disability as a socially constructed category. Disability is at once central and marginal to the anthropological canon. Grounded in fine-grained, long-term ethnographic fieldwork, anthropological studies of disability have drawn attention to the relational nature of disability as a category that is variable despite its quality as a universal human experience. This entry starts by explaining the difference between 'impairment' and 'disability' before reviewing the trajectory of anthropological studies of disability – in mostly Western industrialised contexts – from a 'medical' to a 'social' framework of understanding. It then turns to consider some of the theoretical orientations this has produced and examines a more recent shift to studying the lived experience of disability beyond the Euro-American west. It concludes by reviewing some of the developments in studying disability in recent years, in which scholars focus on social organization, technology, and personal, embodied experiences.

Introduction: disability and difference, disability and impairment

The experience of disability is both unique and universal. The embodied limitations of impairment are something all humans experience in either the very early or late stages of life (Davis 2006: 4; Kittay 1999). Disability is a form of otherness marked by such limitations: disabled people are often labelled as different from people who are able-bodied in one way or another. Unlike social categories such as gender, race, or generation, however, disability is a form of alterity that anyone can enter at any time, although disadvantaged groups have a higher chance of becoming disabled (Eide & Ingstad 2011; Puar 2017). Because all human bodies are vulnerable, researchers argue for anthropological attention to disability as essential to understanding human nature and diversity (Fineman 2008).

What is considered to be a disability in different sociocultural settings, however, is highly inconsistent. 'Disability is a profoundly relational category, always created as a distinction from cultural ideas of normality, shaped by conditions that exclude full participation in society of those considered atypical', Faye Ginsburg and Rayana Rapp assert, pointing to anthropology's key contribution to the study of disability as a form of alterity that 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' (2013: 54). This observation has led anthropologists, and disability scholars more widely, to establish disability as a category that is fundamentally socially constructed. It is not an impairment that creates a disability, but rather the incompatibility of impaired bodies with social norms and material environments that are determined by the able-bodied majority, and the discrimination that frequently follows.

While scholars differ in the terminology they use, they nonetheless agree that we cannot take terms and concepts such as ‘impairment’ and ‘disability’ for granted. Russell Shuttleworth and Devva Kasnitz, for example, choose to make an explicit distinction by defining impairment as ‘a negatively construed, cultural perception of a bodily, cognitive, or behavioural anomaly in terms of function or some other ethnopsychological or ethnophysiological status’, and disability as a negative social response to a perceived functional limitation (2004: 141). By using the hyphenated term ‘impairment-disability’ they seek ‘to problematize anthropologists’ use of these term and to highlight their relationship and the need for their analytical separation’. Ginsburg and Rapp similarly choose to draw attention to the complex and enduring ‘relation between embodied limitations and social discrimination’, by using ‘disability’ and ‘impairment’ interchangeably (2013: 54); I follow this model in this encyclopedia entry.

This entry aims to serve as a brief introduction to some of the historical highlights of anthropological engagement with disability as a fundamentally relational category.[1] Anthropology is a latecomer to studying disability, but the discipline has made significant contributions to the wider field of disability studies rooted in the discipline's core methodology of long-term, fine-grained ethnographic fieldwork. The empirical ethnographic approach provides nuanced, penetrating ethnographies of the lived, embodied experience of disability and the social lifeworlds of disabled people. By considering personal views of what is disabling, anthropologists have thus contributed to deconstructing assumptions about normality and abnormality in cross-cultural settings.

From a medical to a social model

The earliest studies of disability by anthropologists were focussed on specific impairments from within a medical anthropology framework, while disability increasingly became part of mainstream social and cultural anthropology (Kasnitz & Shuttleworth 2001). Prior to the 1960s, for example, Ruth Benedict (1934) analyzed cross-cultural understandings of epilepsy, pointing out that a condition may be considered abnormal and undesirable in one sociocultural setting but a highly desirable characteristic of psychic manifestation elsewhere. Jane and Lucien Hanks (1948) similarly took an early cross-cultural perspective in their study of how a similar physical characteristic such as a scar has a different effect on status in a variety of settings.

