



Disability as Intercultural Dialogue

Guest post by Jessica M. F. Hughes & Mariaelena Bartesaghi

Ethnomethodologist Carolyn Baker argues that culture is not a pre-made context for action to unfold, but rather an ongoing moral order of categories and categorization, where locally produced categories become “locked into place” (2000, p. 99). This is how we understand—and are able to talk about—disability in terms of culture, as an assemblage of voices, bodies and actions within a contingent and shifting social order(ing). Just as Bakhtin (1986) tells us that there is no first speaker, but rather language as coordination over time and amidst utterances in relation, disability can only mean in terms of what we are able to (co)produce it as meaning. In our book, *Disability in dialogue* (Hughes & Bartesaghi) contributors set out on empirical projects designed to trouble the categories of disability within several cultural frames: geographical settings, diagnostic accounts, political action, crisis events, and everyday occurrences.

Inasmuch as disability is a culture, an ordering of relations and identity projects, of what is and might be possible, of what is historically entrenched and institutionally regulated, then disability is also an intercultural doing. This is the case not merely in the exchanges between a culture of able bodiedness to which disability owes its constitution, but between the multiple and diverse identity positions of those who are incumbent within the culture of disability. These exchanges are dialogic through and through, for they always mirror, borrow, and often oppose each other. In Shotter’s words (2015), these dialogues are occasions for attunement (p. 8) and intercultural betweenness.

Definitions of disability and diagnoses lock cultural discourses of disability into place. They are, in Bakhtin’s phrase, “authoritative discourse.” By measuring deviation, diagnoses reinstate the *normate*, that is, “the corporeal incarnation of culture’s collective, unmarked, normative characteristics” (Garland-Thomson 1997, p. 23). The normate is communicatively constructed in the ubiquitous and “entrenched assumptions that ‘able-bodiedness’ and its conceptual opposite, ‘disability,’ are self-evident physical conditions’ ” (Garland-Thomson, 1997, p. 6). The normate is an invisible bystander in interactions in which disabled people are stared at (see Garland-Thomson, 2009) or asked intrusive questions (see Bircher, 2023).

Of course, disability is not always readily apparent—though it is often in fact impossible not to see, for those who care to look. Invisibility around disability is a cultural commonplace especially pervasive in medical contexts. For instance, people with ‘invisible’ disabilities like fibromyalgia, myalgic encephalomyelitis/chronic fatigue immune dysfunction syndrome (ME/ CFIDS) “work overtime to have their body-mind trouble acknowledged while doctors and the media ignore and

trivialize it” (Clare, 2017, p. 73). Making disability invisible in this way helps to reinforce medical authority to “[dismiss] what we know about our own visceral experiences” (Clare, 2017, p. 73).

Tobin Siebers’ (2011) theory of complex embodiment accounts for the myriad cultural meanings of disability by understanding “the economy between social representations and the body not as unidirectional...or nonexistent...but as reciprocal. Complex embodiment theorizes the body and its representations as mutually transformative” (Siebers, 2011, p. 25). To understand complex embodiment, we must account for the ways in which cultural norms invite themselves into our interactions and the representations we construct and consume. As Rosemarie Garland-Thomson (1997) points out, definitions of disability rely on and perpetuate cultural expectations. For instance, in the definition of disability used in the Americans with Disabilities Act (ADA),

[e]ssential but implicit to this definition [of disability as impairment that limits activities] is that both “impairment” and “limits” depend on comparing individual bodies with unstated but determining norms, a hypothetical set of guidelines for corporeal form and function arising from cultural expectations about how human beings should look and act. Although these expectations are partly founded on physiological facts about typical humans—such as having two legs with which to walk upright or having some capacity for sight or speech—their sociopolitical meanings and consequences are entirely culturally determined. (Garland-Thomson, 1997, pp. 6-7)

In *Disability and discourse analysis*, Grue (2015) observes that the term disability is as polysemic as it is ever present, for it indexes the nexus of social institutions, mental and physical human conditions, and actions to claim benefits and accommodations. His examination of the varied social and political roles played by different conceptions of disability is useful in tying different meanings of disability to power structures, and understanding how disability discourses vie for control. “Debates over the definition of disability have continued for decades: within the World Health Organization, within social science research, and particularly within the disability movement” (Vehmas & Shakespeare, 2014, p. 45). These debates are, of course, also common within disability studies, the “academic discipline that examines disability—as both a physical or psychological impairment and a social, cultural, interpersonal, and political phenomenon—and the lived experience of people who identify with disability” (Society for Disability Studies, n.d.).

Within disability studies, opposition to medical model definitions of disability as impairment (e.g., Oliver, 1990) gave rise to arguments for a social model that explained “the problems disabled people faced were not caused by our impairments but were caused by the way in which society failed to organize itself in a way which allowed disabled people to be included...[changing disability] from a medical issue to a human rights issue overnight” (National Union of Students UK, 2018). In turn, this perspective brought about calls for phenomenological models of disability that account for embodied experience (e.g., Hughes & Paterson, 1997; Shakespeare, 2006; Wendell, 1996). As Goodley (2011) notes, these debates are ongoing.

Discursive struggle is also evident in arguments around categories of co-membership from within the disability community. While many prefer person-first language (PFL) and PFL terms like ‘person with a disability’ have been written into legislation like the ADA, others argue that PFL is

premised around an understanding of disability as spoiled identity (Titchkosky, 2001) and push for identity-first language grounded in an understanding of disability as a dimension of difference (Sinclair, 1999/2013), signified by terms like ‘disabled person.’ Still others reclaim the term “crip” (short for “crippled”) as a means of empowerment and to convey disability pride (Pulrang, 2018). As all of these different ways of defining disability and referring to members of the disability community collide, they open up new realms of possibility for how people see themselves and enter into relationships with others.

Requests for accommodations make this plain. Jay Dolmage (2017) describes this experience for college students as a process of navigating “a path strewn with barriers” (p. 24), as disabled students must interact with peers and faculty “who have little familiarity with disabilities, hold stigmas about people with disabilities, or even consider academic accommodations for students with disabilities to be an unfair advantage” (p. 24). Notifying faculty of accommodations they are legally entitled to, students often “find themselves in a position of explaining to faculty details about eligibility for accommodations, the accommodation process, and the range of available support to students with disabilities on campus” (p. 24). In these interactions, paperwork, policies, diagnoses, and doctors speak through students, staff, and faculty. Access, exclusion, and deepened or damaged relationships emerge from them. Crip time is another temporal reality that emerges as disability changes disabled students’ relationships to time. Acting in crip time means amending schedules to accommodate bodymind needs (Kafer, 2013). Living in crip time also involves a lot of waiting—for returned emails and phone calls, appointments, paperwork, diagnoses, accessible transportation, or for pain or flares to pass.

Each of the chapters of *Disability in dialogue* press for an understanding of disability as culture in action: a dialogic understanding of our multiple social identities that is intrinsically intercultural. Analyzing disability discourses means appreciating dialogic tensions, the centripetal and centrifugal forces at work, the constant interplay between dialogue and monologue. And it means listening to the diverse voices that, as Bakhtin remarked, are everywhere and always in relation.

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