Attention to disability in anthropology, however, became more prominent in the 1960s and 1970s, as the disability rights movement and Independent Living Model brought it into the public eye, particularly in North America. Robert Edgerton (1967) was the first anthropologist to make disability a focus of study with his work with people with what was then called ‘mental retardation’ or intellectual disabilities in the 1960s. His monograph, *The cloak of competence* (1967), drew attention to the historical changes in American institutional public life, as the inhabitants of asylums were moved to communities as part of an international movement dedicated to closing asylums. As people adapted to living in mainstream society after a life in long-term institutionalization, Edgerton highlighted the strategies they developed to counteract the stigma in their lives and learn to 'pass' as normal.

It was in the 1970s and 1980s, however, that medical anthropology started to provide a fertile space for ethnographic work on impairment-disability. Louise Duval (1986) initiated the *Disability and culture* newsletter and founded the first Disability Research Interest Group as part of the Society for Medical Anthropology, providing a forum for social science studies of disability and a presence at the yearly American Anthropological Association (AAA) meetings (Kasnitz & Shuttleworth 2001). Gelya Frank brought a pioneering phenomenological perspective in her book, *Venus on wheels* (2000 [1982]). Frank provided a personal perspective – rare for its time – of the life of an American woman named Diane DeVries, who was a ‘congenital amputee’, a woman born without arms or legs. Where previous studies had focused on symbolic descriptions of disability by outside observers, Frank’s portrayal of DeVries’s personal perspective was part of a wider shift in anthropology from objectified representations of the body to subjective experiences of living through the body. This approach highlighted the lived experience of disability: Frank questioned common perceptions of DeVries as someone who was missing arms and legs and considered instead DeVries’s personal experience of ‘normalcy’. Frank also reflexively explored the development of her long-term relationship with DeVries, where research transformed into friendship and care, involving a deeper level of personal involvement and self-disclosure than was customary for the time.

Several of these anthropologists started to provide a critique of medicalization from within medical anthropology itself. 'Medicalization' refers to treating disability as a technical, medical problem. In this framework, the individual impaired body was central, and medical conceptions of disease and healing were used to explain disability, thus directing focus towards cause and cure, or therapeutic transformation. Such a biomedical model of disability became criticised as carrying an assumption that disability is a negative problem of individuals. Disability scholars, consequentially, became people with a ‘mandate’ to make disabled people ‘normal’ (Shuttleworth & Kasnitz 2004: 142). An alternative framework that considers instead the cultural and social factors that underlie understandings of disability has been glossed as the ‘social model’ in anthropology and wider disability studies (Shakespeare 2013), a refinement that draws attention to how social and material conditions shape impairment into disability.[2]

Nora Groce and Joan Ablon, among others, were part of this paradigm shift from ‘the clinic to the community’ (Whyte & Ingstad 1995: 4). Groce (1985) chose to highlight community creation and communicative practices in her study of deafness on the island of Martha’s Vineyard, Massachusetts.[3] In this insular community, hereditary deafness was so common that deafness was not considered unusual and the hearing population learned sign language. Because all inhabitants were able to participate in public life, being deaf was thus not considered to be disabling. The title of her book, *Everyone here spoke sign language*, highlights how normality is defined socially, as sign language was a part of local public culture for deaf people as much as for the hearing population.

Medical anthropologist Joan Ablon (1984; 1988; 1999; 2010; for a comprehensive review of her work see Shuttleworth & Kasnitz 2004) influenced generations of anthropologists interested in disability with her work on the lives of stigmatised groups of people with genetic differences, such as the 'little people' of America (1984). Her ethnographic approach focused on their support networks and strategies of normalization, privileging the lived experiences and voices of her research participants. Her work has been considered pioneering for shifting the focus from individual bodily difference as a source of disability to the social reactions of the community as disabling. Her ethnographic focus contributed to broadening the scope of disability studies beyond the therapeutic interests of medical anthropology for the study of disability and behavioural, cognitive, or physical difference.

Studies such as those by Groce and Ablon reframed disability more in terms of identity and difference than in terms of ill health. While dynamics of illness and disease are clearly relevant to disability studies, as Staples and Mehortra (2016: 39) point out, 'bodily states that, in certain contexts, underpin disability do not necessarily define individuals as ill or as suffering, but sometimes as different in ways that may be valued in their own right.' In his *History of disability*, Henri-Jacques Stiker (1999), for example, argued that societies reveal themselves in how they manage difference. He gave a Foucauldian genealogy of how disability emerged as a category of difference in western societies that was not initially distinguished from other types of poverty, but developed into a category of bodily abnormality. In communities of people with disabilities, shared experiences can form the basis of a subculture or culture, such as Deaf culture (see, e.g., Breivik 2013; Groce 1985; Friedner 2015a; Green 2014; Nakamura 2006). Cultural identification with deafness is represented by capitalising 'Deaf' where the lower case spelling 'deaf' refers to the audiological condition (see e.g. Baynton 2015); referring to both simultaneously is written as 'd/Deaf' or 'D/deaf'. People who identify as d/Deaf sometimes reject labels of disability in favour of being viewed as a linguistic or cultural minority (e.g. Fjord 1996; Haualand 2007). While the idea of Deaf culture that crosses other boundaries is mainstream, researchers also warn of the dangers of imposing a single minority group identity onto a very diverse group of people (e.g. Mugeere, Atekyereza, Kirumira, & Hojer 2015; Susman 1994; Zola 1993).

Stigma, liminality, and reconciling the exceptional with the ordinary

The studies above have been influenced by theoretical approaches that emphasise difference.[4] Analytical orientations around stigma and liminality have been particularly influential in interpreting ethnographic data. The sociologist Erving Goffman (1963) famously described stigma as the result of deviance. If we understand deviance as ‘deviation from prevalent or valued norms’, stigma is then ‘the evocation of negative responses’ (Susman 1994: 15, 16) or, in Goffman’s words, having a ‘spoiled identity’ due to an ‘attribute that is deeply discrediting’ (1963: 13). Because disabled bodies stray from the norm and are often socially devalued as a result, a host of anthropologists have used the concept of stigma to theorise their experience.[5]

Other disability scholars have preferred to analyze difference in terms of liminality (e.g. Barrett 1998; Stiker 1999). In developing the concept, Victor Turner referred to the context of ritual to describe liminal entities as ‘neither here nor there; they are betwixt and between the positions assigned and arrayed by law, custom, convention, and ceremonial’ (1969: 95). The disabled anthropologist Robert Murphy (1987) considered the concept of ‘liminality’ more suitable than stigma to describe the implicit and subtle discrimination he encountered during his own process of becoming gradually paralyzed in the United States due to a spinal tumour, an experience that is the subject of his influential book, *The body silent.* He connected a lack of acceptance to the status of long-term, physically disabled people as ‘undefined, ambiguous people’ (1995: 154). They were in-between dominant American understandings of normality: ‘neither sick nor well, neither dead nor fully alive, neither out of society nor wholly in it’ (1995: 153-4).

Goffman’s approach to stigma in particular continues to be highly influential, but simplified accounts of stigma that focus on individual bodily differences alone to the detriment of wider contextualising factors such as politics, gender, or age have been widely criticised in favour of more nuanced ones (e.g. Shuttleworth 2004; Murphy 1987; 1995; Staples 2011b). Michele Friedner (2015), for example, draws on her fieldwork with deaf multilevel marketing employees in India to argue for a rethinking of stigma. Such businesses produce a space where deafness can function as a valued condition, allowing deaf people to work almost exclusively with other deaf people and transform social networks into financial capital. Stigma, she argues, can thus be a source of inclusion as much as exclusion. Bearing such critiques in mind, Friedner and others (see, e.g., Devlieger, Rusch, & Pfeiffer 2003; Staples 2011b) argue for an approach that reconciles the exceptional and ordinary aspects of the lives of disabled people. While discrimination may play an important role in their lives, they pursue the same goals as other people.

Beyond the Euro-American west

The roots of most scholarship on disability are in the civil rights movements of the 1960s, particularly in the disabling contexts of industrialization and the rise of capitalism in the Euro-American west. The vast majority of disabled people, however, live elsewhere, and anthropologists interested in disability have increasingly turned their attention to how cross-cultural understandings of disability may challenge dominant assumptions based on theorising in Euro-American environments.

Disability was explicitly put onto the worldwide public agenda in the 1980s, when the United Nations declared 1981 as the International Year of Disabled Persons, followed in 1983 by the beginning of the United Nations' Decade for Disabled Persons. Scholars working beyond Europe and America thus frequently draw attention to the connections between the global and the local to avoid assumptions of isolated social worlds, while simultaneously underlining the danger of imposing western models on diverse sociocultural contexts (Ingstad & Whyte 2007). Inhorn and Bharadwaj (2007), for example, draw attention to the local effects of new reproductive technologies in Egypt and India, as wider access to IVF treatment puts the problem of infertility in the public eye. In these pro-natal countries, infertility is considered to be an impairment of personhood with deeply disabling consequences, whereas it is not explicitly understood as a disability in the Euro-American contexts.

Benedicte Ingstad and Susan Whyte (1995) highlighted diverse examples from Nicaragua, Borneo, and various African countries in a pioneering volume to underline that the concept of disability itself cannot be taken for granted (see also Grech & Soldatic 2016). Outside the influence sphere of the liberal identity politics of the Euro-American west, 'disability' as a unified umbrella term either does not exist or is a very recent category applied to people: 'there are blind people and lame people and "slow" people, but "the disabled" as a general term does not translate easily into many languages' (Ingstad & Whyte 1995: 7). The volume focussed on cultural and social circumstances to underline that conceptualizations of impairment and disability need to be considered within specific local worlds.

Some anthropologists thus find more value in using vernacular classifications over the English umbrella term 'disability' (e.g. Kohrman 2005; Geurts 2003; Livingston 2006), and several have documented how 'disability' comes into being and develops as a category in parallel with changing social attitudes. Following the changes in terminology and language is one way of drawing attention to these developments (see e.g. Stiker 1999; Zola 1993). For example, in his monograph, *Bodies of difference*, Matthew Kohrman (2005) described how disability emerged as a category of persons in China in the late twentieth century when gathering statistics became one of the state's techniques of creating a 'biobureaucracy' of welfare. The term *canji* developed from a rarely-used term into a common umbrella designation like the English 'disability' when people labelled as such became able to make claims on the emerging welfare state. While *canji* was non-existent in rural areas, in urban areas it became enmeshed in many locals' daily lexicon and their mode of apprehending existence. Kohrman's analysis also demonstrated how disability was embraced as an object of policy as a result of the interventions of the China Disabled Person's Federation, founded by the charismatic disabled son of a prominent Communist leader. Advocating for disabled people brought them into visibility on a national level while also helping China gain recognition on the world stage. While disability can become a category through top-down initiatives, as in Kohrman's case study (cf. e.g. Petryna 2002; Phillips 2010), other examples demonstrate how disability can evolve into a collective identity thanks to communities that form around treatment institutions of particular afflictions, such as leprosy (Silla 1998; Staples 2007), and/or around economic niches dominated by people with disabilities (e.g. Friedner 2015; Devlieger 2018).

Different notions of personhood have been central to analyzing how people with impairments live in local social worlds (Ingstad & Whyte 1995; Jenkins 1998). Considering conceptualizations of the self, anthropologists studying disability apply wider observations that in many societies, being a person is defined more in terms of a 'sociocentric' value of being connected to other people than it is in contexts where personhood runs parallel with individualism. One theme that is consistently relevant in this respect is how the cultural values of equality and (in)dependence define personhood in different settings and consequently affect understandings of disability. The negative effects of stigma in western societies, for example, are often tied to a negative conception of dependency in societies that assume the primacy of individuality and the subsequent difficulties in engaging in wage labor.[6] During Murphy's (1987) process of becoming paralyzed, for example, he found that he was resented and stripped of status and identity because his very existence subverted an 'egocentric' American dream of self-reliance and personal autonomy.

In descriptions of disability in many other societies, by contrast, the more 'sociocentric' value of being a member of a community or a family may outweigh individual ability as a value, and have consequences for perceptions of disability (see, e.g., Ingstad & Whyte 1995: 11). In Julie Livingston's (2005; 2006) analysis of 'debility' in Botswana, for example, Tswana notions of kinship and personhood stress the permeability of the body: bitter, angry, or jealous feelings have the potential to harm, while love and sympathy can help to sustain and strengthen.[7] Because people are interconnected, the disruption of a person's mental or physical competences are viewed as the consequence of the negative actions of others. This sociocultural conception of dependent personhood does not free Tswana people from disability stigma but places the emphasis elsewhere: the bulk of the stigma may be directed towards the mother of a disabled child, if her child is considered as living proof of her deviant sexual behaviour (Livingston 2006: 122). Scholarship on disability has thus pointed out that values that are often taken for granted in western settings such as individuality, equality, and independence may clash with notions and aspirations of interdependency in other settings. When these values are promoted in universal (human) rights-based ideas such as those of the Independent Living Movement, they may be irrelevant or even harmful (Staples & Mehrotra 2016).

At the same time, anthropologists interested in disability are quick to caution against constructing false dichotomies between 'individualistic' Northerners and 'communitarian' Southerners. 'The real challenge', Ingstad and Whyte argued, rather 'lies in understanding the way particular characteristics, be they impairments or gifts, inhibit or facilitate individual achievements and relational integration in a given cultural world' (1995: 11). In negotiating opportunities, different sets of values can be called into play and may change according to sociocultural context and historical transformation. Livingston (2005), for example, traces a historic increase in cases of chronic illness and debilitating accidents in Botswana that disrupt expectations about health, 'debility', and care over the course of the twentieth century. 'Sociocentric' expectations of intergenerational caretaking are disrupted as young men and women increasingly leave the rural agricultural economy to engage in wage labour. As social value shifts from an emphasis on experience towards the ability to sell able-bodied labour, society changes from one where a practice of family 'care' is central, to one where care for the debilitated is increasingly seen as the responsibility of the state. Issues such as stigma or personhood thus must be seen in interaction in actual social contexts, where attitudes towards and perceptions of disability are shaped by wider dynamics.[8] Nuanced contextual material is essential for cross-cultural comparisons to go beyond superficial similarities and differences, and to go further than simply modifying western models to other settings.

Recent developments

Citizenship and belonging

In recent years, disability scholarship has turned to concentrate on sociopolitical organization and embodied experiences. In 2007, Ingstad and Whyte published a second influential edited volume, *Disability in local and global worlds*. The case studies therein focused on connections between the local and the global, considering the 'uneven processes of change that can be traced as ideas and technologies spread' (Ingstad & Whyte 2007: 3). Under this rubric they trace the spread of the international disability rights movement, noting that for most disabled people, political awareness may be spreading more rapidly than the conditions to improve their lives. Their volume included topics such as human rights, citizenship, eugenics, progressive politics, and social movements. As Ginsburg and Rapp (2013: 58) sum up, these themes characterise emerging work on disability in recent years, not only in anthropology but also in disability studies in general.

Several researchers have demonstrated how disabled people and their families perform belonging in local environments marked by kinship and ethnicity. Veena Das and Renu Addlakha (2001) use examples from Delhi to demonstrate how citizenship can be enacted in the domestic sphere as much as in civil society associations, where different kinds of publics are created in relation to families with disabled family members. Rapp and Ginsburg (2001) use ethnography from the United States to demonstrate that disability entails a rewriting of kinship: disability can create a sense of relatedness across embodied difference. Dossa (2006; 2009) weaves together life histories of disabled Canadian Muslim immigrant women who claim their humanity by affirming identities as women and mothers where they are stigmatised as racialised disabled women. In Nakamura's (2006) case study of Japanese d/Deaf people, her interlocutors prefer to be referred to as a linguistic minority due to negative associations with Japanese minority ethnicities.

Other studies consider how citizens assert belonging outside the familial sphere to interact with neoliberal businesses (e.g. Friedner 2015), religious organizations (e.g. Goldstone 2017), and state workers (e.g. Kohrman 2005), among others, in negotiating access to welfare resources. Elizabeth Davis (2012) considers the effects of psychiatric reform in Greece, where the modern liberal state invests in a 'rights'-oriented biopolitical project that requires patients to be responsible and cultivate autonomy. Adriana Petryna (2002) and Sarah Phillips (2010) focus their attention on the struggle for disability pensions in post-socialist Ukraine, where people affected by the aftermath of Chernobyl fashion themselves as 'biological' citizens (Petryna), and people with spinal cord injuries use creative strategies to assert claims to a 'mobile' citizenship (Phillips). In both cases, disabled people find themselves performing a 'balancing act' (Phillips 2010: 7) between Soviet and post-Soviet models of disability, as state-based support is scaled back for citizens who were previously considered entitled. Disability is equally contested in Gabrielle Kelly's (2017) case study in South Africa, where doctor-patient encounters are sites of negotiation over who counts as disabled in allocating rights to welfare and health resources.

On the more global/international level, the recent 2008 United Nations Convention on the Rights of People with Disabilities (UNCRPD) has been central to many local struggles for recognition (Meekosha & Soldatic 2011). Several disability activists have embraced the UNCRPD as a toolkit with which to challenge citizenship status and practices, but the Convention is often nationally ratified but not fully implemented. Ethnographic case studies demonstrate that access to (inter)national disability rights often intersects with local models of patronage (Grischow 2015), racial politics (Puar 2017), and corporate social responsibility (Friedner 2015). Sometimes, rights activism may have unintended consequences. In Friedner and Osborne's case study in India, 'disability activists derive moral authority and position themselves as participating in imagined universal disability communities while professional access auditors position themselves as technical experts alone possessing "real" knowledge' (2013: 58). A policy instrument that renders disability into a universal category needs to be studied in considering how disability is perceived within local models of intersecting corporeity (Meekosha & Soldatic 2011).

The effects of technology

Changing access and desires for rights are often affected by technology (Whyte & Ingstad 2007: 18-21). Nuanced ethnographies point out the potentially double-edged consequences of technologies that are not (only) intended for disabled people (such as communication technologies and the media) as well as technologies that are meant to enhance their quality of life (such as sign languages, mobility aids, hearing aids, or braille). Cassandra Hartblay (2017), for example, considers how talk about wheelchair ramps in Russia is embedded in moral obligations between citizens and the state. When such infrastructure is more aesthetic than accessible, the failed design draws attention to how the idea of access circulates as a teleology of progress without necessarily meeting users' needs. Ideas about progress equally play a role in Kohrman's (1999b) analysis of cycle technologies in China. Urban men who struggle to walk can adopt hand-crank tricycles and motorcycles thanks to the initiatives of a state-run federation, but while their physical mobility may increase, the technology draws attention to the fact that they have difficulty walking, thus paradoxically increasing their negative associations with immobility. The virtual world can both augment the sense of agency of disabled people and have disabling effects, as Boellstorff (2015) finds in his ethnography of the online world Second Life. Paul Antze (2010) also underlines this point, demonstrating how people diagnosed with autism use social media to simultaneously embrace and reject the label of disability. Social media provides a mode of communication and a forum for the neurodiversity movement, but a talent for expression may undermine one's credibility as being autistic.

Medical technology in particular increases the capacity to diagnose and define impairments. Improvements in prenatal screening and eugenic technology, for example, make it increasingly possible to choose whether or not to have an impaired child (Landsman 2008). Anthropologists describe the experiences of parents who have access to such technologies and find themselves before weighty moral dilemmas, unwittingly becoming, in Rayna Rapp's words, 'moral pioneers' when choosing for disability (Rapp 2000; see also Gammeltoft 2013). Choosing to change (dis)abilities is equally controversial: the use of cochlear implants for deaf children, for example, has led to worries about the eradication of Deaf culture (Blume 2009): such devices are implanted surgically, and provide sound through an electromagnetic interface. The increased capacity to diagnose has also prompted the creation of new categories such as genetic 'abnormalities' (Berghs 2016: 27) and an upsurge in awareness of conditions such as mental illness, emotional disabilities, and learning disabilities. Petryna (2002), for example, describes how science becomes a key resource for negotiating 'biological citizenship' for the rapidly-growing population claiming radiation exposure as a new category of impairment in order to access government-sponsored healthcare after the Ukrainian Chernobyl disaster. Anthropologists have also considered the effects of the contemporary rise of autism awareness (see Solomon 2010). Antze (2010) describes the tension between the medical and the social where people diagnosed with autism underline the diversity of autism, but must credibly embody the condition they represent to be taken seriously. In the words of Whyte and Ingstad, sensitive ethnographies often demonstrate a tension between the capacity of technology to break the silence and the risk to medicalise disability 'by defining it as a disease that can be treated (at private clinics!) rather than a difference that can be accepted and lived with' (2007: 20).

Reflexivity, narrative, and embodiment

Personal experiences of what is disabling has long been a central part of ethnographic descriptions of disability. As Ginsburg and Rapp set out (2013: 56-7), a significant literature of reflexivity and autoethnography by disabled anthropologists and those in their environments as well as a focus on narrative approaches have been essential to situating disability in a broader terrain.[9] Cheryl Mattingly (2010), for example, draws on long-term research with low-income African-American families to consider the role of narrative in illuminating links between meaning making and experience. Her most recent ethnography (2014) considers the everyday 'moral laboratories' in the lives of African-American families with children with chronic medical conditions to foreground their struggle for a good life as affected by constant uncertainty. Mattingly refers to 'moral laboratories' as a metaphorical realm in everyday spaces like soccer fields or clinic waiting rooms where people experiment in action and in narrative, which ultimately changes the way they view their children and their environment.

These orientations have been related to exploring the paradigm of embodiment and phenomenological approaches, sometimes presented as alternatives to the 'medical' or 'social' model (e.g. Gammeltoft 2008; Berghs 2016: 31-2). Such approaches help to 'bring the visceral, experiencing body back into the picture' (Staples & Mehrotra 2016: 42), while exploring how the subjective experience of disability intersects with political, medical, and religious forms of subjectivity.[10] Exploring the subjective experience of mental illness in contemporary Indonesia, for example, Byron Good and his colleagues (2007) find that the intimate experience of acute psychosis is related to different forms of subjectivity. In an environment with growing access to the expanding global pharmaceutical industry, medical and religious subjectivities come into conflict in the case of a patient who rejects medication in favour of prayer, thus rejecting a biomedical subject position for a spiritual one. Good and colleagues furthermore demonstrate how experiences of psychosis are entangled with Indonesia's postcolonial history: the madness of the psychotic is discursively related to the madness of violent crowds. In her work with Anlo-Ewe-speaking people in south-eastern Ghana, Kathryn Geurts (2003) finds that experiences of disability are intimately connected to a sensorium where balance is a sense, and upright posture and balancing are essential components of being human. She finds that a western five-sense model has little relevance in Anlo culture, and much perception, including a sixth-sense notion of intuition, falls into the polysemous notion of *seselelame*, 'feeling in the body, flesh or skin' (2003: 10). Descriptions of how one moves, and how people think about this, represent a way of being-in-the-world that is socially reproduced and even imbued with moral meaning.

Conclusion

Anthropological studies of disability are late in coming, but they point out that while disabling experiences are universal, they are simultaneously shaped by a wide configuration of specific circumstances. Such contributions have a foundation in the discipline's core methodology of long-term ethnographic fieldwork, giving solid evidence that disability as a category is fundamentally relational, a form of alterity created by sociocultural 'disabling' conditions, and one that is entangled within complex webs of other identities and social dynamics such as generation, gender, or ethnicity. The long-term engagement that comes with anthropological fieldwork makes it possible to pick up on these complexities, bringing nuance to the study of liminality or stigma, while deconstructing assumptions about 'normalcy'. The studies thus demonstrate how people live in a balance between experiences of marginalization and the possibilities within such constraints.

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[1] For comprehensive reviews of anthropological literature on disability, see: Kasnitz & Shuttleworth 1999; Kasnitz & Shuttleworth 2001; Shuttleworth 2004; Whyte & Ingstad 1995; Whyte & Ingstad 2007; Reid-Cunningham 2009; Ginsburg & Rapp 2013; Staples & Mehrotra 2016; Berghs 2016: 26-43.

[2] Many of those who adhere to the social model explicitly use the term 'disabled people' to emphasize disability as something that is imposed on people with impairments (Shakespeare 2013). Those who prefer the term 'people with disabilities', in turn, adhere to a people-first approach, choosing to emphasize personhood first and disability as a secondary identity (Michalko 2002: 10-1). The controversy about preferable terminology has been particularly salient in the United States (Albrecht, Seelman, & Bury 2001: 3). While some anthropologists make their choice of terminology explicit, others use both interchangeably. 'Disabled people' is more common in the United Kingdom, while 'people with disabilities' tends to be more mainstream in the United States and elsewhere.

[3] See Becker 1980; Kisch 2008; Kusters 2010; see also Gwaltney 1970; and Deshen 1992 for community creation between people with impaired sight.

[4] Theoretical approaches to difference include considering deviance (e.g. Susman 1994), labelling (e.g. Zola 1993), anomaly (e.g. Shuttleworth 2004), stigma (Goffman 1963), or liminality (e.g. Murphy 1987).

[5] See, for example, Ablon 1984; 1988; Becker 1980; Edgerton 1967; Friedner 2015; Shuttleworth 2004; Stiker 1999.

[6] See, e.g., Fraser & Gordon 1994; Fineman 2004; Kittay 1999; Davis 2012; Frank 2000.

[7] Livingston prefers the term 'debility' over 'disability' in order to broadly encompass 'both the frailties associated with chronic illness and aging and … the impairments underlying the word disability' (2005: 6; see also critique by Ingstad 2007). Jasbir Puar (2017) similarly adopts the term 'debility' over 'disability' with a different purpose: to highlight the interaction between bodily injury and social exclusion, foregrounding 'the slow wearing down of populations instead of the event of becoming disabled' (2017: xiv).

[8] These dynamics including kinship structures (Das & Addlakha 2001; Kohrman 1999a; Livingston 2006), gender norms (Kohrman 1999a; Murphy 1987), national politics (Kohrman 2005; Renne 2010), economic opportunities (Devlieger 2018; Friedner 2015; Staples 2007), ethnicity (Mugeere, Atekyereza, Kirumira & Hojer 2015; Nakamura 2006), religion (Gammeltoft 2008; Mugeere, Atekyereza, Kirumira & Hojer 2015), and/or migration (Dossa 2009).

[9] For examples of reflexivity and autoethnography see, e.g., Murphy 1987; Landsman 2008; Grinker 2008; Martin 2007. For examples of narrative approaches, see, e.g., Breivik 2013; Frank 2000; Phillips 2010; Nakamura 2013; Dossa 2009; Rapp & Ginsburg 2001.

[10] See, for example, Frank 2000; Kohrman 1999a.